

Close to the Street: The Ethics of Access to Health Care

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Abstract

People who are street involved face inequities in health status and access to health care. The purpose of this study was to contribute to enhancing equity for those who are street involved through an understanding of ethical practice and interactions involving nurses and those who are homeless, experiencing addiction, and mental health concerns. An ethnographic approach drawing on critical and feminist perspectives was used to gain a better understanding of the context of ethical practice and health care interactions that constrain and facilitate access to health care. Data were collected over a period of ten months in two primary health care settings and one emergency department. The main mechanism for data collection was participant observation and interviews.

The primary finding in this study was that forging a chain of trust within a climate of distrust is a central feature of enhancing access to health care for those who are street involved. When the links in the chain of trust are broken or missing and there is an absence of trust, access is constrained. Those who were street involved were often reluctant to access health for complex and multifaceted reasons exacerbated by a loss of faith in the system, surviving the streets and the ‘need to fix.’ Nurses working in primary health care centers forged the development of trusting relationships over time through respect and accepting without judging those who are street involved. Outreach and working within harm reduction enabled nurses to meet people on ‘their own turf’ and ‘where they were at.’ A climate of trust within the primary health care center was a source of support to nurses and enhanced access to health care. Nurses described themselves as “advocates” as they worked to extend the chain of trust to others.

In this study, health care interactions provided an important opportunity for enhancing access to health care services and linking individuals to a broader range of services that impact health such as income and housing. Theoretical insights from this research highlight the importance of feminist and cross-cultural approaches to ethics in nursing. Key insights for policy include implications for critical analysis of policy, development of primary health care programs, linkages between services and involvement of those who are street involved in the policy process.

Table of Contents

Table of Contents.....	iii
Acknowledgements.....	vii
Dedication.....	viii
<i>Chapter 1 Inequities in Health and Access to Health Care</i>	1
Statement of the Problem.....	1
Research Purpose and Objectives.....	3
Background to the Study.....	5
Main Factors Influencing the Research.....	5
Practical and Theoretical Significance.....	10
Review of Theoretical and Empirical Perspectives.....	12
Experiencing Vulnerability and Marginalization.....	12
Surfacing Inequities	15
Inequities in Health Status: Homelessness, Addiction and Health... 16	
Inequities in Access to Health Care.....	19
Financial and Geographical Barriers.....	21
Qualitative/Interactional Barriers.....	22
Health Care Provider Attitudes and Perceptions.....	24
Client Perceptions.....	28
Access to Appropriate Health Care.....	31
The Ethics of Access	35
Framing the Issues.....	36
Moral Commitments of Registered Nurses.....	39
Moral Concerns of Registered Nurses.....	42
<i>Chapter 2 Historical and Theoretical Perspectives in Health Care and Nursing Ethics</i>	49
Health Care Ethics.....	51
Development of Health Care Ethics.....	51
The Rise of Principlism.....	53
Autonomy.....	55
Nonmaleficence and Beneficence.....	56
Justice	57
Emergent Perspectives in Health Care Ethics.....	63
Narrative Ethics.....	64
Cross Cultural Ethics.....	65

Feminist Ethics.....	70
Nursing Ethics.....	77
Evolution of the Field.....	77
Theoretical Developments in the Field.....	82
Existential Phenomenological Perspectives.....	83
Relational Ethics.....	87
Reflections on Narrative Perspectives.....	91
Care Based Approaches: Value, Virtue or Particularity?.....	92
Feminist Directions in Nursing Ethics.....	98
<i>Chapter 3 Research Design, Methodology and Implementation</i>	<i>105</i>
Research Design.....	106
Beginning with Ethnographic Methodology.....	106
Taking an Epistemological Stance.....	116
Theoretical Perspectives.....	124
Critical Influences.....	124
Feminist Influences.....	126
Implementing the Study.....	135
Gaining Access and Entry: Developing Relationships.....	135
Population and Sample.....	143
Primary Participants.....	147
Secondary Participants.....	150
Data Collection.....	151
Participant Observation.....	153
Field Notes.....	157
Interviews.....	161
Supplementary Sources of Data.....	165
Data Analysis	167
Reliability and Validity.....	173
Human Research Ethics.....	176
Primary Participants.....	177
Secondary Participants.....	179
<i>Chapter 4 Chains of Trust and Distrust</i>	<i>183</i>
Forging Trust in a Climate of Distrust.....	184
Climate of Distrust: Broken Linkages.....	187
Reluctance to Access Health Care.....	188
Feeling Overlooked.....	193
Feeling Prejudged.....	196
Being Treated Poorly	204

Being ‘Treated like Garbage’: Wasting Time.....	205
‘Getting Dope Sick’	206
Fear of Being in Pain.....	208
Fear of Negative Consequences: I can’t go because.....	210
Loss of Faith.....	213
Surviving the Streets.....	216
Need to Fix.....	220
Weak and Potential Linkages.....	227
Depends on the Provider.....	227
Depends on the Hospital.....	229
Depends on Who’s to Blame	230
<i>Chapter 5 Crossing Chasms: Forging a Chain of Trust</i>	<i>233</i>
A First Link: Developing Trusting Relationships Over time	234
Respect: Being Treated Like a Person.....	236
Accepting without Judging.....	248
Outreach: ‘On their Turf’	257
Harm Reduction: Meeting People where they are at	268
Respecting Choice.....	272
Not Giving Up: Keeping the Door Open.....	275
Honesty.....	280
A Second Link: Working in a Climate of Trust.....	282
Working within a Team.....	283
Creating the Nursing Role.....	285
Linking Together: Communication and Referral.....	284
Working Together as a Team.....	290
Being ‘Like Minded’	290
Everyone Deserves the Same Care.....	292
Respecting Differences.....	296
Sharing Priorities.....	297
Not Being Alone.....	301
A Third Link: Extending the Chain of Trust	304
Linking to Other Agencies.....	307
Liaising with Hospitals.....	311
Missing Linkages in Policy	318
Linking to ‘Detox’ Services.....	318
Linking to Housing.....	319

Linking to Welfare Policies.....	321
<i>Chapter Six Enhancing Equity in Practice, Theory and Policy</i>	322
Enhancing Equity in Practice.....	322
Developing Trust within Health Care Interactions.....	322
Enacting Justice within Nursing Practice.....	326
Enhancing Equity in Theory	333
Reflections on Principlism and Feminist Ethics.....	334
Cross-Cultural Perspectives.....	338
Trust in Health Care Ethics.....	341
Enhancing Equity in Policy.....	342
Framing Policy Problems.....	343
A Critical Lens for Policy.....	347
Policy Insights.....	348
Primary Health Care Centers.....	348
Interagency Linkages	355
Meso Level Policy: Expanding Harm Reduction.....	356
Linking to Macro Policy.....	359
 <i>References</i>	 365
 <i>Appendix A</i>	 395
Verbal Recruitment Script for Agencies	
<i>Appendix B</i>	397
Health Center Poster	
<i>Appendix C</i>	398
Secondary Participant Information Pamphlet	
<i>Appendix D</i>	401
Registered Nurse/Health Care Provider Background Sheet	
<i>Appendix E</i>	403
Client Participant Background Sheet	
<i>Appendix F</i>	405
Primary Participant Consent: Nurses and Health Care Providers	
<i>Appendix G</i>	410
Primary Participant Consent: Interview Only	
<i>Appendix H</i>	414
Script for Verbal Consent with Secondary Participants	

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Dedication

This dissertation is dedicated to those who are committed to enhancing equity in health care and to those who will benefit from their efforts.

Chapter 1

Inequities in Health and Access to Health Care

STATEMENT OF THE PROBLEM

People experiencing marginalization such as those who are homeless, experiencing addiction and mental health concerns are at greater risk for poor health than other members of society (Aday, 1993; Hall, 1999; Hall, Stevens, & Meleis, 1994; Kreiger, 1999). Access to appropriate health care is an important resource necessary for improving health status of the population (Health Canada, 1999). Along with being at greater risk for health problems, people experiencing marginalization face significant financial, geographic and qualitative barriers in accessing health care (Institute of Medicine, 2002; Stevens, 1992). Thus, they are in ‘double jeopardy’ facing both inequities in health status and inequities in access to health care. For those experiencing marginalization, inequities in access to health care services are particularly morally objectionable because they exacerbate existing inequities in health status.

Equitable access to health care requires attention to the cost, geographic distribution and quality of care (Stevens, 1992). “For health care to be accessible, it must not only be economically attainable and geographically at hand, but also qualitatively appropriate and nondiscriminatory” (Stevens, p. 191). People, experiencing homelessness, addiction and/or mental health concerns, report that discrimination and feeling prejudged by health care providers act as significant barriers to accessing health care (Butters & Erickson, 2003; Crockett & Gifford, 2004; Dinos, Stevens, Serfaty, Weich & King, 2004, Murray, 1996; Napravnik, Royce, Walter, & Lim, 2000). The organizational context has been implicated in the development of discrimination and

judgments of deservedness in health care (Anderson & Reimer Kirkham, 1998; Browne et al., 2002; Corley & Goren, 1998; Johnson & Webb, 1995; Pauly & Varcoe, under review; Stevens, 1998). In an environment of real or perceived resource scarcity in the current organizational contexts, there is increasing risk of care being rationed on the basis of social worth (Carveth, 1995; Corley and Goren; 1998; Fisher, 1995; Johnson & Webb, 1995; Kelly & May, 1982; Liaschenko, 1994, 1995; Pokrasky & Sexton, 1988; Rodney & Varcoe, 2001; Stevens, 1992, 1998; Varcoe & Rodney, 2002).

Discrimination in the provision of nursing care on the basis of social criteria such as class and ethnicity is inconsistent with ethical standards for nursing practice (Aroskar, 1992; Canadian Nurses Association, 2002). Guidelines for ethical practice, as embodied in the Canadian Nurses Association Code of Ethics (2002), clearly promote values and responsibilities that require nurses to be nonjudgmental, provide care on the basis of need and promote social justice. Furthermore, discrimination itself negatively impacts the health of individuals and groups and discriminatory practices contribute to further marginalization (Browne, Johnson, Bottorf, Grewal & Hilton, 2002; Corley & Goren, 1998; Kreiger, 1999). Clients may avoid health care as a result of discrimination. Overall, this may increase the costs of health care and adversely affect the health of individuals and groups. Preliminary evidence from the perspective of those who are street-involved suggests that access is facilitated by respectful nonjudgmental care provided by street nurses and when services are delivered in a primary health care setting (Butters & Erickson, 2003; Hilton, Thompson, Moore Dempsey & Hutchinson, 2001a; Politzer et al., 2001; Stadjuhar et al., 2000). However, little is known about ethical practice and the nature of interactions between nurses and those accessing health care or

the context in which care is provided. Ethical practice is the degree to which nurses are able to practice according to the values and responsibilities outlined in the Code of Ethics (Canadian Nurses Association, 2002). On a daily basis, salient elements of the context (social, historical, political, and economic features) that reinforce and mitigate barriers to accessing health care are enacted in health care interactions and relationships between nurses, individuals, families, administrators and others. Knowledge of ethical practice and health care interactions within a primary health care context is needed to enhance equity in access to health care for those who are street involved.

RESEARCH PURPOSE AND OBJECTIVES

My primary aim is to contribute enhancing equity in access to health care for those experiencing marginalization through a better understanding of ethical practice and nurse-client interactions with people who are homeless, experiencing addiction and mental health concerns. From the initial conceptualization of this study, an important goal has been to inductively generate insights for practice and policy in an attempt to improve access to health care for those who are experiencing marginalization.

Understanding ethical practice and interactions within a primary health care context can contribute to knowledge of circumstances and policies that facilitate or impede access and nursing actions that promote or restrict equitable access (Stevens, 1992, 1998). The context or culture in this study refers to the social, political, economic and historical dimensions embedded in organizational structures and reflected in health care interactions. The following four research questions were identified to guide this project:

- 1) What is the nature of interactions of nurses with people experiencing homelessness, addiction and mental health problems?¹ How do those interactions contribute to the development of relationships?
- 2) How do social relations [context] influence and shape health care relationships and ethical practice of nurses in a primary health care setting?
- 3) How is access to health care affected?
- 4) What are the insights of clients and street nurses that would contribute to the development of more equitable access to health services within the health care system and what are the implications of these insights for policy development and analysis?

The specific research objectives were to:

- 1) Describe the nature of interactions and the development of relationships between nurses and people who are experiencing homelessness, addiction and mental health problems.²
- 2) Explicate the underlying relations (social, economic, political and historical) that support and constrain the enactment of ethical standards and practice within health care relationships.
- 3) Explore the effects of health care relations on access to health care.

¹ In the original research proposal, this question was framed as follows: what is the nature and quality of health care relationships between street nurses and the people they serve? However, as data collection proceeded, it became clear that the real focus was on the nature of ethics in everyday interactions of nurses with people who are homeless, addicted or experiencing mental health concerns. As Hammersley and Atkinson (1995) observe, it is often during the process of the research that the real nature of the research questions emerges. In conducting this research, I had the opportunity both in the clinics and on outreach to talk with many people about the study. I found that early in the study as I struggled to articulate my research questions in a meaningful way, it was through my discussions with participants that the research questions were refined. When I talked about studying access to health care and the role of nurses in facilitating access, there seemed to be an immediate understanding of the importance of relationships as central to enhancing access to care. For example, a key experience for me early in the study was when I was describing the research to a shelter worker. She immediately responded “oh, it’s about the way that people are treated” and indicated she thought that was very important for enhancing access to health care. I remember being riveted to her words and felt as if she had very simply and eloquently described an important aspect of the research.

² In the original research proposal, this objective was as follows: Describe the nature of relationships in a primary health care setting between nurses and clients whom they serve.

- 4) Identify the insights of clients and nurses that would contribute to the development of more equitable access to health services within the health care system .
- 5) Explore the implications of these insights for policy development and analysis.

BACKGROUND TO THE STUDY

In this section, I will provide a brief overview of the main factors that gave rise to this research project. Then, I will describe the practical and theoretical significance of this study before moving to a review of theoretical and empirical literature relevant to the problem posed at the beginning of this chapter.

Main Factors Influencing the Research

The main factors which gave rise to this research project included my experience as a staff nurse working in an emergency department, my clinical work with people who were refugees or had recently immigrated to Canada, and my role as a nurse educator and researcher involved in teaching and research of nursing ethics. As an emergency nurse working in a busy emergency department, I was keenly aware of my inability to address the complex and ongoing needs of those experiencing poverty, mental illness, homelessness or substance use. Often, I observed discriminatory attitudes and behaviors towards people who were from particular ethnic groups, intoxicated, addicted or involved in street activities such as prostitution and drug trafficking. I felt morally distressed³ when I witnessed or contributed to stereotyping or disrespectful treatment of certain groups of people on the basis of these differences.

³ The term moral distress was originally defined by Jameton (1984). Building on Jameton's work, Webster & Baylis (2000) state that moral distress "is when there is incoherence between one's beliefs and one's actions, and possibly also outcomes (that is what one sincerely believes to be right, what one actually does, and what eventually transpires)" (p. 218). They distinguish moral distress from moral residue. Moral Residue "is that which each of us carries with us from those times in our lives when in the face of moral distress we have seriously compromised ourselves or allowed ourselves to be compromised" (p. 218).

As a nurse educator, I had the opportunity to do clinical work with many people who were new immigrants or refugees to Canada. Frequently, the English as second language teachers would consult me when they were concerned about someone's health or when someone was having difficulty navigating the health care system. I saw first hand the impact of social conditions on health such as lack of income. I became acutely aware of the challenges in providing health care across differences in race, class, gender and culture. My experiences working with people from other countries contributed to my interest in exploring factors within health care that both facilitate and constrain access to health care for those who are often marginalized in society.

My involvement as a nurse educator, student and researcher in numerous projects related to nursing and health care ethics sparked my interest in ethics and access to health care for people experiencing marginalization and the decision to pursue this interest in my dissertation research. As a Master's student, I was actively involved in ethics consultation and research at the John Dossetor Health Ethics Center (University of Alberta). While at the Center and following my involvement in research related to relational ethics, I began to focus on the challenges and benefits of ethical practice within health care relationships. In my Master's program of study I began to develop theoretical knowledge of nursing ethics and explore the ethics of caring as a foundation for nursing ethics. My Master's thesis focused on the meaning of caring in health care relationships from the perspective of patients and nurses in an acute care setting.

For the past five years at the University of Victoria, I have worked with a team of nurse researchers engaged in a program of research to examine nursing ethics in the current cultural context of health care delivery aimed at generating positive changes in

nursing curricula and nursing workplaces. A defining moment for me occurred in a focus group during an initial project exploring ethical practice in nursing (Rodney et al., 2002; Varcoe et al., 2004). In this particular focus group, one of the investigators and I were talking with nurses from several medical units about the meaning of ethics in their practice. One nurse in the group described her difficulty of working with hospitalized prisoners while another related her experiences of working with those who are homeless. They identified that working with such people was ethically challenging and they drew on notions of deservedness in justifying their decision to ration nursing care such as spending less time with individuals in these situations. This experience attuned me to the need to better understand the ethics of working with people who might be seen as undeserving of care and resources, such as those with addictions. My involvement in this and subsequent projects on ethical practice in nursing have been integral to my theoretical development and the development of this project. Through my involvement with the nursing ethics research team, I have become acutely aware of the lack of attention given to everyday ethical issues, the inability to enact professional ethical standards within the current health care environment, the importance of ethical practice for both nurse well being and quality patient care, and the moral challenges of caring for certain types of people in the health care system.

Throughout my doctoral program, I have focused my learning and development in two key areas: ethics and health policy. At the same time, I was engaged in research about ethical practice in nursing, I was pursuing my desire to develop knowledge and experience in policy making. I have been particularly interested in developing further the relationship between ethics and health policy. During my program, I have been actively

engaged in ethical analysis of both provincial and national health care policy as a means of generating insights into the implications of changes in funding and the delivery of health care services for citizens. A key insight for me during this time was the need to pay explicit attention to the impact of policy directions for those who are socially disadvantaged. Through my work in ethics and health policy, it became readily evident that changes in the funding and delivery of health and social service programs will have the greatest impact on those with the least income, education and social advantages. In the current health care environment, there is a strong desire among policy makers and others to create a sustainable health care system and a growing emphasis on increasing efficiency and effectiveness. Counter to the prevailing ethos, I believe that addressing inequities in access to health care will contribute to the development of a sustainable health care system and ultimately increase efficiency and effectiveness in the provision of care to those experiencing homelessness, addictions and mental health concerns.

Throughout my nursing career, I have been committed to the role of nurses in advancing the health of the public and have been involved in many professional association initiatives highlighting the important contribution of nurses to the health of Canadians. For example, I had extensive involvement in the Alberta Association of Registered Nurses in a variety of initiatives, such as increasing direct access to nursing services as part of health care reform in Alberta. In my doctoral work, I have researched and evaluated the evidence related to increasing profitization⁴ in health care. Through my involvement in community groups, provincial, and national nursing associations I

⁴ I am deliberately using the term profitization rather than privatization. The term 'profitization' has been used by critics of privatization in the media to emphasize the profit making aspect of privatization. I have adopted this term from them as it was consistent with my review of the issues related to privatization (Pauly, 2004).

have actively sought to address issues related to increasing 'private for profit' health care initiatives and sought to promote primary health care as a viable alternative for enhancing the efficiency and effectiveness of the health care system. My tenure as a board member of a local primary health care center helped to shape my understanding of the issues that must be addressed in order to transform the delivery of health care in the community.

Lastly, I think it is important to acknowledge the critical influence of several personal experiences in the development of my research focus. During my doctoral work, I have had multiple opportunities to reflect on the fit between myself and the area in which I have chosen to conduct research. First, I have always had a passion for nursing. I entered nursing with a commitment to care for others respectfully and compassionately. In my nursing career, I have always been drawn to the work of nurses who are serving the most disadvantaged locally, provincially, nationally and internationally. Upon reflection, I think this interest, while consistent with nursing values, has been fueled by my own upbringing in the Catholic faith and a commitment to serving others, especially those living in poverty. A further influence was my own experience of being negatively judged by health care providers for my choice of a homebirth when I was hospitalized for a post-partum hemorrhage after the birth of my first child. This experience increased my sensitivity to the experience of being marginalized when receiving health care services (Pauly & James, 2005). At the same time, I was working with people who were new immigrants/refugees to Canada and had repeatedly heard about their experiences and challenges of navigating the health care system. For me, this research project is a culmination of multiple long standing interests

and commitments I have had throughout my nursing career and led me to undertake a study that I hope will have practical and theoretical significance.

Practical and Theoretical Significance

First, the findings of this study have the potential to contribute to knowledge for improving health care delivery to people who are street involved. Nurses are uniquely situated in pivotal positions within the health care system with direct knowledge of clients and the health care context (Stevens, 1992, 1998). Examining the social context from the perspective of nurses' interactions with clients could contribute to better understanding and transformation of health care practices, structures and policy (Hall, 1999; Hall et al., 1994; Stevens, 1992). Such knowledge for improving access and quality of health care for marginalized groups is needed throughout the health care system. Findings from this study will potentially provide insights into enhancing ethical practice in other health care settings and be of benefit to other health care providers who interact and provide care to people experiencing marginalization as a result of homelessness, addictions and mental health concerns. This research promises to identify and generate new knowledge of factors that facilitate access to health care for people experiencing marginalization. New knowledge of barriers that restrict access to health care also may be revealed. Further, this study has the potential to provide important insights for health policy development that could enhance the effectiveness, efficiency and equity of health care delivery for all people experiencing marginalization.

Lastly, this study contributes to theoretical development in the field of nursing ethics. The ongoing development of nursing ethics is critical to the development of the profession in order to serve the public interest (Johnstone, 1999; Omery, 1989;

Pellegrino, Veatch & Langan, 1991; Storch, 2004). Pellegrino, Veatch and Langan state that “few issues are more relevant to contemporary society than the nature and ethics of the professions” as the public relies on knowledgeable professionals and because of the role of the professions in defining culture and shaping policy in health care (p. viii).

Although not speaking of nursing specifically, these authors highlight the need to clarify the nature of professional obligations and the moral values that ought to guide practice within health care relationships between providers and those accessing health care.

Johnstone argues that a profession without ethical convictions has no basis for articulating concerns and limited motivation for acting well. In particular, Omery (1989) advocates for the development of a nursing ethics that will be adequate for addressing ethical issues in nursing practice, education and research. She states,

If nursing does not identify its ethics, it runs at least two dangers. The first of these is that nursing itself and society will continue to confuse and/or equate medical ethics with all of bioethics. Second, nursing will stand to lose practitioners as they try but fail to articulate their professional nursing oughts and shoulds for themselves and their patients (p. 506).

While the development of nursing ethics will benefit nurse researchers and educators, “the greatest benefit will be, however, to the practicing nurse as she/he struggles with giving excellent nursing care consistent with a positive nursing ethic” (Omery, p. 507).⁵

I would add that excellent nursing care benefits not only the nurse but the public as recipients of nursing care. In this study, it is anticipated that a better understanding of

⁵ Bishop and Scudder (1990), in a phenomenological study of nursing practice, found that excellent nursing practice is the moral imperative in nursing. Additionally, they found that when the professional sense of practice converged with the moral sense of their practice (demanding the development of personal relationships with clients) nurses felt the most fulfilled. When nurses were unable to fulfill the moral sense of their practice in caring for patients they were least fulfilled. I would interpret this as meaning that when nurses are able to do the right thing they experience less distress.

ethics in everyday nursing practice and the contextual features that affect the provision of care will help improve the practice of nursing for the benefit of citizens.

REVIEW OF THEORETICAL AND EMPIRICAL PERSPECTIVES

In this section, I will provide an overview of theoretical and empirical work related to the research problem posed above. The discussion of relevant research has been divided into the following sections: 1) experiencing vulnerability and marginalization 2) inequities in health status 3) inequities in access to health care and 4) the ethics of access to health care.

Experiencing Vulnerability and Marginalization

Prior to and during the course of this project, I have been constantly revisiting and revising the language I have used to describe the people who are the focus of this research. This is part of an ongoing attempt to respectfully describe those who may be negatively affected by discrimination in health care as a result of homelessness, addiction or mental health concerns. When I began to develop my research focus, I explored the notion of vulnerability and ‘vulnerable groups.’ I learned that children and the elderly are often considered to be more vulnerable than other members of society. Some have argued that all hospitalized patients are vulnerable because of the associated loss of power that accompanies having a patient status (Sherwin, 1998). I would argue that people who are street involved are among those who are most vulnerable in society.

In the development of the research proposal for this project, I explored the concept of ‘marginalization.’ Marginalization can be understood as a process in which people who are relatively different from the dominant norm are moved to the periphery of society because of their identities, associations, experiences or environments (Hall, 1999;

Hall et al., 1994). According to Hall (1999), marginalization is “seen as a socio-political process, producing both vulnerabilities (risks) and strengths (resilience)” (p. 89).

Numerous authors have identified that those experiencing marginalization are most often differentiated on the basis of income, ability, ethnicity, religion, class and gender (Aday, 1993; Anderson, 2000; Anderson & Reimer Kirkham, 1998; Hall, 1999; Hall et al., 1994; Sherwin, 1992).

Aday (1997) uses the terms “vulnerable populations” or “marginalized groups” to describe those “for whom the risk of poor physical, psychological or social health is or is quite likely to become a reality” (p.1). Hall (1999) and Hall et al. (1994) on the basis of their research propose that marginalization is associated with increased vulnerability and poorer health outcomes than the general population. Women, people living in poverty, those who are Aboriginal or from ethnic minorities⁶, seniors, youth, and those experiencing disability and addictions are at a greater risk for poor health than other members of society (Aday, 1997; Cary et al., 1995; Hosein, 1999). People experiencing homelessness, addiction and mental health concerns are among those who may be marginalized and at risk for poor health. Although marginalization focuses on the process of differentiation rather than the vulnerability of the individual, both terms are problematic in that deficits rather than capacities and strengths are highlighted.

As I conceptualized this study, I described the focus of this research as being concerned with people experiencing homelessness and poverty. Many of those I met during the conduct of this study were experiencing poverty as well as a combination of

⁶ Although I have not explicitly examined use of the word ‘race’ here, I would note that it too can be a problematic term in reference to those experiencing marginalization.

homelessness, addiction, and/or mental health concerns. After an initial period of data collection and analysis, I started to use the term 'street involved' to refer to the people receiving care. Throughout this report, I have used the terms 'people experiencing homelessness, addiction or mental health concerns' or 'people who are street involved.' I have adopted these terms because they are the terms used by people and providers who live and work on the street. To use the term homelessness implies a situation in which a person is living without adequate shelter that may be short term, long term, or cyclical. The term street involved refers to a broader range of concerns and activities that take place on the street such as addiction, human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS), hepatitis C, prostitution and drug trafficking. More recently, I have started to explore the meaning of social disadvantage for its adequacy in describing the social circumstances of people who are street involved.

Although I have chosen to use particular terms to describe the people receiving care in this study, I am aware of at least two dangers in using such terms as 'street involved,' 'homeless,' or 'socially disadvantaged.' First, such terms can be accompanied by the tendency to stereotype people on the basis of their association with a particular group. This tendency would reinforce rather than address concerns about stereotyping that are central to this project. Second, terminology can contribute to the development of the assumption that people who are 'homeless' or 'street involved' are a homogenous group of people. It is important to note that those experiencing homelessness are not a homogeneous group (Begin, Cassavant, Chenier & Dupuis, 1999; Hwang, 2001). Youth, women and families with children are increasingly reported among those who are homeless (Begin et al., 1999; Eberle, Kraus, Pomeroy, Hulchanski, 2001; Hodnicki,

1990). Begin et al. observes that the traditional image of homeless, older, alcoholic men is no longer accurate. They state,

With recent changes in the population, it is no longer possible to speak of one profile of homelessness; rather there is a diversity of profiles. The homeless now include women, children, teen-aged youths, the mentally ill, newly arrived immigrants, refugees, women victims of spousal violence, persons recently released from prison and casual workers. Each of these homeless subgroups may be further broken down by age, sex, ethnic, origin and occupational status (p. 16).

In British Columbia, women, children, youth and people of Aboriginal origin make up a significant portion of those who are homeless (Eberle et al., 2001). Thus, there is a changing demographic among people who are homeless. Furthermore, while poverty, addiction and mental health concerns may coexist with homelessness, they are not synonymous. One person may experience one or more of these situations simultaneously and differently. Those who are homeless, experiencing addiction and/or mental health concerns are unique individuals as well as part of a loosely defined group that is frequently marginalized in society.⁷ However, as a group, there are shared inequities in health and inequities in access to health care that I will discuss further in the following section.

Surfacing Inequities

It is well known that health inequalities and inequities exist among groups in society (Health Canada, 1999; Humphries & van Doorslaer, 2000). From a population health perspective, inequalities in health refer to differences between groups that may be positive or negative (Health Canada, 1999). When the difference is unfair/unjust (negative) as a result of distribution of goods in society it is then referred to as an

⁷ As I will discuss later, there are unique differences between people in this group. Also, understanding homelessness as an issue does not imply an understanding of the people who are homeless and the way in which homelessness and addiction cross gender, race and class.

inequity. There are two types of inequities: inequities in health among groups in the population and inequities in access to health care. People from marginalized groups such as those who are homeless, and/or living with addiction or mental health concerns experience double jeopardy. Not only are they at greater risk for health problems but they often experience difficulties in finding and accessing appropriate and timely health care. Thus, they may experience inequities in health status as well as inequities in access to health care. I will begin this section with a brief discussion of homelessness, addiction and health to highlight the need not only for access to health care but access to appropriate health care. Following this, I will review theoretical literature related to financial, geographical and qualitative dimensions of equitable access to care.

Inequities in Health Status: Homelessness, Addiction and Health

By all estimates, the problems of homelessness and addiction have been increasing since the 1980's in Canada and the United States (Begin et al., 1999; McCabe, Macnee, & Anderson, 2001).⁸ Homelessness may refer to living without physical shelter (living outdoors), living in inadequate housing (e.g. shelter that does not meet basic health and safety standards) and sleeping in shelters for the homeless (Hwang, 2001). In 2002, the number of people in Edmonton without shelter or staying in short term shelters was 1,915 (Edmonton Homelessness Count Committee, 2002). A recent homeless count in the City of Victoria estimated that there were about 700 people without shelter or

⁸ At the same time that there are increasing numbers of people who are homeless, communities also have expressed growing concern about the harms of illicit drug use such as HIV (human immunodeficiency virus) and HCV (hepatitis C virus) and the limitations of existing mental health and addiction services. Homelessness, addiction and mental health care are issues of local, provincial and national concern (Begin et al, 1999; Eberle et al., 2001; Edmonton Homeless Count Committee; Victoria Homeless Count Committee). Recently, the need for appropriate mental health and addiction programs and services has received national attention (Standing Senate Committee on Social Affairs, Science and Technology, 2004).

staying in emergency shelters (Victoria Cool Aid Society, 2005). Although people who are or have been homeless are not a homogeneous group, they share the risk of poor health as a direct result of unmet basic needs, violence, discrimination, substance use and environmental dangers (Aday, 1993; Daniels, 1985; Hall, 1999; Hall et al., 1994; Kreiger, 1999).

Among those who are homeless, there is high rate of mental illness and substance use (Fischer & Breakley, 1991). For people who are street involved, homelessness, addiction and mental health concerns frequently co-exist. However, the causal relationships among these factors are not clear. In addition, to health concerns related to mental illnesses and substance use, some common physical health problems among those who are homeless include dental decay, foot problems, tuberculosis (TB), sexually transmitted diseases (STD's), HIV, acquired immunodeficiency syndrome (AIDS), and hepatitis C (Begin et al., 1999; Eberle et al., 2001). There is growing concern and attention to the increasing numbers of people with hepatitis C and HIV infection among those who use injection drugs (Health Canada, 2003a). For example, in 2001, about 30% of Canadians who use injection drugs were HIV positive and 60% had hepatitis C (Health Canada, 2003a). The rate for both in Vancouver and Victoria is higher than the national average. Specific health concerns differ according to individual circumstances, age, gender and ethnicity (Hwang, 2004). For example, women who are street involved are at higher risk for depression, sexual abuse, HIV and sexually transmitted diseases than men. Men are more likely to experience substance use, and older men are at greater risk of hypertension and other cardiovascular disorders.

People who are street involved also experience poverty, inadequate or substandard living conditions, unemployment, and inadequate nutrition, all of which affect health. They are disadvantaged on factors such as income, education, housing, employment, social status and social support (social determinants of health) that have been shown to significantly affect health status (Hwang, 2000). Poor health status has been associated with low socio-economic and educational status (Wilkinson, 1990; 1997).⁹ In fact, differences in socio-economic status are considered to be a significant predictor of health status. Income has been found to vary inversely with health. Those who are homeless, experiencing addiction and mental health concerns face significantly more disadvantages on the broader social determinants of health than the rest of society.

Not surprisingly, people who live or work on the street do not have a life span similar to other groups. People experiencing homelessness are at an increased risk of mortality when compared with other members of society as a result of HIV/AIDS, overdoses, accidents and suicide (Barrow, Herman, Cordova & Struening, 1999; Cheung & Hwang, 2004; Hwang, 2000). The increased risk of mortality applies equally to men, women and youth who are homeless and/or street involved. In conclusion, people who are street involved are at greater risk for morbidity and mortality as a result of disadvantages related to the social conditions that affect health. Thus, as a group, they face greater inequities in health status than other members of society.

⁹ More recently, there is evidence that the health of the population is affected by the overall distribution of income within a country or region (Wasylenki, 2001). The greater the spread in income between the rich and the poor, the poorer the overall health of the population. However, I have concentrated here on the effects of poverty in contributing to poor health for particular individuals and groups.

Inequities in Access to Health Care

The term, 'access to health care' is central to health services and health policy analysis (Gulzar, 1999; Andersen, 1995, 1998). Andersen (1995), who has studied access to health care for more than 15 years states,

Access is the actual use of personal health services and everything that facilitates or impedes that use. It is the link between health services systems and the populations they serve. The conceptualization and measurement of access is key to the understanding and formulating of health policy because they can be used to understand health services use and to promote the equity, effectiveness, and efficiency of that use. (p. 110).

Access to timely and appropriate health care can provide opportunities for improving the health status of those who are experiencing marginalization such as homelessness, addiction and mental health concerns. Addressing inequities in access to care is important and necessary for creating a set of conditions that will enhance the health of those who are street involved. However, in the literature reviewed, there are multiple definitions of 'access' that emphasize different dimensions of 'access' and use of the term is plagued by limited analysis and synthesis (Gulzar, 1999). I am primarily concerned with access and equity.

Stevens (1992) argues that for nurses to work towards the goal of enhancing access, equitable access to health care must be framed within a broad sociopolitical context that includes attention to the dimensions of economic costs, geographical distribution, quality and satisfaction. *Equitable access* directs the focus to questions related to distribution of health care costs, quality and comprehensiveness of care among individuals and groups in society (Stevens, 1992). Who gets care and at what cost? She states,

Equitable access to health care is defined by the following conditions: (1) relative costs of health care are experienced equally across groups; (2) health care availability is based on the health needs and geographic distribution of the population rather than on distribution of wealth; (3) health care encounters are of equal quality and comprehensiveness across all groups; and (4) health care interactions are positively perceived by all groups of clients so that continuing utilization of health care system is facilitated (p. 187).

For the purpose of this study, equitable access as defined above refers to both existing health care services and ensuring the availability of appropriate services for those who are street involved. Each of the four conditions identified by Stevens will be discussed in more detail in the following paragraphs in relation to existing services and the availability of appropriate services for those who are street involved.

Those experiencing marginalization face a myriad of barriers in accessing existing health care services. This means that individuals have fewer resources available to deal with actual and potential health needs (Aday, 1993; Daniels, 1985; Flaskerud & Winslow, 1998; Hall, 1999; Hall et al., 1994; Stevens, 1992). These barriers may be financial, geographic, qualitative and/or interactional (Stevens, 1992). In the following paragraphs, I will discuss financial and non-financial barriers to health care identified from a review of the literature. Perspectives of providers, those experiencing marginalization, academics and researchers are reflected in the discussion. Although the primary focus of this project is to better understand interactions and qualitative dimensions for those who are street involved and accessing health care, I will begin with a review of financial and geographical barriers to illuminate broader contextual concerns affecting the delivery of health care for this group.

Financial and geographical barriers

In the United States, lack of coverage of the costs associated with health care services has repeatedly been identified as a primary barrier to accessing health services for those who are street involved (Barkin, Balkrishnan, Manuel, Andersen & Gelberg, 2003; Ensign & Panke, 2002; Freund, & Hawkins, 2004; Hatton, 2001; Hodnicki, 1990; McKinney, 2002). Canada, unlike the United States (but like many other industrialized nations) has a system of universal public health insurance. An underlying intent of the Canada Health Act (CHA) is to ensure that Canadians do not face financial hardship and are not refused essential health care on the basis of financial resources (Deber et al., 1997; Fuller, 1998; Health Canada, 2003b; Pauly, 2004). This intent is captured in the principles of accessibility and universality in the CHA. In a publicly funded system of health care, the need for health care services and ability to pay are separated. Thus, the establishment of a universal system of health insurance means that financial equity is purportedly enhanced for individuals and groups in Canada.¹⁰

Although financial equity is increased for Canadians, financial and geographical barriers to accessing health care services persist. For example, people who are homeless may not be able to afford the cost of replacing lost or stolen health care cards. In a study of Canadian women who were homeless and using crack cocaine, Butters and Erickson (2003) found that lack of a health care card was a major barrier to accessing health care. For those who do not qualify for social assistance, the cost of obtaining basic health care coverage may be prohibitive. Transportation and child care costs can act as financial

¹⁰ Some provinces in Canada do charge health care premiums that can be a financial barrier to accessing health care. Premiums are usually covered for those who are receiving social assistance. However, not all individuals who are street involved have applied for assistance and others may not be eligible for social assistance.

barriers to accessing health care services for those living in poverty (Williamson & Fast 1999). Pharmaceutical costs pose a significant barrier to those living in poverty and without drug benefits (Hwang & Gottlieb, 1999). People who are homeless and/or living in poverty may not have coverage for dental or eye care as such services are usually provided through private insurance plans in Canada. Geographically, those who live in rural and remote regions of Canada may face greater challenges than other Canadians in accessing basic and specialized services. In urban centers, geographic barriers exist for those who are street involved and not within walking distance of centers that provide a range of needed services.

Qualitative and Interactional Barriers¹¹

In addition to financial and geographical barriers, non-financial barriers can affect access to health care (Lewis, Andersen, & Gelberg, 2003). Quality of care as result of qualitative and interactional barriers varies according to gender, ethnicity, and class (Alter, Naylor, Austin & Tu, 1999; Caesar & Williams, 2002; Gornick, 2003; O'Malley et al., 2001; Schulmann, et al., 1999; Stevens, 1992; Stewart, Napoles-Springer, & Perez-Stable, 1999).¹² There is considerable evidence within medicine that diagnostic and treatment decisions vary by race and social class and a growing belief that race and social class influence medical decision-making and quality of care¹³ (Caesar & Williams. 2002;

¹¹ I have chosen to use the word 'interactional' because it is consistent with the terminology used by Stevens (1992) in defining the conditions of equitable access.

¹² Although not the focus here, assessment of the quality of care requires attention to health care structures, processes (patient-provider interactions) and outcomes (Mitchell, Ferketich & Jennings, 1998; Stewart et al., 1999). In evaluating the quality of care, the focus has shifted over the past three decades from structures to processes to outcomes (Mitchell et al., 1998). In spite of this evaluative shift, processes (including health care provider interactions) are integral to outcomes.

¹³ Some authors in medicine separate technical and interpersonal processes. Stewart et al. (1999), state,

Gornick, 2003; Gornick, Eggers & Reilly, 1999; van Ryn & Burke, 2000). For example, based upon an analysis of clinical encounters, the Institute of Medicine (2002) found evidence of stereotyping, biases and uncertainty on the part of health care providers. In this study, they found that stereotyping and biases lead to unequal treatment and a decrease in the quality of care for people from particular ethnic groups. Lower socio-economic status and being from an ethnic minority were more likely to be associated with inappropriate or inadequate treatment for a variety of medical conditions.

In other research, social criteria have been found to influence the quality of health care when delivered by physicians, nurses and other health care providers (Carveth, 1995; Johnson & Webb, 1995; Kelly & May, 1982; Stevens, 1992; van Ryan & Burke, 2000). In a review of research on health care interactions, Kelly and May (1982) found that patients were treated differently on the basis of their illnesses, social class, occupation, appearance, age, attitude and behavior. In a summary of two decades of research investigating health care interactions, Stevens (1992) found that

the operation of health care providers' unexamined prejudices and ethnocentrism is particularly apparent in health care interactions with women, persons of color, persons of low income, immigrants (especially those who do not speak English), gays and lesbians. These clients are more likely to encounter treatment that does not fit their culture and life circumstances, and they are prone to receive stereotypes reactions and misdiagnoses because of qualitatively insensitive diagnostic procedures. They are more likely to be ignored scolded, patronized,

Technical process, which is often distinguished from interpersonal process, includes tests, treatments, and technical competence in performing diagnostic and therapeutic procedures. Interpersonal process is defined as the social-psychological aspects of the patient-physician interaction, such as communication, friendliness, explanations and being caring and sensitive to patients' needs" (Stewart et al, p. 306).

While separation of technical and interpersonal processes may be useful for definitional purposes, it has been suggested that differences in the medical management of conditions may be attributed to differences in interpersonal processes between patients and providers (Kupperman, Gates & Washington, 1996; Stewart, Napoles-Springer, & Perez-Stable, 1999). I would argue that the way in which care is provided is as important as the kind of care provided and that these processes cannot be separated in practice or as to the effects on patient outcomes.

categorized as 'difficult' patients, subjected to sexist and racist remarks, and provided fewer explanations of the health care they are receiving (p. 192).

Potentially negative attitudes, labeling and stereotyping in nursing contribute to discrimination in health care interactions. Although quality of care is the outcome of multiple factors, discrimination within health care interactions is a significant concern affecting access to quality health care for many, including those who are street involved.

Health Care Provider Attitudes and Perceptions. Research on nurses' attitudes towards those experiencing homeless and addiction, shows several interesting trends. First, there are reports of negative attitudes in nursing towards people who suffer from addiction to alcohol and drugs (Carroll, 1995a, 1996a, 1996b; Corse, McHugh & Gordon, 1995; McLaughlin & Long, 1996). The findings of a few studies indicate that attitudes towards those who use alcohol may be changing as more positive responses towards those experiencing alcoholism have been reported (Gerace, Hughes & Spunt, 1995; Happell & Taylor, 2001; Rassool, 1993). It is unclear whether or not this shift to slightly more positive attitudes applies to those who use illicit drugs since attitudes towards alcoholism and drug use were conflated with substance use in the research reviewed. Negative attitudes continue to persist towards women who are pregnant, mothering, and using substances, including alcohol (Raeside, 2003). Second, there is clear evidence of negative attitudes towards people diagnosed with HIV and/or AIDS, which are potential consequences of drug use. Third, knowledge, age and years of nursing experience have been implicated as factors that affect attitudes towards those who abuse substances (Carroll, 1995b, 1996a, 1996b; Gerace, Hughes & Spunt, 1995; Raeside, 2003; Rassool,

1993). Positive attitudes are more likely found among nurses with greater knowledge of addiction.

In my review of the literature on attitudes of nurses and other health care providers towards those experiencing homelessness, a slightly different picture emerged. Reports of attitudes and perceptions of health care providers towards those who are homeless, ranged from slightly positive to neutral or negative (Hunter, Getty, Kempsey, M., & Skelly, A., 1991; Kee, Minick, & Ptlene Connor, 1999; Minick, Kee, Borkat, Cain, Oparah-Iwobi, 1998; Price, Desmond & Eoff, 1989; Zrinyi & Balogh, 2004). Kee et al. (1999) found that attitudes towards those who are homeless were generally sympathetic and that nursing students and faculty attributed the causes of homelessness to factors beyond the control of the individual. Although, Zrinyi and Balogh (2004) found that nursing and paramedic students expressed generally neutral attitudes to those who are homeless, detailed analysis revealed negative aspects in the provision of care. For example, some respondents admitted to withholding care. While participants expressed a general belief that people experiencing homelessness were treated the same as other people in acute care, 42% of the respondents indicated that people who are homeless did not receive equal care. Hunter et al. (1991) reported that health care providers expressed the view that those who are homeless are entitled to the same care as everyone else. At the same time, this group of providers believed that people who are homeless and experiencing substance use and/or emotional problems were perceived to be less in need and less deserving of care. This suggests that while providers may hold positive values, they do not always act on these values. The direct care providers in this study identified that barriers to accessing care for people who are homeless include the inability to follow

through with care, lack of motivation, limited financial resources and lack of a safe place for discharge.

Thus, some inconsistencies in attitudes towards those experiencing homelessness and addiction are evident among health care providers. However, caution is needed in interpreting research measuring attitudes of nurses and other providers. One concern is that a variety of scales have been used to measure attitudes of health care providers towards people experiencing substance use and many of the instruments do not have reported or well established reliability and validity. A second concern is that primarily convenience sampling was used in the studies reviewed. While caution is needed in drawing conclusions from work in this area, evidence suggests that negative attitudes may be communicated to those accessing health care. Health care providers may not conscientiously act on negative attitudes, but such beliefs may be conveyed without the awareness of health care providers and can contribute to labeling and stereotyping of certain groups of people.

Those experiencing homelessness and/or addiction are often included in those labeled as 'difficult' or 'problem' patients. Labeling and stereotyping may be defined as "the use of expectations about social groups in making judgments concerning individual members of those groups" (Corley and Goren, 1998, p. 101). Patients may be labeled as good or bad, difficult or demanding, likeable or unlikable on the basis of individual characteristics and behaviors or as a result of association with certain social groups (Carveth, 1995; Corley & Goren, 1998; Kelly & May, 1982; Liaschenko, 1994, 1995). Certain individual characteristics and behaviors, as well as gender, race and class, have the potential to evoke negative labels and stereotypes that are readily applied to

individuals and groups (Corley & Goren, 1998; Johnson & Webb, 1995; Liaschenko, 1994; Malone, 1996; Pauly & Varcoe, under review). In the literature, such patients have been identified as 'difficult' (Carveth, 1995); 'unpopular' (Johnson & Webb), 'those that nurses do not like' (Liaschenko), or 'frequent flyers' (Malone). In a study of nurses' reactions to 'difficult patients' Podrasky and Sexton (1988) "found the label 'difficult patient' is more likely to be used when the patient has characteristics or behaviors that are modifiable rather than those that are essentially 'not one's fault'" (p. 19). For example, substance use would more likely result in the label of 'difficult patient' than ethnicity.

From the perspectives of health care providers, differences in quality of care exist for those identified as 'difficult' or 'unpopular'. These differences include delaying care, avoiding patients, inaccurate assessments, withholding of treatment, providing limited care (e.g. physical care only), providing less information, inappropriate behaviors such as roughness in providing care and negative responses to patients (Carveth, 1995; Corley & Goren, 1998; Johnson & Webb, 1995; Stevens, 1992). Carveth found that specific patient characteristics such as drug and alcohol abuse, being diagnosed with HIV or AIDS, and having impaired communication were more likely to be associated with the label of being a 'difficult' or 'deviant' patient. In their observations of nurse-patient interactions, they found that the number and duration of contacts with patients identified as being 'difficult' were not significantly different than for ideal or neutral patients. However, there were significant differences in psychosocial and physical supportive care for patients perceived as difficult, with the largest discrepancy being in psychosocial care. Several of these authors have identified that the context or culture of health care is an important factor in the development and communication of negative attitudes, stereotypes

and judgments involving social criteria (Johnson & Webb; Corley & Goren; Stevens, 1998).

Client Perceptions. A fourth factor affecting access to health care is a person's perception of the health care encounter (Stevens, 1992). In research exploring the experiences of individuals who are homeless, experiencing addiction or mental illnesses in multiple communities in the United States, United Kingdom and Canada, negative attitudes, judgments and perceived discrimination have been identified as primary barriers to accessing health care (Butters & Erickson, 2003; Crockett & Gifford, 2004; Ensign & Panke, 2002; Gelberg, Browner, Lejano & Arangua, 2004; Napravnik, Royce, & Lim, 2000; Stadjuhar et al., 2001).¹⁴ The only research in which perceived discrimination was not mentioned as a barrier was quantitative research where it is likely instrument was not sensitive to indicators of judgment or discrimination. Barriers such as long wait times, not knowing one is eligible or believing that one is ineligible for care may be indicative of financial barriers and perceived or anticipated discrimination in health care. In particular, those who use illicit drugs felt that their past or current status as a 'drug user' was a barrier to accessing health care and affected the quality of care they received (Butters & Erickson, 2003; Carroll, 1996a, 199b; McLaughlin & Long, 1996; Napravnik et al., 2000). In a study describing the context of Injection Drug Use in Victoria, Stajduhar et al. state,

Almost all of the injection drug users had experienced negative, judgmental behavior on the part of the organized health care system when seeking medical treatment as well as a lack of understanding of the issues related to addictions.

¹⁴ Other non-financial barriers identified by participants included long wait times, not knowing where to access care, believing they were ineligible for health care coverage, being too ill and facing competing priorities such as need to find food or shelter (Barkin, Balkrishnan, Manuel, Andersen & Gelberg, 2003; Gelberg et al., 1997; Hatton, 2001; Lewis, Andersen, Gelberg, 2003).

While all valued the street nurses very highly, few could relate positive experiences with hospitals and their emergency departments (p. v).

According to these authors, lack of recognition by providers that drug use is a health issue contributed to the stigmatization and discrimination against people who use drugs. In part, this can be understood in relation to the difficulties of caring for people with addiction in the absence of adequate education, knowledge and skill in addictions (McLaughlin, McKenna & Leslie, 2000).

Hepatitis C, HIV/AIDS and mental illness are prevalent among those who are street involved and are associated with stigmatizing experiences for affected individuals (Bird, Bogart & Delahanty, 2004; Bunting, 1996; Crisp, Gelder, Rix, Meltzer & Rowlands, 2000; Crockett & Gifford, 2004; Dinos, Stevens, Serfaty, Weich & King, 2004; Napravnik, Royce, Walter & Lim, 2000; Valdiserri, 2002; Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003). Negative experiences with the health care system have been reported by those with hepatitis C, HIV/AIDS and mental illnesses both for those who are street involved and others. In reports of perceived discrimination among people who have hepatitis C and HIV/AIDS, drug use is implicated as a source of stigma.

Negative experiences and discrimination in health care can affect patient outcomes. For patients, negative experiences and feeling prejudged decreases the likelihood that they will access care in the future (Browne, Johnson, Bottorf, Grewal and Hilton, 2002; Stevens, 1992; Varcoe, 2004). Stevens raises the question, "How can consumers feel free to seek health care if they believe they were inadequately treated or were oppressed in previous health care encounters?" (p. 191). Because of such attitudes, those experiencing homelessness, addiction and mental health concerns often avoid or delay treatment resulting in fewer opportunities to improve health and the potential need

for more costly care in the future (Browne et al.; Stevens, 1992). For women with hepatitis C, stigma and a lack of knowledge of health care providers, as well as cost contributed to participants' hesitancy to seek care (Crockett & Gifford, 2004). For those experiencing homelessness, negative experiences with the health care system contributed to their reluctance to seek health care (Gelberg et al., 2004). Participants in several of these studies reported receiving insufficient information after being diagnosed with HIV/AIDS and hepatitis C as well as a belief that they were not provided with adequate follow-up care.

Even worse is the impact of discrimination on the health and well-being of persons (Kreiger, 1999). Experiences of stigma may result in feelings of worthlessness, depression, isolation, anger, anxiety and fear (Dinos et al., 2004; Zickmund et al., 2003). Feelings of worthlessness associated with the stigma of having a socially unacceptable disease and illicit drug use may inadvertently be reinforced by the attitudes and responses of health care providers. In one study, perceived discrimination in interactions with health care providers by people with HIV and low socio-economic status was correlated with higher levels of depression and post-traumatic stress symptoms, an increase in AIDS related symptoms, poorer physical health and less satisfaction with care (Bird, Bogart & Delahanty, 2004).

Qualitative and interactional barriers to health care limit real and perceived access to existing health services. Little attention has been given to understanding qualitative and interactional dimensions of access to health care. Research is needed that examines access to health care for those who are street involved that takes account of these factors. A better understanding of the barriers and facilitators within health care interactions that

account for the social and cultural context could contribute to enhancing access to health care for those who are street involved as well as others experiencing marginalization.

Access to Appropriate Health Care

As stated previously by Stevens (1992), the availability of health care on the basis of health needs and geographic distribution of the population rather than financial resources is an important aspect of equitable access. While the *Canada Health Act* (CHA) is meant to ensure universal coverage and access based on need not ability to pay (equality of access), it cannot be assumed that everyone has access to care that is appropriate to their health care needs or geographically accessible (equitable access) (Deber, Mhatre & Baker, 1994). Health care services in the current health care system are dominated by medical services rather than more health orientated services (health promotion and disease prevention) that may be consistent with population health needs and the geographical distribution of the population. In this section, I will focus on issues related to access to timely and appropriate health care suited to the needs of those experiencing homelessness and substance use.

Despite the greater risk for poor health and existing health concerns, people experiencing homelessness and substance use often do not have a readily accessible and consistent source of care and are more likely to seek health care in emergency departments than other members of society (Gallagher, Andersen, Keogel, Gelberg, 1997; Lim, Andersen, Leake, Cunningham & Gelberg, 2002; Robertson & Cousineau, 1986; Trevena, Simpson & Nutbeam, 2003; Wood & Valdez, 1991). This pattern of seeking health care in emergency departments persists even when there is a system of universal health insurance in place (Trevena, Simpson & Nutbeam). Perceived need for health care

as defined by one's subjective health status and presence of chronic illnesses among those who are homeless has been found to be a significant predictor of emergency department use (Kushel, Perry, Bangsberg, Clark & Moss, 2002; Masson, Sorensen, Phibbs & Okin, 2004; Olsson & Hansagi, 2001; O'Toole, Gibbon, Hanusa, Fine, 1999; Padgett, Struening, Andrews & Pittman, 1995). Thus, those who are homeless and experiencing addiction often present in emergency departments and are among those identified as repeat and frequent ER visitors (Olsson & Hansagi; Malone, 1996).

Providers in overburdened emergency rooms and drop-in medical clinics who perceive their role as dealing with acute episodic illnesses and injury, may feel frustrated, unable and unprepared to address the complex health needs of those experiencing homelessness and addiction (Olsson & Hansagi, 2001; Malone, 1995). Repeated use of the emergency department may be judged as inappropriate by providers. This, in turn, may contribute to stereotyping and inappropriate treatment resulting in further marginalization of those already facing inequities in health and access to health care. While emergency departments and primary care physicians provide a readily accessible source of care, they do not provide access to consistent and integrated services that are needed to address the root conditions of their ill health. Primary care physicians working within an illness model and under fee for service funding will have limited motivation to address broader health and social concerns such as housing, addiction, and lack of income that contributes to presenting health concerns. For example, Waitzkin (1991) found that the social context of presenting complaints were rarely addressed within medical encounters and that medical encounters frequently reinforced current ideologies

and social values. Sherwin (1992) explains that understanding such responses can be found in the very structures of the health care delivery system. She states,

The dominance structures that are pervasive throughout society are reproduced in the medical context; both within and without the health care delivery system, sex, race, economic class and able-bodied status are important predictors in determining someone's place in the hierarchy. The organization of the health care system does not, however, merely mirror the power and privilege structures of the larger society; it also perpetuates them (p. 228).

Similarly, Anderson & Reimer Kirkham (1998) have described the inherent biases that exist in the Canadian health care system that structure care on the basis of dominant cultural values and serves to disadvantage certain groups.

In contrast, McCabe, Macnee and Anderson (2001) found that satisfactory care for people experiencing homelessness meant committed care in which practitioners did not give up or reject them, respectful engagement in which they were accepted by providers, having trust and confidence in providers, providers who were perceived to be free of assumptions or lacking prejudice and being included in their care. The participants in this study were recruited from clinics, shelters and soup kitchens. In the report of the findings, however, it was not evident whether particular providers or locations were more likely to be associated with perceptions of satisfactory care. It was not clear if participants were speaking of particular groups of providers or specific sites as providing more satisfactory care.

In all of the literature I have examined to date, negative experiences with health providers were most often reported when care was provided in an acute care setting and with providers who did not have experience in working with people who are street involved as their primary focus. This was consistent with the findings of McLaughlin,

McKenna & Leslie (2000) in their review of the literature. Clients were more likely to report positive experiences when care was provided on the street, in community health centers or from providers with knowledge and experience in caring for people experiencing homelessness, addiction, HIV/AIDS or hepatitis C (Crockett & Gifford, 2004; Hilton et al., 2001a; Stadjuhar et al., 2000; Swanson, Andersen & Gelberg, 2003). In particular, street nurses were identified as highly valued health care providers among those who are street involved (Hilton et al., 2001a; Stadjuhar et al.).

Providing access to health care through community health centers can be an effective means for delivering health care to those experiencing marginalization, especially those who are homeless and living with addiction (Politzer et al., 2001).¹⁵ Consistent with the tenets of primary health care, community health centers are geographically accessible and integrate a variety of health promotion and disease prevention services. Primary health care or community health centers contribute to improvements in the health of 'inner city populations' by addressing not only individual health care needs but also the broader social determinants of health.¹⁶ In the American context, Aday, Begley, Lairson & Slater (1998) argue for the development of a broader continuum of health services, "encompassing prevention-oriented services, long term community-based services, and acute medical care services... to address the health and

¹⁵ I have used the terms 'primary health care center' and 'community health center' interchangeably. Both terms refer to centers that provide a range of integrated services, the use of interdisciplinary teams in the delivery of care, and provision of services based on the needs of the population.

¹⁶ Although I have not chosen to use the term 'inner city populations', others using such terminology have described a population similar to those I am interested in this study. Wasylenki (2001) provides a useful description of inner city subpopulations. He states, "These subpopulations include homeless individuals, people with HIV infection, people with severe and persistent mental illnesses, women at risk due to social isolation, poverty, working in the sex trade or the stresses of single parenthood, and people with addictions" (p. 215). This clearly matches the description of those who might be described as 'street-involved.'

health care needs of the most vulnerable in order to achieve social justice” (p. 183). Community health centers with a primary health care philosophy are consistent with population health models aimed at reducing health disparities and promoting social justice (Aday et al.). Increasing access to primary health care has the potential to benefit those who are homeless, experiencing addiction and/or mental health concerns.

Registered nurses working in the community in primary health care centers and as street nurses are often a first point of contact for people experiencing marginalization. Thus, nurses are an important point of access into the health care system for people experiencing homelessness, illicit drug use, and mental health problems.¹⁷ So far as I have been able to determine, there has been no examination of interactions between nurses and those accessing health care in a primary health care context either on the street or in a primary health care center. Little is known about the nature of interactions for nurses working with people who are street involved or the effect of the primary health care context on nursing practice.

The Ethics of Access

Reduced access to health care associated with a lack of appropriate services and barriers in accessing existing services raise serious ethical questions that go to the heart of concerns about equity and justice in resource allocation, and the organization and delivery of health care services (Buchanan, 1995; Caplan, Light and Daniels, 1999; Daniels, 1985; Institute of Medicine, 2002; Kreiger, 1999; Sherwin, 1992; Stevens,

¹⁷ Although not explored here, nurses have a long history of providing access to health care for those who have limited access to health care services. For example, nurse leaders such as Lavinia Dock and Margaret Sanger provided health care services to people living in low income settings. In Northern regions of Canada, 82% of clients first point of contact with the health care system is with a registered nurse (Brown, 2005).

1992). Collectively, writers in ethics argue that it is ethically unacceptable for health status and access to health care to be reduced as a result of differences in income/class, gender, race, culture, or sexual orientation.

Framing the Issues

Ethical concerns regarding access to health care may be broadly understood within the framework of inequities in health status and inequities in access to health care as outlined in the research reviewed for this chapter. Differences in health status are unjust if members, because of their social circumstances, do not have the same access to health services as other members of society (Daniels, 2001; Levin & Schiller, 1998; Song, 2002). Ethical concerns about health status draw attention to the need for action to improve the conditions that affect health such as education, housing, and income (also known as the social determinants of health). Sherwin (1992) observed that while bioethicists are aware of this situation, these issues have failed to capture the attention or imagination of those working in ethics.

Inequities in access to health care are in part morally concerning because they can contribute to existing inequities in health including physical, emotional and social well being. Addressing inequities in access to health care is highly relevant to the efficiency and effectiveness in health care organization and delivery that contributes to the goal of improving health status (Aday et al., 1998; Institute of Medicine, 2002). Equity or fairness in health care can be defined in terms of the level of care that ought to be available and in relation to an acceptable level of burden for those accessing health services (President's Commission, 1983). With regard to the level of acceptable burden, there is a moral obligation to remove barriers to health care for those experiencing social

disadvantages (Caplan, Light & Daniels, 1999; Daniels, 2001; President's Commission).¹⁸ In the United States (U.S.), where there is no system of universal health insurance, lack of health care insurance has been identified as a primary barrier to accessing health care. An estimated 44 million people in the U.S. do not have health insurance and many more lack adequate coverage (Robert Wood Johnson Foundation, 2003). Lack of access to health care as the result of inadequate or nonexistent health insurance has been identified as a serious moral issue by American bioethicists (Buchanan, 1995; Caplan, Light and Daniels, 1999; Daniels; 1985). From an ethical perspective, publicly funded health care services are essential to address inequities in health status and remove unfair burdens in accessing health care

As discussed previously, non-financial barriers that affect access to health care persist even in the face of universal health insurance. Concerns that race, gender and social class have an impact on diagnosis and treatment of health conditions in professional-patient relationships and that everyone has a right to be treated respectfully in health care interactions have received little attention as serious moral issues (Dickman, 1983; Levin & Schiller, 1998; Stevens, 1992). A third concern identified by Levin & Schiller is that "because of differences in their lived experiences, people of different social classes have differences in values relevant to medical decision making" (p. 41). Song (2002) argues that homelessness raises a special ethical concern. He states,

there is a phenomenological concern of how to understand the moral imagination, perceived needs, and reasoning of homeless persons given their immediate, constant and pervasive struggle for daily survival. This is an issue for the moral

¹⁸ I would note here that a principle of equal access does not provide guidance on what health care services must be provided; questions of resource allocation and considerations of justice are clearly an associated area of concern (Gutmann, 1983).

imagination of the ethics consultants and health care providers as much as it is for homeless people in that we, as persons who are not faced with their struggle, may have a limited basis for understanding their needs and responses to our efforts to help them (p. 210).

Recently, the Institute of Medicine (2002) identified inequities as the result of discrimination and prejudice in health care encounters as a serious moral issue. Ethically, persons ought to have access to a decent minimum of services and that those services should be delivered respectfully (Caplan, Light & Daniels, 1999; Dickman). From the perspective of ethics, the development of services for those who are street involved requires an understanding of their specific needs, values and life circumstances.

In the preceding sections of this chapter, I have separated inequities in health from inequities in access to health care for the purposes of discussion. However, inequities in health and access to health care are linked. For example, differences in health status among groups in the population contribute to inequities in access to health care. Inequities in health are exacerbated when someone is unable, because of living conditions, to complete prescribed treatments or does not have the resources to support health maintenance or recovery (Song, 2002). Inequities in health and access to health care are embedded in particular social, political, historical and economic contexts.

Concerns related to inequities in health and access to health care are of particular relevance to nurses because of their expressed moral obligations to individuals and society. In taking up Stevens' (1992) definition of equitable access to health care, my intent was to draw attention to financial and non-financial barriers affecting access to health care within the current socio-political context for those who are street involved and to highlight the important role of nurses in enhancing access to health care as an

important part of their work. Steven's (1992) argues that enhancing equitable access to health care is an important issue for nursing action that is consistent with the moral obligations of professional nurses. In the next section, I address the moral commitments and concerns of registered nurses in relation to inequities in health and access to health care, beginning with an examination of moral commitments of registered nurses as contained in the current Canadian Code of Ethics for Registered Nurses (2002).

Moral Commitments of Registered Nurses

As a profession, nurses have an expressed moral obligation to ensure equitable access to health care that is evident in documents such as professional codes of ethics (Aroskar, 1992; Canadian Nurses Association, 2002; Corley & Goren, 1998; Stevens, 1992). The Canadian Code of Ethics for Registered Nurses (2002)

is a statement of the ethical commitments of nurses to those they serve. It has been developed by nurses for nurses and sets forth the ethical standards by which nurses are to conduct their nursing practice (p. 2).

In the current Code, expectations for ethical behavior in all areas of nursing practice are described. The Canadian Code is not merely composed of statements of belief but reflects a growing consensus among Canadian nurses about the moral values that ought to guide the profession. The nurse-patient relationship is central to the eight values and related responsibilities articulated in the Canadian Nurses Association Code of Ethics. However, the opening statements in the code indicate that nursing practice requires attention to ethics not only at the individual level but also at organizational, regional, societal and global levels of health care.

The moral obligations of nurses to enhance equitable access at all levels is readily evident in the responsibility statements associated with the values of health and well-

being, dignity, and justice in the current code (Canadian Nurses Association, 2002).

Nurses have a moral obligation to assist individuals to achieve optimal levels of health and well-being. In particular, they are responsible for recognizing and participating with others to address “organizational, social, economic and political factors influencing health” (Canadian Nurses Association, p.10) and recognizing “the need for a full continuum of accessible services, including health promotion and disease prevention initiatives”(Canadian Nurses Association, p.11). Such responsibilities are clearly related to addressing inequities in access to health and enhancing development of appropriate health care services.

The value of dignity requires that “nurses recognize and respect the inherent worth of each person and advocate for respectful treatment of all persons” (Canadian Nurses Association, 2002, p. 13). According to the Code all persons receiving care are worthy of respect and nurses must demonstrate respect for the dignity and rights of individuals in their relationships. Nurses must acknowledge the vulnerabilities of others, preserve therapeutic relationships and intervene if others fail to respect the dignity of persons. Specifically, “nurses must avoid engaging in any form of punishment, unusual treatment or action that is inhuman or degrading towards the persons in their care and must avoid complicity in such behaviors” (p. 13). Such responsibilities under the value of dignity are strong statements of the moral duty of nurses to treat patients respectfully and without prejudice in health care interactions, and to advocate for appropriate services that support persons to live with dignity.

The value of justice requires that “nurses uphold principles of equity and fairness to assist persons in receiving a share of health services and resources proportionate to

their needs and in promoting social justice” (Canadian Nurses Association, 2002, p. 15). The responsibilities of nurses are to “not discriminate in the provision of nursing care based on a person’s race, ethnicity, culture, spiritual beliefs, social or marital status, sex, sexual orientation, age, health status, lifestyle, mental or physical disability and/or ability to pay” (p. 15). Nurses are obligated to fairly ration those health care resources within their control on the basis of individual needs for all persons receiving care. For example, nurses ought to fairly ration their time on the basis of health care need not social worth.

In the promotion of justice, nurses are urged to participate in the development, implementation and evaluation of health policies that improve care for patients based on current evidence. In this regard, nurses have a moral commitment to be engaged in health policy at all levels to address inequities in access to health and health care. The Code not only provides guidance for ethical behavior but points to an active role for nurses in shaping the context through the health policy process in order to enhance ethical practice for the benefit of the public. According to the Canadian Nurses Association (2002),

differing responsibilities, capabilities and ways of working toward change also exist at these various levels. For all contexts and levels of decision-making, the code offers guidance on providing care that is congruent with ethical practice, and for actively influencing and participating in policy development, review and revision (p. 5).

Nurses have an ethical responsibility to engage in the policy process within health care to improve the context of their practice and the provision of care.

Under the value of justice, nurses have a responsibility to “advocate for fairness and inclusiveness in health resource allocation, including policies and programs addressing determinants of health” and to be aware of broader health concerns such as homelessness in working towards social change (Canadian Nurses Association, 2002,

p.15). Building on the legacy of Alma Ata¹⁹ in which the role of nurses in the implementation of primary health care was specifically articulated, the Canadian Nurses Association has long been active in promoting primary health care as a key strategy for health care reform (Lemire Rodger & Gallagher, 1995).

The values of health and well-being, dignity and justice point to a moral imperative for nurses to engage in addressing inequities in health and access to health care as part of nursing practice at the bedside and beyond. As stated previously, ethical practice can be understood as the degree to which nurses are able to practice according to the values and responsibilities outlined in the Code of Ethics (Canadian Nurses Association, 2002). Within the Code, it is acknowledged that the ability of nurses' to enact their moral responsibilities cannot be separated from responsibilities to others (e.g. health care providers, agencies and policy makers) and that nurses practice to the degree they are able within these responsibilities. The Canadian Nurses Association (2002) states:

The ability of nurses to engage in ethical practice in everyday work and to deal with ethical situations, problems and concerns can be the result of decisions made at a variety of levels – individual, organizational, regional, provincial, national and international (p. 5).

Thus, nurses enact their ethical responsibilities within a context or set of social relations.

Moral Concerns of Registered Nurses

Within nursing, theoretical and empirical work has begun to identify the moral concerns of nurses in providing health care to those experiencing marginalization.

Several nursing authors have identified labeling and stereotyping of patients as a moral

¹⁹ At the Alma Ata conference in Russia in 1978, primary health care and the introduction of a central role for nursing in achieving primary health care were firmly established (Lemire Rodger & Gallagher, 1995).

concern because of the potential to influence negative behaviors on the part of the nurse and lead to inaccurate judgments of patients, affect quality of care and contribute to unfair distribution of resources (Carveth, 1995; Corley & Goren, 1998; Johnson & Webb, 1995). Corley & Goren state,

Social justice requires that persons be given a fair chance in life when their disadvantages are not of their own making. Yet, the criteria used to allocate limited resources may include gender, race, IQ, accent, national origin, and social status (Corley & Goren, p. 102).

While all patients are potentially subject to being labeled, there is considerable evidence that when nurses and others care for people who differ from the dominant 'norm' in terms of, race, class, religion, age, income, or sexual orientation, there is a greater risk for social judgments and resources being allocated on the basis of social worth and deservedness (Carveth, 1995; Corley & Goren, 1998; Grief & Elliott, 1994; Johnson & Webb, 1995; Kelly & May, 1982; Liaschenko, 1994, 1995; Malone, 2000; Podrasky & Sexton, 1988; Stevens, 1992, 1994).

Furthermore, in recent years the ever present emphasis on rationing has been heightened. There is serious concern that social worth is more likely to be a criterion for rationing care in the face of resource shortages. In the Institute of Medicine study (2002), time pressures, the complexity of patient needs and cost-containment pressures enhanced the likelihood of discrimination and interfered with the ability of providers to meet the needs of clients. At the same time that policymakers are navigating difficult ethical questions about rationing of financial resources among various budgets, nurses and other health care providers must make difficult ethical decisions about resource allocation at the bedside because of policy decisions at organizational, regional, provincial and

national levels of governance. Registered nurses in hospitals, for example, are increasingly pressured to ration already scarce resources such as the nursing time needed for appropriate assessments, management of symptoms, health teaching, community development and referrals, which increases the risk of resources being allocated on the basis of social worth or deservedness.

Social judgments involve the valuing, “judgment and labeling of the social worth of persons” by others and are a focal consideration in moral decisions and action (Johnson & Webb, 1995, p. 472). Moral or social judgments that imply a sense of valuing or devaluing of the ‘other,’ may contribute to further marginalization and influence moral action (Corley and Goren, 1998; Johnson and Webb). Particularly concerning is that negative labels and stereotypes are achieved collectively, through consensus of nursing staff and can be rapidly communicated from one nurse to another (Carveth, 1995; Johnson & Webb). This further disadvantages certain persons. Although nurses report secret attempts to resist negative labels and stereotypes (Johnson & Webb), they also face challenges in making moral choices between resisting their peers and preserving working relationships in order to ensure the delivery of good care into the future (Fisher, 1995).

As I indicated earlier in my review of the literature, nurses often find it difficult to establish and maintain relationships with those who might be labeled ‘difficult’ or ‘demanding.’ (Corley and Goren, 1998; Liashchenko, 1994; Malone, 1996). This has been identified as a serious moral issue because the nurse-patient relationship is central to the provision of care. In a study of ethical practice, people with substance use problems were identified as some of the most challenging clients for nurses in their work (Pauly &

Varcoe, under review). In particular, nursing students, in that study, identified their ethical concerns about micro-rationing care to clients such as those experiencing addiction. In working with patients identified as difficult or demanding, nurses may experience guilt, distress, shame and disembody themselves from their work (Corley & Goren, Fisher, 1995; Johnson & Webb, 1995; Schroeder, 1992). Nurses may experience moral distress when a disjuncture exists between the ideals and realities of practice. The experience of distress may be accentuated and accumulate over time if they perceive that others have been treated unfairly on the basis of social criteria such as race, class or gender by others and they do not take action in response.

More recently, 'othering' has been identified as an ethical concern in nursing practice (Peternelj-Taylor, 2004; Varcoe, 2004). Canales (2000) defines 'othering' as the process of engagement with those perceived as different from oneself. Critique of the process of 'othering' has its roots in feminist, postcolonial and critical theory (Canales, Peternelj-Taylor). Persons may be identified as 'the other' on the basis of race, gender, sexual identity or class. Inclusionary 'othering' is a way of engaging in which the power within relationships contributes to positive outcomes such as consciousness raising and inclusion (Canales). Exclusionary 'othering' is a negative process of engagement in that power differences contributes to labeling, stereotyping, alienation, marginalization and stigmatization (Canales; Corley & Goren, 1998; MacCallum, 2002; Peternelj-Taylor). People may be identified as 'the other' on the basis of race, gender, sexual identity or class. Those most vulnerable and experiencing marginalization (such as those who are homeless, living with addiction and mental illness) are more likely to be the object of

negative forms of 'othering' (Bunkers, 2003; Canales; MacCallum, 2002; Peternelj-Taylor, 2004).

Theoretically, work on 'othering' supports the belief that exclusionary 'othering' in health care can negatively affect the development of health care relationships and the health of individuals accessing care (Canales, 2000; Peternelj-Taylor; 2004). Varcoe (2004) argues that ethical analyses of nursing practice, "particularly practices that involve certain forms of 'othering'" (p. 414), will contribute to enhancing ethical practice and address social conditions of access to health care. Negative or 'exclusionary othering' is understood to be inconsistent with ethical standards of practice in nursing. 'Othering' operates not only at the individual level but within "families, communities, and society as a whole" (Canales, p. 16). Varcoe (2004), using violence as an example, argues that we ought to broaden the scope of ethics to include ethical examination of issues that involve 'othering.' She argues that ethical analysis of issues such as violence may reveal new insights and understandings that are germane to exploring and finding efficient, effective, and ethical strategies for addressing social concerns. From a theoretical perspective, 'othering' has considerable conceptual merit for transforming practice because of the dual dimension of inclusionary and exclusionary 'othering' and the need to acknowledge the context in which 'othering' occurs.

Nurses have long focused on concerns related to the provision of humanistic care. According to Lamb (2004), a major ethical concern during the middle period of nursing's modern development (1930's to 1960's) was the depersonalization and dehumanization of patients associated with hospital care. In response, there was a call for nurses to uphold nondiscriminatory attitudes, patient-centered approaches to care, and to

respect the worth and dignity of each person. She states that during this period within nursing ethics, “human rights and the dignity of person began to receive emphasis, as well as a shift to focus on the primacy of obligations to the patient” (p. 29). The international focus on human rights in the 1960s further intensified a growing emphasis on non-discriminatory care, respect for all people regardless of race and religion and notions of patient advocacy in the development of nursing ethics.

Little attention has been given to research in nursing ethics that explores the context in which ethical practice within health care interactions and relationships is enacted in order to generate insights for broader ethical concerns, particularly in relation to inequities in access to health care. The field of nursing ethics is rich with research related to ethical decision-making (for example, Kelly, 1998; Ketefian, 1981; Kuhse et al., 1997), moral experience of nurses (for example, O’Conner, 1996; Woods, 1999; Van der Arend & Van den Hurk, 1999), and ethical concerns of nurses in a broad range of practice areas (for example, Killen, 2002; Oberle & Tenhove, 2000; Omery et al., 1995). Increasingly, in nursing ethics, researchers are turning to ethical questions and concerns that are relevant to the everyday practice of all nurses (see for example, Fisher, 1995; Liaschenko, 1994; 1995; Rodney, 1997; Storch et al., 2002; Rodney et al., 2002; Varcoe et al., 2004; Wood, 1999). In gathering literature to support this dissertation, I found only a few studies exist that explored the ethical concerns and practice of community nurses (Aroskar, 1989; Oberle & Tenhove) and none were found that specifically studied street nurses or nurses working with people who are marginalized.

Aroskar (1992) observed that the moral commitments of nursing to promote equitable access have primarily been understood as the provision of nondiscriminatory,

respectful and nonjudgmental care rather than on taking action to impact policy that would enhance equitable access. She provides several reasons why nurses and others have focused on issues of individual patient care even though nurses have a moral imperative to work to effect changes in the conditions for equitable access. First, codes of ethics have a strong emphasis on respectful care of individuals. Second, there is a focus on individuals in the advocacy literature in nursing. In addition, professional discourses of saving lives at all costs, a context of societal values emphasizing individualism, and a prominent focus in bioethics on individual rights and autonomy have dominated health care. However she states, “Such realities do not serve as justification for a continuing lack of attention to access issues in nursing practice, research and theory development” (p. 202). The intent in the next chapter is to examine some of the historical influences which have narrowed the field of health care ethics and consequently nursing ethics. I will examine a variety of theoretical perspectives that hold potential for illuminating ethical concerns about inequities in access to health care as well as to identify potential theoretical frameworks for analysis of issues related to access to health care.

Chapter 2

Historical and Theoretical Perspectives in Health Care and Nursing Ethics

Given the diversity of people to whom nurses provide care, inequities in health status and access to health care for people who are street involved are of concern to nurses working in a variety of settings and at all levels in the health care system. However, little is known about how to counter such inequities in practice or the relationships of these inequities to the social, political, economic and historical context in which health care is delivered. My purpose in this research is to learn more about ethical practice and health care interactions within a broader social context that affects access to health care for people who are street involved.

There are a number of reasons for examining historical and theoretical perspectives in health care and nursing ethics as part of this work. First, as described in chapter 1, inequities in health status and access to health care are morally concerning. Second, little attention has been given to ethical analysis of access to health care concerns, particularly discrimination in the delivery of health care. Third, nurses, as described in professional codes of ethics, have an ethical commitment to enhance access to health care in their relationships with individuals, families and groups, in health policy and through collaboration with others. Fourth, while nurses have a broad range of ethical theory upon which to draw, there has been a disconnect between traditional bioethical theory and ethical practice in nursing (Liaschenko & Peter, 2003; Varcoe et al., 2004). However, the development of ethical theory is important to ethical nursing practice. Johnstone (1999) states,

As in everyday life, theory has an important role to play in assisting us to give meaning and order to our everyday moral experiences. Theory, or more accurately, moral/ethical theory, does this by helping us to describe the moral world, devise meaningful moral standards and prescribe moral ideals, distinguish ethical issues from other sorts of issues, and to provide a systematic justification of the actual practice of morality (p. 65).

Further, as Johnstone observes, ethical practice provides a framework for evaluating well-developed ethical theory. She states,

In several respects, therefore, the relationship between moral theory and ethical practice is symbiotic; just as ethical practice cannot be evaluated independently of its theoretical underpinnings, neither can moral theory be evaluated independently of moral experience (including that of applying both ordinary and formal moral theories) (p. 66).

The field of nursing ethics has developed in relation to the field of health care ethics.

In this chapter, several historical and theoretical developments in health care and nursing ethics will be examined and discussed. Through an examination of diverse theoretical perspectives in health care and nursing ethics, my aim is to identify theoretical perspectives that are useful in the ethical analysis of issues related to inequities in access to health and health in research, policy and practice. I will begin with a discussion of the influences and forces that have shaped, and in some respects narrowed, the field of health care ethics. Next, I will discuss and critique principle based ethics as one theoretical approach to work in bioethics. Then, I explore other theoretical perspectives from narrative, cross-cultural and feminist ethics that have expanded the field of health care ethics and have the potential to enhance the field of nursing ethics.

In part, my goal is to point to areas within health care ethics that might enrich the theoretical development of nursing ethics. I argue that feminist and cross-cultural ethics are important areas of exploration for nurses because they help to illuminate the context

of nursing practice. Feminist and cross-cultural approaches have the potential to illuminate issues related to inequities in access to health care for people who are street involved as well as providing a rich theoretical source that could inform ethical analysis. Finally, I discuss the development of nursing ethics in the midst of health care ethics and identify the specific requirements for a theory of nursing ethics needed to guide research, policy and practice.

HEALTH CARE ETHICS

Development of Health Care Ethics

Ethics is “a generic term for various ways of understanding and examining the moral life” (Beauchamp & Childress, 2001, p.1). Within the field of ethics, there are three forms of inquiry: descriptive, meta-ethics and normative (Beauchamp & Childress; McDonald, 2000). Descriptive ethics is concerned with systematically depicting moral values. Meta-ethics is concerned with analysis and meaning of moral terms, concepts, and methods of reasoning (Beauchamp & Childress; Rodney, Burgess, McPherson & Brown, 2004; McDonald). As McDonald observes, normative ethics is inquiry about the values that “people **ought** to have” and involves the making of moral judgments (p. 10). Practical or applied ethics “refers to the use of theory, argument and analysis to examine moral problems, practices, and politics in professions, institutions, and public policy” (Beauchamp & Childress, 2001). According to Beauchamp & Childress, practical ethics describe ‘what ought to be’ to be the case and thus, is readily understood to be normative. Although descriptive and meta-ethics have normative implications, my focus in this project is on explicitly normative aspects of health care and nursing ethics.

Inquiry in the field of bioethics can be defined as a concern with the “rightness and wrongness of various actions, character traits and social policies” in health care (Arras, Steinbock & London, 1999, p. 2). Arras, Steinbock and London suggest that since we are concerned with right and wrong, bioethics is “inescapably *normative*.” In the past, the terms bioethics, biomedical ethics, medical ethics and health care ethics have been used interchangeably (Johnstone, 1999; Rodney, Burgess, McPherson & Brown, 2004). I am using the term bioethics or health care ethics²⁰ to refer to the broader field of ethical inquiry in health care concerned with the moral dimensions of health care relationships, professional practice, organizations, societal structures, and health policy (Storch, 2004). The purpose of such inquiry is to “find a way to motivate moral behavior, to settle disagreements and controversies between people, and to generally bind people together in a peaceable community” (Johnstone, p. 64).

While morality and ethics has been a subject of debate and study in philosophy since Plato, Socrates, and Aristotle, contemporary bioethics as a field of inquiry gained prominence in the early 1970s (Arras, Steinbock & London, 1999; Johnstone, 1999; Storch, 2004). The rise of modern bioethics during the post World War II era came in response to concerns associated with technological advances in health care and human experimentation in research (Arras, Steinbock & London, 1999; Fox, 1990; Pellegrino, 1993; Rodney, Burgess, McPherson & Brown, 2004). Early theoretical influences in the field came from philosophy, theology and law (Arras, Steinbock & London, 1999; Rodney, Burgess et al., 2004). Philosophers brought to bioethics an interest in foundational theories, particularly, utilitarianism, deontology and contractarianism as

²⁰In contrast, I take references to biomedical or medical ethics are specific to physicians.

the theoretical basis for bioethics. The influence of theology and law was reflected in theoretical perspectives such as natural law, virtue theory and rights theory. More recently, the field of bioethics has been often equated with biomedical ethics which has been influential both in defining issues of concern and in the development of ethical theory (Johnstone, 1999). Johnstone states,

Today, the dominant concerns of mainstream Western bioethics are still essentially mediocentric, with the most sustained attention (and it should be added, the most institutional support) being given to examining the ethical and legal dimension of such 'exotic' issues as: abortion, euthanasia [and many others]Not only has mainstream bioethics come to refer to and represent these issues, but, rightly or wrongly, has given legitimacy to them – through the power of naming – as *the* most pressing bioethical concerns of contemporary health care in the Western World (Johnstone, p. 44).²¹

While nursing has an important voice in these issues from a unique perspective in health care, placing such issues at the center of health care ethics marginalizes other issues of concern to nurses- such as those presented in this study. As Johnstone points out, it is a mistake to equate bioethics or health care ethics with medical ethics in spite of the powerful influence of medicine in the development of health care ethics.

The Rise of Principlism

Historically, the growing interest in ethics among practitioners and policy-makers, the difficulties of applying grand theories to real life situations, as well as other societal and professional forces contributed to the rise of the principled approach in health care

²¹ Johnstone (1999) lists many other issues such as organ transplantation, reproductive technology, ethics committees, informed consent, and confidentiality, economic rationalization of care, medical futility and research ethics.

ethics (Evans, 2000; Pellegrino, 1993; Rodney, Burgess, McPherson & Brown, 2004).²²

The introduction of mid-range ethical principles, derived from multiple ethical theories, were a significant theoretical development in health care ethics. The principles received wide attention and it was hoped that delineation of such principles would aid moral reasoning in real life situations (Rodney, Burgess, McPherson & Brown, 2004).

Pellegrino (1993) observed that the rise of principlism in the 1960s occurred as the tenets of the Hippocratic Oath were being questioned by the civil rights movement, feminism, and consumer activism in North America. As the oath became less relevant for the practice of medicine, medicine turned to moral philosophy and principlism in an effort to deal with ethical issues.²³ At the same time, interest in a set of mid-range principles was fueled by a growing interest among policymakers in the United States in articulating clearly defined statements of the ethical basis of research as a justification for policy positions (Evans, 2000). Furthermore, principlism, as a response to foundationalism, seeks to balance competing theories through the delineation of a set of mid range principles. In that regard, the bioethical principles have been instrumental in providing a common language for discussion of ethical concerns in health care, enhancing clarity in identification of ethical issues and providing a systematic approach to ethical analysis (Pellegrino, 1993; Rodney, Burgess et al., 2004).

²² My observation and concern is that nurses and others have focused mainly on the application of the principles in ethical analysis to a set of narrowly defined concerns consistent with dominant issues in bioethics. Thus, obscuring concerns related to ethical practice.

²³ I am not suggesting that principlism is the only approach within medical ethics; rather it is an approach that has dominated health care ethics and has most often been adopted in nursing.

Principlism is an abstract, deductive, rational approach grounded in moral philosophy that is tied to action rather than to notions of the good life (Diamond, 1983; Fox, 1990; Pellegrino, 1993). According to Wolfe (1994), ‘principlism’ is

an approach to reasoning about ethical problems that proceeds in the main not deductively from higher-order theory, or inductively from fine-grained attention toward the situation presented, but from middle level principles down to the case presented (p. 400).

Beauchamp and Childress (2001) have been the most influential in the development and promotion of a principled approach in health care ethics.²⁴ Beauchamp and Childress (1989) point out that both, deontology and utilitarianism, “converge on the same principles and rules” (p. 62). According to Pellegrino (1993), in adapting a set of principles for medical ethics, Beauchamp & Childress chose the four principles most relevant to medicine: nonmaleficence, beneficence, autonomy and justice.²⁵ In the past, “nonmaleficence and beneficence have played a central historical role in medical ethics” (Beauchamp & Childress, 1994, p. 38). Today, respect for autonomy and justice have become more prominent. Each of the four principles will be defined and discussed in relation to inequities in health status and access to health care as described in chapter 1.

Autonomy

The principle of autonomy is concerned with respecting and enhancing the decision making capacity of individuals (Beauchamp & Childress, 2001). Respect for

²⁴ Beauchamp and Childress (2001) do refer to their work as a theory. However, they do not claim to present a comprehensive ethical theory but that the principles present some elements of a comprehensive and general theory.

²⁵ Beauchamp and Childress (2001) describe the use of principles as “the four-principles approach to biomedical ethics” (p. 23). The four clusters of principles are (1) respect for autonomy (a norm of respecting the decision making capacities of autonomous persons), (2) nonmaleficence (a norm of avoiding the causation of harm), (3) beneficence (a group of norms for providing benefits and balancing benefits against risks and costs), and (4) justice (a groups of norms for distributing benefits, risks, and costs) (p. 38). I think it is important to note that each principle is not one but a clusters of principles.

autonomy is broadly understood as the “recognition that patients have the authority to make decisions about their own health care” (Sherwin, 1998, p. 19). Health care providers ought to acknowledge the decision-making rights of people and act to assist persons to make autonomous decisions. Support for the principle of autonomy is derived from the work of John Stuart Mill and Immanuel Kant.

Mill’s position requires both not interfering with and actively strengthening autonomous expression, whereas Kant’s entails a moral imperative of respectful treatment of persons as ends in themselves. In their different ways, these two philosophies both support the principle of respect for autonomy (Beauchamp & Childress, 2001, p. 64).

Autonomy is closely associated with decision-making in health care. Therefore, considerations of autonomy are primarily concerned with consent and refusal of treatment (Beauchamp & Childress). However, as Sherwin (1998) observes respect for autonomy is enacted within health care relationships. The understanding that health care relationships are central to acknowledging, recognizing and supporting capacity for decision-making especially for those experiencing social disadvantages is only beginning to emerge (Sherwin, 1998).

Nonmaleficence and Beneficence

Nonmaleficence refers to the duty of health care providers to take due care to avoid harming patients. In their description of nonmaleficence, Beauchamp & Childress (2001) focus on the prevention of physical harm to others. They state,

Though harm is a contested concept, everyone agrees that significant bodily harms and other setbacks to significant interests are paradigm instances of harm. We will concentrate on physical harms, especially pain, disability, and death, without denying the importance of mental harms and setbacks to other interests (p. 117).

Beauchamp and Childress observe that the principle on nonmaleficence may be brought to bear on ethical concerns of assisted suicide, intending and foreseeing harmful outcomes, withholding and withdrawing treatment and extraordinary and ordinary treatments for those who are terminally and seriously ill (Beauchamp & Childress, 2001). These are important concerns but the focus on physical harms and a related range of concerns does not illuminate the harms of inequities in health status as a result of social circumstances or inequities in access to health care.

Closely related to the principle of nonmaleficence is the principle of beneficence. The principles of nonmaleficence and beneficence are derived from several ethical theories, particularly utilitarianism. Not only do we have a duty to refrain from actions that cause harm but a duty to act in ways that benefit or promote good for others (Beauchamp & Childress, 2001). In health care ethics, preventing and removing harms and promoting good are particularly germane to discussions of paternalism and risk/benefit analysis of treatments in health care decision-making. In this regard, I would suggest that the principles of nonmaleficence and beneficence could be extended to ethical analysis of issues related to inequities in health status and access to health care. For example, to what degree do practitioners use social criteria in assessing risk and benefits of particular treatments for those who are street involved?

Justice

The fourth and final principle is that of justice. Beauchamp & Childress (2001) observe “the terms *fairness*, *desert* (what is deserved) and *entitlement* have been used by various philosophers in attempts to explicate *justice*” (p. 226). Justice is not so much understood as a single principle but a cluster of concepts grounded in utilitarian,

libertarian, communitarian and egalitarian theories of justice (Beauchamp & Childress, 2001). According to Beauchamp & Childress (1994) “The term *distributive justice* refers to fair, equitable, and appropriate distribution in society determined by justified norms that structure the terms of social cooperation” (p. 327). The primary focus of concerns related to notions of distributive justice is fair allocation of resources in health care.²⁶ Distribution of resources such as health care are proposed on the basis of different sets of criteria including equality, need, merit, effort, contribution and free market exchange (Beauchamp & Childress; McDonald, 2000; Rescher, 1989).

In the United States, distribution of health care, in many respects, is left to the forces of the marketplace and health care is treated as a commodity rather than a right of citizenship (Beauchamp & Childress, 1994, 2001; Daniels, 1985). For example, in the United States, private health insurance is more predominant than in Canada and it was estimated that approximately 44 million people were without any health insurance in the year 2001 (Robert Wood Johnson Foundation, 2003; U.S. Census Bureau, 2002). Many more have inadequate health insurance coverage.²⁷ This reflects a more libertarian than egalitarian view of justice. Achieving equity in a libertarian distributive paradigm focuses on concerns related to the availability, organization and financing of health services and satisfaction of users of the system (Aday et al., 1998). Social justice concerns arising from an egalitarian or communitarian perspective of justice are largely ignored. Aday

²⁶ It is important to note that resource allocation is only one aspect of justice. Other considerations of justice include procedural justice, compensatory or corrective justice and justice as punishment (McDonald, 2000; personal communication, M. McDonald, June, 28, 2005; Rescher, 1989). In health care, considerations of justice are often related to resource allocation rather than other considerations of justice.

²⁷ As mentioned previously, the lack of health insurance in the United States has been identified as a serious ethical concern by some American bioethicists (Buchanan, 1995; Caplan, Light & Daniels, 1999; Daniels, 1985)

describes the meaning of social justice grounded in a non-libertarian perspective. She states, social justice is

concerned with health disparities and the fairness and effectiveness of the procedures for addressing them. The ultimate test of the equity of health policy is the extent to which disparities or inequalities in health persist among subgroups of the population. Substantive equity is reflected in minimizing subgroup disparities in health. Procedural equity refers to the extent to which the structure and process of care, for achieving these outcomes may be judged to be fair (p. 2).

Beauchamp and Childress (2001) acknowledge that it is difficult to balance competing notions of justice within a principle based approach. Beauchamp and Childress (1994) state that theories of distributive justice will only be partially successful “in bringing coherence and comprehensiveness to our fragmented visions of social justice” (p. 335). They raise concerns about the incompatibility of ideals that promote “equal access to health care for everyone including care for indigents, while maintaining aspects of a free-market competitive environment” (p. 231). They argue that different concepts of a just society underpin each of these ideals and that working to achieve one will be at the expense of the other. I take this to mean that, in the American context, there is a tendency to lean towards a libertarian perspective of justice over other concepts of justice because of strongly held societal values.²⁸ I would suggest that, in particular, egalitarian notions of justice are more likely to illuminate concerns related to inequities in

²⁸ A libertarian view of justice would suggest that justice is achieved when rights to property and liberty are protected (Beauchamp & Childress, 2001). Beauchamp and Childress (2001) appear to lean towards a libertarian view of justice that would be consistent with and that reflects dominant cultural values. Others, such as Aday et al., (1998) and Daniels (1985; 2001) have conceptualized justice within a communitarian and egalitarian perspectives. However, it remains that Beauchamp and Childress (2001) have received wide reading and application within the field of health care ethics not only in the United States but in Canada and abroad. Thus, my concern is with the import of dominant cultural values into other societies that may be operating from a different value base (Coward & Ratanakul, 1999). The problem in this regard is the failure to recognize the value base of ethical theory and acting as if the principles are value neutral.

health and access to health care such as those raised here.²⁹ While Beauchamp and Childress acknowledge the work of Daniels (1985; 2001) in promoting egalitarian concepts of justice, they appear to refute egalitarian perspectives on justice in favor of more libertarian views.³⁰ It has been argued by several authors that conceptual differences, incoherence among various conceptualizations and lack of clarity in defining justice have contributed to the lack of focus on issues related to access to health care in nursing and among ethicists and policy makers more broadly (Aroskar, 1992; Caplan, Light and Daniels, 1999).

Considerations of justice in resource allocation may be divided into micro, meso and macro-level allocation concerns (Rodney, Burgess, et al., 2004; Yeo, 1993; Yeo & Moorhouse, 1996). Thus, the focus is on the type of resources being allocated. This is highly relevant to my focus of concern in that inequities in health status and access to health care may be mitigated or reinforced at every level in the health care system on the basis of decisions made by nurses, other health care providers, administrators and policymakers.

Macro-level allocation is concerned with fair distribution of resources among various sectors in society in order to achieve public good. For example, at the governmental level (provincial and federal), the focus of concern would be on the allocation of funding between sectors such as education, health and social services

²⁹ Egalitarian theories would support equal access to health care on the basis of need and equality rather than individual liberty (Daniels, 1985; 2001). The implications of egalitarian concepts of justice will be discussed later in the chapter on policy. A related observation is that research on Canadian values as well as current intentions embodied in the Canada Health Act strongly suggests that Canadian favor a more egalitarian perspective on justice (Pauly, 2004).

³⁰ Egalitarian theories would support equal access to health care on the basis of need and equality rather than individual liberty. The implications of egalitarian concepts of justice will be discussed later in the chapter on policy.

(Rodney, Burgess, et al., 2004). Meso-allocation concerns would focus on questions related to the division of health care resources among multiple and competing health care programs and services. Decision-making about meso-allocation of resources can be at the level of governments, health regions or institutions and seeks to determine fair allocation of resources previously dedicated to health care. “Micro-level allocation is the distribution of services to individual patients” (Rodney, Burgess, et al., 2004, p. 66). This involves determination of who should or should not receive particular services and treatments in the delivery of direct patient care. In nursing, there is a growing recognition that decisions made at the macro and meso levels have a profound effect on the actions of health care providers at the micro-level (Canadian Nurses Association Code of Ethics, 2002; Rodney et al., 2002; Varcoe & Rodney, 2002). Health care providers under pressure to contain costs and working with limited resources may ration care to those considered less deserving in society (Rodney & Varcoe, 2001; Varcoe & Rodney, 2002; Varcoe, Rodney & McCormick, 2003). Thus, inequities in health status and access to health care may be exacerbated by resource shortages. Alternatively, inequities in health status and access to health care may be mitigated when health systems resources are allocated at the macro and meso level of health care that seek to address the determinants of health.

In the preceding paragraphs, I have attempted to outline the way that a principled approach to ethical analysis illuminates some concerns related to inequities in health and access to health care. As Rodney, Burgess, et al. (2004) observe, the four principles are no longer adequate as the singular basis for analysis in health care ethics. They state,

this traditional approach does not help us to understand and to deal with the personal, social, and cultural aspects of health as well as the complex sociopolitical climates in which health care is delivered and in which resources for health are embedded. In philosophical terms, we see the principles as necessary but not sufficient (p. 66).

This raises two important considerations. First, careful attention must be paid to the values inherent in different theoretical perspectives and that we ought to consider a broad range of theoretical perspectives in examining the moral life in health care.³¹

Beauchamp and Childress (2001) concur that, “rights, virtues, and emotional responses are as important as principles and rules for a comprehensive vision of the moral life” (p. 14). In addition to the principles they explore concepts of rights, virtues and emotions in relation to the four principles. In their now classic text, they have interpreted and further specified the four principles through discussion of the meaning and limitations of veracity, privacy, confidentiality and fidelity as expressions of these principles within professional-patient relationships (Beauchamp & Childress, 2001). Although not as clearly stated as in the 1994 version of their text, it is evident that they never meant the principles to be used exclusively in ethical analysis.³² In practice, one might ask, ‘what theoretical work would be most helpful to me in considering what is good and what action I ought to take in providing care to those who are street involved?’ Through an examination of three emerging perspectives in health care ethics, my hope is to further

³¹ Although Beauchamp and Childress (2001) refer to their work as a theory, they clearly acknowledge that the ‘principled’ approach is lacking in all of the elements required for a complete theory.

³² It is interesting to note that in the 1994 version of their text, Beauchamp and Childress have a very clear statement that locates narrative, intuition and other forms of ethical knowledge as complementary to the four principles. I could not find a similar statement in the 2001 version.

highlight theoretical perspectives that illuminate issues related to inequities in health and access to health care.

Emergent Perspectives in Health Care Ethics

During the past decade or more, there has been a continued search for other approaches to work and scholarship in health care ethics (Wolf, 1994; Pellegrino, 1993).

Wolf states,

There is a proliferation of alternatives to principlism: a demand for even more abstract moral theory deductively applied, advocacy of specified principlism, a revival of casuistry, the call for an inductivism based on empirical information or ethnography, interest in narrative bioethics, and the articulation of care -based ethics (p. 400).

One might describe this growing set of alternatives under the umbrella of contextualist ethics (Rodney, 1997; Rodney, Pauly & Burgess, 2004). Winkler (1993) defines contextualism as

The idea, roughly, that moral problems must be resolved within concrete circumstances, in all their interpretive complexity, by appeal to relevant historical and cultural traditions, with reference to critical institutional and professional norms and virtues, and by utilizing the primary method of comparative case analysis (p. 344).

In order to understand the complexities of moral life that be missed in other approaches, there has been a turn to theoretical work in several areas including narrative bioethics, cross-cultural ethics, feminist ethics, and care based perspectives (Coward & Ratanakul, 1999; Nisker, 2004; Sherwin, 1992, 1998; Storch, Rodney & Starzomski, 2004; Tong, 1997). In particular, work in feminist and cross-cultural ethics provides new theoretical perspectives for analysis of particular concerns in health care, such as inequities in access to health care for marginalized groups. In the following sections, I will discuss

developments in narrative, cross-cultural and feminist ethics relevant to inequities in health and access to health care.

Narrative Ethics

Interest in narrative approaches to ethics within health care has grown in recent years, as both an alternative and complement to principle based approaches (Arras, Steinbock, & London, 1999; Benner, 1991; Bergum, 1998, 2004; Frank, 1995; Gadow, 1999; Murray, 1997; Nisker, 2004). For example, Arras (1997) states that narrative is “an essential element in any and all ethical analysis [and] constitutes a powerful and necessary corrective to the narrowness and abstractness of some widespread versions principle- and theory-based ethics” (p. 84). According to Nisker, the value of narrative is that stories bring us closer to understanding the uniqueness of individuals for whom we care and thereby, can assist in clinical and moral-decision-making. Narratives may be in the form of poems, stories, plays, or movies. Regardless of the particular form, narratives have the characteristic of being ‘thick’ in personal and social details rather than ‘thick’ on medical detail (Nisker). Nisker observes that narrative is the place to begin exploration in bioethics.³³ He states,

Stories, whether true, fictional, or fictional based on truth, can help bring the reader or audience to the position of the person requiring health care, thus allowing a much deeper appreciation of that person’s needs, rights, and desires than is possible in health care and philosophy tomes. By approximating empathy for the person at the centre of the decision-making, ethics explorers and educators can better contribute to moral resolution of the issue at hand, and provide better care (p. 291-92).

³³ Similarly in nursing, Benner (1991) sees narrative as the place to start in ethics but she moves beyond the notion of sensitizing others to the uniqueness of persons receiving care. She states, “ethics in health care must start with a practice-based understanding of what it is to be a person, what constitutes the relationship among the health care worker, patient, family, and community and what constitutes care and responsibility toward one another” (p.18).

He suggests that the approximation of empathy for individuals and subsequent sensitivity to all patients is increased with the use of narrative and enhances the provision of better patient care.

In sum, the power of narrative in health care ethics helps to generate and sustain compassion among health care providers. Further, Nisker proposes that narratives are of value in health policy making:

Narratives, by surfacing ethical issues from the perspectives of a person central to the issue, can recruit the thoughts of the public, health care providers, ethicists, scholars and policy-makers for their moral exploration. Stories inform the heart thus have the potential to educate toward compassionate health care policy development (p. 300).

Nisker, like others writing in the field of narrative ethics, focuses on patient stories told by the individual person or someone else such as a care provider. Work in narrative ethics is particularly valuable in relation to traditional as well as emerging theories in bioethics. I would argue that many of the alternative and complementary approaches to principled ethics draw on the insights from narrative ethics in which story and dialogue became an important method for doing work in health care ethics. Qualitative data is often in the form of stories that can help to highlight particular issues and concerns in ensuring access to health care for those who are street involved.

Cross-Cultural Ethics

As I pointed out previously, the ethical principles reflect particular cultural values. Several authors have observed that the field of health care ethics has been dominated by medical and Western cultural values (Coward & Ratanakul, 1999; Fox, 1990, Johnstone, 1999). From a cross-cultural perspective,

modern Western biomedicine and its health care system is itself a culture with its own belief system, social structure, initiation rituals, language, dress and educational system. Modern medicine does not occupy a neutral position from which to relate itself sensitively to other cultures. Rather modern Western medicine is itself a culture alongside the other cultures -Muslim, Buddhist, Hindu, Chinese, etc. (Coward & Ratanakul, p. 3).

All North American ethical theory (libertarian, utilitarianism, rights based and others) reflects Western cultural values and is inherently ethnocentric (Rodney, Pauly, & Burgess, 2004). Cross-cultural ethics helps to illuminate the value foundations of accepted theoretical perspectives and cross-cultural dialogue has the potential to enrich our understanding of ethics (Coward & Ratanakul, 1999).

Cross-cultural critiques charge that there has been a lack of attention to the social and cultural context of ethical concerns and a failure to recognize the influence of Western and biomedical cultural values in health care ethics (Weisz, 1990; Coward & Ratanakul, 1999). Respecting autonomy is often treated as a universal truth rather than one value system among many (Burgess, 1999). Yet, autonomy as a primary value is problematic in many cultures where the self may be understood collectively or in we-self rather than I-self terms (Coward & Ratanakul; Hoffmaster, 1999). “And why, then, could it not be argued that health care in North America ought to learn from the family-centered and community-centered cultures it encounters, rather than try to force those cultures to become more patient-centered?” (Hoffmaster, 1999, p. 150). Concepts such as autonomy may be inappropriate in other cultures and of limited assistance in cultures where the person is not clearly defined from the family or community. “Aboriginals, Buddhists, and Chinese would argue that collective notions of personhood that are fundamental for the traditional Aboriginal, Chinese and Buddhist worldviews, for

example, are radically different from the individualism and autonomy presupposed in much contemporary European and North American thinking” (Hoffmaster, p. 152). Disrupting individualistic notions of health and culture is central to the work of cross-cultural ethics. In cross-cultural ethics, health is conceptualized as a social rather than an individual responsibility that helps to illuminate the social conditions that affect health and the need to address injustice such as inequities in health among groups in society.³⁴

The dominance of individualism as a cultural value has profoundly affected the range of ethical issues that are recognized within bioethics and the development of bioethical frameworks to address these issues (Fox, 1990; Stephenson, 1999). Privileging individual ethical questions removes ethics and bioethicists from involvement in social problems (Fox, 1990). Stephenson (1999) reflects a similar concern that valuing individualism and valorizing personal control of events while ignoring collectives and powerlessness of individuals “leads to neglect of minority groups and to a view of public health that is not constructed or understood in ethical terms” (Stephenson, p. 88). Inequities in health status and access to health care do not emerge as a significant ethical issue in traditional health care ethics.

Stephenson (1999) argues for an expanded notion of culture in bioethics to broaden the scope of ethical concerns and address group concerns. He states, “culture can be thought of as a broad and deep influence on all human behavior that is simultaneously personal and social with implications for our species as a whole” (p. 71).

³⁴ Individualistic views of health are essential to beliefs that emphasize personal responsibility for health. Thus, those in poor health, if it is seen as of their own making such as in the case of addiction, are considered to be responsible for their ill health and could reverse their ill health if they took action such as abstaining from addictive substances. Such views blame the individual and ignore the effect of social conditions on health (Anderson and Reimer-Kirkham, 1999).

He observes that we have a very constrained view of culture that treats culture as one variable among many that determines human behavior. Culture, if addressed in health care and nursing ethics, is often interpreted as ethnicity (Rodney, Pauly, Burgess, 2004). The limitation of defining culture as ethnicity is that it becomes visible only when we meet 'others' of a different ethnic background without necessarily revealing the ethnic background of White English speaking health care providers (Coward & Ratanakul, 1999).³⁵ Stephenson observes the dangers of taking a limited view of culture,

Culture cannot be reduced to a manipulated variable called 'cultural beliefs' without considerable collateral damage being done to the people to whom the narrowed concept is applied. In a narrow construction of culture as a residual and manipulated category, the subject population (patients or clients) have 'health care beliefs' (culture), while professionals are the bearers of Medicine- a supposedly value-free entity which is valorized as entirely 'good' and 'objectively true' (science) (p. 71).

One cannot simply add culture as another element to consider within traditional ethical approaches. This would merely repeat and perpetrate the problem of cultural imperialism found in Western bioethics.³⁶

The problem is not the value of Western bioethics for other cultures but rather the cultural imperialism inherent in application of Western bioethics in cross-cultural

³⁵ Doane and Varcoe (2005), in a discussion of the benefits of pragmatism for nursing theory and practice, point out that if we accept the "idea of culture as shared values and beliefs, as something closely associated with or even equated with ethnicity or nation, and as a 'thing' that belongs to groups of people. It became evident that such theoretical understandings direct nurses away from the actual experiences and meanings of families and individuals, and make their thinking vulnerable to stereotypes and assumptions. Conceptualizing culture as a thing that belongs to groups leads to a rather static understanding of culture and fosters a process of 'othering' - that is, those who belong to groups in which as nurses do not claim membership are seen as 'other'" (p. 86). Thus, notions of culture as ethnicity serve to alienate rather than being nurses closer to understanding the experiences and meanings for people.

³⁶ In nursing, Lutzen (1997) and Lutzen and Nordin, (1993) have initiated exploration of moral concepts and principles in relation to culture in the development of nursing ethics. Other nurse authors have attempted to adapt traditional ethical theory and ethical decision-making frameworks to include a cultural component (e.g. Gripp, 1995). The latter approach treats culture as one variable among many, primarily that of ethnicity.

situations as if it were value neutral (Coward & Ratanakul, 1999). Cross-cultural dialogue and understanding provides an approach that illuminates the values inherent in all cultures and provides a point from which to view the worth and validity of different perspectives in ethical analysis. Recognizing the worth and validity of different perspectives is an extremely difficult task because of the inherent ethnocentricity and tendency to regard our own point of view as obviously true, “and the views of other cultures as wrong, difficult to understand, or even immoral or disgraceful” (Jameton, 1990, p. 444). However, respecting and tolerating different values does not require that we have to hold such values as our own truths. For example, cross-cultural dialogue provides an opportunity to examine societal values that deem illegal use of substances to be immoral without condemning the worth of the perspectives of those who use illicit drugs.

Since morality occurs in a cultural context, it is critical to understand the cultural beliefs and practices ‘from the inside’ before we judge such practices. Taylor (1992) suggests that the study of any other culture begins with the ‘presumption’ that “we owe equal respect to all cultures” (p. 66). In cross-cultural dialogue, as described by Coward and Ratanakul (1999), one would appeal to bioethical theory in other cultural traditions in order to better understand an ethical dilemma. For example, Burgess, Rodney, Coward, Ratanakul and Suwonnakote (1999) analyze the situation of parents who refused life-saving treatment for their infant son from the perspective of ethical principles, a First Nations perspective, as well as Thai Buddhist and Hindu perspectives. It is interesting to think about concerns related to inequities in health status and access to health care and a

broad range of different cultural perspectives that might be brought to bear in consideration of such questions.

Embracing expanded notions of culture and health means beginning with respect for marginalized and socially disadvantaged groups such as those who are street involved and working to reveal the underlying conditions that affect their health status and access to health care. Expanded notions of health and culture, as proposed by those doing work in cross-cultural ethics, has the potential to 1) illuminate the cultural values that are embedded in traditional concepts of health care ethics; and 2) open new avenues for work in health care and nursing ethics that could inform the development of equitable policy and practice. Additionally, theoretical perspectives in cross-cultural ethics point to the importance of public participation in health care policy making at the micro, meso and macro level (Blue, Keyserlingk, Rodney, & Starzomski, 1999). Drawing on cross-cultural ethics holds promise not only for illuminating issues related to inequities in health and access to health care but also for informing health policy that enhances access to health care for those who are street involved. Likewise, feminist ethics, which I will discuss next, has the potential to illuminate concerns related to inequities in health status and access to health care.

Feminist Ethics

Feminist ethics as a branch of philosophy emerged in the late 1970s. Jagger (1991) describes the development of feminist ethics this way,

The two parallel strands of feminist ethical work – the attention to contemporary ethical issues on the one hand and the criticism of traditional ethical theory on the other – together gave rise to the term ‘feminist ethics,’ which came into general use in the late 1970’s and early 1980’s (p. 81).

Johnstone (1999) identified two important tasks of feminist ethics that of moral critique, and the development of radical moral theory. As a form of moral critique, the purpose of feminist ethics is to examine and expose theories in which women and others are excluded, to develop new ways of moral thinking, identify ethical concerns in everyday life and to make visible the contributions of feminist thinking (e.g. role of emotion in ethics). According to Jagger (1991), in the development of moral theory

feminist ethics must be dedicated to rethinking the deepest issues in ethical theory-what counted as moral issues and by what means they might properly be resolved-in a light of a moral sensibility perceived as distinctively feminine (p. 82).

In feminist ethics, a primary concern is with the realities of everyday moral life.³⁷ (Calhoun, 2004; Johnstone, 1999). Feminist ethicists, although theoretically diverse, share a common focus on the nature and importance of interdependency within relationships and the broader socio political context in which morality is lived (Calhoun; Jagger, 1991; Johnstone; Sherwin, 1992, 1998, 2000; Wolf, 1994).

For instance, Calhoun observes that women philosophers in feminist ethics share attentiveness to everyday moral life particularly, “our vulnerabilities and dependencies on each other and the sociopolitical context in which moral life is conducted” (Calhoun, p. 4). According to Wolf (1994), a claim of feminist ethics “is that analysis of power and morality cannot proceed without careful attention to context and difference” (p. 406).

Susan Sherwin (1992), a feminist ethicist and philosopher, states that feminist ethics

³⁷ There is a sense of realism that characterizes feminist ethics concern with everyday moral life. Calhoun describes,

by ‘realism’, I mean attentiveness to what moral life is really like - what moral agents are really like, to what the production and acquisitions of moral knowledge is really like, to what the social practice of morality is really like, to what character development is really like, to what practice decision making is really like – *as opposed* to the conventions within moral philosophy for describing these same things (p. 4).

“demands explicit focus on the social and political contexts of individuals in its moral deliberations” and is attentive to power inequities in moral relationships (p. 40).

Although there is no single feminist ethical theory, a common theoretical theme is seeing the self as ‘being in relation’ rather than seeing the self as an autonomous moral agent and bringing to the fore the context in which moral decision making and action occur (Johnstone, 1999). To this end, feminist authors have addressed the separation of ethics and politics (Malone, 1999; Tronto, 1993). Tronto observes that boundaries exist that demark the limits of ethics including a boundary between ethics and politics.

Malone (1999) reminds us that policy has a moral dimension to it because it involves decisions that affect others who may or may not be involved in the process of deciding how a particular problem should be addressed. Likewise, all ethical theories and arguments become meaningful and relevant within a social and political context (Tronto, 1993). The relationship between ethics and politics is integral to theoretical work in feminist ethics. In particular, the important role of the political context in moral theory and decision-making is emphasized (Wolf, 1994; Sherwin, 1992, 1998). Increasingly, others have recognized the importance of reconnecting ethics to policy and politics to enhance the good in society (Bernstein, 1991; Blue et al., 1999).

Feminist ethics is unified by a shared political need (Calhoun, 2004; Johnstone, 1999; Liaschenko & Peter, 2003). Calhoun states:

The point of having a distinct category of philosophy called feminist ethics or feminist philosophy is to promote the development of conceptual, theoretical, and interpretative tools that will enable philosophy to be responsive to the fact that gender and other hierarchies of power have important and damaging effects on human, personal, social and cognitive life (p. 9).

Work in feminist ethics and bioethics has evolved from bringing the perspective of women's experience into the field of ethics, to recognition that other factors such as race and class have an important impact on human experience and moral life (Calhoun, 2004; Lebacqz, 1991; Olesen, 2000; Sherwin, 1992; Warren, 1989; Wolf, 1994). As such, the focus on gender, race and class, age and social orientation are concerns with difference (Lebacz, 1998). Difference is not understood as inherent to individuals but as a social construction of how we perceive each other in our relationships and is politically significant (Lebacqz, 1998). As such, difference is politically significant. Difference, as Lebacqz (1998) explains:

then is partly a matter of power- of who has the power to define difference. Dominant groups often define *others* as different, neglecting the fact that they themselves are just as different to the other (p. 20).

Difference is morally relevant when it is associated with discrimination, oppression or injustice (Lebacqz). Through the lens of recognizing and valuing difference, the contribution of feminist ethics in health care has helped to illuminate issues often obscured in traditional bioethics such as sexism, inequities, stress, and power in relationships, conduct of ethical discussions and the introduction of theoretical diversity in ethics.

Writing from a feminist bioethics perspective, Sherwin (1992) observes that within bioethics there is awareness that individual health care needs vary inversely with power and privilege. She urges all bioethicists to attend to the effects of poverty and those who are at risk for experiencing poverty. She argues that people who are oppressed on the basis of gender, race and class are the ones to experience greater health problems and have least access to health care. Sherwin states:

The damaging connections between oppression and illness are profoundly unfair. Because this situation is ethically objectionable, bioethicists have a responsibility to consider ways in which existing medical institutions can be modified to challenge and undermine these connections, rather than contribute to them. Ethical analyses of the distribution of health and health care must take into consideration the role that oppression plays in a person's prospects for health and well-being (p. 223).

Sherwin provides a compelling argument to consider questions of equity in access to health status and health care from an ethical perspective. However, as mentioned previously, outside of feminist ethics concerns about inequities in health status and in access to health care have received limited attention within the field of health care ethics.³⁸

In health care ethics, Sherwin (1992, 1998, 2002), drawing on feminist theory has made a significant contribution to the development of contextualized understandings of central bioethical concepts including autonomy and justice. From a feminist perspective, personhood is understood as being relational. Sherwin (2002) explains,

Specifically, relational theory requires us to supplant the familiar ideal of the independent, rational, self-interested deliberator of liberal individualism with a relational subject who is (at least partially) constituted by social interactions. Rather than understanding persons as ontologically prior to society, a relational account envisions persons as beings who are created – in large part- through their social relations (p. 288).

Sherwin describes the work of feminists in conceptualizing autonomy as follows,

Accounts of relational autonomy make explicit the fact that autonomy is both defined and pursued in social contexts; as well, social conditions significantly affect an individual's very ability to exercise autonomy. Hence, where liberal individualist theories either look at the generic conditions required for an individual to exercise autonomy (in political theory) or they focus on the quality

³⁸ Ethical concerns about inequities in health status and access to health care are sometimes raised within the field of public health as concerns of social justice. However, these discussions are often removed from the field of bioethics. Although the field of public health ethics is evolving in an attempt to explore the ethical underpinnings of inequities in health status and health care, at this time, there is considerable controversy over the focus of the field (Anand, Peter & Sen, 2004; Bernheim, 2003; Bayer & Fairchild, 2004).

of decision-making by individuals as they are presently constituted (in practical ethics), feminist relational accounts explore the social conditions that support- or inhibit—each person's ability to identify and pursue her own concerns. Feminist accounts are particularly sensitive to the ways in which oppressive structures limit the types of choices available to members of particular social groups and interfere with the opportunities members of oppressed groups have for developing the skills necessary for exercising autonomy (Sherwin, 2002, p. 290).

In her work on relational autonomy, Sherwin (1998) acknowledges the virtues of respect for autonomy but argues for a relational concept of autonomy that is 'socially situated' or 'contextualized' with particular attention to the effect of the political context on relationships and delivery of health care. She elaborates,

Under a relational view, autonomy is best understood to be a capacity or skill that is developed (and constrained) by social circumstances. It is exercised within relationships and social structures that jointly help to shape the individual while also affecting others' responses to her efforts at autonomy (p. 36).

The person not only is offered the choice but there is an opportunity to develop the skills to make choices, to experience respect for decisions and encouragement to reflect on personal values. Sherwin's work identifies the relational nature of the enactment of ethics in practice and the way in which health care delivery is enmeshed in the social context. Sherwin's notion of relational autonomy illuminates new concerns and focuses on removing barriers and constraints that might interfere with the ability of people to be autonomous within a particular social context. For example, one might ask, 'Were there adequate opportunities for respectful encounters with health care providers in which patients are able to reflect on the values informing their decisions and choices?' Given the research reviewed for this dissertation, this would be particularly important for those experiencing marginalization including those who are street involved.

Several feminist ethicists focus on the importance of exploring and redefining concepts of justice (Lebacqz, 1998; Sherwin, 1992, 2002; Young, 1990). Young (1990) argues that instead of “focusing on distribution, a conception of justice should begin with the concepts of domination and oppression” by acknowledging and attending to group differences (p. 1). She explains further, “the politics of difference sometimes implies overriding a principle of equal treatment with the principle that group differences should be acknowledged in public policy and in the policies and procedures of economic institutions, in order to reduce actual or potential oppression” (p. 11). Sherwin (2002), drawing on Young (1990) provides insight into the need to conceptualize justice in feminist relational terms within health care.

This requires supplementing considerations of distributive justice with questions of social justice. Traditional liberal individualist accounts tend to focus narrowly on question of distributive (and retributive) justice. Distributive justice is designed to address allocations of quantifiable, finite, material things and does not capture the conditions necessary for proper access to social goods such as rights, opportunity, power, and self-respect. In contrast, feminist accounts of social justice provide tools for investigating ways in which sexism, racism, and other forms of oppression support unjust arrangements of social goods. They encourage us to look at effects of policies, procedures, and practices at the level of social groups and to pay particular attention to ways in which oppression structure relationships among different groups (p. 292).

Work in feminist ethics to conceptualize and contextualize central ethical concepts such as autonomy and justice demonstrate the contributions of those working in feminist ethics to the development of health care ethics (and as will be shown later) potentially nursing ethics.

Feminist ethics points to the need for attention to both the particulars of relationships and to the context in which providers and clients are embedded.

NURSING ETHICS

Evolution of the Field

The focus in the field of nursing ethics is the provision of ethical norms and guidance for nurses in practice as well as ethical analysis and the development of ethical theory relevant to nursing (Yeo & Moorhouse, 1996; Johnstone, 1999). Johnstone describes the central focus of the field of nursing ethics,

Drawing on a variety of ethical theoretical considerations, nursing ethics at its most basic could thus be described as a practice discipline which aims to provide guidance to nurses on how to decide and act morally in the contexts in which they work (p. 47).

According to Yeo & Moorhouse, the term nursing ethics has at least three meanings associated with it. First, the term refers to the ethical norms (values, virtues, principles) of the profession that ought to guide everyday practice and are found in professional Codes of Ethics. Nursing ethics, in this first sense was discussed in chapter 1. While codes of ethics describe the ethical norms that ought to guide everyday practice, even though achieved through consensus, such norms are ideal. However, due to constraints, actual practice may be guided by other norms. A second meaning of nursing ethics is an examination of how nurses actually conduct themselves. A third meaning of nursing ethics refers to the growing body of literature that

deals with the moral dimension of nursing wherein various ethical issues are analyzed, discussed and debated. Used in this sense, nursing ethics is not a set of norms, actual or ideal, but a field or discipline in which such norms are explored and analyzed (Yeo & Moorhouse, p. 3).

In this section, I will first turn to discussion of key debates and developments within the field of nursing ethics. My primary intent is to consider the current development of nursing ethics and future directions for development in nursing ethics. In particular, I

am concerned with future directions that will inform the enactment of ethical standards of practice that will enhance access to health care for those experiencing marginalization.

In the past, nursing ethics was viewed as subcategory of medical ethics (Veatch, 1981; Fry, 1989a). According to Veatch, both nursing and physician ethics were subcategories of medical ethics within bioethics and that “there is very little that is morally unique to nursing” (p.17). As Fry (1989a) observed, “if nursing ethics is a specific form of inquiry under the more general category of biomedical ethics, then any theory of nursing ethics will necessarily follow from biomedical ethics theory” (p.11). Initial views of nursing ethics as a subset of medical ethics meant that nurses focused on borrowing theory from biomedical ethics, and principlism was uncritically adopted as a central ethical approach in nursing (Brown et al., 2004; Fry, 1989a, 1989b; Omery, 1989; Yeo, 1989).³⁹ Fry (1989a) questioned this tendency to merely adopt the moral foundations of medicine as valid moral foundations for nursing ethics. She stated, “It is important to question whether the values appropriate to the practice of medicine or the

³⁹ Yeo (1989) has raised concerns about uncritically borrowing from other disciplines. I agree with his point about uncritically adopting the work of others. As Fry (1989a) has observed this is problematic as the value foundations of nursing differs. Yeo (1989) advocates that nursing ethics should arise “from nursing itself” and points nurses to consider nursing theory in the development of nursing ethics (p. 39). As Yeo (1989) has observed, nursing ethics and nursing theory, while attempting to address the same issues such as “the nurses’ role and responsibility in relation to patients, other health care professionals, and society in general” have the shared goal of defining a professional identity for nurses (p. 33). However, there has been little communication between the field of nursing ethics and the development of nursing theory.

While one might agree that nursing theory is a better source to borrow from than moral philosophy or development psychology, this too cannot be done uncritically. Another concern is Yeo’s assumption that nursing theories are taken as representative of nursing experience and practice. Nursing theories represent ideal or artificially constructed conceptualizations of nursing that may or may not be true representations of nursing practice and experience. As a result, there often exists a gap between theory and practice. From this logic, it appears to make sense that it would be wiser to return to nursing practice itself and the experience of nursing as a source for informing the development of nursing ethics. This provides a context for understanding the desire for more phenomenologically based approaches to nursing ethics such as Benner (1991) and Bishop and Scudder (1991).

moral foundations for the physician-patient relationship are necessarily applicable to the practice of nursing or the nurse-patient relationship” (p. 14). Jameton (1984) argued that nursing ethics was unique as a form of ethical inquiry within philosophy. According to his view, nursing ethics was conceptually located alongside rather than within the field of health care ethics. Fry (1989a) outlined a third possibility in which nursing ethics is a subset of health care ethics alongside medical ethics. At the same time, it is important to remember that the discipline of medicine had a profound influence on the development of health care ethics and therefore nursing ethics (Coward & Ratanakul, 1999; Fox, 1990; Johnstone, 1999; Peter & Liaschenko, 2003; Wolfe, 1994). In this study, I understand nursing ethics as a form of inquiry within the field of health care ethics positioned alongside but distinct from medical ethics.

Nurses in practice and those in education attempting to learn the language of ethical principles have found that traditional ethical theory does little to highlight ethical concerns in their practice, and may even discount their concerns (Peter & Liaschenko, 2003).⁴⁰ Peter and Liaschenko (2003) observe,

To hold that nurses can participate fully to the extent that they know the theory is illusory. Such a belief ignores that the conception of morality that inheres in bioethical theory, defines what a moral problem is, authorizes who can label a moral problems as such, and specifies the form of thinking that must be used in approaching the problem. Definition, authorization, and specification follow from particular values and social arrangements of various relationships (p. 259).

⁴⁰ I am reminded here of my own experience of taking my first undergraduate medical ethics course in which not only was I introduced to contemporary ethical theory but introduced to what counted as ethical issues. I still remember being surprised and somewhat shocked that the concerns about ethics which had arisen from my practice and lead me to learn about ethics were not in fact important or even legitimate ethical issues because they did not fit into the range of extraordinary ethical concerns. At the end of the course, I still felt as if the four principles were foreign to my practice and that I was somehow deficit in my ability to understand and apply them. However, I continued to believe that learning more about ethical theory would help me to understand and address those concerns in everyday practice that had brought me to the study of ethics. While I have been fortunate to be able to continue and enrich my learning in ethics, my experience in other projects suggests this is not the case for many nurses.

Particularly concerning is that the moral concerns and experiences of nurses may be sidelined, dismissed, or redefined (Brown et al., 2004; Peter & Liaschenko, 2003). Thus, the moral concerns of nurses 'get disappeared' in bioethical discourse and may contribute to "nurses' moral self-doubt that calls into question the legitimacy of their concerns and their often highly astute moral understandings (Peter & Liaschenko, p. 261). This is concerning not only for nurses but also for those receiving nursing care.

Early in the development of nursing ethics, Levine (1977) stated there are ethical challenges to be found in everyday activities of professional practice that have been overlooked in favor of an emphasis on life and death issues. Ethical behavior, she asserted,

is not the display of one's moral rectitude in times of crises. It is the day-by-day expression of one's commitment to other persons and the ways in which human beings relate to one another in their daily interactions (p. 846).

Levine highlighted the nature of our interactions and relationships with others as important everyday ethical concerns in nursing. Fry (1989a) has argued that nursing needs more than bioethical principles not only to legitimize everyday ethical concerns in practice but to enhance the capacity (moral agency) of the nurse to act ethically. She argued,

The context of nursing practice requires a moral view of persons rather than a theory of moral action or behavior or a system of moral justification. Present theories of medical ethics tend to support theoretical and methodological views of ethical argumentation and moral justification that do not fit in with the practical realities of nurses' decision making in patient care and that, as a result, tend to deplete the moral agency of nursing practice rather than enhance it. (p. 20).

According to Fry, knowledge of principlism is useful to ethical analysis in nursing but knowledge of principlism alone is insufficient for an ethics of everyday nursing practice and will actually undermine the moral agency of the nurse.⁴¹

Within the field of nursing ethics, there has been considerable discussion and disagreement about the appropriate moral foundation for nursing ethics and a theory of nursing ethics (Bishop & Scudder, 1987; Cooper, 1988; Curtin, 1979; Huggins and Scalzi, 1988; Liaschenko, 1993; Packard & Ferrara, 1988; Salsberry, 1992; Winslow, 1990; Yarling and McElmurray, 1986). Additionally, during the past decade, there have been continued, but isolated, efforts to articulate the moral foundation of nursing ethics using a variety of approaches (Benner, 1991; Brody, 1988; Cooper, 1988; Fry, 1989a, 1989b; Gadow, 1985, 1990; Liaschenko, 1999; Lutzen, 1997; Peter & Morgan, 2001; Yeo, 1989). However, there is growing agreement about the centrality of the nurse-patient relationship to nursing ethics⁴² (Benner, 1991; Bishop & Scudder, 1987; Brody, 1988; Cooper, 1988; Curtin, 1979; Fry, 1989a, 1989b; Gadow, 1985, 1990; Liaschenko, 1993, 1999; Lutzen, 1997; Packard & Ferrara, 1988; Peter & Morgan, 2001; Yarling and McElmurray, 1986; Yeo, 1989). Fry (1989a) states,

Any theory of nursing ethics should consider the nature of the nurse-patient relationship within health care contexts and should adopt a moral point of view that focuses directly on this relationship, rather than on theoretical interpretations of physician decision making and their associated claims to moral justification for this decision making (p. 20).

⁴¹ According to Rodney (1997), the enactment of moral agency can be understood in relation to the fulfillment of nurses' moral responsibilities and accountabilities and the manner in which nurses deal with ethical concerns in everyday practice.

⁴² A number of different models for the nurse patient relationship have been proposed. For example, Curtin (1979) proposed advocacy as the basis for the nurse patient relationship. Other proposed models have been based on trust, caring, contract, fiduciary or convental relationships (Cooper, 1990; Peter & Morgan, 2001).

In a review of the historical development of nursing ethics, Lamb (2004) observed that there has been a gradual shift in the focus of nursing ethics over the past three decades “from basic human rights to the rights of patients in health care to an exploration of the nature of the nurse-patient relationships as a basis for ethical conduct” (p. 34).

The understanding that ethical practice within relationships is enmeshed in a matrix of relations that are socially, historically, economically and politically situated is only beginning to emerge (Liashenko, 1994, 1995; Liaschenko & Peter, 2003; Rodney et al., 2002; Rodney & Varcoe, 2001; Storch et al., 2002; Varcoe & Rodney, 2002; Varcoe, Rodney & McCormick, 2003; Varcoe et al., 2004; Woods, 1999). Thus, nursing needs a theory of nursing ethics that is attentive to both interpersonal and political requirements of nursing practice (Bowden, 2000; Liaschenko & Peter, 2003). In other words, nursing needs a theory of nursing ethics that is attuned to the dynamics of relationships and reveals the relatedness of nursing practice to the broader social context as well as actions to modify the context (Bowden, 2000). Since barriers to accessing health care for those who are street involved can be present within health care relationships and within the structures of the health care system, such a theory would provide moral guidance for addressing inequities interpersonally and systemically.

Theoretical Developments in the Field of Nursing Ethics

In nursing, as in the field of health care ethics, there has been interest in the development of other sources of ethical knowledge including theoretical perspectives drawn from narratives of practice, care based and feminist ethics (Benner, 1991; Bergum, 1994, 1998, 2004; Bishop and Scudder, 1990; Fry, 1989a, 1989b; 1999; Gadow, 1994, 1999; Wolf, 1994; Pellegrino, 1993; Peter & Morgan, 2001; Peter & Liashenko, 2003).

Fry (1999) observed that “All of these approaches are laden with different theoretical presuppositions and the potential for influencing the way that the nurse recognizes ethical conflict, and names and addresses it as part of the clinical judgment process” (p. 11).

I will examine three theoretical perspectives within nursing ethics: (1) existential/phenomenological (2) care based and (3) feminist.⁴³ Although all three perspectives include a focus on the interpersonal nature of relationships, each perspective differs significantly in the conceptual focus brought to bear on the broader social context and supporting nurses to enact their ethical commitments in enhancing access to health care. I begin with a discussion of work by Benner, (1984, 1991). Bishop & Scudder (1987, 1990) provide important insights into the nature of ethics in nursing primarily centered in caring and relationships that arise from existential phenomenological perspectives.

Existential Phenomenological Perspectives⁴⁴

The meaning of what is good and notions of ethics are embedded in nursing practice (Benner, 1984, 1991; Benner & Wrubel, 1989; Bishop and Scudder, 1987, 1990). “To examine notions of the good life, what is worth being and preserving, one must study everyday ethical expertise and narrative embedded in the practices of communities” (Benner, 1991, p.1). Both Benner (1984, 1991) and Bishop and Scudder (1990) used phenomenological approaches in developing narratives of excellent nursing practice.

⁴³ In putting forth these categories, I am not proposing a rigid typology but merely a useful way of differentiating between different approaches found in the nursing literature. It is important to note that there are overlapping and complementary features in each category as well as features which conflict. Although I have attempted to be reasonably comprehensive in my review, I do not claim (nor have I aimed) to include all approaches or the work of every relevant author. I have chosen those approaches that have predominated in discussions and debates of the development of nursing ethics.

⁴⁴ Johnstone (1999) has referred to such approaches as existential phenomenological.

From their analysis of nurse narratives, Bishop and Scudder (1990) contend “that nursing is essentially a moral enterprise involving personal relationships with patients,” and that excellent nursing practice is the moral imperative of nursing (p. 27). Nursing practice is viewed as an inherently ethical activity and ethics as integral to the practice of the nurse.

According to Bishop and Scudder (1990), a phenomenological approach “brings to consciousness the sense of nursing which is already inherent in practice, rather than imposing meanings on it from outside” (p. 5). Thus, the meaning of ethics as well the moral issues and problems emerge from nursing practice rather than being imposed from the outside. Bishop and Scudder observe that issues such as dealing with conflicting loyalties, and maintaining appropriate professional boundaries (balancing intimacy and distance) often missed in traditional ethics, are revealed in a phenomenological approach.

In particular, Bishop & Scudder (1990) argue that the nurse is in a privileged ‘in-between’ position. They contend that,

In practice, nursing ethics is based primarily on trust and mutuality. This implies that the in-between situation of nurses, which is such a thorn in the side of those who stress autonomy, is actually a privileged position from which to make moral decisions concerning patient care (p.11).

They believe that the ‘in-between position’ of the nurse (between patient, physician and organization) does not render the nurse powerless and unable to enact as an autonomous professional but rather provides the context for nurses decision making in health care. In fact, the nurse can still exercise her legitimate authority in moral decision making:

from the vantage point of her expertise as do the physician, patient and hospital bureaucrat. However, the nurse, unlike the others, is in the privileged position for reaching such decisions because she is accustomed to deciding from an in-between perspective (p. 141).

Bishop and Scudder's (1990) notion of the 'in-between' position as a position of privilege may be theoretically useful. In reality, however, it is often a position of difficulty and distress when organizational constraints impact and prevent nurses from doing the right thing such as resisting stereotypes or advocating for difficult or 'unpopular' patients (Fisher, 1995; Liaschenko, 1994; 1995). As Bowden (1997) observes, Bishop and Scudder "assume a level of communal solidarity and 'in-between' privilege that seems to overlook the widespread conflict and dissatisfaction that is such an outstanding feature of nursing practice in contemporary western institutions" (p. 127). Bowden concludes that such a position is disabling when nurses are expected to maintain excellent nursing practice while faced with unreasonable demands in an unsupportive environment that does not acknowledge the authority of nurses.

Based on research of everyday nursing practice, Benner (1991) has concluded that the dominant ethics in nursing is one of care and responsibility and that "ethics in health care must start with a practice-based understanding of what it is to be a person, what constitutes the relationship among the health care worker, patient, family, and community and what constitutes care and responsibility toward one another" (p.18). According to Benner (1991), knowing a patient as related to others and embodied is central to the ethics of care and responsibility. Embodiment allows for understanding at the level of common humanity and protection of vulnerability. In nursing, engaged knowledge of patients and families provides wisdom and direction for acting ethically. Benner's work is based on nurse narratives and excavating the good in practice from the nurses perspective.

There are few patient narratives in the nursing ethics literature. As a result, we know little about the experience of 'doing good' from the perspective of patients - Where is the voice of the patient? Would the patient agree? Did they feel that their integrity, dignity and worth were respected? What do patients want? What do patients expect? What about times when the nurse fails to know a patient because of lack of commitment to caring, lack of skills to know the patient who is different or 'other than' or is working within a system that does not encourage the nurse 'to know' (Corley & Goren, 1998)?⁴⁵ Focusing only on the good as a foundation for nursing ethics, is particularly problematic when there is a failure to recognize the 'dark side'⁴⁶ in health care encounters or the moral situatedness of the nurse (Corley & Goren). Furthermore, Bowden (1997) pointed to a significant omission in Benner's work and the failure to address the structural relations in which nursing practice is enmeshed. Valorizing heroes in nursing through narrative does little to acknowledge the contextual constraints that affect nursing practice and may inadvertently reinforce or lead nurses to be held responsible for contextual constraints (Storch et al., 2002; Rodney and Varcoe, 2001; Varcoe, et al., 2004). Thus, individual nurses may be held solely to blame for negative experiences in health care among those who are street involved.

⁴⁵ Additional concerns related to care/caring as the basis for nursing ethics are outlined in the section on care-based perspectives in nursing ethics. Also, some concerns related to Benner's (1984, 1991) use of nurse narratives are taken up later in this section as part of the more general critique of narratives in nursing ethics.

⁴⁶ The 'dark side' is a term used by Corley and Goren (1998) in which nurses act in ways that do not respect the worth of persons.

*Relational Ethics*⁴⁷

Bergum (1994, 1998, 2004) has put forth the notion of relational ethics as a new perspective within health care ethics.⁴⁸ In describing relational ethics, Bergum (2004) draws our attention to the importance of relationships as the site of connection between nurses and their patients and the quality of relationships:

With relational space as the location of enacting morality, we need to consider ethics in every situation, every encounter, and with every patient. If all relationships are the focus of understanding and examining moral life, then it is important to attend to the quality of relationships in all nursing practices, whether with patients and their families, with other nurses and with other health care professionals, or with administrators and politicians (p. 487).

Relational ethics is one of a few perspectives that draws on both patient and provider narratives as a source of knowledge (Austin, Bergum & Dossetor, 2003). Relational ethics is grounded in hermeneutical phenomenology. Hermeneutical phenomenology begins with description but extends beyond pure description to interpretation and the creation of meaning (Jardine, 1992; Smith, 1994; van Manen, 1997). It is in our

⁴⁷ I would also include in this category the work done by Gadow (1994, 1999). Using methods of philosophical analysis, Gadow (1999) provides an explanation of a framework of three ethical layers: “subjective immersion (ethical immediacy), objective detachment (ethical universalism) and intersubjective engagement (relational narrative)” (p. 57). She suggests that in the integration of the layers, “nursing becomes more than a moral high ground from which difference is excluded. It becomes, instead, a region of existence large enough to accommodate, even encourage, diversity among those who live there” (p. 66). The first level safely carries us through most situations, the ethical principles steady us when dilemmas arise and “finally there are situations where no edifice can alleviate our vulnerability and in those cases we can only turn to each other and together compose a fragile new form of the good” (p. 66). In this last layer, in what sense, can this be understood to be normative good?

⁴⁸ Although Bergum has articulated relational ethics as a form of health care ethics in general, her work has particular relevance for nursing and many nurses, including myself, have been actively involved in her research on relational ethics. Some of the understandings of relational ethics articulated in this paper are drawn from the author’s own experience of working as a member of the research team both as a research assistant and co-researcher to the Ethics of Nurture Project (1993-1997) and the Relational Ethics Project (1997-2000) and as a student in a Ph.D course taught by Dr. Bergum on Interpretive Inquiry (Spring 1999).

relationships with others that self-understanding and meaning is created. Smith (1994) states,

One of the most important contributions hermeneutics makes to all contemporary social theory and practice, then, not just to curriculum and pedagogy, is in showing the way in which the meaning of anything is always arrived at referentially and relationally rather than (for want of a better word) absolutely (p. 119).

In relational ethics, ethical practice is located within relationships and ethical knowledge such as knowing how to act and doing the right thing is developed within our relationships with one another (Austin, Bergum, & Dossetor, 2003).

Environment, engagement, embodiment and mutual respect are central themes in the development of relational ethics (Austin, Bergum & Dossetor, 2003; Bergum, 2004). The theme of environment illuminates the health care system as a living system in that practitioners, through their actions in the delivery of health care, are embodying and giving life to the health care system. The actions of practitioners are constantly shaping and changing the social, political and even ecological environment in which care is provided. Thus, individual actions are constantly shaping the social, political and environmental context of our work. The theme of embodiment is a call to reintegrate mind and body, scientific knowledge and human compassion in that emotions are as important as physical signs and symptoms. For providers, the importance is to see the patient not just as a body but as embodied. Like patients, health care providers are embodied and in need of self-knowledge and self-respect in order to care for others. For example, what do I value and believe about those who are street involved? How am I physically responding to an individual? What am I communicating verbally and non-verbally?

The theme of mutual respect calls us to respect others. Bergum (2004) observes that mutual respect is “probably the central theme of a relational ethic” (p. 495). She observes that it is easy to say everyone deserves respect but that “respect for difference (e.g. power, knowledge, beliefs and values, experience, attitudes) does not come easily” (p. 495). She points out that professionals who are working within their own perspectives may fail to realize the value of other perspectives and that “with the theme of mutual respect, we are asked to look for ways to achieve cohabitation or coexistence between people who are different but of equivalent worth and dignity” (p. 495). The challenge of working within difference is made possible within the fourth relation theme of engagement (being true to oneself while attending to the other). Ethical action begins with seeking to understand the other through meaningful engagement.⁴⁹ While there seems to be a general awareness of ethical concerns related to over-involvement, she reminds us that we ought to be concerned about under involvement with people as well. Genuine engagement opens new possibilities for developing trust, identifying patient needs, sharing knowledge, building capacity, creative problem solving and creating time by being with patients in critical moments. The relational themes of environment, embodiment, engagement and mutual respect are enacted through dialogue.

In relational ethics, ethical principles and theories can be placed within the context of culturally, technologically and socially diverse relationships. Knowledge for ethical care is constructed in the relationship between the professional and patient as they work to understand meaning within the patient’s experience rather than outside (Bergum,

⁴⁹ Bergum (2004) acknowledges that the inability to meaningfully engage with the other should be recognized as an ethical issue in that lack of engagement is an ethical concern.

1994). Knowledge for ethical care is multi-layered and consists of descriptive, abstract and inherent knowledge. As Bergum (1994) puts it,

The knowledge for ethical clinical judgment must evolve through three kinds of knowledge: *descriptive* knowledge of subjective experience (listening to a patient's description of symptoms and experiences), *abstract* knowledge or scientific, technological thinking and rationality (analysis and diagnosis), and *inherent* knowledge of lived meaning (p. 78).

This means we would begin with the client's description of their experience. What is your experience? What is your story? What is the meaning of this decision for you, for your relationships with others? Such questions might help us to develop the descriptive knowledge needed for ethical care. As part of the abstract knowledge, we would consider traditional ethical principles and theories. From this, the creation of new meanings (inherent knowledge) can be developed within the context of relationships. This approach demands that we begin with an exploration of narratives and that we enter into, rather than stand back, from an analysis of the situation. Can nurses always be open and able to put aside judgments in providing care? For instance, I have noted in chapter 1 that at times and for a variety of reasons, nurses make social judgments in caring for those who are street involved. Within the themes of embodiment, engagement, and mutual respect there are important insights that would contribute to removing qualitative barriers in health care interactions and enhancing access to health care. The theme of environment points to the need to extend ethical considerations beyond interpersonal relationships into broader health system relations. However, it is not clear how broader contextual concerns such as the very structures of health care that contribute to inequities in health and access to health care would be addressed by nurses.

Reflections on Narrative Perspectives

Benner (1991) and Bergum (1994, 1998, 2004) agree that ethical principles alone are not adequate for ethical action. Both of these authors have suggested that narratives need to be introduced into practice in order to promote individual ethical action. Benner (1991) states

Generalization and the search for commonalities take the form of abstract principles or objectified accounts. But these forms, abstract principles, analytical reporting and objectified generalizations do not evoke everyday ethical comportment. They cannot attend to qualitative distinctions, relational and contextual issues, or engaged care. We need to reintroduce narrative both in our practice and in our discourse on ethical practice, so as to extend, alter, and preserve ethical distinctions and concerns (19-20).

Phenomenological/existential approaches can be useful to nursing ethical practice in naming, recognizing and understanding intimacies of the nurse-client relationship. As Murray (1997) writes, excerpts from narratives

vibrantly capture centrally important scenes from human lives. Those images and excerpts are crucial raw materials for making and justifying moral judgments. They are intimately tied to the central project of morality – the effort to understand and to live a good, fully human life (p. 17).

Narrative approaches are valuable in surfacing ethical concerns, enhancing sensitivity in our relationships with others as well as providing new insights and understanding into the lives of others (Benner, 1991; Bergum, 2004; Nisker, 2004).

As Nisker argues, narrative ethics is a place to begin in ethics. However, it is not clear how or if narrative ethics can provide normative direction to a profession for taking broader social action and addressing structural concerns that perpetuate inequities in health and access to health care. Approaches such as that of Benner (1991) and Bishop & Scudder (1990), provide important insights into nature of ethics at the level of

interpersonal relationships with individual patients but provide little insight into the social, political economic and historical factors that affect practice and the action needed to address inequities at the system level. I would argue that nursing needs a theoretical approach that provides an understanding of the ethics of interpersonal relationships and the socio-political context of practice if nurses are to enact their ethical commitments in enhancing access to health care.

In putting forth relational ethics Bergum (2004) takes a broader view of relationships beyond the nurse-patient dyad to relationships with other health care providers, administrators and policy-makers, it remains essentially an interpersonal approach.⁵⁰ As an interpersonal approach, it seeks to address relationships in a broader social context but not the conditions that shape the context itself. Several authors in nursing have pointed to the need for attention to the structures that contribute to the development of the conditions that affect the ability of nurses to practice ethically (Rodney & Varcoe, 2001; Varcoe & Rodney, 2002; Rodney & Starzomski, 1993). The approaches discussed thus far do not call attention to concerns with the very structures of health care or meet the need for a nursing ethic that provides support for broader social action collectively and politically.

Care Based Approaches: Value, Virtue or Particularity?

The emphasis on caring in the development of nursing ethics has arisen out of criticisms of justice based medical ethics as an appropriate foundation for nursing ethics (Fry, 1989a, 1989b, 1999; Liaschenko & Peter, 2003; Parker Spreen, 1990). Salsberry (1992) observes that in articulating a nursing ethic based on care, nursing authors are

⁵⁰ This idea of an interpersonal approach is taken from Bowden (2000).

pointing to the need to recognize and accommodate the relational bases of nursing, the context of ethical decision making and the development of persons, not just acts, as important to ethics. In an attempt to articulate an ethics of care, nursing authors have emphasized caring as a feminine ethic drawing on work from developmental psychology, conceived caring as both a value and a virtue, and have conceptualized the relationship between justice and care. Each of these approaches is discussed separately below although it is clear that they are overlapping and complementary approaches. This is well illustrated by the work of Gadow (1985, 1990) that seems to transcend the boundaries created here.

Some nursing authors have argued that caring should be the foundational value underpinning the development of nursing ethics (Fry 1989a, 1989b; Gadow, 1985, 1990; Watson, 1988). Gadow (1985) articulates a belief that caring is a moral ideal that provides a foundation for nursing ethics that is aimed at the protection and enhancement of human dignity. Watson, building on the work of Gadow, views caring as the core of nursing and caring as a human value and the ‘moral ideal of nursing’ that protects, enhances and preserves “humanity by helping a person find meaning in illness, suffering, pain and existence” (p. 54).

Other nurse authors have proposed that caring is a virtue (Brody, 1988, Salsberry, 1992).⁵¹ According to Fowler (1986), virtues “are learned, practiced, cultivated or habituated; they are not a matter of heredity or personality” (p. 528). Brody (1988), in an examination of virtue ethics as a foundation for nursing ethics, identified caring as a basic

⁵¹ Similarly, there has been increased interest in the virtue ethics in the broader field of health care ethics (Pellegrino, 1993).

nursing virtue. He argued that 1) caring as a personal attribute means that nurses “are expected to carry out their professional duties with a sense of goodwill and respect toward the patient” (p. 92); 2) caring as a virtue can be defined “as the individual’s action, which is reflective of the agent’s moral nature” (p. 90); 3) caring must be demonstrated and “it is the caring *act* that is virtuous” (p. 93). Lastly, Brody states that “virtue is seen as the ability of individuals to meet the moral obligations of a collectively defined role they have assumed” (p. 90). Thus, nurses are virtuous when they fulfill their professional obligations to society.

Salsberry (1992) identifies three issues associated with virtue ethics forming the basis of professional commitment. The first is the difficulty in identifying a set of virtues. Second, even if caring is adopted as a virtue, what are the personal attributes of caring and is it possible to educate nurses in these virtues? Lastly, “even if we can identify the virtues and habitually practice them as to ‘produce’ virtuous humans, is that desirable?” (Salsberry, p. 17). She raises the concern that individuals may lose self-awareness and self-examination of their actions. Veatch (1985) observes, “to the extent that a robust virtue theory frees up actors to ‘sin bravely,’ and to act on the conviction that their motives are good, it may actually facilitate wrong acts” (p. 337). Viewed in this way, caring could be a vice (Curzer, 1993).

Nurses building on work in moral psychology have focused on and examined the moral reasoning and behavior of nurses using first the work of Kohlberg (Crisham, 1981; Ketefian, 1981a, 1981b), and then Gilligan (1982, 1988).⁵² In attempts to articulate an

⁵² According to Gilligan (1982; 1988), Kohlberg proposed that moral development occurs in stages and the highest level of moral development is rooted in a perspective of justice characterized by logical, rational

ethics of care, nursing authors have also turned to Noddings (1994) in education in addition to Gilligan. Caring, according to Gilligan, is relational, based on receptivity, response to the other and informs ethical decision-making. Gilligan's work has been used by nurses to articulate a care-based approach to ethics (Cooper, 1988, 1990; Davis, 1986; Huggins and Scalzi, 1988).⁵³

With Gilligan as a starting point, some nurses have turned to Noddings (1984) for a theoretical explanation of ethical caring (Fry 1989b; Kuhse, 1996). Noddings argues that caring ought to be an ethical way of being in relationships. In her view, caring relationships are characterized by "engrossment and motivational displacement on the part of the one-caring and a form of responsiveness or reciprocity on the part of the cared-for" (p. 150). The one caring feels with the other and acts to promote the other's well being and the one cared for is receptive and responsive to the one caring. "As we examine what it means to care and be cared for," she states, "we shall see that both parties contribute to the relation; my caring must somehow be completed in the other if the relation is to be described as caring" (p. 4). Noddings believes that ethical caring in practice is rooted in natural caring which she defines as "that relationship in which we

decision making. Kohlberg found that girls more often than boys never achieved the highest level of moral decision making in that they were able to reason using the principle of justice and that females were at an arrested stage of moral development. Gilligan (1982, 1988), interpreted these findings differently. She hypothesized that there are two modes of moral judgment, that of justice and that of care. Following additional research with both men and women, she concluded that "(1) concerns about justice and care are both represented in people's thinking about real-life moral dilemmas" and that people tend to focus more heavily on one orientation than another; and "(2) there is an association between moral orientation and gender such that men and women use both orientation," although a care focus is more likely to be presented by women (Gilligan, 1988, p. 82).

⁵³ According to Yeo (1989), nurses have borrowed uncritically from both Kohlberg and Gilligan. He suggests that "the moral lesson to be drawn from Gilligan's critique of Kohlberg is a profound one: rather than trying to speak the language that happens to be authoritative, one should learn to speak unashamedly in one's own voice and to celebrate one's difference rather than apologize for it" (p. 41).

respond as one caring out of love or natural inclination” (p. 50). In ethical caring, we act out of natural caring, the remembrance of natural caring, or the desire to be virtuous.

Criticisms of the care based approach raise concerns about an inherent gender bias and exclusion of men from caring, reinforcement of negative stereotypes, promotion of dependency, emotional attachment, over-involvement, and caring as contributing to burnout (Curzer, 1993; Nelson, 1992). In response to such concerns, some nursing authors have proposed the development of nursing ethics that accounts for both justice and caring (Brown et al., 2004; Cameron, 1991; Cooper, 1990).⁵⁴ An ethic of caring is not a complete ethical theory nor has it evolved from traditional moral theory (Cooper, 1990; Pellegrino, 1993; Sherwin, 1992; Wolf, 1994). Gilligan has been accused of creating a dualism between care and cure, nursing and medicine, women and men while Noddings (1994) has been criticized for offering a feminine rather than feminist ethics and for her failure to illuminate gender biases (Liaschenko, 1993). Bowden (2000) articulately summarizes the concern with a feminine understanding of a relationally based understanding of ethics of caring. She states,

⁵⁴Nelson (1992) observed that one cannot just add justice and stir as these approaches are philosophically distinct. Several authors have observed that caring is a partialist concern that has been pitted against impartial Kantian notions of justice (Nelson, Kuhse, 1997; Cooper, 1990) According to Cooper (1990), “the justice perspective, as described by Kohlberg, is a rule-and-principle-based ethic which was built upon a Kantian model of moral agency” that focuses on autonomy (p. 210). From her examination of the relatedness of the justice and care perspective within four concepts (autonomy, posture of the moral agent, considerations of universal or particular, and the role of rules and principles), she argues “that the frameworks of justice and care are mutually exclusive” and that false dichotomies between the two have been created in western culture (p. 216). Such dichotomies are created by the value placed on autonomy over relational concerns. Cooper, Kuhse, (1997), and Nelson, (1992), suggest that caring conceived as a particularist concern can exist within a larger framework of social justice. As Kuhse states, “an adequate ethics, an ethics suitable for combating injustices, an ethics suitable for nurses and for nursing, needs impartiality as well as care” (p. 141). However, given the concerns outlined above, it does not seem useful to continue to explore a marriage of caring and justice but rather to pursue other approaches to understanding the particular within relationships and in relationship to notions of social justice. Within, feminist ethics in nursing, one attempt to reconcile the personal, the particular with a perspective of justice has been presented by Liaschenko (1999).

But these discussions largely ignore the direct impacts of institutionalization effects on the constitution of nurse/patient relationships and focus almost exclusively on the interpersonal dynamics within the dyad (p. 47).

Furthermore, as Nelson observes,

The ethics of care, because it restricts itself to intimates and the proximate stranger, can provide no basis for larger questions of social justice. It can guide the nurse's deliberations only so far as to obligate her to care for nonpaying clients that the agency has already accepted, but it cannot tell her what to do about potential clients, as they lie outside the scope of her care" (Nelson, p. 11).

Bowden suggests that by extending the understanding of the ethics of care to relationships with other health care providers and administrators these concerns are more readily addressed. She states,

From this perspective, relationships with medical practitioners, administrators and patients alike all fall within the ethos associated with the ethics of care. The specific ethical possibilities and pitfalls of relationships of varying vulnerabilities, thrown into sharp relief when we reflect on conventional caring relationships, point to the importance of bringing the full resources of the ethics of care to bear across the whole range of institutional relations in which nurses are involved (p.44).

However, even extending such an ethic to interpersonal relationships more broadly does not necessarily address structural, social and ideological conditions that affect enactment of moral practice (Liaschenko & Peter, 2003; Varcoe & Rodney, 2002). In part, this is because proximity is required for the enactment of ethical caring. As Liaschenko and Peter (2003) observe, some situations require action outside of the interpersonal domain and/or require collective action of professional groups. Taking such action is particularly important to addressing inequities in health and access to health care for those who are street involved.

Feminist Directions in Nursing Ethics

Several nursing authors have suggested that feminist ethics holds potential for the development of nursing ethics (Brown et al., 2004; Johnstone, 1999; Liashenko, 1993; Liashenko & Peter, 2003; Rodney, Pauly & Burgess, 2004). Liashenko (1993) believes that nursing needs a feminist ethic that attends to the cultural ethos, that is, those “explicit and implicit ideals of conduct, ideology and social and political structure and organization” (p. 71).⁵⁵ I have chosen to focus on feminist insights primarily because of the fit with the focus of my concerns and the viability and compatibility of feminist and nursing ethics (Liashenko, 1994, 1995; Liashenko & Peter, 2003; Peter & Morgan, 2001; Rodney, Pauly & Burgess, 2004; Peter, 2004; Rodney, 1997; Varcoe, 2001; Varcoe & Rodney, 2002). The understanding that the ability of nurses to practice ethically is contextually situated has been identified in numerous studies of nursing practice (Chambliss, 1996; Fisher, 1995; Liashenko, 1994, 1995; Olson, 1995; Rodney, 1997; Street, 1992; Varcoe, 2001).

In the current health care context of resource scarcity, the corporatization of health care delivery and nursing shortages, the ability of nurses to practice ethically is being jeopardized (Storch et al., 2002; Rodney and Varcoe, 2001; Varcoe & Rodney, 2002; Varcoe, et al., 2004). In Canada, trends toward for-profit health care, cost containment and the introduction of business models into health care have profoundly affected the practice environment, impacting the ability of nurses to practice ethically and

⁵⁵ Liashenko (1993) stresses the importance of a feminist rather than feminine ethic for nursing. Feminine ethics, as discussed previously, has been a response to traditional moral theory that has tended to have a gender bias towards women with women being viewed as deficient in their moral development and capacity for moral thought and ethical decision-making (Sherwin, 1992).

contributing to the moral distress of nurses (Pauly, 2004; Storch et al., 2002; Varcoe & Rodney, 2001; Varcoe et al., 2004). According to Lamb (2004), as early as the mid-1960s, nurses expressed concern about their ability to meet these obligations to their patients because of contextual constraints. Growing financial constraints and cost containment have contributed to an almost untenable situation for nurses, influencing experiences of moral distress, burnout and attrition (Hamric, 2000). Writing in a U.S. context more than a decade ago, Stevens (1992) noted

Clearly, practicing nurses have been enlisted in the 'battle to contain health care costs' but have not had theoretical or tangible ethical support to advocate for consumers against cost containment policies that negatively affect the availability and quality of health care. Nurses' unofficial assistance in the silent 'rationing' of health care creates a moral and philosophical discord so intense that it is probably a major factor in the distress and disappointment experienced by so many practicing nurses who exist from the profession (p. 191).

The moral issues for nurses are the degree to which they are co-opted and complicit in the subtle rationing of health care in the face of competing values to provide health care on the basis of need. As Rodney and Varcoe (2001) remark, nursing work is often overlooked and invisible when there is a sole focus on economic evaluations of nursing practice in health care policy development and evaluation. They urge us to complement economic evaluation with ethical inquiry in order to ensure a health care system that is humane, effective and efficient for nurses and patients. The ability of nurses to undertake such actions draws us to the importance of the political requirements needed for a theory of nursing ethics.⁵⁶

⁵⁶ Here I would like to emphasize that I do not necessarily mean political in the formal sense of voting or supporting political candidates or as a member of my dissertation committee. Colleen Varcoe has often said, 'it does not mean writing a letter to the editor.' Although voting and letter writing are important political activities, I am more concerned about the political aspect of nurses work and the ability of nurses

Liaschenko and Peter (2003) argue that the ethical concerns of nurses need to be politically situated and that nursing ethics would be enhanced by introduction of ethical concepts such as 'trust.' Trust has been identified as an important relational concept in feminist and nursing ethics (Baier, 1985, 1986; Peter & Morgan, 2001). As trust is an important aspect of the findings of this research project, I will return to a conceptual discussion of trust in presentation of the findings (chapter 4) and the discussion of the findings (chapter 6).

Johnstone (1999) observes that nursing and feminist ethics share some important similarities. First, the majority of nurses are female and nursing issues, like those of women in society, have often been marginalized in mainstream health care. Second, on a theoretical level, within both fields there has been a critical gaze directed toward abstract, decontextualized approaches to ethical theory and the emphasis of reason over emotion. Both nursing and feminist ethics seek to contribute to ethical discussions and expand the field of health care ethics in terms of important ethical considerations and analysis. Work in nursing ethics has the potential to contribute to the development of health care ethics that will benefit patients, families, and communities as well as informing developments in other disciplines (Brown et al., 2004). Therefore, work in nursing ethics is important not only to nurses, as a source of practice guidance, but is important to the well-being of clients and the development of ethics in other disciplines in shared areas of concern such as ethical care within health care relationships.

to take action to change the conditions and climate of their workplaces and to enhance the delivery of nursing care for the benefit of patients.

Drawing on the work of Sherwin (1992, 1998), Young (1990), and others, Rodney, Pauly & Burgess (2004) state that for nurses “feminist theory draws attention to the quality of relationships-particularly the power in those relationships-at individual, organizational and societal levels” (p. 84). Furthermore, work in feminist ethics provides a basis to conceptualize justice in health care differently, assists in the process of ethical dialogue and “draws our attention to important contextual feature of the peoples’ lives and social circumstances” (Rodney, Pauly & Burgess, p. 86). For example, in her exploration of feminist contributions to understanding social justice and the role of emotions in connecting personal values to the enactment of social justice, Liaschenko (1999) provides a beginning point for the way in which nurses might draw on feminist ethics understandings within nursing.⁵⁷ Liaschenko (1999) calls on nurses to act socially and politically, as nurses and citizens, individually and collectively. Oppression and domination, she claims, “are important to nursing because violence, marginalization, cultural imperialism, exploitation, and powerlessness affect health” (p. 47).⁵⁸

An ethically conscious culture and a positive moral climate in health care are central to ethical nursing practice and the quality of health care relationships (Corley & Goren, 1998; Rodney & Street, 2004). Corley and Goren (1998) suggest we need

⁵⁷ Liaschenko (1999) argues that justice (a universalistic account of morality) and personal values (particularistic account of morality) can coexist. Her claim is “that those personal values that work in such a way so as to include previously marginalized others in the group of those who have access to the goods of social life are the personal values that are compatible with justice” (p. 37). She describes social justice as being fundamentally concerned with relationships between groups in society. Personal values are “understood not as arbitrary preferences, but rather, as reflective of our commitments” and justice “has as its central concern the conditions of enablement for participation in social life and for access to the goods of that life” (p. 45). Emotions are the connection between the two.

⁵⁸ As individuals, she suggests that nurses need to morally appraise the policies of those they elect. “A nurse cannot say she or he stands for health care if she or he votes for those who would further disenfranchise people and promote an unjust system” (Liaschenko, 1999, p. 47).

ethically conscious cultures where the 'dark side' of nursing and health care delivery is addressed openly and supportively. I would interpret an ethically conscious culture as referring to the moral climate. Rodney and Street define moral climate as "the implicit and explicit values inherent in nurses' workplaces" (p. 216). There is a need to enhance moral climates in nurses' workplaces to provide support for nurses to enact their moral commitments in practice.

Beyond the organizational level, we need collective and professional action that addresses conditions of nurses' work and contributes to developments that will improve access to health care for those experiencing marginalization. Insights from feminist ethics have the potential to contribute to theoretical developments in nursing ethics that provide moral guidance to nurses in enacting their ethical commitments both at the interpersonal and systems level. More research is needed to understand contextual forces and the nature of ethical practice within health care interactions and relationships in nursing. Only recently have nurses begun to focus on ethics for everyday nursing practice as the focus of study and inquiry in nursing ethics. The knowledge that ethical practice in nursing can only be understood relationally as situated within particular social contexts is emerging (Rodney, Brown & Liaschenko, 2004; Varcoe, Rodney & McCormick, 2003). Peter and Liaschenko (2003) urge us to begin with the idea that morality/ethics is enacted in practice and not lodged in ethical theory.

In summary, nursing ethics, as a field of study has turned away from applying bioethical principles to a set of narrowly defined ethical issues towards inquiry about the meaning of ethical practice of nursing, including the dynamic relationship between nurses and the context of their practice. Seeking to reflect the value base of nursing and to

explore ethical issues in nursing practice, the field is evolving as distinct from medicine within the field of health care ethics. Historically, theoretical work in nursing ethics has been influenced strongly by work in traditional health care ethics. More recently narrative and care based perspectives have received wide attention within nursing ethics unlike feminist and cross-cultural ethics. From my preliminary review of the literature, cross-cultural approaches appear to have received less attention.⁵⁹ This may be due, in part, to the historical trajectory of nursing ethics as well as the recent establishment of new and emerging fields of inquiry in health care ethics. Cross-cultural and feminist approaches are important areas for exploration by nurses both for their power in naming ethical issues and as alternative approaches to examining ethical concerns in health care. Examination of these approaches could enhance the development of nursing ethics. It is timely for nurses with an interest in ethics and good nursing practice to engage with theoretical work in feminist and cross-cultural ethics to more fully explicate the ethical concerns related to inequities in health status and access to health care for those who are street involved.

The Canadian Code of Ethics for Registered Nurses (2002) highlights the important responsibility of nurses in shaping the context of their practice, but more research is needed to understand contextual forces and the nature of ethical practice within health care interactions and relationships. In particular, little is known about the nature of interactions, relationships and practices with those who are street involved within a primary health care context. Moreover, little is known about the salient features

⁵⁹ I did find several articles referring to cross-cultural approaches in nursing ethics (Lutzen, 1997; Griep, 1995, Brown et al., 2004). Griep suggests that culture be considered as a variable within a four principled approach to ethics in nursing.

of a primary health care context that promotes or restricts access to health care or what is needed to enhance access to health care. Knowledge from front line providers and people accessing health can be a source of valuable insights for policy makers and are needed to enhance the effectiveness of health care delivery throughout the system. Furthermore, a better understanding of the delivery of health care in a variety of settings including a primary care context has the potential to contribute to the enhancement of health policy that will benefit nurses and clients. To explore the ethical dimensions of health care interactions in relation to access to health care for those experiencing marginalization, I have chosen to draw on ethnographic methodology to illuminate the social context in which practices are embedded. In the next chapter, I will discuss the methodological approach I have chosen to guide this project and describe the implementation of the research.

Chapter 3

Research Design, Methodology and Implementation

Ethnographic designs are particularly appropriate when the aim is to understand practices and experiences within a broader cultural context (Hammersley & Atkinson, 1995; Laine, 1997; Roper & Shapira, 2000; Smith D.E., 1987). In particular, Hoffmaster (1993) has argued that ethnography is an important methodology for research in ethics with the potential to reveal the way in which ethical concerns are historically and culturally situated. He argued that contextualizing concerns would yield important knowledge necessary to improve ethical practice within professions. Contextual understandings of ethical practice and health care interactions with those who are street involved will contribute to knowledge of health care and nursing ethics as well as provide insights for the development of ethical policy and practice. *After examining a variety of qualitative methodological possibilities, I chose a qualitative ethnographic approach informed by critical and feminist perspectives to guide this research project.*

In this chapter, my purpose is to describe the methodology used in the design of this research project and to describe the implementation of the research. I begin with a discussion of ethnography as a methodology originating in the social sciences. In particular, I discuss some characteristics thought to be common to ethnographic work. I understand ethnography to be a methodology that may be grounded in a variety of epistemological and theoretical perspectives (Atkinson & Hammersley, 1994; Hammersley & Atkinson, 1995). Therefore, after a discussion of ethnographic methodology, I discuss the epistemological and theoretical perspectives that I have drawn upon both in the development and implementation of this research project (Crotty, 1998).

Lastly, I will describe the implementation of this research project including gaining access, recruitment of participants, data collection, data analysis and attention to ethics in the research process.

RESEARCH DESIGN

Beginning with Ethnographic Methodology

Ethnography originated within anthropology and may be described as the study of people and their cultural contexts (Atkinson, Coffey, Delamont, Lofland & Lofland., 2001; Tedlock, 2000; Vidich & Lyman, 2000). Although the history of ethnographic work can be traced back to the Renaissance period and beyond, the beginnings of modern ethnography is most often linked to the emergence of fieldwork done abroad by anthropologists such as Malinowski, Boas, and Radcliffe-Brown as way of describing and understanding non- Western cultures (Atkinson & Hammersley, 1994). Significantly later, within the discipline of sociology, individuals such as Robert Park at the Chicago School of Sociology promoted the development of ethnographic work as a way of describing people experiencing marginalization within Western Industrial society (Atkinson & Hammersley). Today, ethnographic methodology has been adopted by many other disciplines within the social sciences (Atkinson & Hammersley, 1994; Atkinson et al., 2001; Tedlock, 2000; Vidich & Lyman, 2000). Atkinson & Hammersley (1994) state,

Furthermore, in recent years ethnography has witnessed great diversification, with somewhat different approaches being adopted in different areas, guided by different concerns (from traditional sociocultural description, through applied work designed to inform policy makers, to a commitment to advocacy and furthering political emancipation). And these different goals are variously associated with different forms of ethnographic practice: traditional, long-term, in-depth investigation sometimes being abandoned for condensed fieldwork or primary reliance on unstructured interviews, or for consultancy work or participation in political struggles (Atkinson & Hammersley, p. 251).

Applications of ethnographic methodology can be found in women's studies, cultural studies, human geography, organizational studies, counseling, nursing, education, law and other fields of inquiry.

In reading about anthropological ethnographic work, I found that at least one year is frequently identified as a guide for achieving an adequate level of immersion and that many ethnographers live within the community they are studying (Boyle, 1994; Germain, 1986). As a nurse, I was studying a cultural context that is close to home geographically but not living within the community that I was studying. Also, I conducted this research project within a health care system that is familiar to me as a registered nurse.⁶⁰ I would describe this research project as a qualitative study drawing on ethnographic methodology rather than a 'true' ethnography in the anthropological or sociological tradition. As will be discussed later, I have drawn on theoretical approaches from sociology in the design of this research.

Furthermore, I undertook this project with a fairly defined focus of concern within the broader context of access to health care. As Van Maanen (1998) observes, in the sociological tradition, "the culture of interest is at least partially known at the outset of a study" (p. 21). Other authors have suggested that 'focused' or 'mini' ethnographies are suitable for addressing the interests and questions of health care practitioners where the

⁶⁰ While this research was conducted geographically close to home and the majority of participants were English speaking, living and working on the street is relatively foreign to me as a white middle class woman. I have never worked as a street nurse or in an inner city primary health care center. So, while the culture of nursing and the health care system are familiar to me, the language and experiences of living and working on the street are not. My primary interest in doing this research arises from my clinical experiences in acute care in which I felt it was morally wrong to treat people differently on the basis of class.

goal is to improve practice (Boyle, 1994; Laine, 1997; Roper & Shapira, 2000; Wolcott, 1995). A 'focused' or mini ethnography draws on ethnographic approaches but "focuses on a distinct problem within a specific context among a small group of people" (Roper & Shapira, p. 7). Researchers in professional and applied fields frequently work with time constraints, that make focused ethnographic work more attractive because the focused nature of the work can be accomplished in a shorter period of time (Laine; Roper & Shapira, Wolcott). A significant disadvantage of focused ethnographic work is that there is typically less time spent in the field and therefore the researcher runs the risk that the researcher may not have gotten it right (Stewart, 1998).⁶¹ However, in settings closer to home that are familiar to the researcher, less time may be needed. In this study, I wanted to draw on ethnographic methodology to better understand the context of health care interactions with those who are street involved and I strived to learn about ethnography in the anthropological and sociological traditions. At the same time, I was aware that I needed to be clear about the degree to which it was possible or even desirable to integrate ethnographic methodology within the research design for this project. In the following paragraphs, I will describe ethnographic features of this project.

⁶¹ I would note here that Stewart (1998) is particularly referring to various forms of case research which emphasize rapid appraisal and may rely exclusively on focus groups and interviews as data sources. However, I do take seriously his warnings about threats to validity that are associated with inadequate time spent in the field. My decision to limit data collection was based on the overwhelming sense that the patterns I had identified were repeatedly emerging again and again. While I recognized that there was still much to learn, I had achieved a level of saturation adequate to answer the research questions posed at the beginning of this study. In this study, strategies for ensuring immersion and getting it right were important to counteract the potential of the researcher to miss important data, to misunderstand or to gain only superficial understandings. For example, even when I decreased data collection, I continued to have contact with people in the setting and had several opportunities to discuss further the findings of this project with participants. I will discuss this and other strategies further under implementation.

Although ethnography may be viewed as a philosophical paradigm, Atkinson and Hammersley (1994) describe ethnography as a methodological approach to be used in the social sciences to construct knowledge and greater understanding of phenomena within a particular social context. Thus, ethnographic work in different fields is linked not by a common definition but rather by a set of distinctive features (Atkinson et al., 2001; Atkinson and Hammersley, 1994; Boyle, 1994; Stewart, 1998). Atkinson & Hammersley (1994) state,

In practical terms, *ethnography*, usually refers to forms of social research having a substantial number of the following features:

- a strong emphasis on exploring the nature of particular social phenomena, rather than setting out to test hypotheses about them
- a tendency to work primarily with “unstructured” data, that is data that have not been coded at the point of data collection in terms of a closed set of analytic categories
- investigation of a small number of cases, perhaps just one case, in detail
- analysis of data that involves explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations, with quantification and statistical analysis playing a subordinate role at most (p. 248).

The explicit interpretation of meanings and actions requires that the researcher pay careful attention to language used by participants and that the researcher is concerned with illuminating the meaning of experiences from the perspective of participants. This research can be considered ethnographic in that I was exploring a social phenomena, I collected unstructured data and a small number of cases were studied in order to elicit the meaning of particular behaviors and actions. I listened carefully to participants to determine what was meaningful to them and the meaning of their experiences.

Building on the work of others, Stewart (1998) outlines five additional features which he argues are characteristic of ethnographic work.⁶² They are participant observation, holism, context sensitivity, sociocultural description and theoretical connections. I will briefly discuss each of these characteristics and the degree to which these characteristics were incorporated into this study.

Participant observation is a key feature of ethnographic work (Atkinson et al., 2001; Atkinson & Hammersley, 1994; Stewart, 1998; Tedlock, 2000). Participant observation means that researchers have first hand experience of social and cultural settings and employ the use of observation and participation (Atkinson et al., 2001). Stewart describes participant observation as up close involvement with the researcher as participant in the setting being studied.⁶³ Tedlock (2000) observes,

Wherever it has been adopted, a key assumption has been that by entering into close and relatively prolonged interaction with people (one's own or other) in their everyday lives, ethnographers can better understand the beliefs, motivations and behaviors of their subjects than they can by using any other approach (p. 456).

⁶²Having studied and used other forms of qualitative methodology, it was readily apparent to me that the four characteristics described by Atkinson and Hammersley (1994) alone were not enough to distinguish ethnography from other forms of qualitative research. For example, in my Master's research, I used an exploratory descriptive design that incorporated features of grounded theory methodology. In that study, I would have said I was studying a social phenomenon (e.g. caring), using unstructured data (interview data), working with a small number of cases, and seeking interpretation.

Stewart's (1998) work brings together a number of authoritative sources from well known authors in the field of qualitative research and ethnography such as Agar, Geertz, Hammersley, Lofland, Van Maanen, Wolcott and others. The five characteristics he identified resonated with other sources I had read and was reading in the field such as Atkinson et al. (2001); Atkinson and Hammersley, (1994); (Hammersley and Atkinson), 1995; and Geertz, (1973). I found his naming of particular characteristics useful in the conduct of this research. I have included them here as a means of articulating important features identified by many writers as characteristic of ethnographic methodology.

⁶³ Geertz (1973) argues that participant observation is valuable because the researcher engages participants as persons rather than objects. "But to the degree it has lead the anthropologist to block from his view the very special, culturally bracketed nature of his own role and to imagine himself something more than an interested (in both senses of that word) sojourner, it has been our most powerful source of bad faith" (p. 20).

Although multiple approaches to data collection are used, the primary instrument is the “ethnographer’s own inquiring experience, in joint, emergent exploration with people who once were called *natives*” (Stewart, 1998, p. 6). I began this study with the explicit intention to undertake participant observation with nurses employed as street nurses or working in a primary health care setting. I felt participant observation would give me the opportunity to see and learn first hand what was going on in primary health care settings.⁶⁴ Through my participant observation with nurses, I had multiple opportunities to observe and talk with people who are street involved as well as regularly visiting several sites they frequented. Initially, I had planned to collect data in two different primary health care settings primarily for reasons of anonymity and confidentiality. As the study proceeded, my initial analysis suggested that an emergency department would be an important additional setting for exploring the phenomena I had chosen to study. However, after gaining entry into the emergency room setting, it quickly became apparent that my ability to fully immerse in a third setting was beyond the scope of this project.

Holism is the second characteristic of ethnographic research identified by Stewart, (1998). He suggests that there are two important aspects of holism in ethnographic work.

⁶⁴ I recall as I was thinking through questions of methodology, one of my committee members observed to me that seeing what people are doing provides insights into behaviors that may not be revealed when the primary method of data collection is interviews only. As the study progressed, I came to a fuller understanding and appreciation of her words. First, I was able to observe first hand what people were doing which lead me to ask questions and seek understanding of experiences from their perspective in a way that would not have been possible if I had only conducted interviews. Second, I had an incredible opportunity to see people in relation to others in the setting and to observe their interactions and reactions in the moment that care was being provided which again identified areas of understanding and important meanings for those involved in the research. I recognized that my observations were simply my observations and my constructions of what I was seeing were an attempt to understand the constructions of others.

First, holism conveys a sense that the researcher, through a synthesis of observations, can create a broader understanding of the context and individuals are best understood in relation to that larger context. Clearly, from the onset I wanted to understand beliefs, meanings and practices in relation to a larger context of health care delivery. Second, holism might, in at least a limited way, convey a sense of comprehensiveness in “that the range of observations transcends academic disciplines and specialties” (Stewart, p. 6). I found that in proposing this study to one manager, her immediate response was to suggest that although I was primarily interested in following nurses, I should buddy with other health care providers such as physicians to gain an understanding of the whole. I am thankful for her advice and direction. By observing and interviewing other providers in the primary health care setting my understanding of the larger context in which nurses were providing care, as well as the relationship of nurses to the rest of the health care team, was enriched.

Closely following from the characteristics of participant observation and holism, is the feature of context sensitivity (Stewart, 1998). Stewart states,

Immersion within a particular setting leads the ethnographer to see linkages among various strands in holistic – that is, comprehensive – data. Ethnographers explain one set of observations in terms of connections with others, and with concepts used for their fit with the context (p. 7).

I think the most difficult question for me in understanding this characteristic was the degree to which I might contextualize what I was seeing and hearing. For example, at one point, I developed a diagram in which I mapped the political, social, economic and historical contexts that I might include or explore in an analysis of the findings. It was useful to learn that spatial and temporal limitations on fieldwork may limit contextual

explanations to “the context that is locally observable” (Stewart, 1998, p. 7). While there are practical limitations of the degree to which one can describe the context, the notion of context sensitivity provided me with an important conceptual understanding of the broader context of health care. This understanding was important given my research questions related to generating insights for health care policy from the perspectives of participants. I began thinking of the findings of this research as embedded in an ever widening possibility of contextual understandings. For instance, as I observed and listened to participants, I began to think of health care interactions and relationships as embedded in particular settings and settings as embedded in regional, provincial, national and global health care contexts. This kind of thinking was useful in structuring my analysis and recognizing what I was able to do in this project and the limitations.

Fourth, ethnographic work is characterized by sociocultural description (Stewart, 1998). Sociocultural description is consistent with the aim of understanding practices and experiences within a broader social context in that it is the “detailed depiction and analysis of social relations and culture” (Stewart, p. 7).⁶⁵ Geertz (1973) describes the concept of culture as socially constructed webs of significance that requires interpretative analysis rather than identification of universal laws. Culture is located not in structures or value systems but within people and conveyed through behaviors and meanings. Thus, culture as embedded in broader social, political economic and historical contexts is

⁶⁵ Wolcott (1990) suggests that it is not only the process but the product that make research ethnographic. He states,

To pursue ethnography in one’s thinking, doing, and reporting is to engage simultaneously in an ongoing intellectual dialogue about what culture is *in general*-and how....culture influences without controlling-while attempting to portray specific aspects of the culture of some human group in particular (p.84).

revealed in moment to moment interactions and relationships (Doane & Varcoe, 2005).

A classic feature of ethnographic work is to not only describe but to provide ‘thick descriptions’ which seek to provide insights into the meaning of behaviors and an understanding of the cultural context in which they occur (Geertz, 1973).⁶⁶ According to Geertz,

Cultural analysis is (or should be) guessing at meanings, assessing the guesses, and drawing explanatory conclusions from the better guesses, not discovering the Continent of Meaning and mapping out its bodiless landscape (p. 20).

Represented or arrived at meanings are really constructions of the ethnographer of the meaning that others attribute to a particular experience or event.⁶⁷ In doing ethnographic work, the researcher must be mindful that she is both the instrument and a participant in the process embedded in her own webs of significance.

Lastly, Stewart (1998) proposes a fifth characteristic of ethnographic methodology related to the use of theory. He suggests that the relationship between theory and ethnography is one in which ethnographer is not focused on generating theory but on reconsidering or reconstructing theory on the basis of observations and

⁶⁶ Geertz (1973) describes ethnography as ‘thick description’ or ‘densely textured facts’. ‘Thin description’ would be a description of observable behaviors: ‘thick description’ is the “piled up structures of inference and implication through which an ethnographer is continually trying to pick his way” (p. 7).

⁶⁷ An important point addressed by Geertz (1973) is the fact “that what we call our data are really our own constructions of other people’s constructions of what they and their compatriots are up to – is obscured because most of what we need to comprehend a particular event, ritual, custom, idea, or what is insinuated as background information before the thing itself is directly examined” (p. 9). Later, he argues that participant observation is valuable because the researcher engages participants as persons rather than objects. “But to the degree it has lead the anthropologist to block from his view the very special, culturally bracketed nature of his own role and to imagine himself something more than an interested (in both senses of that word) sojourner, it has been our most powerful source of bad faith” (p. 20).

contextualized understandings.⁶⁸ I found this very useful in providing me with a lens from which to view theory in relation to the findings of this research.

As a methodology, ethnography has been informed by a variety of theoretical and epistemological perspectives (Atkinson & Hammersley, 1994; Atkinson et al., 2001; Hammersley & Atkinson, 1995; Tedlock, 2000).⁶⁹ Atkinson & Hammersley (1994) state,

There are common threads and recurrent motifs running through the entire ethnographic tradition. Yet there is no simple one-to-one relationship between

⁶⁸ Stewart (1998) states that both ethnography and grounded theory within the research process work to generate understanding and comparisons of data and theory but that there are important differences. He states, "Further, ethnographic theory is 'grounded,' as ethnographers prioritize trying to think through observations in terms of their immanent context, before trying to construe the data in the light of existing theories" (p. 9). Grounded theory can be distinguished from ethnography in that less immersion in the setting is needed because the researcher is more interested in concepts than context and the goal of grounded theory is to produce theory rather than the specifics of particular situations.

⁶⁹ Historically, the tradition of ethnography has been characterized by diversity and even controversy rather than a stable set of beliefs (Atkinson et al., 2001; Atkinson and Hammersley, 1994; Hammersley & Atkinson, 1995; Lather, 2001; Marcus & Fischer, 1986; Tedlock, 2000; van Maanen, 1988; Vidich & Lyman, 2000). Atkinson et al. state,

Over the development of ethnography there has been a repeated dialectic between what might be thought of as a dominant orthodoxy and other centrifugal forces that have promoted difference and diversity (p. 3).

In particular, there has been considerable critique of realism in ethnographic work and challenges to the belief that social phenomena exist independently and can be described objectively (Hammersley & Atkinson, 1995; Marcus, 1998; Tedlock, 2000; Vidich & Lyman, 2000). In realist ethnography, there is a belief that the researcher can produce objective descriptions of social phenomena which are value neutral. However, as Atkinson & Hammersley (1994) observe "once we come to see ethnographers as themselves constructing the social world through their interpretations of it, there is a conflict with the naturalistic realism built into ethnographic methodology" (p. 11). The decline of positivism, rejection of colonizing influences and postmodern critiques have challenged early beliefs about 'going native', the position of the detached observer, the quest for generalizations instead of thick descriptions and interpretations, and illuminated the inherently Eurocentric values that permeated earlier ethnographic research which colonized the 'other' (Tedlock, 2000; Vidich & Lyman, 2000). Hammersley & Atkinson (1995) conclude,

While realism has not been completely abandoned by most ethnographers, the idea that ethnographic accounts can represent social reality in an unproblematic way has been rejected; and doubt has been thrown on the claims to scientific authority associated with realism (p. 14).

These authors propose the possibilities of a moderate realist ethnography in which reflexivity plays a central role in producing legitimate accounts of the social world through acknowledging the researcher role and exploiting the opportunities for creating knowledge as a result of the researchers' participation in the setting. Discontent with realist ethnographies have contributed to the development of other forms ethnographic work including biographies, memoirs, autobiographies, travelogues, autoethnographies, novels, short stories, poems and plays (Tedlock, 2000).

ethnography and any given theoretical perspective. It is not the case that all ethnography has been undertaken under the auspices of one epistemological orthodoxy. Rather, the distinctive characteristics of ethnographic work have been differentially appealed to by different disciplines and tendencies (p. 258)

These authors argue against categorization of different types of ethnography. Rather they support the possibility of drawing on different theoretical and epistemological perspectives to support the use and rationale for adoption of ethnography within the social sciences (Atkinson & Hammersley). They state, “one has to recognize different theoretical or epistemological positions, each of which may endorse a version of ethnographic work” (p. 257). I take ethnography to be a methodology informed by different theoretical and epistemological perspectives and aimed at producing knowledge of social phenomena within a social context (Hammersley and Atkinson, 1995).

Ethnographic methodology is characterized by distinctive features such as participant observation, the use of unstructured data and the attempt at holistic representations. As a researcher drawing on ethnographic methodology, it is important for me to outline the theoretical and epistemological perspectives underpinning this particular research project. I will now turn to a discussion of epistemological considerations to further describe the way in which critical and feminist perspectives have informed me in the development of this research project.

Taking an Epistemological Perspective

Epistemology is ‘a theory of knowledge’ (Harding, 1991) and “concerned with questions about the nature of relationships between the knower (inquirer) and the known (or knowable)” (Guba, 1990, p. 18). There have been numerous approaches for classifying different epistemological approaches to knowledge development (Allen,

1985; Allen, Diekleman & Benner, 1986; Crotty, 1998; Guba, 1990; Habermas, 1996; Lather, 1991; Lincoln and Guba 2000; Schwandt, 1990, 2000). While one might argue for or against different classifications, researchers through discussion and consideration of different perspectives in the philosophy of science, can make “intelligent, informed and flexible methodological decisions” (Allen, Diekelmann, & Benner, 1986, p. 23). I was interested in finding an epistemological perspective that had both the production of knowledge and social action as goals.

In preparing to undertake this research, I examined several different paradigmatic classifications. Among the different classifications, I found the typology proposed by Lincoln and Guba (2000) to be a helpful starting point for articulating the epistemological underpinnings of this project. As I thought about their system of classification in relation to other classification schemes, I was able to distill a general sense of the epistemological implications for research methodology. In addition, conceptually locating my chosen methodology within different paradigms helped me to think more fully about the beliefs, goals and aims that I hoped to further in this project. I will begin with a brief discussion of the five paradigms identified by Lincoln and Guba (2000).

Lincoln and Guba (2000) describe the following five paradigms: positivism, post positivism, critical theory, constructivism and participatory paradigms. They consider the first two paradigms as being characterized by received views while the last three are considered newer paradigms of inquiry. “The basic belief system of positivism is rooted in a *realist* ontology, that is, the belief that there exists a reality *out there*, driven by immutable natural laws...The ultimate aim of science is to predict and control natural phenomena” (Guba, 1990. p. 19). In the positivist paradigm, epistemology is objectivist

in that the inquirer must take a distant, noninteractive stance. The postpositivist takes the position of the critical realist in that “reality exists but can never be fully apprehended” due to the human inability to perceive it (p. 23). Objectivity remains an epistemological ideal, which can be approximated. In contrast, critical theorists adopt a historical realism (reality is shaped by social, political, cultural, economic, ethnic and gender values over time) combined with a subjective epistemological stance that is mediated by values with the aim being to raise the consciousness of the oppressed and transform the world. Constructivism supports relativist ontology. “Realities exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold them” (p. 27). Knowledge is generated in the process of interaction between the researcher and participants. The participatory paradigm is described as a cooperative form of inquiry in which co-creation by researcher and participants is fundamental to the research process.⁷⁰ *At this point, I would describe this research project as drawing on features of both the critical and constructivist paradigms.* Critical, in that I wanted to attend to the context of ethical practice and health care interactions for the purpose of enhancing equity (social change) and constructivist in accepting the existence of multiple truths and co-creation of knowledge. As will be demonstrated later, although not a primary focus, there were participatory elements that were incorporated into the research process.

⁷⁰ Lincoln and Guba (2000) draw heavily on the thinking of Heron and Reason (1997) in describing the participatory paradigm. I had decided early on in the development of this project, that for practical reasons, I would not develop a highly participatory research project. Here I am speaking of the type of participatory research in which the participants are co-researchers and engaged in every aspect of the research process including the development of research questions. Although this would be an ideal form of research for enhancing equitable access to health care in which I might work closely with participants, it is not something I was willing to undertake as a doctoral research project. However, I did include participatory features where possible in this project as I will describe later. Additionally, in sharing the findings of this project with participants, my hope is to generate direction for future potentially participatory research.

Since I am locating my work within the newer (post modern) paradigms of inquiry (primarily the critical and constructivist), I needed to come to terms with an understanding of postmodernism that was consistent with the goals and aims of this project. In the following paragraphs, I will outline some thoughts on postmodernism in relation to this project. Crotty (1998) describes postmodernism as “the most slippery of terms” (p. 183). Postmodern approaches in research are not methods per se “rather, postmodern approaches are a way of thinking about the world that shapes the type of research that is done and the types of analyses that are made” (Cheek, 1999, p. 4). I take postmodernism to mean the refusal to accept grand narratives as described by Fraser and Nicholson (1990). “The postmodern condition is one in which ‘grand narratives’ of legitimation are no longer credible. By ‘grand narratives’ Lyotard means... overarching philosophies of history like the Enlightenment story of the gradual but steady progress of reason and freedom” (p. 86). However, the refusal to accept grand narratives can become paralyzing in that we are left without principles from which to move forward in policy and practice (Bernstein, 1991; Squires, 1993).

Squires (1993) argues that postmodernism, although liberating in its refusal of hierarchy and uncertainty, it is “paralyzing in the deconstruction of all ‘principled positions’” (p. 1). The primary focus of the postmodern movement is to be critical, “but on the other hand, there is also a questioning, undermining and deconstruction of any and all fixed standards of critique, a relentless questioning of any appeal to *archai* or foundations” (Bernstein, 1991, p. 7). Bernstein asserts that without being clear about ones’ purpose there is “the danger of the critical impulse consuming itself” (p. 6-7). He raises the question, “critique in the name of what?” (p. 6). As Carspecken (1996)

observes, “Why do research to help the disadvantaged if there are no grounds for claiming this sort of activity to be desirable, moral, good and right?” (p. 15).

Furthermore, Carspecken observes that if all values are arbitrary, any descriptions generated in critical research would be interpretation and their only force would be the power of persuasion. He states, “Therefore, many contemporary critical researchers seek to appropriate postmodern insights while retaining some notion of truth and some standards for valid argumentation” (p. 15). Other researchers, such as Lather (1991), Kincheloe and McLaren (2000) and Squires (1993) suggest adopting a weak form of postmodernism. Squires states,

The strong form holds that the subject is merely another position in language. It rejects historical narrative that focuses on the macro rather than micro and condemns all of western metaphysics for an imputed grounding of Truth in the Real. The weak form, on the other hand, posits an embedded rather than fictive subject. It also involves the rejection, not of all macro-narratives, but of essentialist and monocausal grand-narratives. Finally, it involves the assertion of philosophy as the investigation of empirical conditions under which communities of interpretation generate validity claims (p. 4).

Unlike strong forms of postmodernism, weak postmodernism allows for normative standards. Kincheloe and McLaren (2000) describe a form of ‘resistance postmodernism’ that

is not based solely on a textual theory of difference but rather on one that is also socially and historically located. In this way, postmodern critique can serve as an interventionist and transformative critique of Western culture (p. 294).

It is in the sense of weak or resistance postmodernism, that this project may be conceived as postmodern. It is a way of escaping search for *the* truth without succumbing to a completely relativist position in which no truths are possible. Thus, it would be possible

to gain an understanding of the nature of ethical practice and health care interactions within a particular context that facilitates and/or constrains access to health care.

According to Lincoln and Guba (2000) the call to action provides a clear distinction between received and newer (postmodern) paradigm perspectives. Positivists and post positivists “view action as a form of contamination of research results and processes, and interpretivists, who see action on research results as a meaningful and important outcome of inquiry processes” (p. 174). Lincoln & Guba observe that the call to social action has always been fundamental to critical theorists. More recently, there also has been a shift in constructivist and participatory paradigms toward social action. This has been a result of first, a concern about the under utilization of research findings and a desire for follow-up of evaluations of recommendations with action plans; and secondly, a view of action as an ethical and political commitment. The shift to connect research, policy analysis, evaluation, and social deconstruction “has come to characterize much new-paradigm inquiry work, both at the theoretical and at the practice and praxis-oriented levels” (Lincoln & Guba, p. 175). While both the critical and constructivist paradigm share a call to action, there are significant differences in defining the nature of reality and the goals of research. Elements of both paradigms are viewed as having value in structuring this inquiry.

Constructionism or social constructionism, has been identified as a worldview that can bridge critical and constructivist paths of inquiry (Schwandt, 2000).

Crotty (1998) defines constructionism as

the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices being constructed in and out of interactions between human beings and their world, and developed and transmitted within an essentially social context [italics in original] (p. 42).

In this view, constructions have a historical and sociocultural dimension.⁷¹ “We do not construct our interpretations in isolation but against a backdrop of shared understanding, practices, language and so forth” (Schwandt, 2000, p. 197). Schwandt (1990) observed that researchers are informed by tradition in the social construction of reality (similar to ethnographers) “but it takes on an avowedly moral and political character. These individuals seek to restore the idea of social science as public philosophy, to reunite social sciences with moral analysis” (p. 268). For constructionists, there is a focus on knowledge that is ideological, political, value-laden and influenced by social factors (Schwandt, 2000). As Schwandt (2000) observes, “some neopragmatists, critical theorists, and feminists are committed to the task of interpretation for purposes of criticizing and dismantling unjust and undemocratic educational and social practice and transforming them” (p. 202). However, as Kinchloe and McLaren (2000) observe, and I would concur, one must be cautious in the use of transformation and emancipation in critical research for several reasons.⁷² First, sociopolitical contexts may never be

⁷¹ A purely constructivist position would not account for the social or historical context. However, I do accept the existence of multiple truths that is characteristics of the constructivist paradigm as described by Lincoln & Guba (1994; 2000). Crotty (1998) draws upon Geertz (1973) view that an understanding of culture as a guide to human behavior is valuable in the development of constructions. Crotty states,

Thus, while humans may be described, in the constructionist spirit, as engaging with their world and making sense of it, such a description is misleading if it is not set in a genuinely historical and social perspective. It is clearly not the case that individuals encounter phenomena in the world and make sense of them one by one. Instead we are all born into a world of meaning. We enter a social milieu in which a ‘system of intelligibility’ prevails. We inherit a ‘system of significant symbols’. For each of us, when we first see the world in meaningful fashion, we are inevitably viewing it through lens bestowed upon us by our culture. Our culture brings things into view for us and endows them with meaning and by the same token, leads us to ignore other things (Crotty, p. 54).

⁷² The agenda of ethnography remains grounded in a search for description, interpretation and explanation of people and cultures rather than critique and transformation (Hammersley, 1992; Quantz, 1992). Quantz (1992) states, “as a ‘project’ critical ethnography is recognized as having conscious political intentions that are oriented toward emancipatory and democratic goals” (p. 448-449).

completely transformed. Second, no one is ever completely emancipated from the sociopolitical context in which they live. Third, “many have questioned the arrogance that may accompany efforts to emancipate others” (Kincholoe & McLaren, 2000, p. 282). However, research may be transformative in that participants gain new understandings and may be changed in the research process (Anderson, 1991, 1996; Lather, 1991; Oakley, 1981). Thus, an important consideration in this project is clarifying the nature of social action that might be the aim of this study.

Hammersley and Atkinson (1995) propose a modest view of the nature of transformation and social action that has been helpful to me in constructing this research project. They state, “sometimes the concern is with rendering research more relevant to national policy-making or to one or another form of professional practice...” (p. 15-16). Based on the concerns identified above, I would situate my research as transformative with the intent of making the findings of this research relevant to policy making and professional practice. Additionally, the possibility that participants might gain new understandings and insights through their involvement in the research process exists.⁷³

⁷³ I would argue that this has happened on two fronts both within and beyond the actual conduct of the research. First, within the research, nurse and patient participants had the opportunity to share their experiences through dialogue with the researcher. These opportunities may have generated new insights for participants. Evidence of this is most apparent in statements made by one nurse and one patient after completion of the study. The nurse shared that her experience in the research forced her and her colleagues to put into words what they were doing. In part, my understanding based on this and other conversations is that the research validated and strengthened the nurse’s awareness of the nature and importance of the work she was doing with people who are homeless and experiencing addictions. One man involved in this study shared that he hadn’t been feeling very good about himself lately and wanted to participate in the study as way of doing something that would help him to feel better. At the end of his interview, he stated that his goal had been achieved. Additionally, he stated that from his perspective the research was important because people are needed “who have a foot in both worlds”, his world and the university world. He encouraged me to share my understandings of his world with people at the university. I would interpret this as his belief that change would be possible if there was greater understanding among those he perceived to have power and influence.

Theoretical Perspectives

Kincheloe and McLaren (2000) describe social theory as “a map or guide to the social world. In a research context it does not determine how we see the world but helps us devise questions and strategies for exploring it” (p. 281). In the development of the research questions and strategies outlined in this paper, I have drawn on critical and feminist theory.

Critical Influences

Critical theory has been identified as a relevant theoretical foundation for nursing inquiry and research (Allen, 1985, 1995; Allen, Diekelmann, & Benner, 1986). Kinchloe and McLaren (2000) observe that there are many critical theories (not just one), that the critical tradition is constantly evolving and that “critical theory attempts to avoid too much specificity, as there is room for disagreement among critical theorists” (p. 281).⁷⁴

⁷⁴ Critical theory is a much debated and often misunderstood term (Kincheloe and McLaren, 2000). In part this may be understood by looking at the evolution of critical theory from its roots in the Frankfurt school (termed critical social theory) to late twentieth century reconceptualized critical theory informed by post-modernism and post-structural thought (Kincheloe & McLaren, 2000). An early contribution to the development of critical theory was that of Antonio Gramsci. His main contribution to critical social theory was the concept of hegemony (Bellamy, 1994).

Hegemony referred to the ideological ascendancy of one or more groups or classes over others in civil society. “Capitalism continued to survive because the workers accepted its general outlook – the cultural dominance of the bourgeoisie made the resort to political force unnecessary to maintain their power. Thus the masses had to be freed from enthrallment to the cultural hegemony of the capitalist classes before a successful challenge to the state could occur (p. 33).

Gramsci was concerned with identifying properties of false ideologies, identifying criteria for true ideologies and strategies for engendering the true ideology among the masses. False ideologies had the property of absolute truths and “a second identifying feature of erroneous ideologies was their function in upholding or legitimizing unjust social institutions and practices” (Bellamy, p. 34). His work was understood as being grounded in the search for true and absolute ideologies that would replace false ideologies. In understanding critical methodologies, Schwandt (1990) provides some useful insight about the notion of true and false consciousness as absolutes.

The overriding regulative ideal in critical science is the achievement of true as opposed to false consciousness and the kind of empowerment and emancipation that this entails. However, this ideal does not presuppose a conception of absolute truth (p. 274).

They describe the shared and common features of critical theories as “concerned in particular with issues of power and justice and the ways that the economy, matters of race, class and gender, ideologies, discourses, education, religion and other social institutions, and cultural dynamics interact to construct a social system” (Kincheloe & McLaren, p. 281). Carspecken (1996) observes that critical researchers share a common value orientation. He states,

we are all concerned about social inequalities, and we direct our work toward positive social change. We also share a concern with social theory and some of the basic issues it has struggled with since the nineteenth century. These include the nature of social structure, power, culture and human agency. We use our research, in fact, to refine social theory rather than merely to describe social life (p. 3).

This research project is consistent with the common features and value orientation of critical theory and research as described above.

In designing this study, I wanted to find a way to capture the particularities of ethical practice and health interactions while providing an understanding of the broader context that is being enacted within interactions and relationships. In the early development of this project, I found Bourdieu’s (1994) notion of ‘habitus’ to be particularly useful. Bourdieu’s notion of ‘habitus’, that social space that is created by history and is itself embodied history, allows the examination of practice as historically, socially and culturally situated and brings an analysis of social structures to bear on the way in which practice is enacted. Lather (2001), a critical feminist, describes

Schwandt reinforces his argument by citing an explanation from Bernstein (1976, p. 7) who states, “we can show the falsity of an ideology without claiming that we have achieved a final absolute, ‘true’ understanding of a social and political reality.” In the wake of Gramsci and Althusser, Lather (1991) states, “ideology is viewed as something people inhabit in very daily, material ways and which speaks to both progressive and determinant aspects of culture” (p. 2).

ethnography influenced by the sociology of Pierre Bourdieu and others as having “attachments to local knowledge and to illuminating the exercise of power in culturally specific yet socially reproductive processes” (p. 479). She describes this kind of ethnography as “reworking Marx after Gramsci, Althusser and Foucault” and being infused with feminisms, post-colonial and critical race theories. In examining practice, the context is revealed. Both critical and feminist theory share a common focus on the social, political, and historical context that shapes practice. Nursing practice within health care interactions has the potential to both facilitate and constrain access to health care within particular contexts. By examining practice and health care interactions, elements of the context would be revealed. Next, I will discuss the feminist perspectives that have informed this research project.

Feminist Influences

Skeggs (2001) describes feminism and ethnography as complementary and suited to each other. She states,

They both have experience, participants, definitions, meanings and sometimes subjectivity as a focus and they do not lose sight of context. Just like any feminist research, the ethnographer maps out the physical, cultural and economic possibilities for social action and meaning (p. 426).

Only recently within feminist research, has there been a shift “from ethnographies on women to ethnographies informed by feminist theory” (Skeggs, 2001). This study would be consistent with the latter. It was important for me to realize that since there is not a distinct feminist methodology and that ethnography has been informed by a variety of epistemological and theoretical perspective, it was consistent and appropriate to bring feminist insights to ethnographic work.

Feminist research is characterized by a profound concern with ethics and power within relationships between the researcher and the researched (Skeggs, 2001). Thus, reflexivity is central to the feminist research process. Reflexivity throughout the research process requires examination of self as researcher in relation to the values and beliefs that one brings to the project, examination of self in relationships with research participants and examination of self in relation to the data (Lather, 1991). Furthermore, reflexivity is central to validity in feminist and qualitative research. In this sense, my intent from the onset was to pursue a highly reflexive research design. Strategies for achieving reflexivity will be discussed in the sections dealing with data collection and analysis.

During the proposal development phase of this project, my thoughts about data collection and analysis were influenced by the work of feminist theorists including Dorothy Smith (1987, 1999), Patti Lather (1991), and Joan Anderson (1991, 1996, 2002) among others. Reading their work proved very useful in thinking about how to proceed in the conduct of this research. I was very interested in the perspectives of nurses and those accessing health care. I did not see myself as taking a particular standpoint, such as that of the nurses, but rather I was interested in a multiplicity of perspectives.⁷⁵ For example, while the nursing profession is dominated by women, I perceived that men working in this area of health care or receiving health care services had equally valid perspectives to

⁷⁵ Donna Haraway (1997) describes standpoint thinking as follows: "...standpoints are cognitive-emotional-political achievements, crafted out of located social-historical-bodily experience-itself always constituted through fraught, noninnocent, discursive, material, collective practices" (p. 304). Oleson (2000) explains the value of this perspective.

This carries with it the view that all knowledge claims are socially located and that some social locations, especially those at the bottom of social and economic hierarchies, are better than others as starting points for seeking knowledge not only about those particular women but others as well (p. 222).

Dorothy Smith (1987; 1999) is a sociological theorist who has contributed significantly to standpoint theory.

offer on the concerns I was interested in studying as did those accessing health care services. It was the focus on local knowledge that I found helpful as well as the understanding of everyday experience shaped by contextual factors. According to Smith, social processes exist in people's actual activities and practices and in their interactions with others (e.g. working together, competing, conversing, co acting). She states that the terms activity and practice require not only observation but include the 'subjective side' or consciousness (p. 123). I found this thinking a useful adjunct to what I had been reading in ethnography in assisting me to think about the embeddness of the social context in everyday experience. Such thinking affirmed the importance of focusing on everyday practices and experiences and assisted me to ask questions of participants aimed at gaining an understanding of the broader context from the their perspective.

Although I had examined post-colonial feminist work (Anderson, 2002; Anderson & Reimer Kirkham, 1998; Reimer Kirkham & Anderson, 2002), I did not specifically draw on insights from post-colonial theory except in the sense that some of the goals of this research project were commensurate with those of post-colonial work.⁷⁶ Anderson (2002) states,

Post-colonial feminist scholarship opens up a space for marginalized voices and provides direction for research and theory development in nursing with the aim of

⁷⁶ Post-colonial theory and scholarship provides an important perspective for understanding that knowledge is constructed from various standpoints that are embedded within particular historical and colonial contexts (Anderson, 2002). Reimer Kirkham and Anderson (2002) describe postcolonialism as follows:

Clearly far from being a unified field, several central themes are nonetheless associated with postcolonialism, including *race*, ethnicity, nation, subjectivity, identity, power, subalterns, and hybridity. Overall, the project of postcolonialism today centers on theorizing the nature of colonized subjectivity and the various forms of cultural and political resistance (p. 3).

Anderson and Reimer Kirkham have explored the contribution of postcolonial theory and argued that post-colonialism offers a much needed perspective that will contribute to knowledge development in nursing (Anderson, 2000; 2002; Anderson & Reimer Kirkham, 1998; Reimer Kirkham & Anderson, 2002).

producing transformative knowledge to guide transformative action. Transformative knowledge is knowledge that is constructed from the social location of those who have been marginalized; it gives direction for addressing unequal power relations, both in the 'clinic' and in the wider social context. It challenges racialised and culturalist theories that reinforce racial and cultural stereotypes (p.23).

Anderson (2002) emphasizes further:

Post-colonial feminist scholarship calls for a health care system that is responsive to the varied social locations of its clients. The post-colonial feminist researcher has a social obligation and responsibility not only to revise theory, but to communicate this revision and to ensure that new knowledge is used to address and correct past injustices and inequities (p. 23).

Previous work by Anderson (1991, 1996) was immensely useful in directing me to think about the meaning of participatory work and the role of the researcher in field work.

According to Anderson (1991, 1996), participants through the process of discussing their experiences gained new insights into their situations.

In this light, we can come to see field work as one of the processes through which knowledge is constructed, and see our interactions with participants as part and parcel of the context of the social production of knowledge (p. 117).

In this sense, the research process itself may be empowering. Anderson (1991) describes,

More importantly, however, by recognizing that the research process constitutes unequal power relations, researchers can be more sensitive to ways of equalizing the power between women and themselves. This calls for critical examination of the process of the interview...Feminist critical scholarship in nursing therefore offers hope for empowerment of the disadvantaged and oppressed through their engagement in the process of research (p.118).

This view of the research process as empowering is consistent with Lather's (1991) view that transformation can occur with the research process itself. Transformative knowledge, according to Anderson (2002), generated in the research process reveals the underlying context that shapes health care delivery and organizes health care relationships. In the research process, this means "beginning with people's experiences, and working back to explicate the context of these experiences" (Anderson, 2002, p. 20).

Anderson (2002) and Reimer-Kirkham & Anderson (2002) both argue for the use of Dorothy Smith's work in developing institutional ethnography as an appropriate methodology consistent with post-colonial feminist theory and a critical feminist epistemological perspective. Although I did not undertake an institutional ethnography, I did focus on the experiences of participants to gain an understanding of the social context and the effect on access to health care.

Further to the notion of transformation, I was informed by a feminist understanding of research as praxis (Lather, 1991). Atkinson & Hammersley (1994) acknowledge that ethnography by its very nature of representation of others is associated with ethical and political responsibilities but achieving this is complex due to the diversity of individuals and groups, the lack of homogeneity within groups, and the lack of clarity regarding interests of individuals and groups. They state that collaborative research through involvement of practitioners in the research would make the research more relevant and useable. Lather (1991) provides an important understanding of research as praxis that informed the design of this research in an attempt to make the research relevant and useable. The goal of research as praxis is to "encourage self-reflection and deeper understanding on the part of the researched at least as much as it is to generate empirically grounded theoretical knowledge" (p. 60). To achieve this goal, research designs require reciprocity ("mutual negotiation of meaning and power" p. 57) both in the collection and the analysis of the data.

Reciprocity can be achieved by conducting interactive interviews in which there is exchange between researchers and participants. Both Anderson (1991, 1996) and

Oakley (1981) describe the role of self-disclosure in not only creating rapport but facilitating understanding and change on the part of participants. Sequential interviews to “facilitate collaboration and a deeper probing of research issues” also enhance reciprocity (Lather, p. 61). Lastly, Lather advises that some degree of involvement of participants in the analysis is required for reflexivity. She suggests that negotiating meaning at a minimum “entails recycling description, emerging analysis and conclusions to at least a subsample of respondents” (p. 61).⁷⁷ This thinking sensitized me to the need to think carefully about strategies for involving participants in the data analysis that I will discuss in the following section.

In 2004, as data collection on project was underway, I was introduced to the work of Barbara Thayer Bacon (2003) by two members of the nursing ethics research team. Thayer Bacon articulates both a feminist and ethical perspective that is relational in the sense of linking particular practices to the broader social context. Relationality between the micro, meso and macro levels is reflected in the everyday interactions and relationships of nurses and clients. As I read about relational (e)pistemology,⁷⁸ I felt that many of the important elements I had pulled together from various other theoretical perspectives were integrated in her writing. While Dorothy Smith’s (1987, 1999) work assisted me in structuring my observations and interviews and beginning thoughts about

⁷⁷ While these strategies encourage participation and collaboration of participants, participants were not involved in the design of the study nor was the primary goal transformation beyond the research process. In this sense, critical ethnographic work differs from participatory action research.

⁷⁸ Thayer Bacon (2003) specifically uses the term (e)pistemology rather than epistemology to highlight her departure from other views of epistemology. She asserts that she is co-opting the term instead of abandoning it.

data analysis, I drew more specifically on Thayer Bacon's work in structuring the data analysis for this study.

Thayer Bacon's (2003) relational view of (e)pistemology, is a 'pragmatic theory of knowledge as inquiry' which locates relationality as a focus for knowing the world. Relationality, rather than language (for example), is a way of being in the world through which knowing is possible. She describes,

My relational (e)pistemology is a pragmatic social feminist perspective calling for active engagement, aiming at democratic inclusion, joining theory with praxis, striving for awareness of context and values, tolerating vagueness and ambiguities. I argue that knowing is something people develop as they have experiences with each other and the world around them. People improve upon ideas that have been socially constructed and passed down to them by others. They do this improving by further developing their understandings and enlarging their perspectives. With enlarged perspectives people are able to create new meanings for their experiences. In summation: *My relational (e)pistemology views knowledge as something that is socially constructed by embedded, embodied people who are in relation with each other.* (p. 8-9)

The term relational is characterized by the "theme of connection to others, including people, ideas, or even inanimate objects" (p. 76). An important feature of relationality is that as a person, I both affect and am affected by others. According to Thayer Bacon, relations are transactional. She draws on Buber's (1958) notion of mutuality to describe the meaning of transactional.

Relationality, according to Thayer Bacon (2003), can be understood from the perspective of personal, social, w/holistic, ecological and scientific relations. Personal and social relations explore "the connection between individual knowers to other people, at a personal level and at a social level" (p. 77). W/holistic and ecological views as outlined by Thayer Bacon help us to understand connections between people as knowers and the larger spiritual, material and natural world within which we live. She states, "Not

only do we exist in relation to other human beings, we also live our lives in relation to our environment” (p. 11). Scientific relations point to the relational nature of scientific ideas such as relativity theory, quantum mechanics, general systems theory, co-evolution, and genetics. In this project, I have drawn primarily on her understanding of personal and social relations.⁷⁹

Personal relations, as an important aspect of relationality, explore connections between individuals (Thayer Bacon, 2003). However, in exploring connections between individuals it becomes readily apparent that we are interacting with people “who are embedded within a larger social context” (p. 79). She explains,

Thus, we begin to understand that while starting an exploration of relationality from the micro level of personal relations helps us understand how we are intimately connected to others and highlights the primacy of interpersonal relations, we quickly come face-to-face with the public, social effects on the private relation at a macro level. The boundaries between private relations and social ones begin to dissolve (p. 78).

She draws our attention to the work of Nel Noddings and Martin Buber as providing good sources of understanding a relational (e)pistemology at the micro level. While we live in relation to one another, “our personal relations are located within larger social contexts” (p. 81). Nurses, as health care providers, are deeply embedded in the social

⁷⁹ Although beyond the scope of this project, it would be very interesting to think about ever widening circles of relations in which we are embedded. For example, in doing this project, some interesting and somewhat surprising insights about ecological relations emerged. Among individuals who are homeless, I found there were times when I observed a great deal of care for the environment. One day, a woman staying in a shelter, handed the nurse a broken needle attached to a syringe at the beginning of an interaction with the nurse. When the nurse asked if she wanted an exchange, the woman said, no she doesn't use needles but that she had found it in a nearby park. She said she gets really upset when people leave their needles and garbage lying around. In reference to the park, she stated, this is my home and I want it to be clean. Analysis of ecological relations provides insight into the connections between ourselves and others, such as those who are homeless. Homelessness and drug use has an effect on the environment. For example, the presence of drug related paraphernalia (e.g. used needles, packaging, condoms, sterile water containers) can be found in any part of the city and poses a risk to others, particularly children. Thus, the environment is a shared connection between us. The presence of needle exchanges, safe injection sites and outreach teams can reduce such risks both for people and the environment.

context within which they work, as are the clients for whom they provide care. Thayer Bacon draws on Dewey to explain the dynamic interaction between individuals within their own social groups and between other social groups. “Dewey helps us understand that individuals are greatly affected by individuals and other social groups but social groups also are greatly affected by individuals and other social groups” (p. 83). Any split between the personal and social is artificial and Thayer Bacon’s work helps to bridge not only this gap but the gap between theory and practice which has plagued nursing scholarship. Thayer Bacon (2003) provides a relational (e)pistemology as a way of knowing relationally in the world. It is a theory of knowledge as inquiry that sets up how one might explore a problem such as inequities in access to health care.

Thus far, my intent has been to set the methodological, theoretical and epistemological stage for what is to come as well as providing support and rationale for the decisions made during implementation of this research project. In summary, I have drawn on ethnographic methodology consistent with the common features of ethnographic research described by Stewart (1998). I have taken a view that knowledge is socially constructed through human interaction between the researcher and participants. In the development and conduct of this research, I have been informed by critical and feminist perspectives. My chosen research methodology is consistent with the value orientation of critical research and aimed at social change both in the process of the research and in providing insights for enhancing equity in practice and policy. Feminist influences, particularly that of Anderson (1991, 1996, 2002), Lather (1991), Smith (1987, 1999) and Thayer Bacon (2003), resulted in the choice of a highly reflexive research design, a focus on local knowledge and experience as a source of gaining insight

into the social context, the possibility of transformation in the research process, and a relational frame for data analysis.

IMPLEMENTING THE STUDY

In this section, I will provide a description of the process of gaining access and entry to sites, data sources (field notes, interviews and documentary sources), data analysis procedures, reliability and validity and ethical considerations. I began data collection on January 28, 2004 and completed the formal period of data collection in November, 2004 when I conducted the final interviews for this project. Data for this project was collected in three sites: two inner city primary health care centers⁸⁰ and one emergency department in a large tertiary acute care hospital. There was a total of 24 primary participants in this study with whom I did participant observation and/or conducted formal interviews.

Gaining Access and Entry: Developing Relationships

As Roper and Shapira (2000) observe, there are no standards for gaining access and that “you have to rely upon your ability to work effectively with people to negotiate and build trusting relationships” (p. 64). While it is critical to gain trust to facilitate initial access, it is especially important that the researcher demonstrate a high degree of awareness and sensitivity to situations that might be not appropriate for observation

⁸⁰ I have chosen to refer to the settings where I collected data for this project as primary health care centers even though they might be called community health centers in their communities. In part, this is for consistency with references to primary health care in the initial chapters. I am aware of the potential confusion of primary health care with primary care. I take primary care to mean the initial point of access to medical or physician care. Primary health care has been defined more broadly to include a range of integrated services that are accessible to the community at a cost they can afford and based on the needs of the community. The term, primary health care is consistent with a broader focus on health that includes addressing the social determinants of health. In practice, use of the phrase, community health centers, can also be misleading as some hospitals and health units in Canada have been renamed community health centers.

through the process of the research to preserve that trust as a part of the process of reflexivity. I was aware that my experience as a registered nurse in a variety of clinical settings (emergency department, a small rural hospital, large urban hospital, a refugee center and agencies that serve the inner city) would be an asset in gaining access and developing trust. In particular, my work in a variety of different community agencies with nursing students contributed to my knowledge of issues related to working with people experiencing marginalization. Throughout my career in nursing education, I have taught extensively in the area of human relations and have been committed to my own interpersonal awareness and development. As a beginning researcher, I had the opportunity to participate in a study of ethical practice within a hospital setting as a member of a large research team. I felt I had benefited from the knowledge and insights of the experienced nurse researchers conducting this study. For example, in that study, I had done participant observation with registered nurses in a clinical setting. I anticipated that this knowledge would benefit me in the conduct of my own research. Several members of my dissertation committee were experienced ethnographic researchers and I knew I would have access to their knowledge and expertise throughout this project.

Initial contacts with the managers of potential primary health care centers were made by phone during the development of the research project by phone (Appendix A). Since I had not worked in this area of nursing, I needed to develop some contacts, gain some insights into the issues and assess the potential interest of managers in supporting the conduct of this study in their center. I made an appointment with one of the managers during which I shared with her a summary of my research project. She was enthusiastic and invited me to recruit participants from the center as soon as I had received ethical

approval. I received similar expressions of support and interest from all of the health center managers I contacted about the study. In fact, as I contacted various managers and described the research, the contacts invariably led to conversations about the barriers that their clients face in accessing health care both in their center and more mainstream venues. Although this was not data, their observations and comments supported the need for this research and provided me with invaluable insights as to how to proceed in the conduct of this research.

After sending an e-mail note to one health centre manager indicating I had received ethical approval to proceed, I had a phone call the next day from a nurse in that center who was interested in participating in the study. All of the managers except one expressed a keen desire to have this research conducted in their centre.⁸¹ The first emergency department (ED) manager I contacted immediately agreed to provide me with the letter of support needed for ethical approval and facilitated me to work with the assistant manager to make arrangements for undertaking observation in the ED.⁸² I applied for and received ethical approval both from the University of Victoria and from

⁸¹ One of the managers was particularly interested in having a nursing research project conducted in her center because she felt that staff did not have the same opportunity to participate in nursing research as other types of disciplinary specific research. Another manager, one of the six I approached, indicated that although the study was of interest, the health center was involved in a several other research projects and was concerned that the timing was not right to have another researcher in the setting. However, this manager arranged for me to meet with the clinical educator of that health center and to have a tour of the center.

⁸² It is interesting to note that the manager in the ED, like the health care center managers, was very interested in this study but articulated different reasons for her interest. While health center managers verbalized concerns about the importance of their clients gaining access to health care services without prejudice, the ED manager and assistant were interested because of the challenges of caring for people experiencing addictions and homelessness in the ED. She and others wanted me to understand from the beginning that they were doing as much as they could for this group of people.

each of the health regions in which the research was conducted prior to beginning the research.⁸³

The managers of each of the three sites facilitated my introduction to nurses in the site as well as other health care team members. After receiving ethical approval to conduct the research in a particular site, the manager introduced me to nurses and other staff either individually or in groups. With the nurses, I had the opportunity to explain the study to them and determine whether or not they wished to participate. Often as I explained the study, nurses immediately shared their thoughts or comments about the issues and concerns related to accessing health care for people who are street involved. In part, most of the nurses in the two sites where this research was conducted expressed an interest in participating because they felt that their role and responsibilities were developing and that it would be timely and interesting to participate in a nursing research study. Based on my experience in a research study of ethical practice, I had anticipated that the nurses might see me as judging their practice. However, this did not appear to occur with any of the nurses I followed in this study. I would note that, usually early in my relationship with each nurse, he or she might make a comment to the client that I was there to watch the nurse rather than the client. My perception was that this was to help put the client at ease.

⁸³ The process of gaining ethical approval continued throughout the study. First several amendments were submitted to the University of Victoria human research ethics committee as modifications to the process of informed consent for secondary participants that were needed once I had entered the field. I will discuss these later under ethical considerations. Secondly, I received ethical approval from the health region to begin data collection in the first health care center. As data collection was proceeding in the first site, I applied for and received ethical approval to collect data in the second and third site from the respective health regions.

Throughout the study, I tracked my observations about the development of my relationships with individual nurses and others in the setting as well as my feelings of comfort and discomfort at each site. My relationship with each of the nurses in the primary health care centers developed over time as I came to know them better through the process of participant observation. I recall the day that one nurse by way of introduction said to a client, “have you met my friend, Bernie,” up to this point, she had struggled with whether or not to call me a nurse or a researcher.⁸⁴ Several weeks into the study, I noted the day when in one health centre, the receptionist simply rose from her chair when I walked into the reception area and provided me access through the locked door to the main clinic area. On one occasion, a manager, indicated that “of course, I should come to a meeting, because I was one of them now.” For me, these experiences pointed to the growing sense of trust between myself and others in the setting. However, I was aware that I had the privilege of being in this setting as a researcher and that I needed to maintain that role. My guideline was to foreground my role as a researcher while being myself as I got to know the staff. I would openly talk about the research, what I was thinking and seeing when it was appropriate. I also took an interest in people as individuals, which is characteristic of how I would work in any setting.

An important activity in each setting was to share information about the study with all staff who worked at the site. As I was introduced to secondary participants (doctors, receptionists, social workers, pharmacists, and shelter workers) I would provide

⁸⁴ The reference to me as a friend, might be interpreted as a concern about the development of a personal relationship beyond the scope of this project. However, in this context, it was used in the sense of a colleague. With all clients, I explained I was both a nurse and a researcher. One nurse, part way through the study, introduced me as a nurse researcher, a title that conveyed both of those roles in a relatively straight forward manner.

them with both verbal and written information about the study.⁸⁵ I found that this required considerable time as many of these participants had interesting questions and thoughtful comments that were germane to the purpose and objectives of the study. For example, one nurse, working in a street nurse role said, “this is exactly the kind of study we would do if we had the time.” Among the secondary participants in the health centers, shelters and drop-in programs there was unanimous support and interest in topic of the study. In fact, at times I felt overwhelmed by the interest and need expressed by participants. I recall several secondary participants saying to me, “I want to talk to you” after they had heard about the study. At first, I thought they had concerns about the study but I quickly came to understand that they wanted an opportunity to share their views on access to health care for people who are street involved. I interpreted this as a passion and commitment to enhancing quality of life for people who are experiencing severe social disadvantages.

My observation was that the study was of interest because it seemed to be consistent with an important focus of concern for nurses and others working with people experiencing addictions, mental health concerns and homelessness. In fact, my observations based on reactions and comments of participants in the study is that the important role of relationships in facilitating access to care was a given based on their experience. As I mentioned in chapter 1, early in the study as I struggled to clearly articulate the purpose of the study, a shelter worker said to me, “Oh, you mean that the way people are treated makes a difference to their care.” I felt surprised by the clarity

⁸⁵ Although I did meet with groups of staff to tell them about the project at formal staff meetings, it was evident that the main mechanism for communication was one to one interactions in the coffee room or between meetings.

and simplicity of her response in articulating the primary focus of the research. The understanding that respect was a basic assumption of providing care to those who are street involved was prevalent among most of the service providers that I meet during the conduct of this research.

As I followed nurses in their everyday practice, I came into contact with many people receiving care who, by virtue of being seen by the nurse, were secondary participants in the study. A poster was developed and pamphlets were available in the waiting area of the primary health care center describing the study (See Appendix B & C). When I explained to clients that I was doing a study about access to health care, the role of nurses in facilitating access and what might be done to improve access, they often would make comments about their experiences in health care or provide their opinions on access to health care. Their stories and comments often took one of two forms. One response was to tell me how wonderful the nurses were and how much they appreciated receiving care from them.⁸⁶ The alternate story was one in which they would comment on their experience in an emergency department or hospital. Frequently, this second response reflected a negative experience with the health care system and a perception that they had been treated unfairly.

Of the multiple clients that I encountered over the ten month period, only two clients choose not to have me present. As data collected proceeded, I experienced a growing sense of ease and rapport during participant observation with clients even when

⁸⁶ Often individuals would tell me this and talked about the nurse as if she were not present. In one situation, a woman told me that her cat doesn't like people and avoids coming out when others are present. However, she said that her cat comes out when the nurses are there and stated that "I think she knows that they are helping me." One nurse later expressed surprise to me at the woman's comment saying, "I am never sure what she is thinking."

encounters were relatively brief. One manager observed that the high rate of acceptance of myself as a researcher speaks to the respect that clients have for the nurses in that center and that respect and trust is extended to me both because I am a nurse and because I am with nurses. This same manager had advised me early in the study that I should tell clients that I was a nurse as well as a researcher. She indicated that my nursing status would be important in gaining their trust because of their past experience with nurses in the centre. Throughout the remainder of the study, there were multiple examples in which it was apparent that nurses are highly respected and trusted within the community.⁸⁷ I identified three reasons that contributed to my acceptance among those receiving services. First, the trust that is accorded to nurses as professionals was extended to me as a nurse and a researcher. A second factor was the existence of already established relationships between the nurse and a particular client.⁸⁸ A third factor I identified was my ability to approach each client with respect: smiling, shaking their hand, and telling them about the research without talking down, listening to their comments and thanking them. Early in the study, one nurse gave me the feedback that she was surprised that people told me so much so quickly and added that she thought it was because of who I was. I think an important rite of passage within the health care centers was my ability to demonstrate the standard of respect that practitioners feel is owed to their clients.

⁸⁷ I would note that such status enhances the opportunity for nurses to interact with clients in locations that might otherwise be perceived as unsafe.

⁸⁸ There were 2 clients in one setting that declined to have me present. Neither had an existing relationship with the nurse. One client was a woman with whom the nurse had been working to develop a relationship over some length of time. She stated that the development of the relationship is essential if the person is to accept suggested treatments and health care. In this case, the nurse talked about how many months she had been working with this woman to encourage her to have a 'pap test' (papanicolaou test).

In the emergency department (ED), there was evidence of interest in the study by nurses and others. Most of the nurses I encountered in the ED were interested in sharing their experiences formally and informally. Several secondary nurse participants in the ED felt it was important for me to understand that the ED could not 'do makeovers.' I came to understand that this meant they felt unable to deal with the complex health and social issues that they encountered when caring for people who were homeless or experiencing addictions because of the need to keep the flow of patients moving in the department. I think my most striking experience was when nurses in the ED came to me to tell me about someone they believed I would be interested in knowing about because the patient was 'one of them,' or as one nurse said in reference to a man with a history of addiction, "he's one of yours." In many regards, I was surprised by the interest and willingness of ED nurses (both primary and secondary participants) to talk openly about the way people are cared for in the ED and the problems of working with people with addictions and homelessness. Based on my involvement in other research, I was aware of the growing pressures on emergency departments and the impact of the current socio-political context on emergency nursing practice (Rodney, Hartrick, Storch & Varcoe, 2002-2005). My hunch is that their interest arose, at least in part, from their concerns about their inability to care for and meet the needs of those who are street involved while meeting the demands of caring for others in the department and upholding the values and structures of the health care system.

Population and Sample

Participants in this study were recruited from two primary health care centers and one emergency department (ED) in Western Canada. I chose primary health care centers

as a site of data collection because of the preliminary findings from other research in which positive experiences among those who are street involved had been reported (Hilton et al., 2001a; Politzer et al., 2001; Stadjuhar et al., 2000). With my committee, I determined in advance that having at least two primary health care sites would be needed in order to protect the confidentiality of the participants. I did extended participant observation in one primary health care centre. The second centre and the ED became secondary sites for collection of collateral data. The choice of particular sites was based on the willingness and interest of managers and nurses to participate in the study. The decision to undertake observation in the ED was made during the process of the research. During data collection in the primary health care centers, those receiving services frequently reported negative experiences in the ED. Part way into the study I had identified a consistent theme of avoiding health care, particularly the ED, among those experiencing addictions, homelessness and mental health concerns.

The primary health care centers were located in two large urban centers.⁸⁹ The mandate of both centers was to provide primary care services to those who are street involved and provide an alternative to seeking care in emergency departments. Both centers were funded primarily through regional health authority budgets and physicians were salaried rather than paid fee for service.⁹⁰ The communities served by both centers

⁸⁹ In addition, I visited two other primary health care centers. In one center, as mentioned previously, the manager felt that the timing was not right to get involved in another research project. I did have an opportunity to spend some time in a fourth center that provided very low threshold services in that clients did not require appointments. In fact, health care services were provided primarily on a drop-in basis and clients were not asked for their names although the nurses knew many of those seeking access to health care. The main emphasis in this center was assessment and referral to other services such as a primary health care center or ED. Although, I had an opportunity to meet and talk with one nurse in this setting on two occasions, the nurse declined to be formally interviewed for the study. However, these visits did serve to reinforce or contradict my observations more generally.

was similar in that many of the people accessing services were at risk or positive for HIV, hepatitis C, sexually transmitted diseases (STDs), and were experiencing substance use, poverty, unemployment and homelessness. The centers provided services to both men and women. Neither centre provided services to children. In both centers, people of Aboriginal origin comprised a significant number of the people accessing the center. For example, one center had employed staff with expertise in Aboriginal health.

Both clinics were described as primary health care and/or community health centers, and were staffed by interdisciplinary teams providing a range of medical, nursing, counseling, nutritional, pharmaceutical, and complementary services. The center (Site A) in which I did extended participant observation was a first point of access for anyone who is street involved. Outreach was an important aspect of the services in this center and was done through planned visits to a variety of community agencies by the same nurses, physicians and social workers who provided services in the health centre. This meant that on a weekly basis and within selected community agencies, anyone could access health care from the health centre staff on a drop-in basis. Services included primary care of illness and injury by nurses and physicians, prevention of injury, education, counseling, and treatment of people experiencing homelessness, and people at risk for HIV, hepatitis C, substance abuse, violence, and trauma. This centre is located in a diverse area of the community with a mix of high end and low cost housing available. A number of other agencies known to provide services to those experiencing poverty, homelessness and addiction are located within walking distance, although a few services

⁹⁰ Although both were funded by regional health authorities, there were differences in the relationships between the individual center and the health region in the management and governance of the center.

for those who are street involved are located outside of the defined area. In general, the area near the centre is populated by a mix of agencies and businesses accessed by people from all income levels. Those accessing the centre came from all parts of the city including outlying areas.

The second center (Site B) was considered to be a primary care center for people undergoing treatment for HIV and hepatitis C, as well as providing assistance with methadone maintenance, drug rehabilitation and other related health concerns. Outreach was provided by nurses associated with the centre but as part of two different programs with different mandates than the primary health care clinic. A small group of nurses had partially implemented their vision of doing primary care outreach and worked closely with a physician to provide outreach services on a drop in basis within community agencies. This centre is located in a defined community that was known to have a high rate of homelessness, poverty and substance use. In the community, there is low income housing and services for those living on the street and experiencing addiction. Those accessing the centre were from the local area except for people who were currently living outside the area as a result of participation in a drug or alcohol rehabilitation program.

During the study, providers frequently referred to the need for low threshold services for people who are street involved. For example, being able to see people on a drop in basis and providing outreach services at needle exchanges and other agencies on a regular and planned basis meant less barriers to accessing services. While there was time and space for walk-in clients in both centers, they varied in their operations. For example, in one center anyone could walk-in and become a new patient while in the other center walk-ins were for established patients. At this site, I observed that there often was

confusion about whether or not staff should be seeing people who walked in but were not registered patients with the centre.

The third site (Site C) was an emergency department located in a large tertiary care hospital. The hospital provided services to people from all social classes. In particular, this department was known to serve people who live in the inner city as well as a large number of seniors and those with mental health concerns. The nearby community was densely populated with a mix of houses, apartments and townhouses. The emergency department was geographically located outside of the inner city area. Any nurse working at each of the three sites who worked either regular or casual was eligible to participate in the study.

Primary Participants

Primary participants included registered nurses, other health care providers and clients with whom I conducted participant observation and/or formal interviews. In this study, there were a total of 26 primary participants. Different levels of participation were negotiated with each primary participant. In total, 203 hours of participant observation and 24 formal interviews were conducted with primary participants. Of the 26 primary participants, there were 13 nurse participants, 4 client participants, and 9 health center participants.⁹¹ The core sample for this study was composed of 7 registered nurse participants working in two different primary health care settings. I have described this group as the core sample because I focused primarily on learning from them and because of their contribution to both the ongoing and final analysis.

⁹¹ Health center participants refers to other health care providers (e.g. physicians, social workers) and health center staff (managers and medical office staff) who were members of the interdisciplinary team in the primary health care centers.

I did not collect demographic data at the beginning of the study because I was not sure what might be relevant information to include. However, part way into the study, I did collect this information, based on discussions, knowledge and experience with previous research that demographic data would be important in presentation of the final research project. I was able to obtain demographic data from 12 of the 13 nurse participants and two of the four client participants (Appendix D & E). All of the nurse participants (13) were female and all except two identified themselves as being Caucasian. They ranged in age from 27 years to 59 years of age. Three of the nurses had a diploma in nursing; eight of the nurse participants had a baccalaureate degree and one had a Masters degree as their highest level of preparation. Six of the nurses had obtained specialty certification in either emergency nursing or advanced nursing practice. Years of experience in nursing ranged from 4 to more than 35 years in nursing (ten of the nurses had 12 or more years of experience). Nine of the nurses worked .8 of a position or greater. One nurse identified herself as working part-time and two were employed on a casual basis. Three of the nurses described their current position as being in a nurse practitioner role and two identified themselves as working in a primary care nurse role. Of the remaining 7 nurses, one identified herself as working in a clinical leadership role and six identified themselves as working in a staff nurse position. The nurses working in nurse practitioner roles had the broadest scope of practice. They saw clients for a wide variety of concerns and had advanced preparation in physical assessment and diagnosis as well as community health. All of the nurses who completed demographic data sheets had been working at least 1.5 years in the agency where they were currently employed. Four of the nurses had previous experience working as street nurses.

During the course of the research, some people who are street involved and health care staff (administrative and professional) expressed an interest in being more involved in the research and became primary participants. As mentioned previously, there were 4 client participants and nine health center participants. They became primary participants on the basis of their interest, manager's suggestions and/or through informal discussions with me. These individuals became primary participants because they were interested and/or willing to be observed or interviewed, and their insights were used to further explain, support or provide a contrast to the analysis of contextual data. The 9 health center participants included physicians, social workers and administrative staff.

Of particular importance was the conduct of formal interviews with four people experiencing homelessness, substance use and/or mental health concerns. I did not actively recruit client participants for interviews. Two people receiving services in one of the community health centers saw the poster about the study in the waiting room of the clinic and asked to talk to me more about the study. A third person called me through the University research office because a social worker he knew mentioned the study to him and he really wanted to contribute because of his 30 year experience of living on the street. The fourth person was a woman I had met several times on outreach. During an informal discussion, she expressed an interest in the study and indicated an interest in sharing her health care experiences with me.⁹² Three of these participants were men and one was a woman. They ranged in age from their mid-twenties to mid-forties. All told

⁹² On several occasions, a client I met would express interest in knowing more and helping with the study. Several of them provided me with information and indicated they would be glad to do an interview if needed. Initially, at the beginning of the study, I was not sure how or if I would interview clients and then later in the study when I attempted to arrange an interview, it often did not come to fruition. However, my initial discussions with clients was a rich source of informal interview data.

me that they were on social assistance and/or receiving income from a disability pension. One person was currently homeless and had been homeless for approximately thirty years. One person indicated having an active addiction and one person reported he was currently recovering from an addiction. Three shared with me that they had a current or past history of mental health problems. All had experience with street nurses, primary health care centers and emergency department services. They all expressed a high regard for street nurses and nurses working in primary health care centers although they did not always differentiate between the two types of nurses.

Secondary Participants

It was anticipated that during the course of observations I would interact with numerous other health care team members, patients/clients, their families, administrative and clerical staff. Secondary participants included other nurses, health care providers and individuals receiving services that were observed or informally interviewed during the course of participant observation with the primary participants.

These participants would only be 'participants' in that their interactions with primary participants would be observed. Since one nurse cares for a significant number of patients in a day, the number of patients was significant. It was anticipated that I would encounter more than a hundred patients over the course of the study. The secondary 'client' participants in this study were often experiencing homelessness, alcohol/drug use and/or poverty as well as a range of physical and emotional health concerns. They ranged in age from late teens to adults in their fifties. The nurses told me (and I observed) that it was rare to see anyone beyond the age of 50 because few people survive life on the street beyond their fifties. Both men and women were among the primary participants. It was

anticipated that the majority of clients would be competent. However, there were several situations in which I was unable to obtain verbal consent of a secondary participant due to a client being under the influence of drugs, disorientated or experiencing severe symptoms of mental illnesses. Depending on the particular situation, I may have stayed but did not record or include my observations of them in the analysis.

The health care team members included individuals from other health care disciplines; administrative staff as well as health care team members employed by other agencies (e.g. outreach services, mental health). It was anticipated that other health care team members would be from a variety of disciplines such as medicine, social work and psychology. In the process of implementing the study, I had contact and interactions with physicians, pharmacists, social workers, office assistants, shelter workers, as well as community development workers in a variety of agencies.

Data Collection

Data collection for this project was undertaken in two primary health care centers with the express mandate of providing health care services to people who are homeless, experiencing drug addiction or mental health concerns and in one emergency department. It was anticipated that data collection would take place over the period of 7-9 months. As I indicated earlier, the period of formal data collection was from January 29 to November 30, 2004.⁹³ During that time, I gathered data through participant observation as well as

⁹³ While this represents a span of 10 months, the first five months was a period of more intense immersion than the following five months. The first five months were spent in one agency with the time in the later five months being split between two other agencies. There was a one month period in the summer in which I did limited data collection because of the need to gain access and ethical approval as well as to take vacation time. My involvement in the second and third agencies was less intense and of less duration than in the first setting. Observations in the second and third setting tended to be made over longer rather than

formal and informal interviews. Data collection proceeded in three phases. The first phase consisted of five months spent in one primary health care site. During the second phase, data was collected in one emergency department and in the third phase, participant observation and interviews were undertaken in a second primary health care site. In each setting, participant observation and formal interviews were conducted with primary participants (nurses, other health care providers and clients). Informal interviews were also conducted with all primary and many secondary participants.

As mentioned previously, early findings included a frequent and persistent theme evidenced both in client and health care provider data of avoiding hospitals, particularly emergency departments. This finding was discussed with my dissertation supervisor and a member of my supervisory committee. Both agreed it was an important finding and that it was important to gain a better understanding of this finding by doing some participant observation in ED. After contacting the manager of the ED and receiving ethical approval to proceed, I began data collection in an urban ED department. Through the manager, one nurse was identified who was interested and willing to participate. During the process of initial observation, I had the opportunity to talk with many of the nurses about the study. Two additional nurses expressed an interest in having me buddy with them. I was unable to buddy with one of the nurses because of conflicting schedules. With another nurse, when I arrived for our buddy shift I was informed that she had called in sick but had made arrangements with the team leader for me to buddy with another

shorter observation periods. For example, in the first agency I typically would spend 3-6 hours at a time and in the second and third agency I consistently was in the setting for 8 hours per observation.

staff member on shift that day.⁹⁴ I did offer each of these two nurses the opportunity to participate by doing a formal interview. One of the nurses was willing and interested in this option. In the ED, I completed 16 hours of participant observation and conducted four formal interviews with ED nurses. During the course of the study, a fifth acute care nurse with experience in ED contacted me because she had heard about the study and expressed an interest in being interviewed. Data collection in the ED was completed between June and September of 2004.

While completing data collection in the ED, I began the process of gaining ethical approval and access to a second primary health care site in another city in Western Canada. I undertook data collection in this site from August until November 2004. During that time, I also had the opportunity to visit two other community health centers on three different occasions. In each site, data was collected in the form of field notes made during participant observations with nurses, interviews with nurses, those receiving services and other health care providers as well as supplementary data sources. Data analysis of field notes and interview transcripts during began during the process of data collection.

Participant Observation

The primary method of data collection in ethnographic work is participant observation in which the researcher participants in the life of those being studied, “watching what happens, listening to what is said, asking questions - in fact, collecting whatever data are available to throw light on the issues that are the focus of the research”

⁹⁴ Initially, I was concerned that this nurse might not have felt free to refuse. I indicated expressly to her that it posed no problem for me to reschedule a shift with the original nurse volunteer. She indicated that she was interested and would like to participate.

(Atkinson et al., 2001; Atkinson, and Hammersley, 1995, p. 1). As mentioned previously, one manager as well as others it was suggested that it would be important and useful to do observations with other members of the interdisciplinary team. In part, I think this suggestion spoke to the importance of valuing the whole team as well as to understanding the essential nature of interdisciplinary work in primary health care centers. All participants were informed of my role as a researcher, my intention to observe while care was being provided and the purpose of research to contribute to understandings that have the potential to improve access to health care. Potential participants were provided with the opportunity to ask questions, make comments or express concerns about my role and the purpose of the study.

Some authors have suggested that participant observation may be placed on a continuum from full participation to complete observation (Laine, 1997, Roper & Shapira, 2000; Tedlock, 2000). I anticipated that I would fluctuate between being a participant-as-observer to an observer-as-participant, which is common in ethnographic work involving practitioners (Roper & Shapira). As a registered nurse, I am subject to professional and ethical standards for research and practice. Professional and ethical standards for practice as well as clinical knowledge and experience were used as guides for judging an appropriate degree of involvement and activity throughout the study. Additionally, as a student I had access to committee members as a resource for addressing professional/ethical issues that arose during the course of the research project.⁹⁵

⁹⁵ It is interesting to note that the most challenging issue I confronted was not in terms of clinical practice but in relation to research ethics. During fieldwork in an agency, several of the nurses raised concerns to me about ethical violations that they perceived had occurred in the conduct of another research project.

I anticipated I would spend approximately six to eight hours per week in data collection. Initially, this was in the form of participant observation to allow for immersion in the setting. Later, I was engaged in interviews as well as participant observation. The number of hours spent in participant observation was recorded weekly. Approximately 8-12 hours per week was allocated to writing field notes and analysis of the data. Initially, as I was unsure of what would be important information to record, I found that it took me much longer than the allocated amount of time to write comprehensive field notes. However, as the process of writing field notes became more refined, the actual time spent doing field notes decreased. The length and amount of time spent doing participant observation was continually evaluated and assessed based on the quality/quantity of data; availability and willingness of participants, and both anticipated and unanticipated events in the setting during the course of the study.

I did participant observation with 10 nurse participants and four other health care providers. The period of participant observation with each primary nurse participant varied based on the nurse's availability, interest, and the amount of time I spent in the particular site. I had three nurse participants with whom I spent 2-4 hours each week over a five month period. In addition, I accompanied one nurse participant on three four hour shifts and four other nurse participants on two eight shifts. I did participant observation with two emergency nurse participants (one eight hour shift each). Participant observation with the four health care provider participants consisted of one four hour period of observation each.

They shared these concerns in the context of talking about their practice within the agency. Additionally, they were seeking advice and I was able to direct them to some resources on human research ethics.

The focus of observations was the interactions of nurses and others as they engaged in their daily work. The intent was to focus on their relationships with clients and others as well as the context (culture) of nursing practice in order to gain insights for enhancing access to health care. During the initial phase of the research, I worked to establish trust with participants and developed a general understanding of the participants and their setting. Establishing trust with participants was achieved through respectful interaction, explanation of the study and sensitivity to the needs and demands of their work and the environment in which we were located. In order to develop a general understanding of participants and their setting, I was attentive to all aspects of the setting such as the physical location/layout, organizational structure, type of services provided and by whom, people accessing the center, relationship to other relevant organizations, background/experience of participants, important issues or dominant concerns of participants, dominant values and organizational norms. During the initial phase, participants are selected and particular issues, events and activities will provide direction for more focused inquiry. This initial phase of paying attention with all of one's senses is important for getting a big picture or general survey of the group being studied and is usually followed by a phase of more focused or selective inquiry (Roper & Shapira, 2000; Laine, 1997). Later phases of the research include the acceptance or working phase and withdrawal. During the process of the research, I found myself more and more taking on the attitudes, values and beliefs of participants. For example, many of the staff in one agency rode their bikes to work: I began riding my bike as well since I saw the value to my health and well-being in a new way. Over time, my relationships with each of the participants as well as other members of the staff became more natural and relaxed.

When I visited one of the sites, more than six months after data collection had ceased, the front desk staff greeted me by name, told me that the nurses are in back and after a brief chat proceeded to let me in through the locked door.

Field Notes

It is essential to capture observations in field notes (Laine, 1997, Emerson, Fretz & Shaw, 2001). In this study, I started with the intention to write or jot down phrases, key words or quotes during the course of observation at a time it is appropriate to do so. As Roper and Shapira (2000) observe it is also “helpful to cultivate the habit of remembering what you observe and hear” by making mental notes (p. 84). These initial jottings of observations and quotes would be used as the basis for the development of a more complete set of field notes. These authors suggest that completion of full notes from initial jottings is best done within a day of the period of observation to ensure that written descriptions and interpretations are as full and complete as possible. I found that while jotting notes was a quick way to work in the field, the notes were often lacking in sufficient detail and sometimes were indecipherable when I went to write my full field notes. This was a particular concern if for some unanticipated reason a few days had elapsed since the observation. I found given my other obligations it was often difficult to find time to write full field notes within 24 hours.

As the study proceeded, I developed a process for writing field notes that combined the making of mental notes, development of more extensive written notes in the field and review of field notes after leaving the field. When I was in the clinic setting with nurses, I had multiple opportunities to write extensively in my field note journal what I was hearing and seeing. The nurses always charted after each patient visit and

while they were charting I would work on my field notes alongside them. Although the standard appointment time was 20 minutes, it varied based on needs of the individual from 15 to 45 minutes generally and up to one hour or more in unusual or complex situations. Thus, I normally had the opportunity to write field notes about every 30 minutes to an hour. Also, while the nurses were busy catching up on paperwork, I was busy catching up on my field notes. As the study progressed and my observations were more focused, one to two hours might lapse between writing of field notes. At the end of observation period, I would review my written notes. This allowed me to add or clarify anything that was unclear in my initial notes. Within a few days of the observation, I would either review or transcribe my field notes using the computer into a word processor program. I found reviewing and transcribing field notes to be an excellent time for reflecting on my observations in the field and an opportunity for beginning analysis.

Three types of field notes were kept: descriptive, analytic and reflexive. In the descriptive field notes, description of observed events, activities and interactions were recorded. In my analytic field notes, interpretations, analyses and thoughts for further questions were tracked. Reflexive field notes and journaling were used to record personal reactions and feelings. Analytic and reflexive field notes frequently emerged during the process of transcribing field notes. Thus, transcribing field notes became an important mechanism for tracking decisions made in the process of the research and for reflexivity. For example, even though I was following nurses, I anticipated that I would experience an initial period of disorientation and lack of clarity about my role as well as the need to process reactions to situations that I observed, given that working with people who are homeless and living in poverty in their environment is a relatively new

experience to me. In fact, particularly at the beginning of the study, I found that most of my field notes were reflexive in nature as I was confronted and at times overwhelmed with the health care concerns of people experiencing addiction, mental illness and homelessness. For example, I recall an early experience in which a man was seeing the nurse for an infected finger and my response to that situation. I was struck by the recollection that two days earlier I had a similar cut that was almost completely healed. I realized in that moment the vulnerability of people seeking health services and the impact of the social determinants on the health of individuals (e.g. his ability to heal being compromised by lack of facilities for hand washing, sleeping outside, and lack of adequate nutrition). Even more obvious were persons presenting with a frequent complaint of a toothache and the sign of absent or decaying teeth as a result of inadequate dental care and poor nutrition. The totally preventative nature of such concerns was overwhelmingly apparent. Another issue of concern for me during the initial entry into both of the primary health care centers was the concern that I felt for my own personal safety given the location of both of the centers. In another instance, I experienced a great deal of discomfort while doing outreach at a particular agency. I dealt with this primarily through reflexive field noting and through discussions with the nurses.

Roper and Shaper (2000) suggest that some researchers have found it helpful to divide each page of the field note journal in half. On the left side, the researcher writes down descriptive field notes (activities, conversations, comments) while the right is for recording analytic ideas, inferences and interpretations. It may not only be difficult but undesirable to separate out descriptive, from analytic and reflexive observations. From the beginning, my intent was to experiment with different formats and to develop a

personalized format using a word processing program. My experience was that writing field notes was simultaneously a descriptive, analytic and reflexive process. Often when entering or leaving the field, it would be a time in which I was thinking about myself in relation to the research. Therefore, my field notes often began or ended with reflexive thoughts. When I was transcribing my observations, I would often turn to thinking and reflecting on my own experiences, responses and way of being in the research. Initially, I tried to separate out my reflexive notes but found that it made the most sense to write these thoughts as they occurred within the text of the field notes. These reflexive notes then became an important aspect of the data analysis and I was able to track my thinking. Sometimes, analytic insights would occur in the moment of observation, during reflection at the end of the observation or when I was transcribing my field notes. I would then record these insights as part of my field notes for that day, usually at the end of the field notes. In this way, I was able to track when these insights occurred and what triggered them, as well as flag them for follow-up if needed. Using this method, about six weeks into the study, I mapped the conceptual insights I had generated during the initial period of observation. This conceptual map was revised twice during the period of data collection as new insights were generated.

I anticipated at the beginning that field notes would be extensive and contain considerable detail consistent with capturing a general view of the participants and setting. At the beginning, I found that I was absorbing and attempting to record everything as I wanted to get a sense of the setting in relation to my research questions. However, over time, my field notes, like my observations became more focused and selective. As part of the field notes, I tracked the date, length of observation, location and

kept a cumulative total of participant observation hours. It was extremely useful to keep this record as part of the field notes throughout the study in order to organize field notes and to link data in meaningful ways. I developed an electronic record of my observation experiences using the word processor and I updated this record regularly during the study. I would record the pertinent data in my daytime organizer and then enter it into the form I developed prior to transcribing my field notes.

Interviews

It is important to link what the researcher observes with the meanings that are ascribed to it by the participants (Roper & Shapira, 2000; Laine, 1997). Formal interviews were conducted with 12 of the nurse participants, all of the client participants and 8 of the health center participants.⁹⁶ Interviews provide an important source of data collection that gives meaning from the view of participants about what has been observed. It was proposed that both formal and informal interviews would be used during the course of this project to gain insight into the meaning of activities, practices, interactions and events. Roper & Shapira describe informal interviewing as asking questions about observed events and interactions immediately after they occur. Such interviews assist the researcher to help identify values and beliefs that provide insight into the meaning of observed activities, events, and interactions. In a sense they are casual conversations that link observations to meaning. However, the researcher must be

⁹⁶ With one nurse participant, it was mutually agreed that since we had considerable time during the period of participant observation to discuss her experiences that a formal taped interview would not be conducted. She indicated to me that she wasn't sure what more she would say in an interview. In one center, I was invited to do participant observation with a physician specialist. During the course of observation we had the opportunity to conduct an informal interview. In future work of this nature, I would plan to carry a small tape recorder with me that I could use to record spontaneous interview data if participants consent to do so.

skilled and aware of the appropriateness of such questioning as well as ensuring that it does not add to the burden of participants. Informal interviews with primary participants occurred sporadically during observations dependent upon the workload of the nurse and the ability to talk confidentially. Walking on outreach activities and between patients was often a good time to find out more about what a particular nurse was thinking or feeling and to ask questions about particular policies and processes. Sometimes, there were opportunities in-between seeing patients or while the nurse was charting and I was recording field notes to have a brief conversation about something that had occurred. During the course of the study, I found that I had multiple opportunities to informally interview clients. For example, when the nurse might leave the room to get additional supplies or consult the doctor, the client and I would chat about the study or their situation. Also, while clients were waiting to see the nurse on outreach they might chat with me informally. These conversations were rich and provided genuine and 'in the moment' views of client participants.

Formal interviews were conducted following a period of immersion in the setting and observation with selected participants in order to gain depth and insight into observations made by the researcher. At the beginning of the study, sample interview questions for nurse participants were generated that included the following:

- Describe to me the meaning of ethics in your practice.⁹⁷
- Describe times you were able to practice ethically and when you were not.

⁹⁷ In the interviews I began with questions related to ethical practice as a means of understanding the nature of their practice within health care interactions, the effect of the context on the practice and ultimately access to health care. In later and subsequent interviews, I would explain or remind them of the focus of the study rather than using semi-structured questions.

- What supports your ability to practice ethically and what interferes with your ability to practice ethically?
- What resources support you to practice ethically?
- What difference do you think your ability to practice ethically has for patients?

In formal interviews with nurse participants, I usually began by reminding them of the purpose of the study and asking them to: Tell me what does ethical practice mean to you? The nurses would frequently provide examples to illustrate the meaning of ethical practice and I merely had to prompt them to expand or explore particular examples. During the course of the interview, we would often discuss particular experiences or events that had occurred during the times I had accompanied them. In this way, I was able to gain a greater understanding of the context within which care was being provided. Support and resources for practicing ethically were also discussed. There was often limited discussion about what interferes with their ability to practice ethically.⁹⁸ Since the nurses knew that I was interested in access to health care within the context of their practice and relationships with people, they often made links and references to their practice and access to health care, which we explored as they arose in the interviews.

Client participants who agreed to be informally interviewed became primary participants and informed consent was sought prior to the interviews. Sample questions for patients included:

- Tell me about your experiences with the health care system?
- Describe a time you have received good care and a time when you did not?

⁹⁸ This was somewhat surprising to me as in a previous study of ethics in nursing practice in which I had assisted with data collection, nurses were more likely to talk about times when they were not able to practice ethically (Rodney et al., 2002-2005).

- What is good care to you?
- What difference did the quality of care make for you?

In the client interviews, I began by telling them about the purpose of the study and asking them to talk about their experiences in health care. Taking this approach allowed clients to ‘tell their story’ which I learned was an important aspect of the interview for them. Three of the four individuals interviewed began with their negative experiences in health care. When I asked them about positive experiences they may have had, all three talked about their experiences either with street nurses or nurses working in the primary health care centers. Frequently, they talked about the effect of these experiences on their feelings about themselves and shared with me rich descriptions of their lives that provided me with new understandings of the context of their lives and the meaning of their experiences in health care. In formal interviews with clients, discussion of the health care system emerged naturally not only because I asked them about their experiences (both positive and negative), but I was interested in knowing what they thought might be done to improve their access to health care. I was amazed and surprised at the deep, thoughtful, and knowledgeable insights they provided both in the analysis of the current health care system and for improving the system.

The third group of people I interviewed was other health care providers (physicians, pharmacist, managers, social workers, medical receptionist). The decision and request for an interview with a particular health care provider was usually made either after a focused period of observation or after a conversation in which they had expressed their views in relation to some aspect of the study. These interviews provided a rich source of data that helped to contextualize the data collected from interviews with

nurses and those receiving services, and provided additional understanding and insights about observations made by the researcher.

All formal interviews were conducted at a time mutually agreeable to the researcher and participant at a location convenient and accessible to the participant. For nurses and other health care providers, I was able to interview them in their work setting usually in a clinic office or meeting room to ensure privacy. Client interviews were conducted either in the clinic (usually in an exam room or office) or in a private space at an agency of their choice. For example, one woman was interviewed in an unoccupied room at the shelter where I first had contact with her and where she accesses nursing services. All formal interviews were audio-taped and transcribed.

Interviews were conducted in a manner consistent with feminist approaches as described by Anderson (1991, 1996) & Oakley, (1981) and discussed previously. For example, three of the nurses had specific questions about advanced nursing practice in British Columbia and related educational opportunities. I felt that on the basis of my involvement with a recently completed University of Victoria study of Advanced Nursing project and my knowledge of the advanced nursing practice program, I could provide some thoughts as well as potential resource people to contact. In another situation, when two of the nurses sought advice about a human research ethics concern, I was able to provide them with some information about general principles of research ethics and resources (both human and material) that they might access for further assistance.

Supplementary Sources of Data

In addition, I had proposed that supplementary sources of data such as written policies and procedures, written agency communication, oral history, and/or photos

would provide additional sources of data for this project. Such supplementary sources can provide helpful knowledge for understanding changes overtime and for situating significant events (Roper & Shapira, 2000). Inclusion of this type of data also contributes to the validity and reliability of ethnographic research projects. During the course of the study, I collected newspaper articles and policy documents from local and provincial sources to provide information about the macro context as well as documents and reports specific to the agencies where I was conducting my research (meso context). These included written descriptions of the mandate, goals and vision of each of the respective primary health care centers, interim reports on specific issues, information about community resources and of course, policy manuals. There were few sources of written agency communication available to me because the communication between providers in both agencies was primarily face-to-face individually or in meetings. Providers frequently communicated with one another in the coffee room, hallways, and in their respective offices about clinic issues as well as the care of individual patients. I did pay particular attention to what was posted on staff bulletin boards, in nursing work areas and in client waiting areas. For example, staff bulletin boards consisted primarily of information about upcoming social activities and educational opportunities. Of interest is that in two of the sites, signage indicating that aggressive behavior and foul language would not be tolerated was posted for patients in the waiting area. In one site, the waiting room had numerous large health promotion/disease prevention posters related to topics such as nutrition, hepatitis C or sexually transmitted diseases. Information about testing and other services as well as specific disease conditions was available in pamphlet form in the waiting area. While written materials provided important information about the

context of the setting, they were not subjected to separate analysis but rather used as source of data reflecting important aspects of the meso and macro context in which care was provided.

Data Analysis

I decided to use an inductive approach to data analysis as described by Lincoln and Guba (1985). My intent was that data analysis would proceed concurrently with data collection. The process of data analysis was iterative, following a pattern of immersion in the data, abstraction of themes/categories, interpretation and a return to immersion. Key insights and hunches from field notes and interviews were recorded as part of the field notes. While these activities helped to guide future data collection, emerging concepts, which arose from this initial analysis of the data, were recorded separately. As Hammersley and Atkinson (1995) describe, “ethnographic research should have a characteristic ‘funnel’ structure, being progressively focused over its course” (p. 206). Insights from initial observations were followed in subsequent observations and observations/hunches were shared and discussed with participants as the research proceeded. Thus, there was an opportunity to check and test the insights being generated (Hammersley and Atkinson). Reoccurring themes in interviews and field notes were recorded in separate analytic notes. Interviews often provided deeper understanding of observations in the field and were a rich source of data about the practice of nurses and others with those accessing their services. An initial conceptual diagram emerged after a concentrated period of field work (March, 2004). This conceptual framework included experiences of clients, ethical practice within relationships, nurse to provider relationships, ethical issues within relationships, and relationship between community

agencies and to acute care. This conceptual map evolved as the project progressed and was modified twice.

The initial concepts generated during data collection and analysis could be described as sensitizing concepts that gave rise to definitive concepts through careful and ongoing reading of the data as well as providing data for future data collection (Hammersley and Atkinson, 1995). Hammersley and Atkinson describe sensitizing concepts as “an important starting point; they are the germ of analysis, and they can provide a focus for further data collection” (p.212). Definitive concepts are prescriptive in terms of what to see while sensitizing concepts suggest where to look.⁹⁹ As the period of data collection in the field slowed, line by line analysis of transcribed interviews and field notes was undertaken to develop and modify the emerging categories. Since the goal was to understand the social context, data from all sources was compared and contrasted in the search for relationships, similarities and differences. As part of this process, I proposed that I would negotiate the role of participants in the process of analysis in order to be consistent with the intent to enhance reciprocity within this research project. In the conduct of their ethnographic research with nurses, Manias and Street (2001), made their field notes and transcripts available to participants to review and provide feedback. However, their experience was that this proved difficult, counter productive, and disempowering for participants. As an alternative, they encouraged the participants to “prepare a preliminary analysis of issues with examples from the texts. This method encouraged the participants to challenge the thoughts expressed through the issues” (p. 239). Participants felt valued because their analysis became part of the more

⁹⁹ The original concept of sensitizing and definitive concepts was developed by Blumer (1954).

complex level of analysis. In this study, I took a more modest approach to involving participants and actively sought their feedback on my findings throughout the study in order to clarify and extend my analysis. Hammersley & Atkinson (1995) state,

The value of respondent validation lies in the fact that the participants involved in the events documented in the data may have access to additional knowledge of the context –of other relevant events, of temporal framework, of others' ultimate motives, for example – that is not available to the ethnographer (p. 228).

My approach to involving nurse participants in data analysis was limited and consisted of three strategies. First, during the course of observations, I would frequently share with individual participants what I was seeing and thinking and listened carefully to their responses and insights to what I had described. Informally, throughout the course of the data collection, I spoke to the nurses about my analysis and there were multiple opportunities for them to explain, contradict and expand on what I was finding.

Formally, I invited some of the nurses from the core sample to respond to my analysis at three points in the study. The first was after I had developed by initial conceptual map based on my observations and before beginning to interview each nurse. This initial conceptual diagram was shared with four primary participants for their feedback (March, 2004). At this time, one provider commented, "I can't believe how quickly you have been able to capture what we do." At the end of the formal period of data collection the evolving conceptual categories were again shared with a small group of core participants for their input and discussion (December, 2004). At that time, the nurses gave important suggestions for emphasizing certain issues over others. For example, one participant spoke to the importance of enhancing nursing education to prepare new graduates to work with people who have addictions, are homeless or

experiencing mental health concerns. Feedback from participants was recorded and treated as an additional and valuable source of data rather than as validation of data.

Hammersley and Atkinson (1995) describe,

Whether respondents are enthusiastic, indifferent or hostile, their reactions cannot be taken as direct validation or refutation of the observer's inferences. Rather such processes of so-called validation should be treated as yet another valuable source of data and insight" (p. 230).

Members of the core group of primary participants in this study expressed an interest in reading and commenting on the written findings of the chapter. Therefore, participants will be given an opportunity to review the findings and provide feedback on the findings. Also, the manager and staff requested a presentation of the findings at a staff meeting. Initial presentations to the staff of the two health centers were given in April and June 2005. Of particular interest was the feedback from nurses and others who attended these presentations. They indicated that the findings were consistent with their experiences and what they do. As one nurse participant said, "there is nothing new here." Another nurse participant indicated that the reasons people who are street involved are reluctant to access health care are the same as what she hears from other members of the public. This is an important point and one that has been raised to me previously. A critical distinction is that those who are street involved are significantly different in their vulnerability and susceptibility to negative experiences in health care and the ill effects of delays in health care. A discussion of the reasons that individuals are reluctant to access health care prompted one physician to remind me that delaying care is often based on concerns that an individual has for the well being of their dog and ensuring that their dog is well cared for if they require hospitalization. The nurse participants at one primary health care site expressed a particular interest in pursuing additional research related to a

hospital liaison program. Lastly, a group of interagency providers are interested in having a presentation of the findings and providing future direction on the policy recommendations. This will be planned for fall of 2005 and may serve as a launching point for a second study.

Immersion in the data was achieved by reviewing transcribed interviews and field notes systematically to be able to identify activities, events, and conversations that describe ethical practice and interactions within the social context being studied and for their effects on access to health care. The operations of unitizing and categorizing, as described by Lincoln and Guba (1985), were employed in the analysis of the data. Unitizing refers to the identification of units of information from interviews and field notes that are the initial basis for the development of themes/categories. According to Lincoln and Guba (1985), there are two characteristics of units:

First, it should be heuristic, that is, aimed at some understanding or some action that the inquirer needs to have or to take. Unless it is heuristic it is useless, however intrinsically interesting. Second, it must be the smallest piece of information about something that can stand by itself, that is, it must be interpretable in the absence of any additional information other than a broad understanding of the context in which the inquiry is carried out (p. 345).

I had initially proposed that in the analysis, Dorothy Smith's (1999) idea of social relations would provide a lens for looking at the data. By beginning with experience to examine practice, it is possible to work backwards to examine how social relations (context) organize everyday practice in order to generate what might be in the form of recommendations. Smith's use of the term, 'social relations' refers to context rather than relationships. She explains

Rather it [social relations] directs attention to, and takes up analytically, how what people are doing and experiencing in a given local site is hooked into sequences of action implicating and coordinating multiple local sites where others are active (p. 20).

While Smith's work sensitized me to thinking about the embeddedness of the context in everyday experiences, I did not explicitly use Smith's work in the more fine grained analysis. For this, I drew on Thayer Bacon (2003), which I have described earlier, to look relationally at the context in which access to health care was either constrained or facilitated.

The intent of analysis was to generate units that were then compared to other units in order to develop provisional categories. According to Lincoln and Guba, the task of categorization is to bring together those units that are related to the same content and to develop properties that justify the inclusion of units within a particular category. It was anticipated that data from field notes, interviews and documents would be entered into NVivo to facilitate data management and detailed analysis. In preparation for this, I completed two introductory workshops on NVivo. However, in the actual analysis of the project, only the nurse interview data was entered into and analyzed using NVivo. Analysis of field note data was contained in analytic notes and reflected in the conceptual diagram during data collection. Other interview data was reviewed and relevant sections coded to provide additional description of the context. Insights gained from all data sources were compared and contrasted in the development of provision categories.

Throughout the process of data collection and analysis, emerging categories were constantly reviewed and revised based on new data and ongoing interpretation from interview and field note data. Lincoln and Guba (1985) state,

Categorization can be accomplished most cleanly when the categories are defined in such a way that they are internally as homogeneous as possible and externally as heterogeneous as possible. The analyst should check for that characteristic (p. 349).

Relationships among categories were examined in order to identify new, overlapping and missing categories. The decision to stop the process of data collection and analysis was made on the basis of four criteria identified by Lincoln and Guba: exhaustion of sources, saturation of categories, emergence of regularities and overextension. It became clear near the end of the data collection period that while there was much more to discover about access to health care, the emergence of new data in relation to the research questions posed at the beginning of this project was limited. The decision to stop data collection was made in consultation with my supervisor and one member of the supervisory committee.

Reliability and Validity

The criteria for reliability and validity in feminist research include dependability, adequacy, reflexivity and catalytic validity (Hall & Stevens, 1991; Lather, 1991). Hall and Stevens (1991) propose that dependability and adequacy be the standard for enhancing the reliability and validity of research that is consistent with the goals and aims of feminist research. "Dependability is ascertained by examining the methodologic and analytic 'decision trails' created by the investigators during the course of the study itself" (p. 19). According to these authors, auditing during the process of research is important for rigor and means "systematically documenting the rationale, outcome, and evaluation of all actions related to data collection, sample, analysis and dissemination of the results" (p. 19). Dependability was enhanced by documentation of methodological, analytical and reflexive field notes, discussing findings with the participants, and through feedback from

members of the dissertation committee. In addition, it should be noted that dependability increases with prolonged engagement, persistent observations, use of multiple observers and comparison of multiple data sources in the analysis. All of these were integral to the design of this study.

Hall and Stevens (1991) state, “adequacy of inquiry implies that research processes and outcomes are well grounded, cogent, justifiable, relevant and meaningful” (p. 20). The criteria for achieving adequacy include reflexivity, credibility, rapport, coherence, complexity, consensus, relevance, honesty and mutuality, naming and relationally (working collaboratively). In order to achieve adequacy, throughout the process of the research, continual questioning by the researcher of methods and the impact of the study in a social and political context is a central activity (Hall & Stevens, 1991). Questions relevant to each of the criteria of adequacy have been developed by Hall and Stevens and I used these as a guide during the process of the research.

Reflexivity is central to enhancing reliability and validity (Anderson, 1991; Hall & Stevens, 1991; Harding, 1991; Kleinman & Copp, 1993; Koch and Harrington, 1998; Oakley, 1981). The personal influence of the researcher in the production of knowledge requires the researcher to reflexively consider this influence in both her relationship with participants and in the relationship between theory and data as a means to enhance validity (Lather, 1991). Lather urges researchers to take an “‘openly ideological’ approach to critical inquiry and the necessity of self-reflexivity, of growing awareness of how researcher values permeate inquiry” (p. 2). Reflexivity reforms the notion of subjectivity in research and thus becomes integral to the process of rigorous qualitative research. “Reflexivity offers a tool where the *problem* of subjectivity in research can be

turned into an *opportunity*” (Finlay, 1998, p. 453). Learning to recognize and appropriately use such opportunities is the task of the researcher.

In this study, opportunities to engage with people during observations in an appropriate manner and sharing observations and findings were seen to be opportunities for enhancing reflexivity. Field notes were critical to this process as a strategy for debriefing and structuring experiences, as are discussions with members of the dissertation committee. For example, my experiences of becoming comfortable at different sites provided key insights into understanding the issues of safety in providing care to people who are street involved. I was able to reflect on my own experience of becoming comfortable, which provided new insights and understandings in a critical analysis of the issue of safety. I recognized that the feeling of being unsafe was my concern and explored it from that perspective rather than identifying it as an ethical concern of practitioners working in the setting.¹⁰⁰

In addition, Lather (1991) proposes catalytic validity which “represents the degree to which the research process re-orient, focuses and energizes participants toward knowing reality in order to transform it, a process Freire (1973) terms conscientization” (p. 68). The notion of catalytic validity is grounded in the “recognition of the reality-altering impact of the research process” (p. 68) and the impact of this on self-understanding through research participation. For example, Anderson (1991) found that participants, through the process of discussing their experiences, gained new insights into their illness. She states, “In this light, we can come to see field work as one of the

¹⁰⁰ Similarly, early in the research I had identified what I perceived to be a list of ethical issues relevant to nurses working with those who are street involved. As I proceeded in the analysis, I recognized that issues such as concerns about boundaries were clearly my issues and not necessarily those of the nurses.

processes through which knowledge is constructed, and see our interactions with participants as part and parcel of the context of the social production of knowledge” (p. 117).

It was anticipated that participants in this study might gain insight into important and relevant aspects of their practice and the context of their practice. As discussed previously, several of the practitioners commented on the value of the study in highlighting their work and helping them to articulate what they do. There was an explicit intent from the beginning to development policy implications that will be shared with decision-makers following completion of this report. I have been asked to present the findings of this study to senior management and Board members of both of the health centers involved in this study as well as to provincial decision-makers through connections with an academic centre at the University. In addition to the development of the implications for policy makers, the possibilities for some sort of further action arising from this research might include opportunities for joint presentations with participants and the development of networks or collaborative policy initiatives that I anticipate will arise from presentations to health care centre staff and one interagency group that is interested in the findings of this research project. Such opportunities would provide considerable potential for ongoing research in this area as well as potential for new initiatives and change in the future.

Human Research Ethics

Ethical approval to conduct this study was obtained from the University of Victoria and from two different health authorities in which the respective sites were

located. Initially, I obtained ethical approval to begin data collection in one site. As soon as additional sites were identified, an amendment was submitted to the Human Research Ethics Committee and regional ethical approval was obtained to begin data collection in the additional sites.

Following the University and agency-specific approvals, I attended a number of administrative and staff meetings to explain the purpose of the study. The purpose of these meetings was to 1) assist in the recruitment of nurse participants and 2) begin the process of informing other health care providers, administrators and staff about the study. In this section, I will outline the process of informed consent used for primary and secondary participants in this study as well as procedures for protection of confidentiality.

Primary Participants

Since the number of nurses working in any community health centers is generally small compared to the number that might work on a single hospital unit, it was imperative that nurses not feel coerced to participate.¹⁰¹ Information about the study was shared with the nurses working in the centre either by myself or the nurse manager. Nurses who were interested in being participants in the study contacted either their manager or the investigator directly. After a period of discussion, the nurse had the opportunity to think it over before making a decision.

¹⁰¹ I think this was really brought home to me when one nurse indicated that she felt she couldn't say no when her manager asked her if she was interested in the study. However, as we discussed this further, she did indicate that she thought the topic was interesting to her and that if she had not been interested after meeting with me, she would not have participated in the study.

The process of informed consent for primary participants with whom I did participant observation included discussion of issues related to participant observation, formal and informal interviews. Once an individual had decided to participate, we spent time discussing and reviewing central aspects of the informed consent (Appendix F). For example, with each nurse in the core group, we negotiated the period of participant observation as well as confirming that at least one formal interview would be conducted. Participants were told both at the beginning and throughout the study they could withdraw at anytime from the study without repercussions. In particular, I reminded the nurses at regular and frequent intervals they could ask me to leave at any point during the period of participant observation. Informed consent was obtained from other health care providers for a one time period of observation and/or a formal interview. A modified consent form was developed for those primary participants with whom interviews only were conducted (Appendix G). The signed consent forms were kept in a locked file cabinet in the researcher's office.

For primary participants who were experiencing addiction, homelessness or a history of mental illness, the process of informed consent included their willingness to participate in one formal interview for a period of 1-2 hours. Most of these interviews were 45 to 60 minutes in length. For several of the participants, reading and writing English was difficult. With their permission, I read the consent form to them followed by a verbal discussion of the meaning of the consent. A definite limitation was that the consent form that I had developed and received ethical approval to use was too lengthy and not readily accessible to individuals with low literacy levels.

Although I had received ethical approval to pay client participants whom I interviewed, this raised some interesting questions for me as a researcher about the use of such incentives to encourage participation in research projects among people who are experiencing homelessness, addiction and mental health concerns. Since all of the client participants expressed an interest and most often had approached me about being interviewed, I did not advertise or discuss in advance the offering of an incentive. Instead at the end of the interview, I provided them with a thank-you card that had \$20.00 enclosed. I explained that the \$20.00 was to compensate them for their time. Most of the interviews with client participants lasted about one hour. All of the participants were very pleased with the thank-you card. One man, who had sought out the interview said, "I'm glad I didn't know about the money, it would have changed everything" Earlier in his interview, he had told me about being very touched when a street nurse had given him a Christmas card by saying "a card is something I just don't receive very often." Each of the participants I interviewed expressed his or her wish to contribute something and possibly help others on the street. During the course of the ten months, only one person approached me about doing an interview for money.

Secondary Participants

While nurses were identified as the key primary participants in this study, in the course of observations of nursing activities over the period of the study, I interacted with many other health care team members, patients/clients and their families as secondary participants. Secondary participants were informed about the study through a combination of verbal and written information and were provided with the opportunity to verbally consent or refuse observations. In order to facilitate the process of informed

consent throughout this qualitative study, I spoke with other staff and attended staff meetings to keep professional/providers informed during the course of the research.

As I began participant observation in the first setting, I consulted with each nurse about the best approach for gaining permission/consent from the clients to observe their interactions with the nurse. I initially planned to use consent cards but abandoned that after my first observation when clients disregarded the card, tossed it back at me, or as in the case of one client, became angry. At that point, I modified my consent process from using verbal explanations and cards to verbal explanations and posters (Appendix H). An addendum was submitted to the University of Victoria Research Ethics Committee outlining this change. Posters and pamphlets were placed in the waiting room of the clinic and/or offered to clients. In general, the best approach seemed to be for the nurse to either tell patient about the study or introduce me and my study. Then I would provide additional verbal information ensuring that the patient/client knew I was a researcher, the topic, that I would make notes but without names attached and that it was their choice for me to be present or not. Clients frequently indicated that they did not mind me being present and some stated that they had nothing to hide and that they weren't worried about me being there.

Since I was accompanying the nurses, I was often with the nurse when she introduced me. It was not always possible for the nurse to check with participants prior to care being provided about their willingness to have me present during interactions. At first, this disturbed me as I was concerned that individuals might feel coerced and not free to say 'no' to having a researcher present. This was particularly concerning as many of the people I met would be described as being vulnerable in that there was a power

differential between myself as a researcher and them. However, as some of the staff explained to me, their clients would have no trouble saying 'no' if they didn't want me to be there and that seeing me was important to know whether or not they could trust me. I was able to explain to individuals the focus of the study, their right to refuse to have me present and the measures I would take to protect confidentiality. Furthermore, given the power differential between the researcher and those receiving services, the onus is on me to be attentive and sensitive to situations in which participants may be feeling unable to refuse participation and situations in which participants are not cognitively able to refuse involvement. I had proposed that if I had doubts about their willingness or understanding, I would not include these observations as data in the study. In fact, there were multiple situations where it was inappropriate or I was unable to obtain verbal consent from a participant such as someone who just wanted to informally talk to the nurse, was high or experiencing severe mental health concerns. In such cases, I withdrew or limited my observations to the nurse.

In order to maintain confidentiality all names, identifying details of particular situations were removed or altered from both the field notes and transcribed interviews. All copies of the field notes and interviews were stored in a locked file cabinet in the researcher's office. Documents such as the consent form, which identified individuals, were stored separately from the data. Each primary participant was assigned a code name. Electronic copies of all data sources are only accessible by the researcher via a password on the computer. Access to the data was limited to me, members of the supervisory committee and transcribers. All of the individuals involved in the transcription of data signed an oath of confidentiality prior to beginning transcription.

The data were not destroyed at the end of this study as ethical approval permitted me to keep the data for a period of seven years.

Chapter 4

Chains of Trust and Distrust

In the next three chapters, my goal is to describe and critically reflect on the findings of this study. In this chapter and chapter 5, I will specifically explore the responses to the first four research objectives posed at the beginning of chapter 1. These objectives were as follows:

- 1) Describe the nature of interactions and the development of relationships between nurses and people who are experiencing homelessness, addiction and mental health problems.
- 2) Explicate the underlying relations (social, economic, political and historical) that support and constrain the enactment of ethical standards and practice within health care relationships.
- 3) Explore the effects of health care relations on access to health care.
- 4) Identify the insights of clients and nurses that would contribute to the development of more equitable access to health services within the health care system.

Discussion of the remaining research question will form the basis of discussion in chapter 6.¹⁰² In undertaking this project, my intent was to explore the nature of ethical practice and interactions within a primary health context with a view towards enhancing access to health care for people who are street involved. I took the perspective, as described in chapter 3, that by listening to and observing nurses and those accessing health care, I could learn about the context of nurse's practice and gain insights about access to health care.

¹⁰² The remaining research objective is as follows:

- 1) Explore the implications of these insights for policy development and analysis.

FORGING TRUST IN A CLIMATE OF DISTRUST

I began by listening and observing practices, processes, activities, and events important to nurses, practicing in a primary health care context, and people experiencing homelessness, addiction and mental health concerns. I observed and attended to structures, policies and processes that they identified as relevant to their everyday experiences. In particular, I was interested in access to health care for people experiencing socio-economic disadvantage and in identifying, from a relational perspective of nursing practice, what facilitated and/or constrained access to health care for people who are street involved. What I saw and heard reflected deeply embedded contextual features of nursing practice within health care interactions that affected access to health care. The context of nurses' work in facilitating access in the primary health care setting was one of distrust, in that there are fundamentally disrupted relations of trust between those who are street involved and the health care system.

Within health care interactions, trust was central to facilitating access to health care. *I learned that forging a chain of trust within a climate of distrust¹⁰³ is a central feature of enhancing access to health care for those who are street involved. When the links in the chain of trust are broken or missing and there is an absence of trust, access is constrained.* The chain of trust is a double linked chain in that there are interpersonal and systemic connections needed between individuals and agencies throughout the health care

¹⁰³ Mistrust is defined as "feel no confidence in, be suspicious of" (Oxford Dictionary, 1984, 471). Distrust is defined as "lack of trust, suspicion" (Oxford Dictionary, 1984, p. 214). I have chosen to use distrust over mistrust. Although either term might be used, I chose distrust because it was referred to by participants in this study and it is consistent with literature I consulted. Baier (1986, 1994) uses the term antitrust in the title of her work to refer to a lack of trust but appears to use the term distrust almost exclusively in the text.

system needed to facilitate access to health care. Interpersonal linkages and/or systemic linkages may be strong, weak or broken.¹⁰⁴ To enhance equity in access to health care, there is a need to focus on strengthening existing linkages and forging new links where they are broken or missing.

Nurses, through their work with individual clients in the community, provided evidence of what is needed to forge linkages of trust with individuals, within the community and within the broader health care system in order to facilitate access to health care for people experiencing multiple health and social concerns related to homelessness, addiction, and mental health concerns. In a sense, this understanding of the chain of trust provides insights into access to health care at multiple levels – the individual, organizational, regional, provincial and multiple entry points. The implications of these insights for health policy will be discussed in chapter 6.

In this study, I found that forging a chain of trust begins with creating interpersonal linkages of trust between nurses and those who are street involved.¹⁰⁵ According to Baier (1994), trust as a moral phenomena, requires a differentiation between different forms of trust, those that are moral and ought to be preserved and those that are immoral. In describing trust Baier (1994) states,

Trust, as I have claimed is reliance on others' competence and willingness to look after, rather than harm, things one cares about which are entrusted to their care.

¹⁰⁴ I have adopted the idea of interpersonal and systemic trust from Hall (2005).

¹⁰⁵ I would add that I am not assuming that nurses were always or the only initial link in the chain. It appeared to me based on interviews and observations that other health care providers and workers may have the initial relationship of trust with someone who is street involved and that others facilitated new linkages to be forged with nurses. I have focused on nurses as the initial link because the study was focused on the nature of interactions between nurses and those who are street involved. Although I would observe that nurses because of the nature of their work are uniquely suited and well positioned to be an initial point of access. This will be further developed within the context of this chapter.

The moral test of such trust relationships which I have proposed is that they be able to survive awareness by each party to the relationship of *what* the other relies on in the first to ensure their continued trustworthiness or trustiness. This test elevates to a special place one form of trust, namely trusting others with knowledge of what it is about them which enables one to trust them as one does or to expect them to be trustworthy (p. 128).

In her view, trust makes us vulnerable to the possible but unanticipated ill will of others. In trusting, we hand over something of importance to another. She argues that trust has moral importance particularly when there is a power differential and unequal vulnerability in relationships. In interactions between nurses and those who are street involved, there is a power differential not only in terms of the dynamics of a professional nurse-patient relationship but a power differential exacerbated by the marginalization of those who are street involved within society. In this sense, those who are street involved are not only more vulnerable but there is a greater obligation for nurses to know more about what is needed in developing and rebuilding trust in the face of distrust. The development of trust between nurses and those accessing health care can forge and strengthen linkages in the chain of trust that facilitates access to nursing and other health care services. At the same time, nurses within the health care system, as discussed previously, may be constrained by the context in their ability to enact their moral obligations and address inequities.

In nursing, trust has been identified as central to the development of health care relationships and as a basis for nursing ethics (Peter & Morgan, 2001; Rodney, 1997; Rodney & Street, 2004). Rodney (1997) found that nurses enact their moral agency within a relational matrix of connectedness and trust. According to Peter and Morgan (2001), "trust is important in nurse-patient relationships, it is also important in the

relationships nurses have with their colleagues in nursing and with other health care providers” (p. 3). Drawing on the work of Baier (1986; 1994), they suggest that trusting relationships form a web or network of trust that “helps politically situate one-to-one trusting relationships” (p. 6). In their view trust is located in human relationships and viewing trust within a network of relationships provides direction for moral action within nurse-patient relationships and in relation to the broader system.

Relationships of trust between health care providers facilitated nurses to rebuild trust with those who are street involved and reflected an overall climate of trust in the primary health care setting. Where the interpersonal linkages are strong, a climate of trust develops within and between agencies. According to Baier (1994), trust within relationships thrives when there is a climate of trust. The climate of trust is often intangible except in its absence. Baier (1986) observes,

Most of us notice a given form of trust most easily after its sudden demise or severe injury. We inhabit a climate of trust as we inhabit an atmosphere and notice it as we notice air, only when it becomes scarce or polluted (p. 234).

I will begin with a discussion of the findings that provide evidence of broken linkages and point to a climate of distrust among those who are street involved in which access to health care is constrained.

CLIMATE OF DISTRUST: BROKEN LINKAGES

From interviews and observations with those accessing health care, as well as with registered nurses and other health care providers, I found that there was an underlying lack of trust in health care providers and hospitals among those who are street involved. For example, when I asked Will, who has been living on the street for many years, about his experiences in health care, his first response was “I don’t trust anybody

at the hospital.” As will be discussed later, I heard and observed a fundamental distrust not only of health care providers and health care systems *but of social systems* among those who are street involved. I understood this to be a climate of distrust among those who are street involved.

Reluctance to Access Health Care

In this study, I heard and observed a consistent reluctance of individuals who are street involved to access health care. The reluctance to access health care took at least three different forms: not accessing health care, refusing care and leaving without treatment. Not accessing health care, refusing to go to hospital and leaving without treatment provided evidence of broken linkages in the chain of trust which constrained access to health care.

That afternoon, the nurse and I went to a shelter where she spent about two hours each week seeing people who frequent the shelter. When we arrived, one of the shelter staff immediately asked the nurse to see a woman who was staying there. In a quiet voice, the staff person told us they were concerned about her finger and that they had made a deal with her. They wouldn't give her any more band aids until she saw the nurse. The woman walked by the office door and the staff person immediately guided her into the office saying, "This is Claire, the nurse, she'll look at your finger" The woman barely nodded. The woman was unsteady on her feet, did not make eye contact and seemed ready to flee at any moment. Usually, Claire sees people in a separate room in the shelter for privacy but today, she immediately turned to the woman and began to examine her finger in the office with two shelter workers and myself present. Both she and the woman were standing. Claire leaned over and looked at the woman's finger as she swayed back and forth, nodding at times. Claire immediately thanked her for letting her see her finger and said she was glad that she had stayed to see her. Claire inspected the finger and said the woman likely needed to have a swab done of the finger and a prescription for antibiotics. Claire told her that she couldn't do that here but that she could be seen at the community health center and have it done. The woman neither agreed nor disagreed but continued to sway. Her head nodded but I am not sure if she was nodding in agreement or simply swaying. The nurse told her that she may lose her finger if she didn't go to the clinic and that going to the clinic would avoid a trip to the emergency department. The nurse asked the shelter staff for some bus tickets but staff said that they would get her a cab and

explained to the woman that they would call a cab. Claire called the clinic to tell them that the woman was coming and that she would need to see a doctor. Later, in a conversation with Claire at the end of the day, she told me that although the woman has been at the shelter off and on for several years, she has never sought care from her before. Claire said, it was a big thing that [she] agreed to stay and even have me look at her finger. She described the woman as someone that doesn't access health care very much and that she probably wouldn't go to the emergency department for care. Claire indicated that she was not sure if the woman would stay to be seen once she got to the clinic.

This story points to a pattern of not seeking health care that is subtle but pervasive among those who are street involved. Front line workers, such as the shelter worker in this example, often play a key role in facilitating an individual to access care. After the interaction with the woman, Claire went on to see many other women that day, roughly 10 women in the next hour. Most of the women were homeless; some had a history of mental illness and addiction. At the end of the day Claire asked me, "what do you notice is different on outreach?" I said immediately, "You are seeing patients who may never seek health care at the clinic or anywhere else." She got a slow smile on her face and nodded "yes, that's right".¹⁰⁶ Many of the people the nurse saw that day and on many other days may not have gone beyond the shelter to access health care. I observed that often the first contact with someone was on outreach and that new patients were often connected to the center through outreach. Occasionally, on outreach, it would become apparent that a person would not or did not want to see the nurse.

¹⁰⁶ In this interaction and after debriefing with the nurse, I became aware of the importance of developing relationships over time and the slow process of seeing a client many times before they might even access health care. This was further validated when, in formal and informal interviews with many of the nurses, they articulated that access is facilitated by developing trust and relationships over time. This was a theme I continued to follow and observed throughout the remaining months of data collection, and it will be described later.

A man approached a nurse on outreach demanding to know where the nurse was from; when the nurse replied indicating the name of the centre, he said, “I don’t trust people from [that place].”

Sometimes a person would indicate they wanted to see one nurse rather than another on outreach. For example, when one nurse was replacing another on outreach several of the clients indicated they would wait to see the regular nurse next week. Afterwards, the nurse told me that these people know and trust the regular nurse and ‘I can’t just walk in and expect them to see me.’

Through the nurses, I became aware during the course of the research that there were many clients in the community who did not seek health care even though they might be seriously ill. This became apparent to me when service providers from other agencies would consult a nurse about a particular person living on the street and very ill with an abscess, a respiratory problem or experiencing potential mental health concerns.

During a team meeting, a counselor asked if anyone knew or had seen Dora.¹⁰⁷ The counselor expressed concern for her well-being and asked “what does it mean if she has a black ring below her knee and it smells?” Dora was refusing to come to see a health care practitioner for a leg wound. The counselor described her as very suspicious. A physician said, well, we’ll have to pink¹⁰⁸ her for her own good. The counselor didn’t know if that would be possible because she didn’t know if they could find and assess her.

Nurses, particularly those who did outreach, often made many phone calls and contacts to find someone for whom services were available or to locate a person who had not followed through in accessing services that had been previously arranged. The nurses who did outreach might share with me or another health care provider in the center that they had just learned of someone who was homeless and seemed to be unknown to

¹⁰⁷ Please note that all names used throughout this report are pseudonyms.

¹⁰⁸ To ‘pink someone’ would be to determine that a person is incompetent to make decisions on their own behalf.

providers in the area. For example, one nurse shared with other team members that she had just learned about a man who had been living under a downtown bridge for some time. A primary health care centre physician acknowledged that one nurse, in particular, was amazing in her knowledge of people who might be in need of health care in the community.

It was evident that individuals who are street involved did not access health care, sometimes refused health care and sometimes left without treatment.

Carla had been coming to the health center for several years and greeted most of the staff by name when she came in for her appointments. For a few days now, she had been coming to the health centre daily so that the nurse could check her blood pressure, measure her abdominal girth and check her urine. Carla had jaundice and her liver was enlarged. Her physician wanted to admit her to hospital. So far, she had consistently refused to go. Today, when Carla arrived, she was wearing her best shoes and although her skin was dark, I noticed it had a yellow cast. We smiled and joked about her shoes. The nurse asked her if she would go to hospital today. Carla said only if there was a bed for her. She wasn't going to wait in the emergency department. The nurse told her they had a bed. Carla started to tell the nurse the things she needed to do today. She said she would have to go to lunch at the Center first so she wouldn't miss it and then walk back to get her cheque. Besides she would have to 'take care of business' before going to the hospital.¹⁰⁹ They agreed that the nurse would call the center and ask them to save Carla a lunch so that she could get her welfare cheque on the way to lunch. The nurse picked up the phone and called the Center explaining she was the nurse from the health clinic and asked them to save a lunch for Carla explaining the reason. Carla left a few minutes later. She would walk many blocks today to pick up her welfare cheque, to have lunch, and 'take care of business' before going to hospital.

Jo, a social worker, expressed an interest in sharing her thoughts with me about effective strategies for facilitating access to hospital care. When I asked Jo what she thought facilitated access to health care, she replied

¹⁰⁹ To 'take care of business' was a term used by people who are street involved. It might mean to get their social assistance cheque, get food, and find drugs among other things. I learned that many of the terms used by people on the street often have different meanings to different people and that terms frequently change over time.

The first thing that occurs to me is actually quite the opposite. Like being in situations where people need to get to the hospital, where it's life or death. And usually it'll be an abscess on the neck. And no kidding, Bernie, like abscesses, the size of a friggin' soft ball. And people are resistant to go. And they know what the potential consequences are and the whole resistance is based in past experiences. So I just can't...that always shocks me, that people could know it's life and death and because of having been treated in the past, it's not going to happen for them, or it's going to take just a tremendous amount of community to get them there.

As Jo and many others observed, getting them there would not guarantee treatment because they might leave before treatment is completed. In the emergency department, nurses indicated that often 'street people' leave without treatment. Will and Mona, two people I interviewed for this study, had both left the hospital after overdoses. They both described waking up with no one there and walking out. Although Jo expressed surprise at the reluctance of those who are street involved to access health care in situations of life threatening illnesses, she and other participants also recognized that past experiences of being treated poorly and current priorities can be a powerful deterrent to accessing care. Discontinuing or not following through with treatment or prescribed care occurred frequently, was anticipated and even expected by health care providers as a norm of working with people who are street involved.

In the primary health care centers clients sometimes left before being seen, sometimes returning later that day or the next day. On several occasions, I observed that when the nurse went to call a patient they were not in the waiting room. In such cases, the nurse would call their name a few more times and ask other patients or staff if they had seen them. In one clinic, the nurses also would walk outside of the clinic and look up and down the block to see if the person might be within sight. When the person was unavailable, the nurse would either see the next scheduled person, someone who had

dropped in without an appointment, or catch up on charting and paper work. I did not observe or hear nurses in the primary health care settings express frustration when patients were not available. I did hear nurses express concern for the well being of individuals if they were very ill or for individuals whose pattern of behavior was inconsistent with what they had come to expect. From my discussions with nurses, I came to understand that this was expected and a normal part of their practice.

The reasons that people who are street involved did not access health care, refused health care and left without treatment were complex, multi-faceted and multi-layered, based not only in past experiences with health care but rumored past experiences of others as well as current and past life experiences. In this study, based on informal and formal interviews with individuals, registered nurses and other health care providers, feeling overlooked, feeling prejudged, fear of being treated poorly, and fear of negative consequences (I can't go because....) contributed to the reluctance of those who are street involved to access care in emergency departments and hospitals.¹¹⁰

Feeling overlooked

Clients expressed that one of the reasons that they did not like to go to the emergency department (ED) was because of the length of time that they were required to wait before receiving care. Frequently clients would say in interactions with nurses or to me that they had been to the ED and waited many hours before being seen or had left

¹¹⁰ Since the primary site of my research was in the primary health care centers, I was not truly aware of the degree to which this might apply to the primary health care centers as well. I had a sense that based on observations and interviews there were individuals who did not access care in the primary health care center. It was not clear if these same reasons for being reluctant to access care might be applicable to the centers themselves. In order to better understand more broadly the reasons that individuals do not access health care it would be important for another research project to be conducted that involves more fully the perspectives of those who are street involved. However, the findings of this study are important in explicating aspects of the context of health care interactions and ethical practice.

without receiving care. When I first began collecting data, the norm for waiting in the emergency department (ED) mentioned by clients was five to six hours and increased to 8, 10 or more hours by the end of the data collection period (approximately nine months later).

During this period, there was evidence of growing wait times for all individuals based on media reports of the growing pressure on scarce resources in hospitals. When I interviewed nurses in an emergency department, they stated that waiting for 8, 10 or 12 hours is not unusual and even considered normal unless one had a life threatening illness.¹¹¹ Given what I was hearing in other research and in the media, I concluded that waiting for care is an expected norm in the emergency department.¹¹² It is understood that everyone has to wait and that one will be seen based on the severity of your illness. For some who are street involved, even thinking about going to the emergency department (ED) was a measure of how ill they felt. A woman who was HIV positive and experiencing a severe respiratory infection said to the nurse, “I even thought about going to ER, it is that bad.”

On outreach today, I told one woman that I was researching access to health care. Her immediate response was, “I just got released from the hospital – I’ve had enough health care. I could really tell you about [access]”. She tells me that she waited 8-9 hours in one emergency department before going to another hospital where she was admitted in 10 minutes. “I was blue. If I was so sick they should have known that.”

¹¹¹ It should be noted that the nurses working in emergency were interviewed towards the end of the data collection period in fall, 2004.

¹¹² For example, the Ethics in Action Research Project (Rodney et al., 2002-2005).

Annie, a nurse with years of experience on the street, explained that part of the problem is that individuals who are street involved go from being okay to acute very quickly. She stated,

People go from chronic to acute very quickly. There's often not the in-between piece. Because often they won't actually do that preventative piece. They go from here, okay, to acute, because they either won't take the antibiotics that stop them getting to the acute phase. We have very few sort of cases where you would catch an infection and go to your doctor and get the antibiotic. They won't do that piece....They have to be really sick. They have to have the enormous abscess. It has to be often times really bad before they will do anything. So it's that absolutely acute situation.

There was a perception that even though the person perceived that they were very ill somehow the severity of their illness was being overlooked.

Will has had multiple experiences with the health care system. After telling me he distrusts the hospital, he went on to explain,

Typical example, I had breakfast one day, on Saturday morning, came out of breakfast and went downtown and started spitting up blood, like dark, black blood. I left a trail of blood all the way down the street. I got down there, collapsed in the nursing station there, still spewing up more blood and more blood and more blood. They phoned an ambulance for me and they wouldn't let them clean up the blood because the ambulance might not take me if the blood was cleaned up, they wouldn't believe me because I'm a whatever, homeless street person. Went up to the hospital, sat there from like noon to like eight o'clock at night, never seen anybody, still spewing up blood, finally [the doctor] comes from the street clinic and says let's get the guy a chest x-ray and see what's going on with this guy, right? So he was there for like a couple hours and finally I got the...he said, well you've burst a vein in your throat because I'd had laryngitis for five months and full blown AIDS, diarrhea, wearing diapers, stuff like that. Pretty embarrassing stuff. You know, so you pack around five or six shorts and you know a roll of toilet paper and always be careful, right? I mean, because when you've got AIDS and diarrhea it just goes and it goes, right. And you wake up in the middle of the night and it's like the grossest thing you can imagine for me anyway. So I'm not going to go, I don't go to the hospital unless I absolutely desperately have to go, unless I'm on my deathbed, you know.

Although waiting was often cited as a barrier to care, I came to see that the difficulty with waiting was more than the actual physical constraint of the time but a feeling of being overlooked as a person and in spite of the perceived severity of their illness. Clients perceived that when they went to hospital, even though they were very ill, they were being left to wait because they were homeless or addicted. They felt that they were not receiving the attention required by their medical concerns and that waiting was a function of their social status. As one nurse working in emergency astutely observed, they don't mind waiting, "they just don't want to be ignored." She added, "You have to see them because otherwise, you're going to see them dead." This nurse recognized the importance of acknowledging them in order to ensure access to care and avoid the potentially serious implications of delays in care.

Feeling Prejudged

A second primary concern expressed by clients and nurses in the primary health care setting was that going to the emergency department or being hospitalized would be a negative experience in which clients would encounter negative judgments from health care providers based on their drug use or involvement in street activities such as prostitution. I sometimes heard people who were street involved refer to themselves as an 'addict', 'user', 'junkie', 'a coconut' or a 'pot head' in conversations with nurses and others. Such labels refer to both their general drug use as well as to the use of specific drugs. For example, someone who uses cocaine might refer to themselves as a 'coconut.' In their interactions with nurses and to me, people expressed their fears that they would be categorized or labeled as a drug user or an addict in interactions with health care

providers in the emergency department or when hospitalized. Frank was being seen by a nurse at one of the clinics for wound care.

The nurse asked Frank what had brought him here and then left the room to get the supplies she needed to dress his wound. As we were waiting for the nurse to return, he asked me about my research. When I explained a bit more, he responded by saying that “they [health care providers] prejudge you at [the hospital] ER. They are so used to dealing with the [downtown crowd], they assume you are coming to get a fix of morphine or whatever. I fell on my floor and was lying there for 5 days which is how I got [these] sores which won’t heal”. He related to me that he was in a coma when they found him in his apartment. Although he wasn’t exactly sure of events, he was taken to the emergency department and he told me he thought he spent at least two days in the intensive care unit. “I was living in a hotel where there are lots of drugs so they assumed I was a heroin addict.” He went on to say that he hadn’t used heroin himself for about 8 years and that the place he was staying was the only affordable place he could find to live. When I asked him about the novel in his hand, he told me that he loves to read. “Did you know you can sign two books a day out of the library even if you don’t have an address?” I acknowledged I didn’t know that. We then turned to discuss an upcoming weekend with his children.

Whether they used drugs or not, individuals expressed the belief that they would be prejudged, as a drug user, in the emergency department or hospital. . . .

Labeling can contribute to stereotypical thinking in that general beliefs are attributed to all individuals in a group (Corley & Goren, 1998). I heard repeatedly during the course of this study that people who are street involved have an inability to wait (they want what they want now or they will leave without care), they are intolerant of pain, they are manipulative and demanding and that they are frequent users of the system. In the emergency department, individuals who are street involved, especially those who are addicted, were perceived to have a low threshold for waiting and a low pain threshold. I observed clients telling nurses in the primary health care centers that they had been given little or nothing for pain during a hospital admission or feared going to hospital because

their pain would not be adequately managed. When I asked them, nurses in the primary health care centers acknowledged that they heard this often.

Clients feared that being labeled and treated as a drug user would affect the care they received. Labeling and stereotyping may have serious implications for quality of care. Sue, a nurse in acute care, stated,

I think not judging first and foremost. I mean, it's easy to say, hard to do probably. But you do have to start with a clean slate you know. And it's part of our code. We're supposed to treat everybody equally. And we don't because we take that judgment and we build it into our care in a way, I think. We make a judgment on someone and then we use that as a basis for care I think a lot of times rather than just caring period.

Potentially serious conditions may be overlooked if care is based on stereotypes.

One of the clinic nurses had just finished seeing a patient and was preparing to see the next person. A physician came into the nurses' office and asked if she knew what had been the outcome for a patient he had seen yesterday with vomiting and diarrhea. He had a puzzled look on his face saying, "her symptoms were not typical of a viral illness. And I wasn't sure what was going on." The nurse says, "she ended up going to emergency, waited seven hours with a temp of 40C and was sent home." The physician looks surprised and says, "You mean with her symptoms, there was no treatment prescribed?" They agree that the nurse will call the patient to book an appointment to come back in and see the clinic physician again. The nurse wonders out loud to the physician if the person was dismissed because of their addiction and not taken seriously. The physician left to see another patient and the nurse and I continued to talk about this situation. The nurse identified that the people they see are diagnostically complex. She told me you have to assess their physical symptoms and not assume that presenting symptoms are being caused by drug use. She said me you have to determine what is being caused by drug use and what else might be going on.

Labels and stereotypes may contribute to less thorough assessments and inappropriate provision of care if a provider assumes an individual is acting or presenting in a certain way on the basis of judgments (Malone, 1996). Symptoms and complaints cannot be assumed to be a manifestation of substance use. Knowledge of addiction is critical to be able to accurately assess a patient and determine whether the client is presenting with

symptoms of drug use, mental illness or something else. Otherwise, care may be compromised and access to appropriate care and treatment may be limited.

Stereotypical thinking, like labeling, has the potential to obscure understanding and knowing people as individuals. Will uses cocaine, heroin and multiple prescription drugs daily. He described his multiple medical diagnoses of HIV, hepatitis C and MRSA as layer upon layer of labels. He thought health care providers were afraid to touch him because of his HIV and MRSA. To him, the hospital was a hostile and alien environment in which he feared he would be put “somewhere and hosed off, like some kind of weird chemical thing.” In my interview with him he repeatedly expressed frustration about being labeled. He described feeling like ‘an alien’, ‘a piece of shit’, ‘a piece of garbage’ and ‘a diseased animal.’ As I talked to him, I came to understand that his values and his day to day life and experiences of surviving life on the streets were not even remotely captured or conveyed in the labels that had been given to him by the health care system over the years. He told me that labels stripped him of his identity and his pride.

Will: I mean, the worst thing you can do to somebody is to take their pride away from them or take their identity away from them, you know. Like my identity [as Raging Will] that’s what they know me on the street as, you know. And you know when I go to the hospital, I feel like that identity’s ripped away from me.

Bernie: Yeah, that you’re nobody?

Will: Now I’m HIV (Will) with dot, dot, dot all these diseases behind my name. If they meant money I’d be a millionaire. But they don’t. I sound like a broken record sometimes but over and over...it’s really frustrating to me, to take my identity away from me, to treat me like...I mean, I can see their point of view. They don’t want to catch any diseases, but at the same time, you know, I am a human being, I’ve got feelings too. And if I lash out at you, I’m lashing out because of all the rage I’ve had for 30 years. I mean maybe they don’t understand that, they don’t see where I’m coming from where every day is a survive thing.

Labels strip people of their personhood. For Will, being dehumanized triggered a violent response. Will has been banned from several hospitals and agencies. He told me he is now labeled a ‘violent offender.’ He expressed a wish that hospital staff would just respect him a bit more and listen to him so that they could know him as a person.

Megan, an emergency nurse with over ten years of experience shared her views on ethical practice with people experiencing addiction. She stated,

Megan: I think when I say everyone [is] deserving of care, it’s probably say the [person] on the street, who uses whatever substances and comes into hospital with a big nasty abscess and is sick with it too. He is also withdrawing and...may very well be triaged at a less urgent level than they actually should be, based on their symptoms...and potentially how ill they are because they’re an addict. Once treated, not spoken to as respectfully as other patients would be, not as much information given and options allowed as to you or I if we were patients in the emergency room as in...What am I giving him for pain, that kind of thing, instead of just marching in, barely saying a word, slapping on the tourniquet...not treating them as quite human, really.

Bernie: Do you want to say a bit more about that. Or maybe I’ll ask you...One of the things I’m curious about – what’s that about do you think? What’s going on?

Megan: I guess some people may have backgrounds, may have grown up with alcoholic parents, or, and those people who did seem to be either very caring about these people in crisis, or very hardened against them, I guess depending on the [situation]... I guess they feel that those people are not really, they’re less deserving than the rest of us and better people could be cared for. I don’t... I’ve heard about these kind of patients, the drug-addicted patients ending out lashing out at the staff, I always wonder how they were treated to start with. [The nurse] doesn’t give any explanations and just does things to the person, well, of course they’re going to react.

Although Megan and all of the nurses in the study expressed the view that ‘everyone is deserving of care,’ I heard from nurses in the emergency department that this didn’t always happen in their interactions with people who are street involved. Judgments about the worth of individuals may restrict access to health care and reinforce already existing

feelings of low self-worth and self-esteem. This may be further perpetuated when a negative chain of judgment is set into motion.

Nurses and clients indicated that the potential for a negative chain of judgment exists when someone is labeled and such labels are communicated from provider to provider.

Will: like I can see their point of view. They don't know who I am either. They don't know if I'm going to flip out and be a mental case again. You know, it comes up in my record on the computer and she's looking at it and I can tell right away that they're going, holy fuck, right.

Bernie: You can feel that.

Will: Yeah, I can feel it because I can see him looking at the computer and looking at me and looking at the computer and they see all this shit coming on, right. What I've done or whatever. I don't know what all comes up on there but it must be something pretty wild because I can tell by their eyes they start getting a little bit frantic. Next thing I know there's a security guard behind me.

Bernie: So it starts right from the door.

Will: Yes, right from the door on. I know, OK, here we go. The cops are going to be next right. Either I'm going to get help or I'm going to go jail.

Emma, a nurse, described the chain of judgment that is created when labels are passed from one provider to another. She stated,

You're seeing how other staff, whatever, react to certain clients, so you can see how that domino effect of, I mean when I worked emerg, it was amazing that the ambulance guys would come in and go oh yeah, so and so again; blah, blah, blah and then that is passed on to the triage nurse and then passed on to the nurses you're giving report to ...And you're passing that on to the doctor and so that judgment is all the way down and it was something that it took me a long time to realize, because then all of a sudden you're at the bedside and someone shows up, like a family member or a friend, and they're giving you a different take on what the paramedics picked up. And all of a sudden it's like, oh, I feel bad because we had that judgment happening and so we've been treating that person a certain way and there's actually something else much more complicated going on and we're compromising care because of that. Like we didn't want to deal. And you see that

often with overdoses and things like that. Oh, you're bringing in another overdose. You know. How to break that chain. So that's something that you have to be aware of that.

Similar to what Emma and Will described, I observed several situations in the emergency department in which judgments, both positive and negative, about the social worth of people accessing care were communicated between nurses and others in the emergency department (ED). A negative chain of judgment in which labels are communicated and perpetuated among health care providers can contribute to feelings of low self-esteem for those who are street involved, obscure the identity of the individuals and affect the quality of care. Thus, access to health care is restricted. As will be discussed later, some nurses in the primary health care centers attempted to break the chain of judgment to ensure that an individual received the care required by their medical condition. These findings suggest that breaking the chain of judgment is an important consideration in creating a climate of trust.

Feeling judged included the concern that clients were blamed or found to be at fault for their poor health. One health care provider described this as an attitude of blaming. Jo, a social worker describes,

It could be the attitude that's encountered at any point of access. So whether that's coming in and getting admitted or the blood technicians or the nurses or the doctors whoever that is. A lot of pathologizing...

Bernie: Pathologizing?

Jo: Like blaming. You've got that why the fuck do you keep showing up here with...it's your fault, you know, handle this.

Mona described concerns about the general attitude of blaming that she and others perceived to be pervasive in health care.

Mona: Well, I'll just say one more thing in general. I noticed at [one hospital], I've heard this a lot, has a trend that a lot of people who come in there who, and I can kind of see the way the nurses are about this but anyway that still doesn't make it right. They have drug [habits] or they're drunk and they go and they hurt themselves or you know they're OD'ing or whatever and the nurses are really rude and judgmental and just pissed off and like, well why the hell are you here? You shouldn't be here, right, because you know, you do this to yourself. And it's like they're saying, you're a waste of our time because you could have easily prevented this type of thing, right? So I noticed a lot of them, get that kind of impression from them.

Bernie: What sort of gives you that impression?

Mona: Just, well, I'm just getting feedback from other people, but I mean I've sort of experienced it too, like it's like, oh you're at fault for everything and no one else is. Anyways but yeah you know they'll look at you and think oh what the hell's your problem? Get with it. Ninety-nine per cent of society is fine, why the hell aren't you?

Bernie: That's the message?

Mona: That's the message, yeah. Like they're giving me, they're giving them, like me with mental health and them with the drug habit, like oh get over it. It's so like cut and dried, it's black and white, it's completely fixable.

Bernie: So it's maybe not so much what they say, it's more communicated in other ways?

Mona: Yeah, well, it's what they imply, there you go, it's body language, it's... they're so snappy, like, being a jerk, like oh hold still. [One community] nurse was like that. This is a long time ago, but I mean that's just burnout. I wound up having surgery on my, I'm just like, there should be examples, anyways, I had surgery on my tailbone underneath like I have a sinus they had to drain it and clean it out. So I have this big huge gaping hole under there. And it had to be cleaned out, flushed out by the nurses. So a home care nurse came and the one lady like you know she goes, oh hold the wound open so I can flush it out. And then I was being shot with pain killers because the nerves were all cut, right, and so you know trying to wait out the pain and she goes, and she said, oh hold this and it's like she grabs my hand and sticks is like on my side so I can like hold the wound open and I'm just like, it hurts, you know. I'm just waiting for the pain to go away. And the nurse is like, hold still and she's all mad, just short and tense and just grabs me like roughly and did things like oh fuck hurry up I've got to get this job done and over with. And then bitched at my mom about the weather outside and left. And then I'm like, well thanks. You know if you're sick the worst thing you need is somebody who's going to be a jerk to you because you're

already feeling bad enough as it is. And I mean if someone's an asshole to you of course you're going to feel bad in general so it's going to make you feel even worse if you're sick. And the same, again, it's like it's your fault type of thing.

Waiting a little longer, avoidance, being brushed off, rushing, and rudeness were examples of the way in which individuals felt care was provided differently on the basis of social worth. Megan, a nurse stated,

To act angry with them, these patients, because it's busy, is pretty much saying to them that they shouldn't be there or they cause their own problems which is why they're there and they're making, they those patients are making the situation worse.

Mona has a long history of mental health problems and recently has been diagnosed with schizophrenia. She explains the effect of blaming.

Mona: And I didn't know what was going on. I felt like a complete fuck-up because it's like, oh, here I'm causing all these problems and the other thing is, this is a big problem with the mental health system too, everyone blames you for it. They go, well get your shit together, what's your problem, kid. The self-inflicting things I can see, like, but then again there's people who do drugs and there's people who slit themselves because they're depressed. What's the difference? And then they say, oh well the person who slits themselves, they have a problem because they'll commit suicide and we should help them. The person who does drugs are like, oh well, they're just a user, we should stay the hell away from them. But it's the same thing. Like you're deliberately trying to hurt yourself.

Thus, there is a sense that the individual is not taking personal responsibility to change their situation and that they would be more deserving of care if they did so. Clients not only feared negative attitudes but they feared they would be cared for poorly by providers in hospital.

Fear of Being Treated Poorly

In hospital, individuals who were street involved feared that they would be treated poorly by providers. I heard from clients and providers that they feared being 'treated like garbage,' 'getting dope sick' and being in pain if they went to hospital.

Being 'Treated Like Garbage': Wasting Time

Clients and some direct care providers spoke of the verbal and non-verbal behaviors of health care providers that communicated a fundamental disrespect of the worth of people who are street involved and that people who are street involved are 'treated like garbage.'

I had heard many times that people from the street feel that they are treated like a 'piece of shit' or a 'piece of garbage' and I had wondered about the meaning of these statements. On a day I was doing outreach, I heard a frontline worker refer to this in the context of the way that ambulance personnel treat their clients. So, I immediately asked her to explain it to me. She described her experience and response to ambulance personnel when they say, "Do you really want to go to hospital?" She said, she feels offended when she hears that question combined with the person giving a smile that says, "I don't believe you." She described that this can be translated by the person to mean, "I don't want to waste my time, you're a piece of garbage." She was quick to add that this did not apply to all ambulance personnel by saying, "Some have hearts and know how to relate to people in (this area)."

Providers may knowingly or unknowingly communicate such messages. John said, during his years of drinking, he was taken to the hospital probably about every 10-15 days.

John: Because I think in my experience, because I went a lot of times to the hospital, in the end they give up on you. And they do. You're a fried out brain case and they don't want you no more. And even the doctors aren't even happy with you. You know. You're wasting their time. And, which we were, which I was. You know, there was nothing wrong with me, except my drinking. And, but to let a guy die, well, I wasn't worth nothing. I proved them wrong. I'm healthy now. But it took me, you know, to be that close to death to realize it.

As John indicated, feelings of low self-esteem and self-worth may be reinforced when health care providers give up on you because you're wasting resources. One of the issues I encountered in the ED was that nurses sometimes viewed people who were repeat users of the system as wasting resources. One nurse in the ED raised her concerns about the

financial costs to the system of seeing repeat ‘users’ such as those with addictions. Thus, I wondered if certain individuals may be seen as potentially less worthy or deserving of resources in the future.

‘Getting Dope Sick’

“Getting dope sick’ in hospital was identified as a fear of those who are street involved expressed by nurse and client participants in this study. In hospital, the daily supply of street drugs needed to maintain an addiction and cope with daily life are unavailable to people living with addiction. Will described,

Yeah, you’re hurting man. Like your 8’s will keep you going but they don’t give you that thing like you want. Your body will start going, not doing very good, start getting the diarrhea, start getting dope sick. Like if you’re doing coke it’s even worse. You’re wired to coke, it’s even worse, right. Because one you want to be in a safe environment and a hospital’s not a safe environment for you so you...

As I talked with Annie, a nurse with many years of experience working in the community and on the street, I asked her about the reasons that people may refuse to go to hospital.

Annie: Well their drugs. They can’t get their drugs for one thing.

Bernie: Would you say that’s sort of the biggest?

Annie: Of course. Absolutely. They go in and they are so terrified of being drug sick. You know, somebody that’s not on methadone that uses heroin, it’s their biggest fear that they are going to wake up in the morning shivering and sick. And it’s a fate worse than death a lot of the times. They absolutely hate feeling like that. Or their pain. They have very low pain threshold. High drug tolerance, low pain threshold. They’re never given enough pain medication. And they tolerate pain very poorly. So they can’t stand [it], and they treat their own pain on the street. You get them to emerg and they’re not given enough medication. It makes them walk out. It makes them leave. They will often say yeah. I got two Tylenol 3. You know for my 8 hours there. They buy morphine off the street. Like, two Tylenol 3, their pain is not addressed.

Based on my observations and discussions with participants, I learned that people feared the pain of withdrawal and that withdrawal may be a major contributing factor in leaving without treatment among those who are street involved.

There was evidence in this study that suggested addiction and subsequent withdrawal are poorly managed in hospital and that symptoms of addiction and withdrawal may be obscured by stereotypical thinking. Cheryl, a nurse, with emergency experience and working on a hospital unit known to care for people with addictions stated,

And I had one guy and he said, you are the first person to ask me this. And he comes in and out and in and out and he's in the penal system and he was starting to get a little bit antsy and it was the first time I cared for him and I said, when was the last time you did any heroin and he looked and he said, no one's ever asked me that before. I said, well I need to know. I said, because are you going to go out and get some more heroin or should we put you on methadone? And the more I'm learning and reading you know,... there are doctors that will order methadone, but you just have to know which ones. And it's kept very quiet in the hospital. Lots of people don't know who actually orders the methadone. There's only [a few] doctors that will....And if the nurse that's caring for that patient knows that there are doctors that will order, then the connection is made, but then you have to go through the [hospital] physician... You have to say, you know, there is a bit of an addiction personality here, or we know for sure and if that doctor isn't willing for them to be placed on methadone, they'll just say well, just treat them with what you've got, then that's what happens. So that whole little piece of the puzzle just is avoided.

However, if this client's initial behaviors had been interpreted as a low tolerance for pain rather than a manifestation of a serious and active addiction, the appropriate assessment and management of withdrawal may not have been completed. Cheryl's example as well as other observations suggests that knowledge and use of methadone to treat addiction in

appropriate circumstances may be limited and inconsistent.¹¹³ Nurses, with knowledge of addictions, including management of withdrawal, are an important link in creating a chain of trust in which the client's fear of 'getting dope sick' (withdrawal) may be addressed in hospital. For clients, concerns about withdrawal were closely associated with concerns that their pain would not be adequately managed in the hospital.

Fear of Being in Pain

In this study, individuals who were street involved expressed fear that their pain would not be treated in hospital because they were thought to be an 'addict.' A woman who I met in a shelter had recently released from hospital after suffering kidney failure, she expressed frustration to the nurse and I about her care. "They said I was a junkie and [they] wouldn't give me anything for pain. You're a user. They're prejudiced. They just shouldn't categorize you that way." Nurses in the primary health care centers repeatedly stressed to me that adequate pain management is essential in providing care to people who are street involved during hospitalization. They wished more could be done to educate hospital staff about addiction and wished that providers understood that people with addictions require more rather than less pain medication. They stressed further to

¹¹³ Methadone is a legal substitute for illegal drugs particularly heroin and opiates. Physicians require additional certification and must be registered to prescribe methadone. Pharmacies must be licensed to dispense it. Methadone is a valuable commodity on the street and therefore the prescription and administration of it is carefully controlled. For example, most people on methadone are required to pick it up daily from the pharmacy. In specific circumstances, such as work or travel, they may get 'carries' (a few days supply of methadone) for short periods of time such as over a weekend. The substitution of methadone (a legal drug for an illegal drug) is a source of controversy itself in terms of whether or not one is reinforcing or treating an addiction. Health care providers and clients expressed a broad range of views on this particular issue. The cost of methadone is covered by public funding in the settings where this research was conducted. Some physicians feel strongly that methadone is useful particularly because it creates a situation in which people can lead productive lives and assists with rehabilitation. However, some rehabilitation /recovery programs, will not accept clients into programs if they are on methadone. Nurses expressed various points of view about the amount of coercion/pressure used by health care providers to get clients on methadone as well as concerns that a legal drug was being substituted for an illegal drug without addressing the broader issue of addiction.

me that, as a consequence of addiction, people often have a high tolerance for analgesics. Jason, a physician working a health centre suggested that in some cases, such as short hospital stay for treatment of an infection, practitioners are totally wasting their time by focusing on fears of ‘feeding an addiction.’ He observed,

[Being] in hospital period is a minority of that patient’s experience. They’re not gonna really cause any harm in 10 days, 14 days. Because the problem that they’re dealing with has evolved over 10 years and it’ll ultimately be solved as an outpatient. So they should really just, for their peace of mind, for their actual contentment,and just completing the therapy that usually takes 10, 14 days. Just give them what they need.

He argued that in such situations, “the benefits outweigh the harms.” In his view and that of others adequately treating the pain of people experiencing addictions may be the most ethical way to proceed.

For those who are street involved, using drugs or alcohol is a way to cope with pain. John lost his job, his family and his home after he began drinking to cope with a debilitating back injury. He states further,

My Dad was really sick with diabetes right? And my Mum says, [John], you’ve got to go. He’s on his last legs. And I said, look, he said that a year ago. And as soon as I get up there, he’s going to die. And she conned me – she didn’t con me, but she said, [John], he’s really waiting up there to see you. I went up there drunk. I drank all his beer in the morning before I left. And he died at 4 o’clock in the morning. Because I got the midnight bus. He died four hours later. And then I got drunk that night. The next night after, and I can remember my sister phoning and saying, there’s going to be a funeral on Wednesday....I drank that right through. Didn’t give a shit. Now when I sobered up, I had to go and ask my sister if he was cremated or buried and where his bones are at or whatever. And that’s how sorry a sight I was. You know, I didn’t have enough respect to even do that. But that’s what an alcoholic does.

Although individuals who are street involved expressed fears related to lack of attention to their physical pain in hospital, I learned that addiction often masked psychological and emotional pain such as that associated with abuse. Client fears related to drug

withdrawal and inadequate management of pain are closely associated and interwoven. Stereotypical thinking among health care providers can obscure the reality of such fears and result in inadequate assessment and management of pain.

Fear of Negative Consequences: I can't go because...

Clients often expressed concern that if they went to hospital it would affect their social and economic safety and well-being. Potential concerns included repercussions from the law, loneliness/isolation, obligations to others and financial/housing concerns. Both clients and providers identified potential repercussions from the law as a barrier when accessing health care. Individuals feared that they might be caught for illegal possession of drugs or implicated in other illegal activities if they were to go to hospital. As Will said, I don't trust the nurses not to rat on me. However, when he was hospitalized for an extended period he told me that the nurses did turn a blind eye when his 'dope dealer' visited him with his daily supply. One nurse, working with people who are street involved, described how a man who had received a beating to the head and suffered a serious head wound, bolted when she called the ambulance because he feared the police would arrest him even though the nurse was not aware of any reason for them to do so.

People also feared going to hospital because it meant isolation from their family, friends and community. One nurse working in the community related to me that some people fear that no one will visit them in hospital and that people from the street fear being alone in an unfamiliar or unfriendly place. This is certainly consistent with Will's description of the hospital as an 'alien' and 'hostile' environment. Will said that for most people on the street, their worst fear is to die alone in hospital and that he carries around a

5cc syringe and would kill himself first. As he and others told me, other people on the street are their friends and family.¹¹⁴ They described these people as their ‘street friends.’ One nurse relayed to me a situation in which a young man with an infected hand that was becoming gangrenous continually refused to go to hospital even though his friends, many agency workers and health care providers were urging him to go to hospital. Although there were multiple reasons for his refusal, the primary reason identified by one of the nurses was his concern for the safety of some women he perceived as highly vulnerable to the risks of being alone on the street. From her conversation with him, she related to me that he felt he needed to continue to sleep outside with them to avoid the possibility that they might be harmed. The nurse described him as having a moral obligation to protect others. His eventual decision to go to the hospital came after multiple interactions with nurses in the primary health care centre and on the street. A nurse told me that one day it ‘clicked’ when a nurse whom he trusted told him that the situation was extremely serious. He was hospitalized and had a partial amputation. Thus, his feeling of responsibility to others contributed to delays in seeking health care. An additional reason for delaying care, identified by nurses and other health care providers in this study, was the need of people who are street involved to ensure care for their pets while hospitalized.

Not accessing health care also meant that one could deny the presence or severity of an illness. Claire, a primary health care centre nurse, stated,

[They are] avoiding it for reasons such as fear as well. So fear of finding out that there is indeed something wrong with them and that they may you know, may have [something serious] especially a male population. I find that a lot of men don’t like to access care.

¹¹⁴ I would note here that although for the most part they were referring to others who are street involved, nurses and others who did outreach were sometimes referred to as being among this group.

Men make up a significant portion of those who accessed the health center in both communities (It was estimated to be 70% or more in one of the communities). It is not surprising that individuals may fear diagnosis when there are high rates of HIV and hepatitis C among those who are street involved. As well, given the concerns about fears of being judged and treated poorly, there may be a fear of the way a particular diagnosis might be communicated and how it will affect their care.

For others, entering hospital might jeopardize fragile life circumstances. It might mean missing a social assistance cheque or losing a place to live. I heard many times that 'I will go to hospital or begin treatment once I have a place to live or after I get my welfare cheque.'

The nurse told Martin that he needed to go back to hospital. Martin had discharged himself 6 days earlier. He had a huge ulcer on his coccyx that required dressing changes twice daily. Later, the nurse told me he was a diabetic and probably hadn't had his insulin for many days. Martin said few words, looked straight ahead and nodded as she talked. She told him that he had a bed waiting. After considerable negotiation between him and the nurse, he agreed that he would go back to hospital after he had gotten his social assistance cheque. They agreed he would go to the hospital at one o'clock today by taxi. "You'll go?" she said and he nodded. The nurse told me that we would have to come back and make sure he got into the taxi "you have to wait with them, that's how it is." At one o'clock, he was still waiting to get his cheque and refused to go. The nurse suggested arrangements could be made to have his cheque brought to the hospital. She called a cab and gave me strict instructions not to let the cab driver leave. When the cab arrived, I engaged the driver in a conversation about his work hoping he would wait. After a short time, the nurse came walking towards us without Martin, she said, "he's not going,"

For people, on income assistance who are in hospital, the government may cut back on income assistance because the person does not have to pay for housing (e.g. a shelter bed). In one health authority where this study was conducted, health care providers had

successfully advocated to have this changed to encourage admitted patients to stay in hospital and complete treatment.

The reluctance and refusal of people to access health care can be understood in relation to life circumstances in which each day is a matter of survival and the need to find food, shelter, and drugs. Their reluctance and refusal can also be associated with fears about being overlooked, prejudged and treated poorly by health care providers. Tyndall et al. (2004) interviewed 3300 participants who were street involved and found that the top three barriers to accessing health care were long wait times (61%), difficulty keeping appointments (41%) and being treated poorly by health care staff (34%). The findings in this study are consistent with those reported by Tyndall et al. The findings of this study provide additional insights into the reasons that individuals who are street involved do not access health care.

Loss of Faith in the System

While individuals expressed a feeling of distrust towards providers and often cited many of the reasons identified above, it became evident that the reluctance to access health care was a complex phenomena grounded in multiple layers of shame, denial and distrust of not just individual providers but of systems more broadly. Distrust of individual providers appeared to be grounded in a broader distrust of the health care system.

I met Lorne on outreach at least three times over a period of several months. He would appear at the door just as the nurse was about to leave. Each time he was wearing a dark colored coat and a toque over his grey streaked hair. The coat hung on his thin slightly hunched body. It seemed to be more of a woman's coat and several sizes too big for Lorne. Each time he asked the nurse "do you have any toms?" When the nurse would ask what the problem was, he replied, that he has an upset stomach and that is from some bad food he has eaten. He says he eats

at several different agencies and that the food sometimes doesn't agree with him. He stated that the food isn't always the healthiest and that sometimes it is outdated. The nurse asks him about his symptoms. She asks Lorne if he thinks it maybe his hip C rather than spoiled food causing his GI upset. He denies it saying, "no it is just bad food."

I notice that his skin has a slightly yellow tinge and again note his thinness as he reaches one hand with wrist bones protruding to take vitamins from the nurse. Each time the nurse urges him to come to the clinic for blood work and a physical exam with a doctor. Today, I am with a doctor and Lorne asks the doctor for Tums. Like the nurse, the doctor asks him questions about the GI symptoms and how long has he had them. As he stands at the door, the doctor like the nurse urges him to come to the clinic to have a thorough check-up. Lorne stands at the door and responds by saying, "I don't have a GP" and tells us that some time ago his doctor refused to sign a form for him and that he stormed out of his office ending a long term relationship with his family GP. He expresses disbelief that his GP would treat him that way after many years of being his patient. Lorne moves inside the office and sits down on a chair by the door. He responds saying, "what would you do to help me?" The doctor indicates that in the clinic he could have blood work and a more thorough check-up and fill out the forms needed to apply for social assistance. Lorne shakes his head and wonders out loud again what will he [the doctor] do to help him, almost if he had not heard what was said previously.

At one point, the doctor makes a phone call to the clinic and schedules an appointment for Lorne the following week. There is only a twenty minute slot available but the doctor books him in. The doctor acknowledges that he can only do some initial work in that time but that they can get him in again for another appointment. In response, the man says "that's the problem. I have lost faith in the system." He describes a series of complications he suffered after a surgery that he believes were caused by physician error. He talks quickly, almost without taking a breath, raising concerns about cutbacks in the system, long waits in emergency and the lack of rooms for people in hospital and patients being left in hallways. As he talks, he is becoming more distressed and agitated saying, "You can't treat people that way" and "I don't want to be treated that way." The examples he provides are interspersed repeatedly by statements that he has lost confidence and trust in the system. I couldn't help thinking that given his experiences I agreed with him.

Often when I explained the focus of the study to individuals on the street, they would provide me with an analysis of what was wrong with the health care system.¹¹⁵ People who are street involved expressed an overwhelming distrust of health care providers as well as distrust of the health care system in general. It is important to acknowledge that feelings of distrust were extended beyond health care.

There was evidence that many individuals, based on life experiences were distrustful of systems. Will left an abusive home for the street and has been on the streets for about thirty years. He started selling drugs as a teenager. Will stated,

You don't want anything to do with most people because...I mean a street person, the first moment you meet somebody, you're judging them and how they react to you that first time is how you're going to treat them the rest of the time you meet them, right? So if they're a little bit weird, you feel some weird vibes and you don't really want to talk to them anymore because you've had enough of that already. You know, I get that everyday right?

Later, in the same interview, he stated,

...and just from there[leaving home], from growing up with all the abuse the cops gave me, all the abuse I've gotten from the criminal system, from the hospital system. It's just...like my friend, he just gave up. He threw all his HIV meds in the garbage and said, piss on it. I've had enough. You know, I'm getting...I can see his point of view. I've felt like that, too, about a year or two years ago. Like enough's enough, man. I don't care about myself anymore. And no one really does care about me so why...I just let it go, right.

The mistrust of the health care system was born of negative life experiences with a variety of systems, including health, family, education, and social services. I repeatedly heard and observed that people were distrustful of systems as a result of such experiences. In addition, negative experiences with a variety of systems reinforced and contributed to already existing feelings of worthlessness and low self-esteem. Life

¹¹⁵ I would note that in giving such analyses, nurses were often identified positively. For example, one man stated, "nurses are the only good things in health care" and provided me with a copy of a poem he had written for a nurse who had cared for him when he was hospitalized.

experiences within family, education, health, and social systems had taught them to be cautious and wary. In describing trust, Baier (1994) acknowledges that there may be some situations in which one would not trust another person with anything. She states,

If the network of relationships is systematically unjust or systematically coercive, then it may be that one's status within that network will make it unwise of one to entrust anything to those persons whose interests, given their status, are systematically opposed to one's own (p. 127).

It may be that those who are street involved have experienced a variety of situations that they perceive to be unjust and that their experience in society is one of being treated unjustly. Through my interviews and observations I began to learn that surviving life on the streets is an important aspect of the context that those who are street involved bring to health care interactions. An understanding of 'surviving the streets' provides additional understanding and insights into the lack of trust expressed by participants in this study.

Surviving the Streets

Will described himself as always having been a street guy. He and others helped me to understand that when people from the street go to the hospital they are entering a less familiar world that is potentially unsafe or hostile. He described the world of the street as a 'different world' and that I as a researcher was walking between two worlds. It is easy to be taken advantage of on the street. Mona described herself as vulnerable to being exploited on the street.

And then, you know, I'm condemning them because I'm trying do things the opposite that they are, like not lie, not steal, and all that stuff. And the second thing is, and that's not the main thing, what the main thing is because I'm vulnerable. They see I'm way too trusting and way too honest about things and way too sensible, I mean, you know I have my life together and I have and things so it's like you really wonder when somebody wants to all of a sudden be your friend and you have a place, you have money and all this stuff, and they don't. You know something's extremely wrong there. And then they try and fool you

and say it's for any other reason, and you know its like, don't believe it. Because you know they are going to start, that the person you're going to ask for is the money, the food or whatever it is and you have it and they don't. And I mean, they think they have every right to it as well.

Earlier in the interview, Mona had explained, that although she doesn't use drugs, she got involved with a group who were using and selling crystal methamphetamine. Two of the group lived with her, ate her food, stole from her and got her involved in drug related conflicts and with the police.

Mona: So it just kind of perpetuated it and then finally like I almost got evicted from my place. My place is an absolute dump. I'm losing my damage deposit because they put all these cigarette burns in the window sill and now all this shit's going around, pardon me; stuff's going around the streets about it. You know, and you wonder why I want to get out of this low income crap and the thing is I'm trying to go to those idiots at disability and fight for my disability, right?... You know because I don't want to go to these god damn shelters.

Mona described that she has become more cautious and wary. "So, yeah, there's so many abusers out there, it's not even funny. Every street people I look now at with a jaundiced eye." Will related his experiences of surviving on the street.

Will: I'm different from a lot of people, every day's a struggle for me, every day I've got to be ready to...she [agency worker] doesn't understand why I fight all the time. But you know I tell her I got no choice but... the one time I back down and turtle then everybody's going to pick on me, right. The one time I back down and say, no, no, I don't want to fight you, then the next time it's going to be twice as bad, right. So I can never...

Bernie: So it's survival.

Will: Oh yeah. I can't back down, I can't. It's not in me to do it anyways. But still, if I did, you know then OK, well [Will's] a woos now so you know now you can pick on his women, you can try and rob him for his drugs you know. I mean, I've been beaten in the washroom lots of times. Never lost my dope, never knocked out. Always got back up and fought my way through it. So I've been in lots of knife fights and stabbed and baseball batted and lots of things going on. But I still manage to survive you know.

Will was proud of his toughness and that when the cops were called they have to bring at least five guys to take him down. Nurses in this study told me that life on the streets is hard and people who are street involved have to be tough to survive. From my interviews with Will, Mona and others, I began to understand that daily survival depends on being cautious, wary and distrustful.

In an interview with a social worker, she described street culture as a 'high context culture.' She explained that in a 'high context culture,' knowing if someone is trustworthy (won't betray you) is more important than knowing their qualifications or what a person has accomplished. Will stated,

"On the street you've got to judge people instantly, right. You don't know if it's a narc or a rival drug gang coming after you. So you've got to, on the street man, you look at a person's eyes really quick. And when they make eye contact and there's that rage there, you've got to go like bang. And then all of a sudden you've got to fight right now"

To survive on the streets one has to be hypervigilant to threats from other people and be able to respond quickly when a threat is posed. Later in the interview he expanded on this

Bernie: you really develop a skill at being able to read people quickly and so when you're going, you know, you can pick up on, maybe, the way someone looks at you or...

Will: Oh yeah, by their body language or their eye contact or how they kind of move back in their chair when you start telling them what you got. You know, they're kind of sliding back from you. They don't really...OK, whoa, I don't want to touch this person, right, because you're an infected diseased street person, right.

From Will, Mona and others, I heard that one has to learn to size people up quickly in order to be able to protect oneself from harm. As they stated, it is a matter of survival.

The findings of this study suggest that it is part of what an individual who is street involved may bring to health care interactions.

Nonverbal responses of health care providers may be misinterpreted by individuals accessing health care. For people who are street involved, a distracted response or even the lifting of an eyebrow might be interpreted as communicating a judgment or a negative attitude even though it was not the intent of the provider to do so. For example, a nurse in the community described touching the arm of a client she felt she knew well and that it triggered an unexpected and violent response from him. Contact with institutions may trigger past traumas or irritate unhealed emotional wounds causing them to fester and erupt. Walking up from an overdose, in a full four-point restraint might easily trigger a violent response.

Steve arrived in the health centre, after several days of not sleeping and repeatedly injecting cocaine. His forearm, the site of frequent injections, was hot, swollen and red almost ready to burst. He was tired and disheveled. At one point, we returned to find he had moved from a chair to the stretcher and was lying with his eyes closed. When the nurse aroused him, he asked her if he could have a sandwich and a juice. Later, the nurse told me that she could 'feel her back getting up' when he made this request. After being assessed by the nurse and the doctor, it became apparent he needed to go to hospital for intravenous antibiotic treatment. When he was told this he said, "I don't think I can go back there. The security guards will kick the shit out of me". He related that he had begun fighting and ended up punching one of the security guards when he woke up in restraints following an overdose. Besides that he said, I told one of the doctors to "Fuck off."

As described earlier by Will, the immediate response to fight when threatened is an important survival technique on the street. Being cautious, wary, tough and ready to fight helps one to survive on the street. Being distrustful is necessary to maintain one's physical, emotional and social well-being. Such survival techniques on the street can become barriers to receiving care in the health care system. Combined with lack of

confidence, knowledge and self-esteem, it becomes difficult even impossible to access services that feel foreign and unsafe. Furthermore, there is the potential for feeling emotionally and physically worse as a result of experiences in health care.

‘Need to Fix’

Those who are street involved and experiencing addiction spoke of the ‘need to fix’, to prevent ‘getting the shakes’ and ‘getting dope sick.’ In an interview, I had asked Mary, a nurse what it was helpful to know about working with people who access care in the primary health care center where she works. She said,

Trying to do a thorough enough assessment so that you don’t take too much of their time because often people who are taking say cocaine, experience powerful withdrawal symptoms shortly after, like, it doesn’t stay long in their system and then they tend to rush out and they don’t have time to be seen. They just come in, they say what the problem is, and then say, I don’t have time. I’ve got to run.

Her statement was consistent with many of my observations in both centers and with what I was learning from other nurses about the importance of having knowledge of addiction in caring for people who are street involved. Cocaine has a very short duration of action and people who use cocaine need to inject frequently to maintain their addiction. People who use cocaine often exhibit symptoms of impatience and agitation such as an inability to focus and repeatedly picking at their skin until it bleeds. From being with the nurses, I came to recognize that when a client was unable to sit and frequently jumped up and down, or was pacing, it could be a symptom of their addiction or mental illnesses. I observed and learned that the nurses in the primary health care center often assessed behavior by trying to determine whether or not the behavior of an individual might be associated with an underlying addiction or mental health concern, diagnosed or undiagnosed.

Lori, an emergency nurse began her interview by telling me that I missed the 'perfect clientele' last night; a man with an overdose who had been put in a four point restraint for his protection and theirs. She had expected him to leave this morning because he was a daily IV drug user. She states,

Lori: And that need for the next hit will override the fact that they have necrotizing fasciitis and their arm is going to fall off from injecting into an abscess. So I thought he would walk out this morning but he didn't.

Bernie: So he's still there.

Lori: He's still in the hallway. But then on the other side of that, who's going to give up a warm bed with warm blankets, where someone is going to feed you three square meals a day and you don't have to fight for your life on the streets. You know?

Bernie: So it's like a safe place.

Lori: It's a safe place, but there's so many judgments that come with it you know, from the staff.

Several nurses in the emergency department told me that they know the 'street people' who come to the department and that 'street people' know they can get a sandwich and a warm blanket in the ED. They described the emergency department as a safe and warm place which was in direct contrast to what I was hearing from those who are street involved. I became aware that the emergency department might be seen as a physically but not emotionally safe place.

The nurses from the emergency department that I interviewed for this study indicated that everyone who comes to the emergency department deserves the same care. As described by Megan previously, nurses in the ED acknowledged that sometimes 'drug addicts' didn't get treated very well by some nurses and doctors. Most of the nurses

expressed the hope that they weren't like that and that such attitudes and behaviors were not right. Lori was extremely candid in saying,

Oh well, if they come in complaining of pain, automatically they're drug seeking. They've run out of their own drugs. They've run out of money to buy their own drugs so they have to get free drugs now. And they'll just keep coming back in and you automatically just label them. I've done it myself and it's a horrible thing but it does happen. You know. And you kind of brush them off. I find most street people here don't get treated like people. They're just scum of the society that are here; let's get them in and get them out as quick as we can so we don't have to deal with the actual problem. And that was a big thing when [I was in nursing school] everyone was talking about oh, how we have to do primary care, primary care, change the focus from tertiary to primary. Get the prevention out there instead of band aiding the problem. But we still are. And that's basically all we're going to do.

Lori and the other ED nurses I interviewed indicated that the problem for them was that in the emergency department clients had to be seen and dealt with efficiently in order to maintain a flow of patients through the department. As one nurse said,

We have to fix them fast and get rid of them so we can take in the next person. Or we end up plugged, like we're constantly plugged. And then that of course is a frustration for us. What we ideally would like to do is to treat the acute and send them elsewhere. And as an emergency nurse, that's where our focus is. Let's treat the acute. Don't dig too deep. Don't ask those questions, because if you ask the question, you're going to have to deal with it. Do you have somewhere to live? Do you have somebody that can help you with these dressings? Do you have somebody who can watch you for the next few hours after you've had your hit on the head and you need to be observed? Don't ask those questions because the answers are going to mean that the person stays too long. And that's a really huge frustration to send somebody out that you know is at risk. But at the same time, you can't keep them in your department.

The 'need to fix' was a deeply embedded feature of the context of providing care in the ED. My observations and interviews with emergency room nurses lead me to think that the triage nurse is like a filling in a sandwich, constantly being squeezed from both sides. I observed that there was a press of people wanting to get into ED and behind her the pushing back of staff in the department not wanting to have new patients brought in until

some of the current patients could be admitted. One emergency room nurse described her concern for those with mental health problems in the ED,

And that's the whole thing about the whole mental health thing is mental health is not cut and dried. You can not see the problem. You can not see that someone is bipolar and this is what they need. It's not something there. I can't fix this in 15 minutes with a shot. You can't do that. And so they get shuffled really quick too. They're one of those groups that again are under-cared for because it takes too much manpower. It takes too much money. And there's nowhere to put them. There's no one to house them. There's no one to look after them. So you've got to kind of pick and choose and hope you have picked and chosen the ones that are so critical that you're keeping them safe and you're hoping they're the right ones. And hope that the ones that you [didn't] discharged have not gone out and killed themselves.

The pressure meant that the nurse had to continually make decisions about who was most in need of physical care and at risk of life threatening conditions and then had to convince the charge nurse of the need to bring this patient into the department to be seen. As the statement by the above nurse indicates, the concern was that someone might be missed with serious negative consequences.

As demonstrated by their statements above, the emergency department nurses recognized that much more is needed in caring for individuals than treating their infection, their overdose, or their wounds. However, they felt that the ED setting could not provide such assistance. Beyond taking too much time, there was a feeling that in spite of their actions, many individuals would return with the same problem again and again. The emergency department nurses spoke of 'their regulars' and 'frequent flyers.' After explaining the study to one nurse in ED, she said, "oh, you probably know Jose." She casually pointed to one of the ED rooms and said 'that is Jose's room' because he is here so often. Jose has had multiple and frequent ED visits. A conservative estimate was that he was brought to the ED at least weekly. Several nurses expressed frustration that

‘we just fix them up’ only to have them return again and again. For example, in reference to people experiencing drug related abscesses, one nurse said, “You pump them full of antibiotics, you cure your abscess and they go back out and do it again. It’s very frustrating.” Another ED nurse said,

Sure we can treat the acute problem, but when we’re finished and we’re going to discharge them, you know that you’re just sending them back out to have the same problem occur again and they’ll be back. And that’s a huge frustration to treat a street person who you’ve dealt with the cellulitis, or the problem that has brought them to the emergency department and now we’re discharging them, but we’re discharging them back to the street. So there’s you know they’re going to come back. You know that this is a failure. And as a nurse, we don’t like to fail. We really don’t like to fail. We like to fix it. And we can’t fix that. Because whether they don’t have the resources, they don’t have the ability to deal with that situation, or they choose to live on the street.

This nurse, like others, indicated that the emergency department is not the place to ‘fix the social issues. She went on to say,

It’s very, very frustrating to not give good care, to not give the best care. I mean, we give good care. I’m not saying we don’t give good care, but we’re not giving everything that this person needs. And that for me is a huge frustration. I want to see people who leave our department, fixed. And some of this at risk population, you can’t fix. You just can’t fix. There’s nowhere to put them.

Mona, a woman with a long history of mental health problems described herself as ‘broken’.

Mona: People look at these types of people [who] look normal like everybody else. Oh why don’t you do this like Joe Blow did? One, you don’t fucking compare me to a normal person because I’m not going to work the same as a normal person. If something’s broken it’s not going to work the same as something that’s fixed, right? And so it’s the same idea with me. I’m broken, I have things missing, you know, connections in my brain or whatever. So I’m going to need to do things a little differently. Like I’ll need to spend an extra half an hour getting organized when you only take 15 minutes.

Thus, one might wonder why those who come back to the ED keep coming back. While these nurses valued giving good care to all their patients, they felt morally compromised

to provide the kind of care they perceived was required for individuals who are street involved with complex health and social problems. Nurses in the ED told me and I observed that similar difficulties emerged in their care of those who were elderly and people experiencing mental health concerns.

Nurses in the emergency department often did not have time for their breaks, grabbing a bite to eat or a coffee. I observed that they were left feeling hungry and tired.

Lori, an emergency room nurse describes such a situation,

Lori: That day I said, I have to take a break. I know I'm going to kill someone, whether it's myself or a patient or a staff member. I must step back. And then if you get one of those difficult patients that come in, you've totally just mashed the whole patient/client relationship because they perceive it as you're trying to be aggressive upon them, and it's not – it's because your blood sugar is low and you haven't had lunch. And they're saying, I'm in excruciating pain and yes, well, I'm very tired as well. But you can't say that. You want to say it and sometimes it comes across in your voice and in your body language sometimes. So.

BP: Well then so the tolerance just isn't there?

Lori: Yeah. And that seems to escalate them as well, because they'll either back off and, oh, I'm very sorry, I'm very sorry; or they'll start pushing your buttons even more. And that's the nature of the beast. You don't get breaks here. That day that you were here was actually a pretty slow day.

The nurses told me and I observed that the emergency department was consistently full with admitted patients waiting for beds in the hospital. Nurses appeared to be overwhelmed by the challenges of dealing with addiction, housing, counseling needs, loneliness, isolation and stress on top of the already busy pace in the department. Nurses and others in the community acknowledged to me that working in emergency was a hard job especially in light of increasing pressures. Will summed up the impact of the context on interactions with nurses when he said,

And they're dealing with people that are sicker all the time and they're dealing with greater numbers of them. I imagine they get tired of them after awhile. And then you're hostile to them and they're hostile to you and there's that friction like sandpaper. It's just not great.

When the context of the nurse and the patient collide, the ability to develop trust is severely compromised. As mentioned previously, trust is enacted within relationships (Baier, 1994). Baier asserts that trust is much easier to maintain than to rebuild and it is easily destroyed. She states,

The truster, who always needs good judgment to know whom to trust and how much discretion to give, will also have some scope for discretion in judging what should count as failing to meet trust, either through incompetence, negligence, or ill will. In any case of a questionable exercise of discretion there will be room both for forgiveness of unfortunate outcomes and for tact in treatment of the question of whether there is anything to forgive. One thing that can destroy a trust relationship fairly quickly is the combination of a rigoristic unforgiving attitude on the part of the truster and a touchy sensitivity to any criticism on the part of the trusted. If a trust relationship is to continue, some tact and willingness to forgive on the part of the truster and some willingness on the part of the trusted both to be forgiven and to forgive unfair criticisms seem essential (p. 103).

The findings above would suggest that those who are street involved because of their life circumstances have few reasons to trust people or systems. In this study, I found that being distrustful helps people who are street involved to survive. Since the nurse-patient relationship is one of unequal power, I would suggest that the onus is on the nurse to regain trust by recognizing what has been lost, having a willingness to forgive and being able to look beyond certain behaviors if access to health care is to be facilitated. However, the ability of nurses to act in ways that foster trust are constrained and facilitated within particular health care contexts.

Thus far, I have discussed the climate of distrust that seems to exist between those who are street involved and health care systems. In the next section, I will discuss the weak and potential linkages in the chain of trust.

Weak and Potential Linkages

Although the dominant theme in accessing health care in emergency departments and when hospitalized was primarily negative, there was evidence of positive experiences that highlight weak or potential linkages that could be strengthened to enhance access to health care for people who are street involved.

Depends on the Provider

Lori, an ED nurse, described how a woman walked in and then walked out the night before our interview.

Lori: Yeah. And another person we had in last night, she's a frequent flyer. She lives on the street, IV cocaine user and she gets the bugs.

Bernie: Oh where is she scratching?

Lori: She scratches and she picks herself literally, she picks sores into herself. And she walked in, saw who the triage nurse was and walked right out. They know the nurses. They know which ones they can get in with. They know which ones will let them see the doctor. And the triage nurse last night, she saw her and walked right back out again. We have a lot of them that know which nurse is on then and how long they're going to wait. So they may as well just go out and get their next fix or whatever, or go to another hospital.

One woman, with a history of chronic alcoholism had been experiencing numbness and pain of her left arm for about one day. She told the nurse in the health clinic that it was so bad during the night she "even thought about going to hospital but you never know what kind of doctor you are going to get." In both of these examples, the women had concerns

about access to care that implied that their decision to seek care depends upon the provider.

While the people from the street I interviewed (both formally and informally) almost always spoke first of their negative experiences in health care, they were able to recall positive experiences in health care. Will, who shared primarily negative experiences with the health care system recalled that he had “met some good nurses” who have compassion; and said they “aren’t so hardboiled.” Mona had several admissions to the emergency department and, when asked, described one positive experience with a nurse.

Mona: So I mean just being really clear instead of having the brush off and sort of the general information spiel, you know...it’s just I might not even have asked the question because they don’t even give me an answer. So you know this nurse was trying to be helpful, trying to be more in tune to what I’m asking and like listening not just sort of giving me an all-purpose answer and figuring, oh yeah, she’s happy with that. You know, leave me to my own devices. Like you scumbag, user and stuff like that you know just thoughtful, very thoughtful. You know, like what do you need, like very specific pointed questions and you know it kind of took me aback like, oh yeah, like I never thought of it that way. I mean if you’re clear, direct and honest as possible then, yeah, like so that’s the way of doing things. And simple, like really simple. Like I’m bad at complicating things.

Bernie: Kind of to the point and direct, that kind of thing?

Mona: Yeah, very much to the point specific.

Bernie: Having that second nurse, what difference did that make?

Mona: A lot. (inaudible) I just felt more confident that things would or that I could handle stuff like I just... I can get through this and I’ll just put it behind me. And it made it, even though it was a really bad experience that didn’t make it a worse experience. Like that made it a little bit easier to take.

Mona’s experience highlights the way in which individual providers can contribute to positive experiences in acute care for people who are street involved. The nurse didn’t

brush her off but attended to her. The result for Mona was a more positive feeling of being able to cope with the situation. This is in contrast to the feelings of worthlessness and low self-esteem that accompany the perception of being judged by health care providers. When individual providers are able to attend to the client's priorities such as the need for food, management of pain and withdrawal, and begin to recognize the individual as a person, a link in the chain of trust is created.

Depends on the Hospital

Clients and nurses indicated that they perceived care to be better in some departments and hospitals than in others in the community. Clients described being treated better at one hospital than another. Megan described the emergency room where she currently works as providing very good care to people who are street involved compared to other departments where she has been employed. She stated,

Megan: You know, a patient who'd come in as a heroin overdose and had been given [Narcan] and was now awake and yelling and [general attitudes have] just changed. The patient says, fuck you to the nurse, and the nurse says, have you eaten today? And the patient says, no actually. I haven't. So the patient gets a juice and a sandwich and carry on from there. And I don't know exactly what changed it [attitudes], except like I said, maybe there was enough of [a cultural shift]

Bernie: There's a different culture. That's what comes to mind as you're talking.

Megan: It's a culture of what was acceptable [in that department].

People who are street involved and nurses perceived some emergency departments, and some units to be better than others in the care and treatment of people who are street involved. Some related it not only to individual nurses but to expected norms of behavior in the setting such as the nurse above. Another nurse suggested that it was the nurse manager who set the tone for the unit in this regard.

Depends on Who's to Blame

While nurses in the community certainly heard from clients about their negative experiences in hospital, it was not clear whether or not individuals shared their positive experiences with care in emergency departments and hospitals. When I interviewed Annie, a nurse working with people on the street, she described the frequency with which she heard about negative experiences.

Bernie: [I have often heard] they're worried about how they're going to be treated. Do you run into that?

Annie: All the time. All the time. They hate going to emerg. They feel they're poorly treated. They feel they're judged and they talk about the attitude of the staff and how it's people from down there. And they feel that they are not given enough medication because of their drug habit. So they feel that they're denied proper medication because of who they are. They feel extremely stigmatized all of the time. Oh absolutely. You interview anybody from down here and they will tell you that. How they feel about going to emergency.

I wondered about the effect of this on providers. Star, a nurse working in one primary health care centre stated,

But notoriously, our clients say that they don't want to go to the emerg and they tell stories about how they've been treated there. And so I think that we all have heard that repeatedly so that we probably believe that they are often treated not that well, for a variety of different issues.

Hearing again and again the negative experiences of individuals accessing health care may become a truth. As Star said, "when you hear it that often, you tend to believe it."

One manager described the effect of growing distrust between providers.

I have to keep this client. I can't refer them. They won't. You know. They'll kill them. And I've heard that before. [That health care provider] almost killed that person. By the time we found them on the street they were almost dead at the hands of that person. It probably [has something to do with their HIV disease, they are chaotic, they're not using their meds]

If nurses and other health care providers begin to believe that their clients will be treated poorly, this belief has the potential to erode collaborative relationships and disrupt health care for the client.

I observed in several situations that when clients, told nurses in the primary health care centers about their negative experiences in hospital, nurses appeared to listen to their concerns. For example, the nurse would nod and listen to what the person was telling them without interrupting. On one occasion, after a woman expressed a concern about what she was told by another health care provider, the nurse said, "I am not sure what she said because I wasn't there" and proceeded to share with the person what she perceived to be the accurate information. On another occasion, a nurse listened to a women's concern that she was only given Tylenol #3's after surgery. The nurse responded saying, "you must have been in a lot of pain." What I heard and saw was that nurses placed what they were hearing into context and at the same time acknowledging that it must have been difficult or felt unfair to the individual. On a similar occasions to the ones mentioned, nurses might add to me that their clients can often be difficult in hospital, that they were challenging to care for, that the goals of the hospital are different and that practitioners in the hospital are very busy and have many competing priorities on their time. One physician observed that nurses in the ED are highly skilled in the care of acutely ill patients. Nurses appeared to resist blaming or defiling the health care system by recognizing the challenges of caring for people who are street involved and the limitations of the acute care system, rather than blaming individual health care providers.

The linkages created by individual providers, within certain departments and hospitals are weak linkages because they are variable, inconsistent and insufficient for

building a chain of trust that extends from individual to provider or between agencies. While individuals are respected and treated as people deserving and worthy of care, such connections are variable and the norms in providing access to people are inconsistent. These are also weak linkages because the ability of the provider to build trust is limited by lack of knowledge and resources to address priority client concerns and/or the individual's access to a broader range of services (needed to address the underlying complex health and social issues), is missing. It is important to note that because of the limited amount of observation in the emergency department, a full understanding of interactions from the perspective of nurses and clients in that context is beyond the scope of this project. However, this is an important area for future research.

In the next chapter, I will discuss findings related to forging stronger linkages and provide evidence of the ways in which registered nurses and others are forging linkages that can facilitate access to health care services for those who are street involved. Linkages in the chain of trust assist clients to cross chasms to access services that are needed to meet their health care needs. Interactions with health care practitioners are key opportunities for reducing harm, promoting health, treating illness and providing linkages to other services such as housing and social assistance that can positively impact the health of individuals.

Chapter 5

Crossing Chasms: Forging a Chain of Trust

Building a chain of trust is central to facilitating access to health care for those who are street involved. When there is a lack of trust, chasms in health care act as barriers to accessing health care. The focus of concern in the primary health care centers is to reach those who are hard to reach, those who are socially disadvantaged and those experiencing marginalization and having difficulty accessing other health care services because of homelessness, addiction or mental health problems. The clients who access services in the primary health care centers are highly vulnerable in that they are more susceptible to disease and more likely to be experiencing power inequities within society as a result of differences in class, gender, race, income and education. Although many of the people I encountered were not homeless, they were living with HIV/AIDS, hepatitis C, all forms of abuse, mental illness, and chronic illnesses. Most of the people I met were experiencing more than one of the previously identified problems. Although their presenting concerns were often of a physical nature, there were always underlying concerns related to housing, income, employment, lack of social support, and mental health concerns. Being in poor health was often the result of many years of living with social disadvantages including addiction, violence, poverty, inadequate housing and nutrition.

In the primary health care centers, establishing a relationship of trust created an opportunity to focus more broadly on health and social concerns both in the clinic setting and through linkages to other community agencies. Thus, for access to be facilitated trust was required in relationships not only between providers and clients but between

providers in the health centre, and with other providers and agencies in the community including the hospital. In this research, I found there were links in the chain of trust that enhanced access to timely and appropriate care for people who are street involved. In addition, missing links in policy and practice identified during the course of this project will be discussed at the end of this chapter.

A FIRST LINK: DEVELOPING TRUSTING RELATIONSHIPS OVER TIME

Throughout this study, in formal and informal interviews with all participants, whether they were asked about ethical practice (nurses), experiences in health care (clients) or access to health care more broadly, participants focused on the importance of trust in relationships between nurses and those who are street involved. Participants focused on the way that clients who are street involved are and should be treated in their relationships with others as an important and essential aspect of facilitating access to health care. Although I entered the study with the idea that relationships and the way people are treated is relevant to accessing health care, I was not sure that participants would see it as central or important. I was continually surprised and overwhelmed when participants consistently referred to the treatment of clients within relationships as a barrier to accessing health care, and the general agreement that clients ought to be treated respectfully regardless of their social status.

In this study, access to health care was facilitated by the slow and gradual building of trust through multiple interactions over time. From the perspective of nurses, each interaction with a client was a precious opportunity to build trust and to offer access to health care and other services. This building of trust created the potential to provide

clients with the support and resources needed to maintain and/or enhance their health if and when they were ready to do so. Claire, a health center nurse described,

So for me the most important thing in helping people access care is developing a relationship with them and a relationship of trust. And it's really important that when patients come through the door, when I meet them on outreach, that when I'm approaching them for the first time, I try and let them know what my role is and not, try not to get too invasive initially. Just to let them know that they can come in and what we're here [for], what we're providing for, what we can provide for them and we have sort of the conversation to start and to give them a sense that we're here to listen. We're here to try and help them with their problems and let them know that all of the care that we'll be giving will be done in the most, you know, forthright manner and honest, right. I find that when, a lot of our patients come in and they can be manipulative, they can be drug-seeking etc. and I find that if I'm just very frank and very honest with them up front, it's really good grounds for starting a relationship. And then you know over time we develop that relationship of trust so that when they are in need and can't access care because of you know, because other people are not providing care for them [due to] being judgmental, having that basis of a relationship just allows you to come in and be honest and then to [work from there]

Bernie: Kind of a process over time.

Claire: It is a process over time. Yeah. It doesn't ... it certainly doesn't happen on the first visit. It certainly takes a while, and sometimes the first visit is..., just meeting their immediate needs but letting them know that the door is open... Really it's the basis of providing access to care is that relationship and that sense of trust.

For clients, repeated contact with nurses through multiple interactions allowed trust to build over time. Will stated,

Yeah, and you see them [the street nurses] on a day-to-day basis and they see you when you're high and they don't, you know, like they caught me fixin' outside and I was freaked out about it. And you can sort of build a rapport with them and start getting respect for them and they treat you with respect back, you know. And they listen to you.

He described the street nurses as the best thing that has happened to him and that they provide him with his only access to health care. In this study, I found that as trust

developed in nurse-client relationships, access to health care was facilitated.¹¹⁶

Additionally, nurses worked to extend the chain of trust into the community to further enhance access to health care. Developing trusting relationships over time was facilitated by respectful, nonjudgmental care, providing outreach services, and working within a context of harm reduction. In the next two sections, I will discuss the themes of respect and accepting without judging as described by participants in this research. Then I will proceed to a description of outreach and harm reduction as a context for health care interactions and the development of relationships.

Respect: 'Being Treated Like a Person'

In the previous chapter, 'feeling prejudged' and 'being treated like garbage' highlight a concern about a lack of respect in health care interactions. People who are street involved, nurses and other health care providers spoke to the need for respect in all health care relationships. One man said, "I just want a doctor that respects me and treats me like a person." Will said that the street nurses treated him like a real person.' and that he felt that they had a relationship of mutual respect. Respect for persons was fundamental to ethical practice and needed in order to establish trust and facilitate access to health care. In the primary health care setting, nurses and others expressed and demonstrated a commitment to respect for those who are street involved. Being respectful meant acknowledging the personhood of the individual and enhancing the worth and value of those receiving care.

¹¹⁶ Not just access to care for their physical health but access to a broad range of services that would promote health including assessment, information/education about harm reduction, navigating the health care system, disease specific education as well as health related education, monitoring, coordination and with links to housing, social assistance and mental health care.

Respect for persons was readily evident in interactions between nurses and people who are street involved. I observed that nurses' listened and gave time rather than brushing off people who are street involved when they accessed care in the primary health care center. I did not observe nurses dismiss a client's concern as unimportant or because it was outside of their scope of responsibilities.

Pacing outside the door of the nurse's office was a young man wearing a checkered blue shirt and jeans. He was slightly hunched with one shirt tail untucked from his pants. His hair was tousled and sticking up as if he had been running his fingers through it. As he came in and flopped into a chair, his hand went up to his hair and he began picking and pulling at his hair and scalp. He told the nurse that he thought someone had broken a bottle on his head and that he had glass in his scalp. He continued to pick at his scalp. The nurse donned a pair of disposable rubber gloves. She explained that she would have a look and patiently began examining his scalp by parting the hair at the shaft. After a few minutes of examining his scalp the nurse said, I can't see anything. He jumped up and said, ok, well, I must have gotten it all out and left. I felt surprised by the abrupt end to the interaction. In the few minutes before seeing the next patient, the nurse explained to me that he has been in before with the same complaint. She told me that he uses cocaine and often picks his scalp until it bleeds. I recalled that people who use cocaine often have open sores from picking their skin. As I had watched the interaction, I had assumed from the nurse's behaviour, that there really was glass in his head.

Similarly, when I had been with other nurses, if an individual presented with a concern about their back, neck, leg pain, a concern about their chest or their heart, the nurse after listening carefully would perform the appropriate assessment. On outreach, many clients, like the man above, promptly left after being examined, maybe nodding or grunting a thank-you to the nurse. My observation was that the nurses performed their assessments, accurately and efficiently, neither slow nor rushed in their manner. Dependent on the particular complaint, the physical assessment might include taking a temperature, listening to their lungs, or inspecting a wound as well as asking directed questions. These were not rote assessments but, in my observation, a tangible way of respecting clients by

taking their concerns seriously. After assessing a client's concern, I observed the nurse would discuss what she had found and, if appropriate, discussed with the person what the next step might be.

Often an interaction would begin with a client expressing their frustration, distress or anger at a situation in their life. The nurse might ask, 'what can I do for you today?' Following this question, the person might begin to talk about a problem with a friend, their landlord or the fact that someone had stolen money from them. Problems with housing, income, or conflicts with family or friends were frequently expressed. The nurse would listen patiently and once the client had finished venting, he or she would tell the nurse the reason for their visit. If the individual did not give a reason, the nurse would interject at an appropriate point and ask, 'what can I help you with today?' Initially, I was amazed at the calm and patient way the nurse stayed present while allowing the client to vent. My impression was that the clients were given as much space as needed to vent. Will describes such an interaction with a street nurse.

Will: Like I've been in rages sometimes and gone and seen the street nurse and totally calmed down because I got everything off my chest in five minutes, right. From a totally raging animal to a nice mellow guy again in five minute. I talk to [the nurse]. I tell him you haven't got the golden pill but you've got the golden ear.

Bernie: And it was just [the street nurse] listening?

Will: Yeah. You know, just getting things off my chest. And if I didn't see [the nurse] there, I probably would have went downtown and got in a fight and took my rage out on somebody else, right, rather than talking to the [street nurse]. Yeah, if I didn't talk to those people I would have been, for sure I would have gone out and got in a fight. You know, or would have picked a fight with somebody, right?

Later in the interview he returned to the importance of respect, being non judgmental and just listening. He stated,

And a lot of times it's just the listening part means the whole world of difference from freaking out and going totally ballistic. You know when you're right on the edge, maybe haven't made money for a day or so and somebody's in jail and you're trying to get her out of jail. And you're right on the edge, you know, you're just full of rage. You can talk to [the street nurse] for five minutes or the other girl and you know you get it all off your chest. OK, [Will], just take it easy, we'll phone the lawyer up, you know, phone the judge, do whatever, phone the Crown Counsel, see what they got to say about it and [your girlfriend] will get out. It'll be OK. OK so fine I went in there as a raging bull and came out, OK, well I can deal with this, I can take this on, right. It's not going to be so bad. I don't have to go and...I'll take my rage out on some person I don't even know or you know because that's the way I felt like before I walked in there. I was going to go pick a fight with somebody. You know, full of rage because I didn't understand what was going on, right.

Bernie: And then [the nurse] kind of talked to you...

Will: Yeah, calmed me down.

Bernie: What was it he...was it something he said or...

Will: Yeah, just that he treated me as a person, not as a person with all these HIV things behind my name. He treated me as [Will] on the street. This is what you've got to do [Will] just take it easy, just calm down, count to 10 and we'll talk about this, you know. And he came across like hey just phone, get a lawyer, phone the judge, like you know, in simple terms, not in all these big...not giving me a pamphlet and kicking me out the door type of thing right.

Respect was conveyed when nurses listened and acknowledged the concerns of the person. In my observations, it was the rare circumstance in which a client was cut off in expressing their concerns. Similar to what Will described above, I was surprised when after a few minutes of expressing their anger, distress or frustration the person would abruptly stop, often with a significant shift in their demeanour from anger or frustration to calmness. In both health centres and at the end of many interactions, I was repeatedly surprised when a nurse would ask "Is there anything else?" Initially, I would feel my heart pound thinking this would open a Pandora's Box and a deluge of concerns. I held my breath. The nurse would wait patiently as the person thought about it. Sometimes,

they would say, yes, I meant to ask... Usually, it was a focused question such as when should I come back or when is my appointment with the doctor? Frequently, the clients would say, no, I don't think so. My impression was that the person left looking relieved and that their concerns had been addressed. I observed that the person often would express their thanks in a smile or in a word as they left.

Based on my observations and discussions with nurses, I found that listening did not imply agreement or taking action, rather the purpose of listening appeared to be least threefold. First to convey respect, second to build the relationship and third to figure out what was going on with the person (e.g. what were the priority concerns for the client and what could the nurse do to help). In an interview with Claire, we talked briefly about a young woman who had presented with multiple concerns and who in the space of several minutes spoke rapidly without stopping. When we discussed this later she said,

I was doing a mental map in my head of all the different issues, and then trying to think, okay, well what are the most pressing, what are the most pertinent for right now. And what can we address right now. It's really hard sometimes because you know, people do come in with multiple issues and ...so ADHD, you know, that's something that [she] has, but it's not the pressing issue right now. The pressing issue is the respiratory complaint as well as [something else]. What can we manage today?

As we talked further, she said, it's a matter of balancing what is best and what the client is willing and able to do. As Annie, a nurse described, it saves a mountain of time and a mountain of thinking if you know what the client will do. She said,

You know you're so much better to cut to the chase; say, you know, tell me what you think you can do. Can you get to the clinic today? No, actually I can't.

Treating someone with respect was conveyed by focusing on client rather than on provider priorities.

All of the nurses I interviewed in the primary health care setting indicated that they liked and enjoyed working with the people accessing care in the primary health care centers. They often cited this as a reason for working there. They described the people accessing care as ‘having done interesting things’ or as ‘having led interesting lives.’ One nurse told me that she found ‘cons’ interesting and liked working with them. A physician told me that he never notices how people are dressed, what their hair is like or if they are clean; he described just seeing them as a person. In an interview, he stated,

Carl: I don’t even notice whether they’ve got holes in their clothing. I probably should notice it. I could advocate for them better in terms of getting clothing or more shoes and stuff. The thing is people should be valued.

Bernie: I think one of the things I noticed when I was with you last week was the way that you were valuing people. You knew many things about them, interesting things maybe they had done.

Carl: Oh they’re fascinating.

Bernie: Yeah. And seeing them as a person, that’s sort of what I think I took away with me. Probably most last week was how you value them and see them as a person. And you’ve obviously gotten to know many of those people.

Carl: You have to see them more than just a medical problem. They have personality. You have both.

Nurses described people who are street involved as amazing people with an incredible capacity to survive. The nurses often referred to their clients as ‘survivors,’ not because they had overcome addiction or abuse, but because they had found ways to function and cope with life everyday on the street. When I interviewed Will, I had been ‘in the field’ for about five months. I had learned that life on the streets was tough and hard. Listening to Will’s experiences, I realized in more depth what it took to survive the challenges of living on the street and the capacity of those who are street involved to cope with such

challenges. Will acknowledges he is difficult, that he can be overbearing and that he can't back down, but he is smart, tough and resourceful. I admired him for his ability to survive.

In a video interview, Cathy Crowe, a well known Toronto street nurse, describes people who are homeless as 'strong' and able to face situations most of us couldn't handle for a day (Bishaw Productions, 2002). In my informal discussions with nurses, I acknowledged to the nurses that I don't know if I could survive what many of the people we met had endured in their life.

One day a young woman arrived in the clinic. She had her blonde hair neatly pulled back in a swinging ponytail. She was wearing dress pants underneath a stylish trench coat. She and Brenda chatted briefly and then she pulled up her pant leg revealing a deep to the bone wound. While the nurse was getting the dressing supplies, we had a few moments to chat. She told me that the deep to bone wound has been there for seven years and that it was a challenge to keep the dressing on as well as to get the right dressing supplies. When I asked what happened to cause such a wound, she said, "Oh, it is from injecting drugs" She lifted up her pants and showed me a disfiguring scar on her other leg. At that moment, a physician popped his head in the door and congratulated her because her urine was clean (free of drugs) today.

I wondered how I would cope with such a wound in addition to surviving on the street and recovering from drugs. Particularly poignant were stories of childhood abuse such as being physically beaten by parents, being locked in a room as a child or being forced to eat from a dog dish. I imagined this happening to my own daughter who was 8 at the time and then I imagined it happening to myself as a child. I don't know that I would have survived. In a debriefing with one nurse following a client's disclosure of childhood abuse, the nurse acknowledged that we are privileged and that the life challenges many people on the street encounter are daunting.

Nurses and other health care providers told me that many of the people they work with have been ‘damaged’ by their life experiences. One nurse said that many of the people who obtained services at the clinic have been ‘passed over by the system.’ One physician described them as ‘the untouchables of society.’ I asked him what he meant by ‘untouchables’.

Bernie: And I wasn’t sure if you meant, sort of, specifically all of the people that come here, or if you were thinking in terms of some of the people who have HIV, AIDS or sort of...

Jason: I think more the people who are severely addicted, mentally unwell. And I think that...the severe alcoholics who have trouble maintaining themselves and us[ing] ‘dry housing,’ people who will not or cannot stop injecting drugs. Yeah, more so than the infectious diseases, per se.

These are the people that nobody wants to provide care to who are often labeled as noncompliant and difficult in the health care system. John, a man I met in a community health centre, said several times in his interview that, “you have to find that spark in the person.” He credited all of the health center staff with saving his life, particularly the outreach workers, who he thought must have seen ‘the spark’ in him and didn’t give up on him. However, I learned that the spark may be buried or obscured by layers of anger, shame, guilt and denial and by abuse, trauma and addiction. In respecting people, nurses seemed to be looking for the ‘spark’ in the person and they sought to look beyond behaviors to see the person within.

Nurses told me that beneath many client behaviors and comments are feelings of worthlessness and low self-esteem. In their interviews, Will, Mona and John expressed feelings of worthlessness. Mona stated,

And I think that’s sort of another reason I’m thinking why I crashed... I was thinking of, took note of what I was thinking of right before I did it. I was

thinking of those assholes ...who owe me all that money, and then that's when I went and...I kind of knew I was going out of control so I mean it's almost like I wanted to purposely hurt myself. Like, oh, this is what I deserve because I let them take advantage of me and do this to me. And I must be a horrible person for it because how could I let them do this. And I must be a horrible person because I attract all these fucking losers, you know. What's wrong with me?

John suffered a serious back injury at work that began a downward spiral in which he lost his house, his family and years of his life. He was picking up cans and kept his belongings in the shopping cart.

John: You know. I didn't have no self-esteem. I could not talk to you like this, not one bit. You know, I just looked at the ground. You don't care what you look like. Everything, your self worth is gone. I remember times in the hospital wearing a diaper for 14 days. Not giving a shit. You know.

In this study, the giving of respect not only facilitated the development of trust within relationships but could be viewed as an intervention to enhance the self-worth of individuals.

However, a few nurses told me that there were times when it is hard to find respect for clients. Annie said,

It means that you have to constantly find respect for people that constantly step on you and don't do what it is you're there to help them to do. And you secretly lose respect. You know. You secretly lose respect for somebody that yells at you from the door. You can't help it. You can't help but, you know... when somebody says, Fuck Off! Well, okay. I will fuck off. You know. And it's very hard not to develop that attitude and ... just taking yourself out of it. Try not to take that personally and take yourself out of it and then just try and be as respectful back, it turns the thing around.

I never observed that a nurse responded with a return response that was demeaning, disrespectful or a return challenge even in jest. In our conversation, Jo, a social worker, helped me to understand this.

We had a team that was very much centered in respect, and even if people were going off on us it wouldn't be hard lining necessarily back in their face but a more warm and fuzzy approach. Which worked volumes. But it was that kind of behavior that would throw people off more than... And [I] got to let you know this isn't OK but the last thing I'm going to do is do this dance with you. I'm going to take every opportunity I can to model something different. You're deserving of respect, I'm deserving of respect. So let's work on that.

Interactions can be an opportunity to role model and build respect. Some of the nurses indicated to me that their clients often had poorly developed social skills; meaning that they might present or respond in ways that are socially unacceptable or inappropriate as a result of their socialization. For example, a client might ask a nurse for a date or make an inappropriate sexual comment. Within interactions, respect for the person creates an opportunity to help individuals develop relational skills. When assisting clients to navigate the system, nurses assisted them to identify next steps and rehearsed with them appropriate responses such as how to ask questions of other practitioners.

Nurses said that people who were street involved were owed, and deserved the same level of care as anyone else in society. The difference was that they didn't always get it or know how to ask. Brenda provided the following example,

I just had this guy yesterday in talking about his foot. He had one of those trucks, those pickup, a forklift, that's right. A forklift truck at the bottle depot [near here] right, skinned his heel and we had to put a plate in and steel rods and things like that. And you know, it's infected and he commented on how thin his leg was getting, right? Because he's been in this, well he's been coming to us for a while. So it's [not] in a cast. It's in one of those soft casts, though, the molding soft casts you take off [] And I said, well, what did physio ask you to do? And he looked at me and he says, I don't go to physio. Nobody's told me to go to physio. Yeah. But I go wasn't this work-related and you get worker's comp? And he said, no. Well, not really. I mean, I was working. You know, to collect bottles and to put in, to try and get some money for the steel pieces that I found and the truck, the forklift, it hit me, right? And I said, well, for people like you and I, we would be expecting some kind of compensation. You know? Because that's an accident at a workplace, you know. And he didn't get anything. He doesn't know what's happening. And we were talking about that right. It's because of who he is and

where he's from. He's got a history of cocaine psychosis and doesn't have cocaine induced psychosis or dementia but he is slightly odd. You know, he has a place to stay. It's a single room..., but he's not like the average Joe Blow and I think health care providers need to remember he's a human being. I mean, I think I need to remember that especially people who are marginalized are not going to get that care that we expect [meaning you and I]. Basic care. I mean, you expect physio because somebody hit you. You know, you expect the surgeon to tell you what they've done because you've been under anesthesia and they've done surgery on you. You know, you expect that. You expect to be told when this is going to heal.

This example illustrates the idea expressed by many nurses, in this study, that people who are street involved should receive the same kind of care that everyone else in society expects to receive.

Occasionally, a nurse might indicate that she didn't get along with or wasn't looking forward to seeing a particular patient. In one example, a nurse indicated that she and a client hadn't 'hit it off'. She thought it was because she and the client did not have a relationship and that the client had been hoping to see one of the other nurses. In addition, she mentioned she had been working some additional hours. The woman was her last client of the day and she recalled feeling tired and maybe rushing. She described feeling bad and that it was "not a great interaction." In another situation, Brenda identified one man as someone that she didn't get along with and that he was cantankerous, difficult and aggressive. She indicated that he was not usually scheduled to see her because they tended to 'rile' each other up. From previous experience, I also wondered if she felt unsafe. When I asked her about her relationship with this man during an interview, she stated,

But yes, I guess maybe I need to go see this guy too....You don't have a choice. I must see him because it's my, I have to see him because that's what I have to do. Ethically, I've got to. You know, I can't avoid that, right?

Nurses expressed a moral obligation to ensure access to health care for those who are street involved. Emma stated,

And, even I think, any family practice is going to have a number of clients that are dealing with addictions, and concurrent disorders, mental health and addictions. And I think if someone says in a practice they don't have it, it's because they're choosing not to see it. They're there. And you have to deal with it. But I mean, the other side is that we're not all saints here and martyrs and you know they're all fabulous people and we love them all. There's a lot of them that truly annoy me. And well, I shouldn't say a lot, but there's a number that are not nice people. They aren't. They're in and out of jail. They have anger issues because of head injuries or whatever reason. Very aggressive personalities. And they're very difficult to deal with and that's when I have to think what do I value. And I value that this person still has a right to health care. Now I may have to limit their exposure to health care because they may become a threat to me or... sometimes I have to do it in small doses because this person is difficult to deal with.

After a few minutes Emma continued,

That people have a right to health care. They have a right to good health care – to competent health care, that they should be able to access a practitioner who is knowledgeable and if [the person] doesn't know about something then we'll be able to refer this person or make phone calls to find out about the best way to deal with this.

This nurse and others talked about stepping back, taking a break or saying, "I can't do this now" if they felt triggered or unable to provide care for someone. The right to health care was a strongly held value not only among the nurses but other health care team members and was reflected in their passion and commitment for their work. Even when respecting the person was difficult, nurses and others continued to respect the right of individuals to have access to health care. In the primary health care centers, I found that the provision of health was limited only when nurses and others no longer felt safe and/or there was a potential for violence.

In this section, I have attempted to describe the importance of respect for persons as integral to health care interactions and ethical practice with people who are street

involved. Respect was important to building trust in relationships and could be viewed as an intervention that served to build self-esteem and self-worth. Respect was conveyed by listening and taking concerns seriously. In doing so, nurses were able to identify client priorities and begin to work collaboratively with individuals. Nurses valued those who are street involved as people and sought to ‘find the spark’ in the person. A third aspect of respect was valuing the person’s right to health care. For persons that have experienced severe social disadvantage throughout their life and are experiencing challenges related to homelessness, addiction and mental health, respect within health care interactions restores personhood and is both an ethical way of being and an intervention that can contribute to rebuilding self-esteem and self worth. Over time, respect combined with being nonjudgmental, fosters trust in relationships between nurses and those who are street involved.

Accepting without Judging

You know, [the street nurse] has seen me when I’ve been so stoned I could hardly walk or talk or anything, gibbled, or you know, doing the chicken or whatever they call it, flailing away. And he doesn’t degrade me for it. *Like you know he sort of accepts the fact that I’m a junkie I’m going to be a junkie the rest of my life.* But I’m still a good person inside. I mean I have compassion for people. I try and help people out. But you know he understands that I have compassion for people. (Will, June, 2004).

People who are street involved spoke of their desire to be accepted for who they are. Nurses in the primary health care settings, highly valued respect for persons and the ability to be nonjudgmental in caring for people that are street involved. Being nonjudgmental was an important aspect of ethical practice within health care interactions. The nurses in this study, working in the primary health care centers, through their words and actions, conveyed a conscious awareness that most of the people accessing care faced

a constant feeling of being prejudged as to their worth and value within society. Annie said,

You know I think they are so sensitive about everything because they've been so bruised and so damaged and everything is seen as a reprimand, a spank, put in the corner. They're not able to decipher that out. They see everything as a reprimand.

As Annie and others said, being nonjudgmental is "easy to say, but extremely difficult to do." One nurse stated,

I think what I do is that I'm able to split my thoughts and how I react to these guys when I'm on [the street] Christmas shopping and when I'm having my glass of wine in a wine bar, I do think of my clients as scumbags, addicts, who broke into my car. Get an f in life, go to work. I don't know why we're doing all this to you, right? And I do think of it that way. And when I come here and I'm actually physically caring for them, right? And I'm actually wiping the purulent discharge from the horrible festering cellulitis all over their body and they're telling me how hungry they are because they've only had this whatever it is, I can chit chat with them and really feel for them. So again, it's that overcoming all these prejudices, right? Also, You know, so it's the environment that's along with it, you're with you know, you live the middle class life, it's so totally removed.

Bernie: So the environment, like, being in the clinic with other people?

Actually physically doing it without having this colonial attitude that I'm doing good for these poor little souls and helping them.

Nurses, in this study, expressed an awareness of their own judgments and the need to be conscious of potential judgments. Lillian stated,

Yeah. That's right and so it's very quick to label people and to make a judgment and then that judgment clouds the way that you think. And I'm not in any way saying that I don't label or judge, because I'm sure that I do and we all do. But it's a question of not, of being conscious of it and not letting it interfere with your interaction with the patient. So while I might think, gee whiz you wouldn't have this dental abscess if only you brushed your teeth. But rather to take a step back and say, Lillian, you have no right to judge this person. They probably can't even afford a toothbrush and toothpaste. So what can you offer them that will allow them to at least give a stab at brushing their teeth regularly? So I say, here is a toothbrush. This is where you can get free tooth paste. If you give it a try, it might help. And meanwhile, here's a dentist. So too you have to be conscious that you're doing it, because I think we all do, regardless. I mean, you go in and you have an

initial impression. And that's what we do right? We're trained to go in there and quickly assess the situation. So I go in and say okay, this is obviously a wealthy woman who's used to having everything. That's a quick snapshot. It may not be accurate, but on first glance, it is. And then being sure that okay, you've made that in your mind, now don't go on that assumption. Interview her. Find out, validate your assumptions and then don't judge based on what you're doing. So we need to conscientiously do that and I need to work on that too. There's some people who I just see and for whatever reason, they rub me the wrong way. I [you] have to be really careful that you are conscious of that so when you go in there, you're body language and everything isn't making a judgment.

Being nonjudgmental meant that nurses tried to avoid assumptions and to base care on accurate clinical assessments. They strove to be aware of their judgments so as not to communicate them to those who are street involved.

There are times when it is difficult to not judge or react negatively to someone. Nurses told me that some clients will 'trigger you'. For example, one nurse told me she could feel her "back getting up" when Steve, a man being seen for treatment of an abscess, asked her for a sandwich and a juice.

You always have to be checking yourself doing a mental check, saying, oh, because now I'm more aware of it than I was so that's why yesterday I thought, I'm getting my back up. I need to take a deep breath because I'm not going to be able to help this guy if I'm feeling defensive. It's just a question of breathing through it and recognizing what it is that's triggering me.

This nurse and a few others talked about 'tuning into or being aware of their responses' so as not to pass off a judgment. I found that nurses were aware that clients may be hypersensitive to judgments and in return were hypervigilant in not communicating judgments in their verbal and nonverbal responses. In the example above, the nurse told me the next day how helpful it had been to vent her feelings to me when we were out of the room. Similarly, I observed and heard nurses and other members of team discussing with each other their feelings of frustration and discomfort with particular individuals.

As one nurse explained to me, such discussions help to determine whether or not they were feeling uncomfortable or defensive because of a judgment or if there was a perceived threat to their safety. Another strategy used by nurses and other team members was to consider who on the team felt best able to provide care for a particular person.

Sometimes the need to vent was couched in negative labels such as ‘drug seeking’ or noncompliant. One nurse stated,

And well I suppose it’s no different than when I tease around calling people wackos and crazies. I think some people would take really great offense to that. It’s just something, I don’t mean anything negative about it. It’s just...And I trust that we’re really on board, pretty much all on the same page. I mean, the [front desk] are always advocating for clients to be seen and taken care of [] Even though they know, they are getting pretty good at knowing you know that this guy is just going to talk about his hallucinations, delusions, whatever. He just needs a little [niceness]

My observation was that when a team member vented using negative labels or judgmental language, other team members appeared to listen but did not take up the negative judgment. Rather, as I observed on several occasions, the second team member would respond with a strategy for working with the client or explore the source of frustration or discomfort the other health care provider was feeling.

Accepting without judging included the ability to focus on the person in a life context and meant assuming there is always more to know about the person and their situation. Emma shared with me that people often feel embarrassed and apologize for the odor of their feet when they take off their socks for an exam. She said, “they feel bad about it.” She was pointing out to me they are embarrassed about the smell and apologize for it. Rather than judging them as a ‘stinky rude street person’ she helped me to make a different connection. She helped to connect me to an understanding that the

life context of someone on the street makes it difficult for some people to shower everyday and they don't always have access to clean socks. Thus, rather than judging them on the basis of the smell or focusing on the unpleasantness of the smell for the nurse, nurses can connect to a person in their life context, that of the street.

Connecting to their life context meant that their health problems can be placed in context and insights for providing effective care were illuminated. For example, do they have access to a shower and are they able to keep their feet clean and dry so that a fungal infection can heal? Do they have housing where they can get some rest if they are fighting a respiratory infection?

Whether nurses were seeing clients in the centre or on the street, the norm was to see clients experiencing complex health and social issues complicated by lives of addiction and mental illness. I heard many different stories of the lives of men, women and children.

I met Lindsey when she was 20 years old. She has AIDS. She is dying. The day we met, her skin had a slightly yellow undertone, she was emaciated and her thin hair hung limply to her shoulders, her scalp shining through an area of baldness above her forehead. Her lips dry. Occasionally, a rasping cough would shake her frail body. The nurse asked her about her pain and helped her with her meds for the next week. The nurse told me that Lindsey has lived alternately with one of her parents and another close family member. She was removed from her parents care because of neglect and abuse. Her major concern today was getting her social assistance cheque cashed. She was living a considerable distance from the welfare office and had no means of transportation to pick up her cheque. She asked the nurses if they could drive her.

Lindsey, like many people did not have access to transportation. She not only had AIDS but she had been living with addiction and abuse for most of her life. Lindsay was receiving health care services because she had AIDS. Lindsay's life circumstances of living in poverty, suffering abuse, addiction and a disease such as AIDS make her

vulnerable to negative and judgmental attitudes that blame her for her situation. At a societal level, lifestyles involving addiction, drug dealing, prostitution and other illegal activities generally evoke strong moral responses about the rightness or wrongness of such actions, often blaming the individual for lifestyle choices and for lack of personal responsibility. In reference to many clients she works with Kelsey, a social worker stated,

Well, yeah, and they're an injection drug user because they come from a context that has severely limited the options they have.

What choices did Lindsey have in choosing her life? Is she personally responsible? What capacity does she have decision-making? One of the nurses caring for Lindsey said,

Nurse: Like, you know the other day I said to her, this is really tough. You have no friends your own age. You should be going out dancing and dressing up, looking for boys. And basically that's what she should be doing at [her age]. She should be going dancing and looking for boys, right?

Bernie: Right.

Nurse: And she said, yeah. And I don't think anybody had thought about that. Like her [mother] who constantly says, you're sleeping all day and you're not helping. Well, she's doing exactly what a [20] year old or a 15 year old, which is basically what her age is because she started using drugs at 10. [About] 10. You know, we tend not to think about those things either. Where are they? We don't know, but we have to try and focus on that. Where are they?

Bernie: And how did they get here? What's their story?

Nurse: Yeah, what's their story?

Bernie: I mean, you obviously, I'm just guessing this...

Nurse: We don't know.

Bernie: You don't know. You learn little snippets over time.

Nurse: Only teeny. Only teeny, teeny amounts. And [a physician] has taught us that over the years. You know, even though you've known somebody for say a

year, and you think you know quite a bit. You know quite a bit about the routine of this person for the last year. You know nothing. You know nothing. You don't know what they do after five o'clock. You don't know what they do before you get there. You know nothing. You know nothing about that life. Nothing.

Being non-judgmental meant understanding and connecting to a person and their life context but it also meant assuming you never know the whole story.

While many clients share common stories such as being born into abuse and addiction or a long history of mental illness, I learned there are 'no typical clients.' One nurse working with those who are street involved specifically pointed out to me that she has many clients who are not drug users but they come there because they have lived in the area for a long time.

During an initial shift with a nurse, I was very surprised when the first person the nurse and I met was a middle aged woman wearing a clean white cotton blouse and pressed slacks. She was seeing the nurse for a well woman exam. She was a new patient at the clinic and had previously seen a physician in the clinic who had suggested she see the nurse for a well woman exam. Although the purpose was for a pap and breast exam, there was considerable discussion about her health and previous health care experiences. For example, she told the nurse that she experiences chronic which she manages using acupuncture and massage. She spoke with confidence and knowledge about the management of her pain. At the end of the appointment, I asked the nurse, "was she a typical client?" I will admit I was surprised that the first person I met in this 'street clinic' was a woman with her hair recently styled and who was well dressed and educated. The nurse said no, she isn't in that she is 'very middle class.' However, the nurse went on, she is typical in that she is experiencing chronic health concerns. The clinic we were in is well known for serving people who are street involved, so I asked, "how would she have come to be here?" The nurse said, "Probably because she had burnt out her doctor" with requests for medications and other therapies to treat the multiple chronic concerns she was experiencing.

Anybody could have difficulty accessing health care services and anybody could become homeless. I learned that you may never know nor do you need to know all that has gone

on in someone's life.¹¹⁷ Often nurses would meet a client many times before hearing 'their story' and often people told snippets of their story as they grew to trust the nurse. Emma and others cautioned me that it is better not to get invasive too quickly in order to build trust. Being nonjudgmental means that nurses need to be aware that much has happened and that not only are people vulnerable to the risks of poor physical health because of their current lifestyles but that their history and past life experiences may have left emotional and psychological scars. Thus, they have been left emotionally vulnerable and at risk in relationships. I began to appreciate that being nonjudgmental meant that these nurses knew the importance of connecting to the person, to their life context and assuming that one doesn't know and may never know their the whole story.

By accepting without judging, nurses could tailor their care to the individual person. Mary, a nurse in one clinic, provided the following example:

Trying to put yourself in their shoes and understand the issues that they're talking about and sometimes it's the hardest thing because it's hard for them to communicate their reality and it's hard for you to understand them because the living situations are so different and the lifestyles are so different. Like, one patient told me the [medication she is on] and I told her that it's important to drink lots of water to minimize side-effects. And I asked her how many glasses of water she drinks and she says, well, I just drink coffee in the pharmacy where I pick up my methadone. Then maybe if I buy a coffee in McDonalds. But I don't drink water in my hotel. It's undrinkable. It's disgusting. So to get to the bottom of these details that are crucial for people's treatment, you need time and you have to then think of solutions that would not, that you would not otherwise think in any other situations. Like for most people, you assume that they have running water. It's clean. That they have a roof over their head. That they are able to buy groceries. But in this situation, you have to get rid of your usual expectations and stereotypes.

¹¹⁷ This was particularly brought home to me when I was with a nurse doing a home visit in which I assumed her apartment which was clean, well organized as well as quiet with serene lighting was a calm place. It certainly felt calm. When I observed this to the nurse, I was surprised when the nurse told me 'there is so much more going on there under the surface.' More than I would ever know or need to know.

Understanding without judging, and assuming you don't know the whole story meant that nurses were more able to provide health care that fit the life context of the person.

Presenting concerns of the client could be placed into the context of the individual's life.

Annie provided the following example,

I mean, a ridiculous example is we've said over and over again, never hand anybody a prescription. It never happens. Even that piece we can't get through to their head. They never fill a prescription. It just doesn't happen from there because there's cocaine in the way between that [and the pharmacy].Phone the prescription in at least.....90% of the time, it doesn't happen. The expectation is, we're sending you out with a prescription, so you finish this treatment with PO antibiotics. Well, that piece doesn't happen. So they wonder why they come back because of course, that's never happened.

The usual approach to provide antibiotics, tell them how and when to take it, simply does not work for people, particularly those who are homeless, experiencing addiction or mental health problems. How can someone take antibiotics if they have no money to pay for a prescription? How can they take antibiotics with food if they do not know where or when they might eat that day? Furthermore, what about situations when one does not have housing, money, and may be experiencing depression or delusions? In reference to HIV meds, Annie stated,

Like, a lot of people are started on medication in the hospital because that's a great environment. However, the other piece is never looked at. You know, will this work in the community and what will I really need to do this in the community? You can never tell because you're coming from a hospital environment. You can never tell if it's going to work in the community. It has to be started in the community.

Health concerns cannot be treated or managed out of context because the treatment will only be successful in context. For example, wound healing, if managed out of context, meant slower healing and increased risk of infection. Being nonjudgmental by understanding life context and assuming you don't know the whole story helps nurses to

get past judgments and stereotypes that might render assessments and care inaccurate and enabled nurses to tailor their care to the unique life circumstances of people.

Outreach: 'On their Turf'

Nurses and others described the importance of being 'on their turf.' Outreach meant going to the street or the 'turf' of those who are street involved. Through participants, I came to understand outreach was a key feature of the context that facilitated the development of trusting relationships and essential to forging a chain of trust. As one nurse said, "you have to go where they are." Outreach was a tangible way of reaching out to people and provided opportunities to enhance access to health care especially for those who are unlikely to access services elsewhere. One nurse working in a centre with limited outreach stated, "But we have to do outreach. Because if you don't do outreach, you're missing all these people." Another nurse with many years of experience in doing outreach told me you need to know where to go and find people who don't want to be found just to make that first contact. They won't necessarily come to you so you have to go to them. Annie described.

[Outreach is] that golden opportunity to be able to intervene and maybe change the situation. Although you've had many, many no gos, no shows. Whatever, you can't ever assume that you're not going to be able to turn that around. That's what we wait for. We wait for that golden opportunity. And it happens. It happens and you have to be there. You have to actually be there where they are to make that happen and that's why our model of being in the shelters, being, like we set it up in the [downtown hotel]. Being at [the shelter]. We run a clinic there. You know. We need to do much more or that. We need to do much, much more of that.

She went on to say,

And I mean, one of the street nurses came last week, two weeks ago to talk to everybody here and she said, oh I was out at 9 o'clock last night because that's where I had to be because I knew this person was going to be there and this morning I was in the alley. And I thought, that's where it's at. Will you guys

wake up and listen. Listen to what she's saying. We get criticized for doing that, because we're not within the [health region] boundaries... You know, why are you giving your cell phone number out? Why are you going out of boundary area, like to see [a client. You] should be transferring. No. You just have to do it. There should not be boundaries. We should not be held within these certain four walls and this rigidity. You can't do it with this population. We have to loosen up and we have to just be there where they are. And we have to roam around with them.

On a day I was with Star on outreach, a young woman looking anxious and nervous yelled at another woman to get her stuff and get out. The other woman immediately reacted and there was an almost physical eruption of the conflict. A shelter staff helped the second woman to leave while Star stayed with the first woman who said, I want to talk to the nurse alone. So, I left. Star told me later that the woman had just found out she was HIV positive and wanted to talk about it. She described their previous interactions as not 'very serious.' She said, "You know, we would stop, we'd be in front of the [hotel] and be shootin' the shit." Star stated that she had assumed that this interaction was going to be the same and that she could treat it the same. She explained further,

Well, I mean, for years it was always just I would see her on the street and we would do some exchanges, and she was just one of those people who, you know, we liked each other right away and I don't really know anything about her. And it was always hugs and how are you and if I'd see her, every once in a while I'd see her really sad and dope sick and it would just break my heart and I would [fret, fret, fret] there is nothing you can do about that really, very little. And that's just the nature of the relationship....I didn't even know her last name when this whole thing happened. So it was just the trust there and that day, you know, she wanted to talk about the potential for her future. And you know, what it was going to be like and the relationship with the doctor,... so that really is a perfect example of the kind of thing that I think, what we all talk about, in terms of relationship. No matter how you build it, or what it is, when the time comes for you to help facilitate some change, or for change to be happening or whatever, you are there in some capacity. Or they see you and they go, aha. I recognize them and really that's what was happening (in that situation).

It means you are there and have to be ready when the client is ready to access services.

Within the study, participants described outreach as being ‘where people were at’ physically.

Outreach was provided in shelters and other community agencies on a weekly basis by nurses, as well as other members of the health care team. Outreach was actively supported by the management of both centers and the managers identified outreach as a key component of their services. One community health centre manager stated,

I think looking at providing access by meeting people where they’re at rather than always expecting those people to come to you is really an important role for any community health centre.

In one center, outreach was identified as a key feature of their mission and services in organizational documents. Outreach provides an opportunity for nurses to begin to get to know and build trust with individual clients in settings outside of the clinic, such as a shelter, on the street or at a drop in centre, by providing an easily accessible point of contact for health information, education, counseling, assessment, referral, and treatment.

Nurse: ...having that nurse label, or that nurse designation, people do have a little bit more faith and trust that you’ll be able to you know, help them out or what not. So they are more forthcoming with what’s going on or they are more apt to start that relationship with you as a nurse as opposed to somebody else who doesn’t have a [nursing background]

Bernie: [Outreach] workers too would have, they have a unique relationship.

Nurse: Oh absolutely. Absolutely. But I do find even when I’m with outreach workers that I will be able to garner more information not so much by, well, maybe because I can you know, I can ask more pointed questions that the outreach workers might not have thought of. But I do find that more information tends to come out. Like, I’ve had outreach workers say, oh, my gosh. I never knew that. And oh, that’s so good that you came along because we didn’t know that and they’ve never mentioned that before. I just don’t know if it’s because of the questions that we ask to bring out that information or whether it is just because we are in that role.

The ability of nurses to develop relationships with those who are street involved along, with their ability to assess and discern important information related to a client's health and well being, was highly valued by other members of the interdisciplinary team. Outreach also provided an opportunity to maintain established relationships and to monitor a client's health.

Armed with a modest amount of supplies that ranged from a blood pressure cuff and thermometer to band-aids and vitamins, some nurses in the primary health care centers took their services to clients. Providing outreach in agencies often meant that nurses would move on foot from one agency to another. As we walked down the street, a familiar client might call out a greeting to the nurse. The nurse might stop for a quick chat or a hug. One day when I was with two nurses on outreach, a woman in a wheelchair called as we walked down the street. Both nurses leaned down, one on either side of her wheelchair, embracing her as they exclaimed they hadn't seen her for a while and wondered how things were going. Frequently, as I was walking down the street with nurses in both communities, someone unknown to the nurse might ask, 'are you the street nurses?' followed by a request for band aids, dressing supplies, some vitamins or Tylenol. Although the nurses were associated with the primary health care centers, they were considered 'street nurses' by many of the people on the street because of the outreach component. They were nurses and they were on the street.

While planned outreach occurred in several agencies, the provision of nursing care might be provided on the street as the nurse moved between agencies. One manager recognized and described this important aspect of doing outreach. She stated,

I think that there's another spin-off with [health care providers] doing outreach, and that is that between here and their destination they often meet up with people and that is another point of access quite often. And so there are people where they're kind of seen on the street or they follow them to where they're going, or we're able to encourage them to come back down [here]

Many times as the nurse and I were leaving on outreach, either immediately outside the center or along our route, someone would stop to talk to the nurse and ask for information or advice. Nurses and other health care providers referred to this as the "curbside consult." It was an opportunity to connect with a client to find out how they were doing, to reinforce a personal connection and to provide health care.

Outreach provides an opportunity to assess and offer treatment earlier, such as in the example with Claire and the woman with the infected finger (presented at the beginning of chapter 4). Often because individuals do not access health care early, the prevention or early intervention piece is missed. As Annie described earlier, often people who are street involved are very sick before they will access health care and sometimes other health care providers don't realize that. Outreach facilitates the development of links in the chain of trust that may assist in providing prevention and early access to treatment; it is an opportunity to rebuild trust in the health care system and over time may facilitate access to broader resources.

The consistent presence of nurses 'on the turf' of those who are street involved is an important opportunity for building trust and ensures that the connection to health and social services is available if and when a client is ready. Clients come to recognize and become familiar with the nurse on outreach. They may not even officially consult the nurse but outreach provides an opportunity for clients to repeatedly see and become

familiar with the nurse. Nurses stressed to me that outreach was more effective when the same nurse is present consistently. Emma described,

And so when you've been there consistently, then clients recognize that. They go, oh, I've seen you around before. And they'll talk to you. Front line workers who've been there for a long time...you've become a consistent presence for them too, so they'll start advocating and pull people in to come and see you. So I'll go up to [one shelter] and often there's a front line worker saying, well I told them you'd keep coming around and you're okay. So they'll see you. So that's really important. The consistency.

Consistency increases the opportunity to develop trust and to provide more timely access to care, such as in the story of Claire examining the infected finger of a woman in the shelter described in chapter 4.

In particular, front line agency staff get to know and can more familiar with the nurse.¹¹⁸ Seeing new clients is often facilitated by staff working in the agency, and when the nurse gets to know and establish relationships with front line workers an additional point of access is created.

In the shelter, a staff person approached us as the nurse and I pass through the common room. She tells us that Elizabeth has just told her that she is diabetic. The nurse says she doesn't think she knows Elizabeth so the staff person describes her. The staff member asks for some direction about how to prepare food for this woman or if there are things she shouldn't eat. As the nurses and the staff member are talking, Elizabeth walks into the common room. The staff member quickly introduces the nurse and the nurse takes her into a private office and asks her about her diabetes. How long have you had diabetes? They wait patiently for her to answer before asking, 'do you take medication for it?' At the same time, they check her blood sugar. It is 14.8 and when asked, Elizabeth tells the nurse she has not yet eaten today. It is lunch time and she was on her way to lunch when we intercepted her. The nurse reinforces that it is good she is having lunch. This is Wednesday and the nurses tell her they will return on Friday to check her sugar again.

¹¹⁸ In the study, I had an opportunity to do outreach in several agencies consistently. I recall when I saw one of the staff after a break in the period of observation. He gave me a hug and said, "welcome home."

When the nurse has established relationships with agency providers in other agencies where outreach is provided, access is facilitated. As in the situation with Star above, when the two women were shouting angry words at each other, one of the shelter staff immediately appeared at the door. In addition to facilitating access, shelter workers and others provide an important source of back-up and support on outreach. The relationship with shelter workers and other front line workers is a key to facilitating access and a source of support.

Outreach, when provided as part of the primary health center services, provides an important link to the primary health care center.

Bernie Well the other thing is that...on outreach you're seeing a lot of people that you might not see so starting the relationship and then having that hub.

Emma: Yeah. And often that too is when people know that I'll be here is, I have to say about 95% of the time when I see someone on outreach who's never come to the clinic, and I say well, you have to come into the clinic because we need to do blood work, you need to get a prescription, you know. There's stuff I can't do here. I'll be there. 95% of the time they'll show up for the appointment. Because they're [like] okay, there's someone I know there, rather than having to go to this big scary place where I don't know anyone and I don't know how they're going to treat me.

The nurse on outreach might see one client several times before suggesting that they come to the clinic. One social worker said, because of the trauma they have suffered, people who are street involved "need longer to warm up to services." One benefit of the nurse being connected to a primary health care center is that those who are street involved can see the same nurse on outreach and in the clinic setting. Coming to the clinic was a measure of increasing trust as well as providing access to a broader range of services. A nurse explains,

When I'm out there on my own [what I can do] is limited sometimes and... someone comes to me and says, 'I'm out of my anti-depressants. I can't do that when I'm on outreach, but here I can grab a doctor and say, do you want to re-start this prescription? That is important also in decreasing barriers, that is that if someone comes in and you can deal with [that] We often have people like someone comes in with a bad asthma attack, the doctor writes the [prescription].

When the nurse has an established relationship with the physicians or counselors in the centre they can facilitate an individual to access medical care or counseling services if needed. John supported the need for more outreach workers. They found him wherever he was and accompanied him to his appointments. They linked him to other health care providers. While in 'detox', he discovered that one of the physicians at the clinic had gotten him on disability, for which he was grateful.

Nurses were highly valued as an important part of the outreach team.

On outreach with a nurse, I was in the common room and began to chat with two women who were having a cigarette by an open door. I explained that I was a researcher and doing a study on access to health care. Immediately, one woman said, "I can see the nurse here and I don't have to go to ER and wait 8 hours. The nurses are great."

Physicians face particular challenges in doing outreach. For example, Carl, a physician indicated, "we would be sitting ducks" if we prescribed narcotics on outreach. Jason, another physician said,

And that's where I think the nurse practitioner role is a good one. Or a nurse in general outreach because they can just not have the whole prescribe this or not[thing] hanging over [as an] attraction...they can just focus on, this is information about your health and these are choices you have. And then help people, guide them through that.

Outreach by nurses and others is a critical link in developing and building a chain of trust that facilitates clients to access timely and appropriate care. The nurses have a unique combination of skills well suited to meeting the needs of people on outreach.

While nurses and other participants acknowledged the benefits of outreach, they identified issues and concerns in the development of outreach programs such as the need for consistency mentioned previously. Most of the nurses in both primary health care centers supported the need for more outreach. For example, one nurse mentioned the idea of doing IV antibiotic therapy on outreach for people who are street involved. Another nurse gave this example of what might be done.

Today [I had] this girl with this big abscess, had I had a doctor with me today, that would have solved that problem. But no, she wasn't going to the clinic now. If [name of physician] had been there, we would have lanced and packed this thing right then and there. Having that physician support is very, very important.

Several of the nurses in one center indicated that mobile harm reduction services might be expanded to provide a broader range of services including providing transportation to other services for those who are street involved.

A tension mentioned by several participants in this study was the degree to which services are provided on outreach and the degree to which people are facilitated to access health care in established centers. In the center where outreach was done by the clinic nurses, nurses expressed the importance of being connected to the center because of the support they received from other team members and their ability to link to other providers. Annie described the importance of having the support of team members,

Well they [non-profit agency] hired this one nurse. She lasted 3 months. She was in tears every day. Called us every day. Then they hired another two half-time people, but they were not together. They worked half time opposite each other. They fell by the wayside. Then they ordered, they did another two. So I think there's been a total of 5 or 6 people.

Nurses indicated that working alone without the support of a team is highly stressful given the complex and challenging problems and situations they encounter. Being the

only nurse in an agency, there is no one to consult, no one to provide support and no backup. One nurse, I met, shared with me that it was difficult to refer clients because she does not have existing relationships with health care providers at other points of access such as in other community health centers or the emergency department.¹¹⁹

Based on interviews and observations, it became clear that nurses needed to have the support of other team members as well as being able to link with other providers to address the complex health and social concerns of those accessing health care. For example, access to medical services is essential to address the dramatic and often crisis like physical needs of individuals. When outreach is connected to an integrated primary health care centre it ensures that the link to services such as counseling is there when and if a client is ready to access them. I would suggest that there are differences in the two communities in which this study was conducted that would be critical to take into account in deciding the balance between outreach and clinic services. Regardless, being part of a team of integrated providers in the same center can facilitate a smooth transition from one provider to another. While it may seem ideal for community agencies to ‘hire a nurse,’ this simple solution is likely to be one in which the providers will ‘burnout’ quickly and the benefits of outreach will not be fully realized.

Kelsey, a social worker, indicated that outreach, in general, should be expanded and she summarized what nurses and others said about the importance of outreach in enhancing access to health care for those who are street involved. She stated,

¹¹⁹ This raises for me an interesting question about the nature of street nursing practice (those who exclusively provide services on the street) and the sources of support that they draw upon in their practice. Since I did not specifically study street nurses, those working in defined and mandated street nurse programs and I am aware of only a few studies of street nursing practice, I would suggest this is an important area for future research.

like having nurses do site visits where people can come on a drop in basis for medical care is absolutely fantastic and has greatly improved the quality of life for people. And we need to do that with other services: drug and alcohol services, mental health services. Like I think that the most marginalized street involved people, you know, they cannot make appointments, they don't have watches, they don't have homes, they can't be that organized. That's why they're the most marginalized people we have. So we have to bring the services to them and we have to do it consistently. And we need to, if we're going to really address the problems, it must be done on a non-pilot basis. It must be done as an ongoing program.

She adamantly affirmed the need for consistency and ongoing delivery of outreach programs, because they are better suited to the needs of people who are street involved.

I mean, when you're talking about people with substance use and mental health stuff, we are talking about people...with consistent intervention over time we may see identifiable improvement in three to five years. That does not a six-month pilot project make. And I think when we have these pilot projects, where we do things for a limited period of time with no guarantee of continuity, it is oppressive and abusive. It's saying to people the things they've been told all their lives, which is life is unpredictable, you're not a priority, if you can demonstrate a change in the next six months then maybe we'll continue with you. And none of us with tons of resources and support change within six months. What person stops smoking in a six-month time period, or what person adopts a consistent regimen for exercise in six months, if you look at healthy, middle-class white people who have tons of advantages. And we take marginalized people, we expect them to have changed in six months.

Outreach and other programs must have adequate and stable funding if the goals are to be realized. I would argue that this too, is a matter of ethical responsibility.

In both communities, the nurses expressed a desire for a closer working relationship with other nurses working in the area, such as the 'street nurses.' However, differing program mandates and different program structures restricted coordinated activity between nurses working in the primary health care centers and other nurses providing outreach services. All of the 'street clinic' nurses either had experience as 'street nurses' or had developed individual relationships with other nurses doing

outreach. The nurses in the primary health care centers had informal rather than formal links with each other. For example, they might meet for coffee or a chat. While the informal links are extremely important, they did not allow for referral, development of joint programs or coordinated action on a particular issue, such as development new services or addressing broader health concerns in the community.

Harm Reduction – ‘Meeting people where they are at’¹²⁰

Outreach provides an opportunity to physically meet with people ‘on their turf.’ Nurses, in this study, described harm reduction as ‘meeting people where they are at.’ For nurses, harm reduction was a philosophy and an approach that was integral to developing relationships with those who are street involved and enhancing access to health care. Star, in talking about the interaction with the woman who was newly diagnosed with HIV stated,

And that’s what I think harm reduction is. That’s how I’d describe it. I think we all feel the same way. It’s about the relationship. You can’t really get very much done at all. I mean, the relationship can be at any level and it can be established at any time in any way, but if that’s happening it just has so much better chance of helping in whatever way. And then you’re there, the day the change wants to happen. I mean, you know if that had been for her getting into detox or getting onto methadone or you know, whatever I mean, not that it’s going to last, but that you can help with that next step.

Nurses described harm reduction as meeting people where they are at; accepting them without expecting them to change. Emma explained,

because we're working with the harm reduction model where you know, you don't want to change, what you want to do is change the harm associated with the behaviour without changing the behaviour. And that's what harm reduction is. Someone’s going to go out and they're going to do drugs, and we want to make

¹²⁰ “Where they are at” is a term used by nurses, health care providers and people on the street. I also found this term used by the Canadian Harm Reduction Network (2001) to describe harm reduction strategies.

sure that we minimize the risk of HIV and Hep C so we give them clean rigs. We give them alcohol swabs.

Nurses in the primary health care centers provided clients with ‘clean rigs,’ sterile water and alcohol swabs to reduce the transmission of HIV/AIDS and hepatitis C. Annie provided a specific example of enacting harm reduction.

Instead of saying, looking at that broken crack pipe, would you like a plastic tip for your crack pipe is what you say, that broken crack pipe, I’ll bet you that bothers you. I have a plastic tip in there. Would you like that for your crack pipe? You know, understanding that abstinence from drugs is often not an option in this drug saturated environment as we say. It isn’t even an option to get past that and to get on to the next thing that is, how can I make using drugs safer for you? You know. It’s acceptance isn’t it.

Harm reduction, as an approach, takes the pressure off and shifts the focus away from ‘fixing’ them to accepting that they ‘fix.’ Although clients did not use the term ‘harm reduction,’ Will described the street nurses as accepting his drug use and him as a person. One physician stated, “I can accept the person, I don’t have to change them.” For nurses, harm reduction provided a context for making a connection with people who are street involved ‘where they are at’ in their life.

In interviews with nurses and other health care providers practicing harm reduction was identified as a central feature of their practice.¹²¹ Harm reduction as a feature of practice, provides the relational space to meet clients ‘where they are at’ in their lives. Brenda describes,

So [it] took 3 hours to come into clinic because she popped by several bars along the way and by the time she got here, she was completely plastered. And so she used mouthwash and chewed gum. You know, that kind of [thing] and I said to

¹²¹ During the early period of data collection for this study, I had observed a number of aspects of nursing practice within interactions that were consistently demonstrated. When I shared my observations with one nurse she said what you have just described is what I see as harm reduction. As I proceeded to systematically analyze the data, I came to realize that what I had initially described to nurses based on my observations was consistent with their understanding of harm reduction.

her one day, you know, you don't have to go and mask that alcohol smell; I know you've been to the bar, Alice. And she just giggles, right? And ever since then, we've had a pretty good relationship you know. Because I've been up front. I just said oh, just, I'm not going to scold you, you know for drinking. That's up to you when you're going to stop.

Rather than turning a blind eye, ignoring or rejecting a person using drugs, alcohol or engaging in illegal activities, a harm reduction approach acknowledges such behaviors and provides a basis for developing a relationship with those who are street involved.

Knowledge of drugs and feeling comfortable with drug use were important aspects of working within harm reduction and 'meeting people where they are at.' One nurse described her experience when she first started to work with people who have addictions.

I knew nothing about drugs. I knew nothing about how they actually shot heroin or cocaine. I didn't know how they mixed it up. I didn't know where they got it from. We had to educate ourselves. The street nurse taught us. You know. How they smoked crack and how they mixed heroin and how they mixed cocaine. I didn't know that. So having knowledge about drug use and behavior is so powerful. You know, you can go into a place and know that somebody is using drugs, therefore withdrawal is a huge issue. If you don't understand addictions, you don't understand why somebody doesn't have food. If you don't understand addiction and have a sympathy for it, then you won't go anywhere. Because addiction powers everything down here. Cocaine powers everything down here. So I think the knowledge is very, very important. Feeling comfortable with it. Because if you're feeling stressed with it, that comes across right away. If you're not comfortable with the fact that somebody's just about to shoot up, that the syringe is loaded. Like I've heard nurses say, put that away. No.... They can do what they wish in their own room. But if you go in and this offends you, then this is not the place for you. You can't do this job. That's a big portion. If you're not able to accept that, then it will always be a struggle and you won't be able to help them at all. They'll only let you in so much and they know you've got a problem with that.

In order to work with people who use street drugs, nurses emphasized that one has to genuinely accept and feel comfortable with drug use as well as have knowledge of addiction and drug use. Working within harm reduction, I observed that sometimes

nurses drew on client's expert knowledge of drugs and living on the street. For example, one day a nurse asked a client to tell her again what an 8 ball was. I observed that in response, the client was eager to explain. I observed that, used judiciously and in selected situations, this helped to build relationships while aiding the nurse to work more knowledgably with clients in a respectful way. Respect and being non-judgemental, as described previously, are essential to a harm reduction approach.

Working in harm reduction meant that for those who are street involved nurses tried to consistently minimize harm, not just harm of drug use, but any type of harm that might impact their health or wellbeing. Based on interviews and observations, harm reduction included but was not limited to minimizing the risks of drugs use. What can be done to reduce the harm in this situation? What is the client willing to do? What can I do? For example, if a woman was in an abusive relationship, how can the harm be reduced if she is unwilling or unable to leave her partner? If someone refused hospitalization, what could be done to reduce the harm that was both safe and acceptable to the individual? Star suggested,

And obviously that's the way you should be treating all your clients. You're figuring out who they are, where they're at at moments, and how to work together. So you meet whatever few little goals you have even if that's you know, a good night's sleep that night. It's not about telling them what's good for them. And so that definitely is absolutely relevant in my mind about what I think/see as harm reduction everywhere.

In one situation, Lillian, a nurse, helped to prevent a man from being evicted from his apartment. She said after many times of seeing him on outreach and just chatting, he gradually grew to trust her and allowed her to enter his apartment. When he was in danger of evicted, she was able to help him maintain his apartment by cleaning the

bathroom and helping him to remove literally bags and bags of papers that had accumulated over a long period of time. Harm reduction was an important aspect of ethical practice, often assisting a nurse to determine what appropriate ethical behaviour was in a particular situation. The nurses, as well as other team members, differed on the range of what they were willing to do to minimize harm for clients. In a sense, these different perspectives helped to provide a balanced perspective as to reasonable ethical behaviour in practice.

Respecting choice, keeping the door open and honesty were important aspects of harm reduction identified in this research. Respecting choices helped to build decision-making capacity in individuals who often had limited decision-making capacity because of their life experiences. Keeping the door open ensured that client contact continued and individuals received support even when specific behaviors indicated refusal and clients did not follow through with care. Nurses highly valued honesty in working with people as a way to build trusting relationships in the context of harm reduction. Each of these aspects will be discussed below.

Respecting Choice

Within interactions between nurses and patients, there was a consistent emphasis on client choice. Nurses used questions such as, 'What would you like to see happen?' 'What are you willing to do?' 'What can I do to help?' Within interactions, nurses discussed with individuals their preferred choices as well as the consequences of their choices.

I had heard about Bob ever since I came to the centre. I never met him but he was well known to centre staff and the community. I heard that he was 'being banned'

from a wet shelter¹²² because of incontinence. When the shelter staff was asked about the 'ban', they told the nurse and others that Bob was incontinent and refusing to shower or put on attends when he arrived at the shelter intoxicated. The shelter staff said they felt that Bob was making a choice not to shower or wear attends and that they had to respect his right to refuse. In a brief conversation, Lillian expressed concern to me that if Bob is intoxicated when they are asking him he may not understand the implications of his choice. She expressed her concern and a potential plan to address her concerns to the health center manager that day. The manager acknowledged her concerns and immediately called the administration of the shelter to have the 'ban' reversed. The nurse made a plan to find and talk with Bob at a time she knew he might be the least intoxicated. After that discussion, she planned to have a joint discussion with Bob and the shelter staff to assist them to come to an agreement. The manager encouraged and supported her efforts.

Lillian did not abandon George on the basis that he was refusing care. She worked to preserve and enhance his capacity to make choices. I observed that nurses respected individuals as persons even when their behaviours were not consistent with what the provider might think was in the best interest of the person. For example, they did not exhibit frustration or give up on someone if a client decided to discontinue treatment such as antiretroviral medication for their HIV, if he did not show up for an appointment or if they went on a drinking binge after being dry. While respecting a client's right to say, 'no,' nurses worked to find choices that were acceptable to the client. I did not observe that when client said 'no' that they were labeled noncompliant or unwilling to take responsibility. What I observed was that nurses continued to offer and discuss potential choices and the consequences of different choices.

Nurses and others frequently would observe, 'the client isn't there yet' and we have to keep working with this person at their pace and on their terms. In one center, they might say, the person is still precontemplative, meaning they are not yet ready to

¹²² A wet shelter is one in which a person does not need to be sober or clean in order to stay overnight.

make a change. One nurse told me “you have to expect and get through barriers” to work with people who are street involved. While working to minimize physical, emotional and social harms, I observed that nurses were cautious about pushing enough but not pushing too hard to move clients to the next step if and when they might be ready.

When I arrived at the center today, one of the nurses immediately updated me on a situation with a man that we had seen many weeks earlier on outreach. She told me she had finally broken through his wall of anger and convinced him that she was on his side and wanted to help him. As a result, they had worked to submit an application for disability income. She said, this is the first step. I reflected back to that day when one of the agency staff came to the door and said, “We need a nurse on the floor.” The staff person abruptly turned and walked back to the common area. The nurse and I followed quickly. As the man struggled to get up off the floor, the nurse determined that he was physically ok and discerned that he was taking more than his recommended dose of pain medication. The nurse urged him to see his doctor. He kept saying he didn’t need any help. The nurse told me later that he had injured his back and was in a lot of pain but refusing to seek help for it.

I observed that nurses worked to provide choices, develop decision-making capacity, show respect when people said no and continued to offer choices and support to people. For example, nurses and others in the community paid constant attention to preventing and treating health concerns early and finding ways to provide care ethically in the community without coercing people into hospitalization. If the harm was life threatening, they might say “this is serious, you have to go or you could die.” Working within harm reduction, meant balancing the client’s right to say ‘no’ and pushing but not coercing an individual to take action.

As well as respecting choice, nurses and others also were quick to congratulate someone when they had made particular choices. For example, if someone quit smoking, drinking, injecting for one year, one month, or one day, nurses and others would quickly and consistently congratulate them. In response, the person would often smile and stand

up just a little taller. After a period of time, I found myself starting to do this in my interactions with those who are street involved. It appeared that when a provider acknowledged the positive steps that a client had taken to change, self-esteem was enhanced, as was the capacity for making choices. I came to understand the importance of working within harm reduction to build self-esteem and enhance decision-making capacity.

Not Giving Up: Keeping the Door Open

Nurses and others described that not giving up on people meant ‘keeping the door open.’ No matter how many times a client might fail to follow through, the door was open for them to come back, make different choices and try again. Claire, a nurse said, “ethical practice is when the person can keep coming back without judgments, without recriminations.” Emma said, “We don’t fire people and we don’t give up on them.”

Today, Sharon is wearing a black ball cap. She signals to me and asks if I can tell the nurse that she wants to talk to her. I knew from an earlier conversation, that she is here today to see one of the specialists. The nurse, who is standing next to me, says just a minute Sharon, I will be with you. Although I had only met Sharon once or twice before I know that the nurse has an ongoing relationship with her and that she has been setting up homemaking services, meals on wheels and diabetic teaching for her. When the nurse is almost ready, she asks me to tell the front desk person to put Sharon in the computer as a scheduled appointment. As I do this, the nurse reminds Sharon who I am and asks her if I can observe. As the nurse goes to get the paper for the blood work for Sharon, I explain more to her about the study. When I tell her I am interested in the role of the nurses in facilitating access, she says how much she loves the nurse and that this nurse has been there for her many times. She starts to cry and tells me about how hard things are for her right now and how depressed she feels. She tells me she has started drinking after seven months of being dry. “Seven months... her voice trails off and she hangs her head.

As I am listening to her, the nurse returns and says, “What are the tears about?” The nurse sits down in her chair, which is adjacent to Sharon’s chair and she leans forward and listens intently. Sharon starts to talk saying that she has gotten back with her boyfriend who abuses her. She tells the nurse that she wants to die

because life is so hard right now. "I just can't do it on my own. I need help." She acknowledges that in addition to the nurse, a community leader has been a source of strength to her. The nurse asks "what is happening?" Sharon replies that she is drinking again, that she feels suicidal and that she is in constant pain from her back and legs. They discuss the fact that she has missed her previous appointment with a psychiatrist. The nurse reminds her that she has an appointment today with a specialist and that it is good that she is here for that. The nurse suggests that it may be the alcohol that is making her feel the way she does. "I can smell Listerene on your breath and I think that it is the alcohol that is making you talk and feel this way. I think you need to stop drinking first." Sharon nods and starts to cry. "Don't be angry with me" The nurse leans over and touches Sharon's lower arm and says, "Oh, sweetie, I am not angry at you" Sharon continues to cry. Sharon indicates that she too thinks that it is the alcohol that is making her think and feel this way. At one point, the nurse asks her, do you think you need to spend some time in detox? Sharon asks, "but I can't get in right away can I?" "No, it would take two weeks but I can put you on the list" Yes, put me on the list," Sharon replies.

They talk about the homemaking services, which the nurse had previously arranged for her. Sharon says how she first had this young gay man who was talking about sado-machism, which she didn't like "so I told him not to come back." Then they sent a woman who came one week but that was two weeks ago and she hasn't come back." At one point, the nurse states, "we have put so many resources into place for you and at some point you have to take the ball." Sharon cries and says, I know but I can't do it. Towards the end of the interview, the nurse asks Sharon to sign a contract that she will not harm herself for 24 hours and that she will come back tomorrow to see her. The nurse asks me to witness the contract. The nurse pulls a sheet of yellow unlined paper from the desk draw and writes on it in pen. The contract states that Sharon will not harm herself during the next 24 hours and that she will return to see the nurse the next day.

The nurse indicates that Joe, a community worker, hasn't heard from her and that it would be good if Sharon called him. Sharon says I can't do it, will you do it? No, replies the nurse, you need to call. They continue to talk and at the end of the interaction the nurse reminds her of the need to call Joe. Sharon says again, I can't do it right now will you do it. The tone of her voice and her posture conveys a desperate plea. The nurse agrees she will call Joe and tell him that she has seen Sharon but Sharon still has to call and tell him how she is doing.

Sharon gets up to leave, the nurse asks what else do you need? She replies, "I need a hug." The nurse hugs her. We start to leave and Sharon says, I need another hug. They embrace again. This interaction in the exam room was about 20 minutes in length.

The nurse tells her to wait in the waiting room because the specialist is here and that he will see her soon. As the nurse and I walk back, the specialist stops the nurse to ask what is going on with Sharon. The nurse starts to talk and then moves to open the door behind the reception area. When the specialist asks where are you going? The nurse turns and says I don't want to talk out in the hall. We move into the back area behind the reception desk. The nurse tells the specialist that Sharon feels depressed and suicidal and that she is seeing her old boyfriend. The specialist asks, "what can I do for her?" The nurse replies that this is Sharon asking for help.

On the day that her bed in detox was available, the nurses looked for but could not find Sharon. They told me that her bed would be held until four o'clock that day. They went to her apartment but she was not home and it was surmised that she had left town. A few days later, a hastily scrawled pencil written note was taped to the back of a chair in the nurses' office. It was from Sharon to the nurse. The note said, "I'm sorry, please don't give up on me."

'Not giving up on people' means keeping the door open and not rejecting the client regardless of his or her decisions. It means continuing to be there ready for, but not expecting, change. As one nurse said, "Being ready for change and recognizing that the shift may not happen this time, it may never happen but you have to be ready in case it does." You never know when something might 'click'.

I heard and observed that the nurses in this study didn't expect to fix people or 'save the world.' 'Baby steps' were a measure of success and therefore acknowledged and celebrated. If someone got a case worker, if someone who was hard to house got housing, if someone showed up or kept an appointment, these were successes. It was commonly recognized that successful rehabilitation from addiction might take three, four or more admissions to 'detox' and drug rehabilitation programs. Each time the client was able to stay longer was acknowledged as a success. One manager said,

I think when you work with a clientele who are extremely high risk and their lives are as complicated as they are, that burnout would be far ... there'd be a lot more burnout with staff if we had a different approach. If we were looking for major results and major changes, then you can imagine the frustrations. Many times it

just needs a tiny, tiny baby step for us to be really excited for somebody. And we have an understanding that perhaps there'll be two steps going backward at some point, you know, and not to feel somehow or other that we've failed or that they've failed. So I think it goes a long way for avoiding burnout of staff, having the approach that we have.

In a way, it took the pressure off. One health care provider said, "I don't feel the pressure to do something anymore". Lillian explains further,

Right. I don't know. I think I have found nursing wherever I have worked is quite stressful. And I get tired and stressed out by it. In this particular setting, I do think that the stresses are different and that you learn a coping mechanism and one of the things I've learned, and I've been doing this now since '98, working and so I did street nursing and that's so a similar thing, is to understand that you aren't going to make a huge difference. You aren't going to see a lot of people get well. And what I remember most about all the patients when I first started working in this, and I started doing the street nursing and I took over from a woman who went on sick leave and she was hail Mary, Mother of God kind of person - everybody loved her. And the thing they always said about her is you know, [she] just listened to me and [we] just really had good, they didn't use the word rapport, but we really had a good connection and could talk. But you know what, despite the abscesses and the hepatitis C and the HIV and all the horrible things in your life, and probably the things that [she] has done for you in terms of you know getting you on human resources and dressing your wounds and testing you and treating you, the thing you remember is that she was good to you and so that's something I always tell myself: you know what? Lillian, this person, is going to be a drug addict her whole life, likely. The chances of success are 5% with any given addict, so you know, it's not about what you can do for them. It's about how you can treat them. How you can increase their self-esteem. And that's sort of the mind set that I use for myself to not get burned out and frustrated with these people. You know what? It's not about whether I write them this note so they can get their \$40 cheque or not get their \$40 cheque. It's how I tell them I'm not able to write that cheque, or to write that note so they get the cheque. Right? It's if I can do it in a kind, compassionate way. That's what they'll remember. Anyway, so that's how I sort of get around the burnout.

While nurses and other health care providers in the primary health care settings endorsed, supported and practiced harm reduction, providers identified situations that raised difficult issues for them related to harm reduction. Emma provides an example,

But that becomes hard when you have a woman who's pregnant who comes in and asks for a rig. Because your instinct is, that first reaction is to say you shouldn't be

using; you have a baby. But the harm reduction would be, well, we could prevent that baby from being exposed to HIV into an infection and that the mom might end up being in hospital and needing antibiotics, a skin infection or something like that. The Mum becoming desperate and doing some kind of drug that's more harmful for the baby lets say than what heroin is. By this attitude of 'don't harm the baby' are we then actually putting the baby at more risk because then the Mum is also being judged when she comes in to health care so if something does come up, she's not going to come back and see us because we've judged her and said no, we're not giving you that needle. I think what happens then is that when you are practicing harm reduction and that people do have a right to health care, is that then people feel that they can trust you and fall back on you; that well, I will be treated with respect here and will be treated as a human being. So then they're more likely to access care when they need it and if there is going to be a change in their life, they're willing to walk through this door.

There were concerns about balancing individual and community harms raised by clients, nurses and other health care providers. Harm reduction may be viewed as an 'ethical' approach to working with people experiencing social disadvantage because they are not forced to change and their choices are respected while trust and opportunities to access health care are preserved.

Harm reduction is a way of minimizing individual harms and can minimize community harms. For example, needle exchange programs have significant benefits for the community, such as keeping the environment free of drug related paraphernalia including syringes that might pose harm to others.¹²³ However, the benefits and disadvantages of interpreting harm reduction in a broader sense are not clear. For example, if someone makes a decision that might put others at risk, such as discontinuing antibiotic treatment for a wound that is MRSA positive. This and other issues related to harm reduction will be explored further in next chapter 6.

¹²³ An interesting observation was that some people who are street involved expressed an active interest in participating in needle exchange programs as part of their moral obligation to protect the environment and others in the community.

Honesty

Nurses spoke to the importance of honesty both as a basis for building a trusting relationship and as part of harm reduction. Earlier Claire had said,

We're here to try and help them with their problems and let them know that all of the care that we'll be giving will be done in the most, you know, forthright manner and honest, right. I find that when, a lot of our patients come in and they can be manipulative, they can be drug-seeking etc. and I find that if I'm just very frank and very honest with them up front, it's really good grounds for starting a relationship.

If clients requested something that was inappropriate or unavailable, a nurse might say, I can't do that. Honesty included calling them on their behaviors in certain circumstances. For example, if a client repeatedly doesn't show up for appointments, one nurse said, we need to call them on it. Also, if a client's behavior is something we can't tolerate as nurses we need to let them know it is inappropriate.

However, honesty was used judiciously. For example, one man told a nurse that he had stopped using drugs. When she went to draw blood from him, I thought I could see the fresh track marks on his arm. However, the nurse never indicated either verbally or nonverbally the discrepancy. When I asked the nurse about this, she said that there was no need to call him on it because at that point it wasn't central to the reason that he was seeking care.

A woman and her son came to the clinic. The woman had dropped in for random drug screen as part of maintaining regular visitation with her son. Before going into the bathroom to provide the urine specimen, the nurse and woman chatted amicably about how things were going in her life. The nurse talked with the son about school, what grade he was in and what he liked about school. The woman smiled broadly as he talked. After a few minutes, the nurse asked the woman if she wanted to do the urine sample now. The woman left to go the bathroom. When the nurse and I were alone, she told me how on a previous occasion she had caught the woman using some else's urine to submit for the random drug screen. The nurse said she knew she had to call her on it and she told me that she did it as

honestly and gently as she could by saying, "You know that is some one else's urine and I can't take it."

The nurse felt that while she was honest, the relationship had been preserved because of the way she had addressed the issue in a direct manner.

In this study, nurses also described honesty as important in fully explaining to clients' information about their health and the resources available to assist them with health and social concerns. One nurse described, "Always to present the facts to the clients in an honest and forthright manner I think it is of most importance. And that's not always done." She elaborated further,

I mean sometimes it takes approaching the other care providers and discussing it with them and you know, pointing out to them that they're not giving the full picture to the client. I or we have to give the full picture to the client. This is the reason why. You know. It can [be] pretty challenging. But I think ethically, the patient has the right to know.

She gave the following example to illustrate what she and others did and referred to as honesty.

A prime example being this morning a young girl that came in and you know, and thought she had genital warts and she may indeed have genital warts. I had to send her to the STD clinic and so wanting to know ... how serious it is and what are the possibilities. And you know I could sort of just say, well, you know, they're a virus you have them in your system. They are sexually transmittable, but they are treatable. Not curable, but treatable. You can get chiro therapy or what not and just leave it at that. Instead of going further and saying that if you do get warts on your cervix, then it can lead to some pre-cancerous cell changes and so giving them that bit more information, not so much as a scare tactic, but so that they do know what it all means; what it all entails.

In this sense, honest explanations meant taking time to explain and not assuming that those who are street involved had the same level of knowledge common among other members in society. I observed that nurses frequently took client questions as an

opportunity to honestly and directly clarify and explain information in way that was respectful and did not judge them for their lack of knowledge.

Developing trusting relationships over time is an essential feature of facilitating access to health care for those who are street involved. Nurses develop trusting relationships over time through respecting and accepting without judging. Outreach and working within harm reduction provide a further context for developing trusting relationships over time. Working as part of an integrated team supported nurses to develop trusting relationships over time. A climate of trust in the health care centre was a second link in building a chain of trust.

A SECOND LINK: WORKING IN A CLIMATE OF TRUST

The first link in a chain of trust is forged when nurses are able to establish a trusting relationship with individuals who are street involved. A second link in the chain is when nurses are able to forge a link between individuals and other providers within the center.¹²⁴ The presence of interpersonal relationships of trust between nurses and other providers supports forging of a second link. I found that when a climate of trust is present within primary health care centers, both nurses and those who are street involved benefit. Access to health care is facilitated when there is a strong relationship of trust among interdisciplinary team members working together in the health care center. Nurses, and it might be presumed others, benefit from and contribute to building a climate of trust in the health center. In both centers, nurses consistently identified that working with a team was central to doing their work and enhancing access to health care.

¹²⁴ I would note here that the second link may also be to health care providers in other agencies but for clarity of discussion I have identified the linking to other agencies as a third link.

In this section, I will begin by highlighting the role of the nurse within the team (working within a team) and then the way that teams worked together (working as a team). Then, I will explore the benefits of building a climate of trust within the community health center.

Working within a Team

Nurses expressed that working within a team was an important aspect of providing care to those who are street involved. Within the team, nurses had different roles and there were different patterns of consultation and referral in each center. Each of these aspects of working within a team will be described below.

Creating the Nursing Role

Nurses described that they had or were creating their role within the health care centers. One nurse expressed an interest in participating in this study as a means to further clarify the nursing role within the agency. In one center, the nurses and others on the team said that the nurses were creating the nursing role. Several of these nurses had nurse practitioner preparation and were developing the nurse practitioner role within the center. I observed that the role of each nurse differed dependant on his or her specific responsibilities, educational preparation and scope of practice. Those in nurse practitioner roles or with primary care experience performed additional primary care functions (e.g. assessment and treatment of common medical conditions; well woman exams) in conjunction with their nursing functions (e.g. education, counseling, social support, referral, decision-making), which was a unique contribution to the team. These nurses also provided a back-up for physicians. In some situations, nurses within the center had specialized in the care of people with hepatitis C or HIV. While the nurses in

both centers often dealt with ‘nursing tasks’ such as dressing changes, medication administration and drawing blood, every interaction was an opportunity to address and provide assistance on a range of issues such as housing, income and social support. Star, a nurse describes,

So often there are so many steps that our clients have to do that the general mainstream clients don’t have to do. You know, in terms of housing and food, and you know, whatever, they, a lot of people are in better shape around all that and maybe they have more support systems, so that that tends to be a big deal. I’m sure you’ve seen lots of people walk in at square zero you know a new admission, you have to get them numbers, get them welfare and get them... then to see the doc to explain what is going on.

The degree to which nurses performed the type of role described by Star varied between the centers. Mary, a nurse with experience in Northern Nursing, whose role was defined as doing the ‘nursing tasks’¹²⁵ stated,

Right now my interactions are very limited. Like I say,...we see people for medication management, like when we give HIV pills, but it’s quite limited. A lot of my time is taken by paper work. Yeah. And just doing kind of little things like taking blood or doing a dressing. Wound care is actually part of things that satisfy me because I do the assessment, but there is a lot of non-nursing things that we do that are less interesting.

She related to me that she thought nurses could be doing more. When I observed her doing wound care, she would ask people about their nutrition (e.g. have you eaten today, what did you have to eat?) and helped them to make understand the connection between good nutrition and wound healing. She recognized, what many of the nurses knew and demonstrated, that every interaction was an opportunity to fully utilize their nursing skills to facilitate access to health care. This included not only addressing specific health concerns in the moment, but assisting and supporting clients to enhance their health by

¹²⁵ For example, wound care, drawing blood, medication administration and monitoring as well as health education were the main focus of nurses in this center.

addressing the broader social determinants of health, such as getting a health care number and linking to other resources such as housing or welfare services.

Linking Together: Communication and Referral

An important aspect of nurse's work was the constant need for communication, consultation and referral with other team members in the center. The centers differed in terms of the flow of communication, referral and consultation between team members. The presence of trusting relationships among team members enhanced a free flow of interdisciplinary referral, consultation and continual communication among the team. I had observed to Emma that nurses often seemed to have a role in coordinating client care.

Emma: it's inherent in what we do but it's not formalized per se like that, because we're not actually recognized as case-managers, although that is a lot of what we do is advocate to make sure that someone gets in with [the counselor] so that they can initiate some counseling and then I'll, you know, prepare them for that or with a nutritionist or you know, get them in first and that.

Bernie: My observation is because you're doing outreach and because you're seeing a lot of people is you have that kind of contact, that initial relationship of trust that then..then you can get them in.

Emma: Then you can get them in. Yeah, and often what I'll do is if I think someone really would benefit from counseling, then well, I'm coming in and I'm talking with you I say yeah, that's fine, but I think you're at a point where you would really benefit from someone that has the expertise that I don't have and then I'll go and see if [the counselor] is free, and then I'll bring them down and say, let me introduce you to [the counselor]. If you feel that this is someone you could talk to, that you feel comfortable with, then this will be great. So sometimes, just initiating that contact and bringing them down. Then they put a face to [the counselor] if they meet him and [counselor] often, if, you know, he doesn't have anybody, he'll sit down with them for 5 minutes and go, well, what's going on, we'll make an appointment will be great and then people tend to follow him through then with that. But, what you have to do and I'm always advocating for the other practitioners too. Oh, you've got an appointment coming up with Dr. So and So, well I don't really like doctors. Yeah, I don't either, but you know, [laughs] this is a good one. I think you'll like this one.

Having seen a patient on outreach, being connected and having established relationships with other practitioners in the center facilitated a chain of trust and access to a broader range of services. One provider could directly link to another.

In both centers, 'hallway communication and referrals' were common. One nurse described the nature and importance of 'hallway communication and referral.'

You need a hub and then people can go out from there. But you come back because it's well a safe place, but also that's where a lot of the communication is happening. That's where, I might not be seeing the person, but I can see the person go down the hallway and then I can ask the doctor, you just saw them, what about this? Or also when you think, oh, did, was that ever followed up? And then I can just get into the computer and see that that person came in or not or I can ask someone what happened when this. It really adds to the continuity. Is that I'm going out to get one patient and I see someone I haven't seen in a while go hey, haven't seen you in a while. How are you doing? Great. I'm actually here to see the nutritionist because we're working on this. Perfect. So you have a better sense of where people are at, rather than if we're all fragmented. And I think that really helps. Because we have a lot of informal case management. It's just that conversation in the hallway.....all the time and it's because we would never be able to accomplish that work if we were all doing our own thing and then we're trying to coordinate meetings where we could sit and we would never get that amount of stuff happening as we do. It's like, okay, well I'll make a note of it and or, it happens all the time you know; I saw so and so and I don't know what happened. Oh, it's okay. I saw them last night. They showed up after you left. It's really helpful.

I observed and heard that physical proximity increased the flow of communication, coordination of patient care, referral and consultation. Thus, communication was primarily informal. In one center, the nurses doing outreach, although physically in the same building, were in a separate area and part of a separate program from the primary health care clinic within the health center. Thus, these nurses did not get to know or link with other providers in the center. Communication and referral was occasional rather than daily. This is no doubt, in part, due to the fact that the nurses in this centre worked within three different program areas and were not functionally part of the same team nor

did they have multiple opportunities to communicate or accrue the benefits of ‘hallway consults’ and ‘hallway referrals.’ Sharing the care was facilitated when providers were able to quickly consult and communicate with each other.

One day, I was in the pharmacy when a man came in for a prescription refill. He had just seen a physician. The pharmacist noted that one of his meds had not been reordered. The pharmacist wondered out loud, ‘I wonder if [your doctor] meant not to reorder [name of drug]?’ The man shrugged, looking blank. The pharmacist immediately pushed a button on an intercom and spoke to a physician in a nearby exam room asking if she meant to discontinue the medication. The physician said ‘no’ and thanked her adding could you make sure that Gil books a follow-up appointment with me in a week? Sure, said the pharmacist and after filling the prescription, promptly booked an appointment on the computer.

Similar scenarios happened between all team members.

Susan, a pharmacist explains the benefits,

Being able to you know, at the drop of a hat, involve a physician or a nurse or a nutritionist. It all goes back to the patient and it’s because of the relationship we have with each other here on the staff. So the patient always benefits in the end.

While practitioners benefited and enjoyed working in the center, the primary benefit of ‘sharing the care’ was for patients.

Susan: I can’t espouse it enough. I have had pharmacy students and interns come through here and for them I think not all of them but most of them, it was an aha! moment. Wow. This is really how pharmacy could be practiced in an ideal setting where you have access to physicians and nurses at the drop of a hat. You know, and it doesn’t have to be for the high-risk marginalized population.

Bernie: No.

Susan: You can see how this translates to a senior’s clinic. If this was a senior’s clinic, that Mrs. Smith could bring her giant bag of pills to see me. We could go over it while she’s waiting to see the doctor. [laughs] You know what I mean? So it would translate to any population.

Jason, a physician, spoke to the difficulty of addressing the needs of individuals with complex problems without the benefit of a team. He states,

Well [here], you just have the support and you have the resources very close at hand and the team. You know, the doctors who are trying to do this kind of work with this population are just, I don't think, rarely getting to the heart of the matter of people. They don't have the time, they don't have the support, they don't have the ability to get them involved in a multi-layered team. And so I think that they're left with just writing prescriptions and doing referrals, and then with the chaos of people who often don't attend those referrals, and so then it's back to them. And they're somewhat isolated as well.

The lack of an integrated team of providers to address the complex health and social needs of individuals can perpetuate rather than address sources of ill health. Without being in the same physical location, it is difficult to develop relationships of trust in which providers can easily and freely communicate, consult and refer.

People that I spoke with highly valued having access to integrated teams of providers. When I chatted with George, a man being seen for a stab wound, he said,

I can get in quickly when I need to. I can see the nurse and she consults the doctor so I don't need an appointment with doctor. This is the whole package. I can get my drugs here even have my blood drawn (but not have x-rays). Much better than going to emergency where you have to wait 5 hrs.

People valued coming to one location and being able to see a doctor, a nurse, a nutritionist and others. People I spoke to highly valued communication and referral that was done quickly. I often thought their commentaries would be amazing 'ads' for primary health care. Since I was interested in the work of nurses, I was particularly struck when a man, starting on a new trial medication, told me that he preferred to talk to the nurses over someone who knew the written information but didn't have experience in giving the drugs because "It's much better talking to the nurses, they've done it, they know what it's really like."

Nurses in each center acknowledged that relationships with physicians were important in doing their work. Nurses spoke to the need to establish credibility with

physicians and that it was their knowledge, confidence and experience that assisted them to do so. Relationships with physicians, as with every member of the team, were collegial. Physicians highly regarded the skills and knowledge of the nurses. Most notably in one center, the physicians particularly valued the nurses role in reaching out, supporting, educating and coordinating care for people, often consulting the nurses on the plan of care in particular cases both formally and informally.

An established expectation in one centre was that physicians were available for consultations with the nurse, if needed, on the care of particular patients. At times, this could be a source of frustration if the number of physicians working was limited or when a complex case required extensive consultation such as someone presenting with severe symptoms of undiagnosed mental illnesses. In the other center, patterns of consultation with physicians tended to occur along the lines of individual nurse-physician relationships. Nurses consulted those physicians with whom trust had been established. One nurse said, "I tend to ask [one doctor] if I need to consult." Thus, nurses consulted particular physicians rather than any available physician, which restricted the development of linkages within the team. This may be due, in part, to the fact that the center was relatively new and roles as well as relationships were still evolving.

In both centers, nurses thought that the manager played an important role in creating and supporting the team. In the case where the manager was responsible for several programs, the responsibility of facilitating and supporting the team was undertaken by one nurse. It was evident that the presence of a trusting relationship with a manager who was accessible and had formal responsibility facilitated access to health care. In other words, the trust between the manager and nurse was essential to facilitating

access. The development of trusting relationships was supported when the manager listened to and believed the concerns of the nurses. When Lillian brought to the manager's attention that Bob, a man with a history of chronic alcoholism, had been refused admission to a 'wet shelter' because of his incontinence, it was the manager who took action to advocate lifting of the 'ban' through formal lines of authority. This manager described herself as being like a conductor of the symphony. She stated,

I'm very visual with these things, so I do see it like as a conductor ... but I don't know how to play the oboe or I don't know how to play the first violin or whatever. Those are the experts. And so my job is to make it sound beautiful, make it work beautifully. And it does.

Working Together as a Team

Based on interviews and observations, I found in this study that 'being like-minded,' sharing priorities and not being alone were important to working together as a team.

'Being like-minded'

Nurses and others described that what supported them was working with people who are 'like minded.' Managers described finding the 'right fit' when they were they looking to hire new staff for their clinic. Being 'like minded' meant that you were committed to working with people who are street involved and shared similar values as other team members. Annie indicated that is was important to work with people who were like minded and who had gotten past their own judgments and barriers to working with those who are street involved,

Sometimes if I get a smushy kiss on there, I'll want to wipe it off and I have to stop myself doing that. But it never dawns on me. Right now to give somebody a hug, or, it's right []. [I don't know] Yeah. And it's something, it's a barrier that you have to get across and if you don't get across that barrier, it won't ever work

for you. It won't ever work for you and I've worked with an awful lot of people... here and they have that barrier.... then you can't do it. All those things, the dirt, the cockroaches, the drugs, the behavior will stop you and you won't ever get past it. It's such a tough job to do. And [it] won't go away.

She described that it was very stressful for her when she worked with other members of the team who had not 'gotten past' their own barriers in working with people who are street involved. When I asked Claire, a nurse, about concerns related to personal safety, she said when you are taking blood and working every day with people that have HIV and other infectious diseases, you can't keep thinking about it or it would stop you from doing the work.¹²⁶ These nurses and others indicated that as individuals each member of the team has to be committed to the same values. Specific shared values identified by team members in both primary health care centers included being inclusive, a commitment to ensuring the right to health care including quality, respectful, nonjudgmental care and respecting differences.

I heard, observed and experienced the importance of inclusiveness as a value in both primary health care centers. Meetings, although a formal time to communicate, were often informal in that they might be over pizza or lunch. For example, in one center, all staff attended staff meetings and any one could place issues of concern on the agenda. In another center, a conflict was created when several of the nurses were unable to attend a weekly team meeting because it conflicted with the time that a number of regular clients were scheduled for blood-work. The nurses were clear that their priority

¹²⁶ I would note here that in some of my initial analytical work, I had included safety as a priority ethical concern. However, I recognized that it was a priority concern for me not for participants. I made many reflexive notes on issues related to personal safety. By the end of nine months of data collection and visiting three different centers, I saw that my own concerns about personal safety had shifted dramatically. In one example, I openly discussed my comfort level about going to one agency with the nurses. Although I felt safer, I still felt that it was being with the nurses, as someone who is trusted, that contributed to my feeling of safety.

was to provide care to those clients. One of the nurses specifically addressed this with several of the physicians and a decision was made to consult the agency running the program to see if blood work for their clients could be rescheduled or if other arrangements could be made without negatively affecting individuals accessing care. My own experience was that I was quickly included as a member of the team in both centers. I was introduced to all team members by their first name and it was automatically assumed I would attend meetings and case consultations. Both centers had a mechanism for meeting weekly.

'Everyone Deserves the Same Care'

Nurses and others identified that if individuals did not have access to health care in their center, they may not be able to access health care elsewhere. Emma described their centre “as the buck stops here.” One man, who had been coming to one of the centers for several years, described it as “the last chance café.” Paul explained,

I mean they're the kind of folks who ignore their health [and] they maybe don't take care of themselves because their life changes so erratically, radically. And but so a lot of people who normally wouldn't bother with their health or the system. They have been seen as and treated as non-relevant, non worthwhile. You just disappear. We're not on the radar but here we're just [people, not street people] Word gets around, so you know.

He had high praise for the nurses and the center. In their interviews, nurses and others consistently expressed that ‘everyone deserves the same care.’ I came to understand that this meant that all people deserve to be treated with respect and have a right to health care resources without judgment of their social status. In other words, people who are street involved deserve the same care as everyone else in society. Many nurses expressed this as giving the same care you would give to others or expect to receive yourself. Some

participants expressed this as everyone having a right to access health care or as a commitment to social justice. A few nurses expressed that everyone has not only a right to health care but also emphasized the right to quality care.

I observed that the value that ‘everyone is deserving’ or worthy of care was often communicated and shared among members of the health care team. In one center, the message ‘that everyone is deserving’ started at the door with the front desk staff and rippled through the clinic. For example, as mentioned previously, sometimes a front desk staff person would advocate for someone to be seen quicker and I observed that clients were always greeted politely and with a smile. I observed that the belief that clients were prejudged or treated unfairly was consistently countered with the value that everyone is deserving of respect and worthy of resources. Ensuring that everyone receives the same care was evident in frequent ‘hallway consultations’, one team member would ask another, “Did I do the right thing?” Thus, questioning and checking out, did I provide the best and appropriate care to the person in this situation, was a common practice.

In ensuring that everyone receives the same care, nurses and others had to constantly navigate two tensions. The first was the tension between a right to health care and managing resources, particularly human resources, wisely.

During a case conference, the team discussed what to do about Carol. Carol was coming into the clinic several times a day demanding to see a doctor or a nurse. I had talked with Carol several times both inside and outside of the clinic over the past couple of weeks. For example, one day, she asked me when I was going to pay her for doing a survey. Several times I heard her yelling in the waiting room. On one such occasion, the nurse immediately took her into an exam room. On another day, she came into the one of the exam rooms without knocking while the nurse and I were with another person. The team expressed a concern about the need for Carol to have a psychiatric consult. A nurse indicated that a psychiatric consult was scheduled for the next week and one physician noted that she had found a good psychiatric consult on her chart that gave some insight into her

current behavior. The nurses and physicians discussed with each other the frequency with which each of them had seen her over the past few days. They identified that in this situation, continuity of care with the same practitioner was needed. Since the center often triaged anxious patients, Carol was being repeatedly seen several times a day by different practitioner. They discussed the need to have her assigned to one doctor only and restrict her visits to once a day. One of the staff indicated that once a day was a lot but someone else observed that once a day was better than the current multiple visits per day. Someone asked are we willing to call the police if needed? The manager indicated that she didn't want to do that until she had been assessed by the psychiatrist. She expressed concern about making sure she shows up for her psychiatric appointment. They talked about precedence in which other clients had been restricted to one practitioner and a limited number of visits per day or per week. They recalled past times when they had needed to set limits with some violent and aggressive drug dealers. Through discussion, they determined which physician, given individual case loads, would be Carol's primary provider. In that discussion, the physician assigned to her care was asked if he would be able to set these limits with Carol. He said he would have to.

The team highly valued Carol's right to access health care and sought to preserve it while not burning them out and managing available resources.

The second tension that both health care teams had to navigate was the tension between the right of an individual to health care and real or perceived threats to personal safety and security. When I asked a nurse if anyone had ever been banned¹²⁷ in the center, she related to me a specific case in which a man had been banned for physically threatening a physician. She said she wasn't sure if she agreed with the decision. In that center, providers were always alert to how they were responding to an individual and sought out other team members to check out their feelings of discomfort to determine whether there was cause for concern. One team member might caution another team member about not being alone with a particular individual. In one example, an individual was restricted to seeing only male physicians because of sexually inappropriate behavior.

¹²⁷ Banning someone means that they would be refused access to services. Bans may be temporary or permanent.

Lillian said she thought that in addition to checking with each other, the manager helped to remind them of their values.

And I think those are things that [our manager] brings to the clinic. And not very often, but now and again she'll have to put down her foot in a staff meeting and say, we're not barring this patient because this is what we do and this is what we're about and we are here to serve that very type of person who is angry and you know, whatever. So she's good at keeping us on track.

In both centers, banning only occurred after extensive team consultation and in the face of serious threats. Brenda identified that ethically care must be provided for even the most challenging and difficult patients. She described,

There's a lot of those here, I tell you. I've never had the experience personally, but there was one, it was a doctor who encountered a very violent, threatening client and we talked that through during our case management meeting and all of us agreed that we were going to ban this individual because he's had a history of violence and it wasn't so much the violence as the fact that he was a known murderer. He's been in and out of federal penitentiary for a couple of murders, I think and you know, he uttered a threat and you know, I really give this doctor credit because he said, I will talk to him and tell him what the decision is that's been made, right? And when [the doctor] talked to him, I remember the security guards standing outside and we're all waiting to hear the outburst and there's this very quiet conversation in the office and then he came out and [he] says, you know what? I'm giving him a chance. So I think sometimes, I guess what I'm trying to say, is sometimes we have these individuals who are very difficult to care for because of their personality, a violent personality, but because it's all they know, that's how they've been socialized, a lot of us, I mean, and people I think have to work as professionals that work in this environment need to have to move on past that; past the stereotype or that of how we see things. And go past that right and try and I think it requires a lot of the patience and a lot more open-mindedness. Because when [the doctor] was first threatened, I saw he was visibly shaken and afraid. He took that off the chin but you know what? He overcame that, right? Past that. [He said], I listened to what this guy had to say and realized that it's all about how this man's been socialized for years. He's been in the pen for years. That's all he knows. His words of threat, that was just how you and I would just say, Bugger off; Leave me alone. I'm mad.

She described the physician, in this instance, as very ethical and that the center where she worked as being known for its tolerance because people are rarely banned. In another

example, when a ban was imposed, one of the teams decided, it would be the social worker who would tell the person because the social worker had the best relationship with the individual. The social worker had banned this person from another agency previously and felt that they still had a good relationship because of their history together. Although the team had decided that they needed to ban an individual, it did not preclude the right of the individual to have it done respectfully and by someone the person trusted.

Respecting Differences

Both in regard to working with certain clients, banning clients, and harm reduction, nurses expressed a value of respecting differences among team members. One nurse said, "You know, you will see any one of us on any given day rolling her eyes; oh, not so and so again." Nurses said they had their 'favorites' or 'those that they clicked with' and there were those people for whom caring was difficult and challenging. In one center, respect for differences was handled by supporting each other to work with different individuals and sharing the care of individuals everyone was finding to be difficult, demanding or challenging among the team. Star stated,

Yeah. And so each one of us has a particularly difficult client that we really click with or that we go to bat for a lot. Or you'll hear the voice and you'll go out and see them or whatever. And that very same person may be somebody that everybody else doesn't really relish seeing. So that can be changing, but it's the same in any environment. If the negativity starts to get too big, and that gets in the way. It generally doesn't. I think there are a lot of people with relatively like-minded philosophies. Some of us are really off the scale in terms of what we would do if we could and how we would do it because that's the depths of how we believe but you know, and having the support for people even when you have a difficult time that people really understand that and then, you know, you debrief around, you know, things like detox and all of the things that are so frustrating. It's good because we have people that are sort of at all different ends of the spectrum in terms of the way you know they see things and the way they practice so you can go to certain people for certain things and support in particular areas

Nurses identified that other team members often provided “a fresh perspective.” For example, one day, a nurse consulted a physician indicating that she wasn’t sure if she believed the patient, the physician indicated that he thought the patient was quite genuine and her symptoms were consistent with her diagnosis. After, the nurse turned to me and said, “See when one of us writes someone off, somebody else sees something different.” In this case, judgments were interrupted. Working as part of a team was a source of support and helped to refocus on important values in providing health care.

While nurses respected differences, they also described times when they felt they would ‘do things differently’ such as in the implementation of various harm reduction strategies. They recognized there were times when they wanted to do more for clients but because of team differences were unable to do so. For example, in one center there were difficulties and differences related to providing needle exchange services. One nurse felt that with more education and resources this could be overcome. Nurses looked for ways to work within team differences and find solutions that would respect team differences as well as promote benefits for those accessing health care. The constant ethical tension that nurses and others navigated in working as a team was balancing their individual comfortable level with the comfort level of the team. What do I feel comfortable with you? What does the team feel comfortable with?

Sharing Priorities

The centers differed in terms of their emphasis on specific priorities. However, common areas of priority included consistency, quick access, promotion of research, and professional development. Consistency among providers was important in ensuring fair and equitable access to health care and preventing clients from working one provider

against another. Nurses and others indicated that it was important that each team member agree and support team decisions so that each team member would be giving the same message to clients. For example, if it had been agreed that a client should see one provider only, it was important for the rest of the team to be consistent in their support of that decision and not see that person even if their time permitted. If another provider were to see the person, it could potentially disrupt trust among the team and set off a negative chain reaction of events.

Providing quick and timely access to clients was a both a priority and a persistent area of concern in both centers. In one center, I heard and observed a daily expressed commitment to providing quick access to individuals; and it was a central focus in the visioning and strategic planning session that I attended. For example, if a client was very anxious or upset in the waiting room, they would be triaged higher and seen as quickly as possible.¹²⁸ First, this prevented their anxiety/distress from escalating out of control and second, it prevented a negative effect on other people in the waiting room. One nurse explained [to me] that if they saw this person quickly and took as much time with them as needed it would actually save time in the long run. She indicated that in her experience they would need less time in the future because they knew their concerns would be taken seriously.

Seeing people on a drop-in basis was a way of lowering the threshold and fitting services to the client's schedule. Thus, clients were less likely to leave without care.

George, a man in his fifties, had received a knife wound to his forearm after being mistakenly stabbed in a conflict over drugs. He had gone to an emergency

¹²⁸ Interestingly, in the ED data, one nurse indicated that she thought anxious ED patients particularly those who were using substances got triaged higher and that the 'sleeping drunk' often waited longer than they should.

department but left after waiting 6 hours. This is the second time I have seen him. I tell him again about the study and he says he remembers me and nods his head smiling, saying yes of course you can come in. He tells me how frustrated he was having to wait 5 and a half hours in ER. He went home and then went to another ER but it was too late to get his arm sutured and infection had set in. He went to a second emergency in which they told him he had waited too long. After several days, he came to the clinic for treatment of his wound. He has been coming to the clinic for several weeks to have his wound dressed and debrided.

George and others accessing services highly valued integrated services and that their needs were met quickly and respectfully. I observed that nurses became anxious when appointment times were delayed, and nurses apologized and confirmed that an individual would get their full attention as soon as possible. A nurse related to me that clients often said they didn't mind waiting for one physician in particular because they knew she would give them her full attention once it was their turn.

Nurses and others supported having longer hours and days of services that suited the needs of the people who are street involved.¹²⁹ This would likely require hiring additional staff and increasing the size of the team. However, a caution is that if the team becomes too large, it might lose its integrity in that it is harder to effectively share communication among large teams and ensure access to services. When I asked Betty, an emergency room nurse for any suggestions for change in the system, she suggested a twenty-four hour clinic.

Betty: Yeah. Being within their system. So many of these kids and the people at risk, the street people are hooked into [name of shelter] already and are hooked into the clinics down there. And if there was a clinic down there that was open 24 hours a day, or if [another agency] for example was open 24 hours a day, some of the things that happen that bring them to emergency wouldn't happen.

¹²⁹ In one community, the center offered evening hours on a weekly basis. In the other community, there were already established centers that provided evening and weekend coverage.

BP: Do you have an example maybe? That would just be helpful if there's something that maybe someone has come to emerg and you thought, oh, if the clinic had been open, or...?

Betty: Yeah. The ones that come for their antibiotics that are documented to have the chronic cellulitis, the chronic problems with their drug abuse, if the walk-in clinics and the [clinic] were open they wouldn't have to come to us and sit for 8 hours.

BP: All right. So they could go at night.

Betty: They could go at night to the clinic that they go to in the daytime. Their records would be there. The meds that they're on would be there. They'd know it. Rather than us struggling with, "Well, I don't know what I'm on. Let me think now." I can't tell you how many times we hear that. And just if it was there for them to, they wouldn't have the long waits. Because we're always going to get the ambulance trips and all that kind of thing and the young person coming in who's got the cut finger or the infection or who's been beaten up and is not in desperate straits is going to sit a lot longer. So one of the things that I think this city and the area in general needs is 24 hour coverage for that kind of thing. Not 9 to 5 coverage.

Extended hours and days of services makes care more accessible to people and creates additional opportunities to develop a relationships of trust and offer care when needed.

Although extending hours and days of service was supported by many participants, I noted that there are some geographic concerns related to locating services in any one area. For individuals who were trying to stop doing drugs or were in rehabilitation, coming to the center might mean the risk of contact with drug dealers, past associates, resurgence of past experiences and memories as well feelings of guilt and shame. One man, said "it is hard to come here' and another woman yelled at the nurses' suggestion that she come to center, "doesn't anybody understand I can't go there. There are people who want to kill me." A manager explained,

Well, I'd like to look at another approach other than just having the appointments. Because I think that there are ways that we can improve access in a respectful way. I'd like to see looking at expanding the whole idea of, for want of a better

word, some satellite clinics in different areas of the city that meet the needs of the particular communities. Because I also recognize that there are times when people will not come down here to the clinic because of where we're situated, for a whole number of reasons, not the least is the downtown drug trade and so on. And the comfort level people have. So finding some ways of ... and I recognize that it's difficult in this financial whatever that we're in now as well as you know dragging the [medical association] to looking at this whole concept of primary health care is a long slog. So building many of several different community health centers like ourselves and [another agency] is perhaps a short-term possibility. But having enlarged outreach components is ... so I am quite excited about working on this [regional committee]...to look at how we can perhaps put some satellites in strategic areas around [the city]. So I see that as a positive way to access.

BP: Improve it by putting it out in the community and making it more geographically ...

M: That's right. And also it would be lovely to pull some of the other disciplines in [the health region] into the community health setting. So having a homecare nurse working out of here, working out of [another area] working out of wherever. Having actual other members of the mental health teams, housing or whatever, working out of here. We're having somebody from social assistance, you know, so, yeah, those kinds of things. Decentralising some of the more unshiftable models.

Thus, services located in one area may be geared to specific needs of individuals. Nurses, physicians, counselors and clients themselves recognized that there needs to be multiple points of access, but that access between different centers needs to be coordinated to facilitate forging a chain of trust.

'Not Being Alone'

Emma: Everyone who works from the front staff to the [counselor], we all have our own role to play....and the other people to fall back on.

An important benefit of working within a team was that you were 'not alone'. 'Not being alone' was particularly relevant to safety, sharing 'difficult patients'¹³⁰ and debriefing.

¹³⁰ I would note that providers used this term rarely and only in reference to individuals in circumstances that an individual was consistently presenting with challenging behaviors such as frequently demanding to see a nurse or doctor or for example, the woman, who consistently locked herself in the only patient

Working together helped to ensure safety. For example, it was recognized by nurses and others in both centers that the front desk staff have a difficult job as the first line of contact with people who are street involved. I observed that nurses in both centers often provided support to the front desk staff in dealing with people who were angry, agitated, and demanding by listening and addressing concerns directly with these individuals in the waiting room or at the front desk. The presence of security personnel in the waiting room was a feature of two of the sites where this research was conducted. I did not spend time with security personnel, except as I observed them interact with the nurses.

However, two important observations can be made based on the data in this study. First, the decision to have security needs to be carefully examined by the team. One center, after considerable debate, chose not to have security and actively pursued other strategies to ensure the safety of team members. For example, a back up plan had been developed for accessing assistance in an emergency. In this center, one front desk staff told me that she worked to develop relationships with each of the clients so that they trusted her and were less likely to become upset. Second, the role of security needs to be clearly addressed and developed if security personnel are employed. While having security may seem a safety precaution to protect staff, it is important to recognize that the presence of security has the potential to become adversarial and contribute to a climate of distrust, if the role is reinforcement. However, recent shifts in community approaches to harm reduction such as local four pillar approaches (treatment, prevention, housing and law enforcement) have generated a shift in the role of police in the community from one of

bathroom in the clinic for long periods of time preventing others from using it. One provider after another would knock and ask her to come out saying something like, 'I know you are using in there.' However, I recall a nurse telling me that when this woman was very ill and too scared to go to hospital, the nurse told me how she calmed her down and called her a cab.

enforcement to support and building relationships of familiarity and trust with individuals.

‘Not being alone’ also meant sharing ‘difficult patients.’ Nurses and others talked about ‘burning out’ with patients. As one nurse said, ‘it can get to you.’ Nurses felt that having the support of a team prevented burnout. They didn’t have to ‘do it alone.’ Lillian said,

There’s no question that the team here makes a huge difference to me. I’ve said numerous times that this is the best environment I have ever worked in terms of team support. And I’m not sure if it starts from the manager and trickles down, but I do really believe that [our manager] sets the tone for the place and she so firmly believes in providing good integrated care to this population and it just trickles down. There’s that trickle down effect and I think everyone that she has on board, that she’s hired or whatever sort of really has embraced those values as well, of providing good care to this population. And it sets the tone. So I just find that yeah, the support we get from each other is what keeps me going. A lot for me right here in the place in the moment. It’s having colleagues who are there to back you up, to bounce ideas off, to, you’re having a tough day to sort of let them carry the heavier load and you take the lighter duties, that kind of balancing act that we can do.

Working together, the ‘team’ was able to share the complexity and challenges of caring for people with multiple and complex health conditions and multiple needs.

In summary, when nurses and others had established egalitarian relationships of trust, there were significant benefits for both the provider and individuals accessing care. Similarly, relationships of trust with other providers and agencies in the community are important to facilitating access for those who are street involved. In this next section, I will discuss findings that provide evidence of a third link in the chain of trust.

A THIRD LINK: EXTENDING THE CHAIN OF TRUST

In the primary health care centers, nurses and others worked to extend the chain of trust into the community in order to facilitate access to care. Nurses frequently referred to linking people with providers and other agencies. In some cases, the links in the chain were strong and sometimes they were broken or missing. Extending the chain of trust required relationships of trust at both the interpersonal and systemic level. There was a need for both interpersonal relationships between providers as well as interagency relationships with established mechanisms for consultation, coordination and referral. In this section, I will describe the work of nurses and others in extending the chain of trust into the community. By community, I am referring to community agencies as well as programs and services within hospitals. Other community agencies included primarily non-profit agencies such as shelters, food banks and drop-in programs. Additionally, I will indicate where potential links to policymakers within organizations and at the government level are missing and needed.

Based on the findings of this study, I would observe that extending the chain of trust into the community is needed in order to address the complex health and social concerns of people who are street involved. When clients were ready, and through the development of trusting relationships over time, nurses worked to link individuals to services not only within the primary health care center but, as needed, to a range of services within the community. One nurse stated,

We try to avoid hospitalizations and to manage them in the community, well because we also know that they're not going to stay in the hospital if they're active drug users, they're never going to get the right medications that they're not going to start getting sick. So we know that they're not going to stay. So we do what we can. Sometimes if there's an infection we'll do a 24 hour trial of oral antibiotics.

Something that can be managed and sometimes that's what we'll advocate. If they can get a bed in a shelter, if they're on income assistance, we'll do a temporary excuse for unemployment. So that they can get a bit of basic income assistance so that they might be able to get a room somewhere and a bit of food. And that's one less worry for them. Because we often get people that often it's not the physical, but it's just mentally they are so exhausted and burned out because they're not getting anywhere with the government to try to give them a bit of subsidy, so they can at least put a down payment on a place. So often what we're having to do is redirect people. Okay. We'll start you on an antibiotic for this infection on your foot. You know, you've been trying to deal with all this stuff at once. We'll write a temporary excuse for unemployment for a month or maybe two months so you can get a bit of income. So what you're going to do is you're then going to go to this place where they're going to help you with housing. Or we'll call [the shelter] and see, can you get them a bed for a couple of nights so they can have a couple of good night's sleep and then feel a bit better. And sometimes that's all people need. Is just someone to go, you know what, you are dealing with a lot. Here's where we can ease it at least for now so you can feel a bit better and then you can keep going. So we've had people that we only see for a very small window because they found themselves in that place. And then we've helped them with paperwork or whatever else, and then within a couple of months, they've got a job. They're not going to come to us anymore. You know. Like they've moved on. So sometimes that's what it is too. Just being able to advocate for them when they can't do it anymore.

Nurses in this study described their role as advocates for their clients to ensure access to a broad range of services needed to address complex and changing situations.¹³¹ Advocacy meant linking clients to needed services and ensuring smooth transition between providers. Advocacy was particularly important because of life circumstances. Star explains,

I guess with our clients you tend to want to advocate for them even more than you would for the average bear. They don't have very good luck, they don't have very good access, they don't have a lot of coping responses, a lot of resources. So I think I tend to... most of us tend to go the extra mile than you might.

She like other nurses recognized that clients often lacked the confidence or self-esteem to advocate on their own behalf. Nurses both advocated on behalf of individuals as well as

¹³¹ Initially, I resisted using the term advocacy because of the lack of clarity and concerns related to its use in the nursing ethics literature. However, nurses in their interviews and in our discussions consistently used this term to describe their work in linking people who are street involved to other agencies.

assisted individuals to advocate on their own behalf. For example, sometimes nurses acted for people by making appointments or phone calls for them. Other times, nurses assisted clients to rehearse what they might say to another health care provider.

Where there were potential grey areas, nurses and others would work towards doing what they viewed to be in the best interest of their clients and most likely to promote their health and well being. Star, a nurse, continued

I think there are times when you really choose not to, there's a good chance that you'll fail. You might be successful that day, but then things could fall apart the next day, two days [after]. You don't ever stop trying, but yeah, I think [] I don't know that I could choose an example but I think we probably do pick and choose our battles with people that we have a general sense may be more successful or need it more.

B: It's more than in terms of ...

N: It's not about deserving. Its about.. Do you know what I mean? It's about whether or not they'll be able to follow through. Or you think that the potential is there for them to follow through.

B: You're not going to go to bat for someone to get housing or something else if it's

N: [If it's] absolutely not going to happen.

B: Right.

N: But then again, you never know. Because if it does happen, then that's the bottom line. When they have housing, it often does change things around. I guess, I don't know because I don't do it on a full-time basis and it's so often I don't do those kinds of things in the work that we're doing now. I think we try a lot to get as much done as possible.

In this study, nurses worked to maximize the chance of success as well as ensuring that clients would benefit from their advocacy.

Linking to Other Agencies

As part of their work in facilitating access, nurses often described linking to other agencies. Based on the data, I found that in order to facilitate access, relationships of trust between providers and agencies are needed. When providers have established relationships of trust they are more likely to refer and coordinate care.

It was my first day at one of the community health centers and one of the nurses was giving me a tour. As she showed me around the clinic, we stopped and talked to a number of the staff. She would introduce me by name and tell the person a bit about what I was doing. I told each of them about the study and most of them, particularly some of the professional staff were interested in knowing more. One of the physicians was quite interested and observed that this clinic shares the same people with many other agencies including other health care providers. He said, "We share the same patients but don't communicate with each other." He told me that yesterday, he saw a man on morphine who had gotten 30 T3s for pain from another doctor the day before. He stated, "I don't know how far your research extends but we are pretty isolated."

I found that communication and collaboration among agencies requires not only interpersonal relationships but also systemic relationships between agencies. Access is compromised when these linkages are missing. One participant described,

I think the agencies themselves need to trust each other and to know about each other. Extremely challenging [here]. There's so much history Everybody has some kind of historical view of where they're working and who their next door neighbors are and what they're doing and how they're doing it. And coming then as an outsider... it's been mind boggling as to honestly, everybody thinks that they'rehere, they're doing it right. And everyone else is doing it wrong. And if only the other person over here could understand that this is the way it should be done, we could save the population. Which of course isn't true. Because if we could save this population, if someone has the answer, it would be you know, we'd know that because all of these people would be all better, cured and going off and that is not happening. But nobody seems to want to see that and to really look and see that maybe there is more than one [route to take]here. Maybe sharing what I'm doing instead of holding onto it tightly would be a good thing

Another nurse told me that individual providers and agencies can be 'territorial.' I observed that when there is a lack of trust nurses and others may become 'territorial,' and

access is constrained when clients are not referred. What I observed is that providers want to ensure that those who are street involved will be treated respectfully and cared for adequately by other providers. It appeared that when nurses and others did not know or trust other providers and agencies they were cautious in referring individuals. Thus, building trusting relationships both within and outside of the center is critical to facilitating access for those who are street involved.

Often, nurses could nudge things along for people in the system. For example, when housekeeping services were promised but delayed, a nurse vacuumed a woman's apartment during her lunch hour. When I asked the nurse about this situation, she said

But for me it was an ethical issue because this woman has been promised, you know, these services, and you know we have been referring her to these services and these services aren't coming through. And so for me, it's like, even though I'm not the one that's supposed to be providing those services, I feel like I'm letting the patient down because it's been so long that they haven't been done. So for me it was an ethical choice to go up and do it for her, to let her know that indeed something is being done. That we are trying our best. So I've put myself in part of the whole system there....After that day I did make a couple of phone calls and since then she's had new carpeting and new flooring in her place. And we've been, it was in this last week.

BP: In terms of like, because you were really coordinating that effort.

N: I was not so much,

BP: Encouraging.

N: Yeah. I was encouraging it. She does have a coordinator. A case manager who was coordinating all of that but it just wasn't, the flow wasn't going. Sometimes just with a nurse giving a quick phone call to sort of you know, say that this is really important. This really needs to be done ASAP, it just gives that extra oomph. Help them to stabilize and get supports in place to address underlying concerns related to housing, employment, income.

Linking individuals to services outside of the 'inner city' community presented a number of challenges. For example, in one center, the team identified that linking their clients to medical specialists was of particular concern. A manager describes,

It is an issue for us in terms of specialists because they take so long to get in, sometimes you're waiting a couple of months or more, and then if somebody doesn't keep their appointments, then they have to go again, unless it's an emergency where you can get somebody more quickly. And often three tries and you're out.

Bernie: Right, that they won't be very tolerant.

So we have to look at that. And we have to look at how can we get people to see those specialists. Well one of them is bring them down here..... The other is looking at some ... being able to work with other agencies for peer support people to actually physically take [them] or make it easier to get together.

In the meantime, they adopted a strategy of setting aside time in the schedule of the current psychiatrist so that providers could consult them on urgent patients until a full psychiatric work up could be done. In the absence of the necessary services within an agency or outreach workers to do accompaniments, nurses often worked with individuals to assist them to keep appointments. Paul told me he feared going to other medical offices because he was not sure he would be treated very well. However, after establishing a relationship with a nurse at the centre, he told me he wanted to come for his appointments to the center because of the climate in the center. The particular nurse working with him related to me that after multiple tries he had finally kept an appointment with a specialist.

Referrals to other agencies were more readily facilitated when there were established relationships of trust between providers. Just as within the community health center, nurses might nudge an individual to take the next step to see another health care

provider by saying oh, he's alright, you'll like him, she's cool, she's ok, and they're good. I know that person there, you can trust them and they will treat you well was the implicit and explicit message. Nurses might ask the person to check back and tell them how it went with the other practitioner. I observed that this was part of creating a chain of trust that extended from themselves to other providers. When I described this to Kelsey, a social worker, she said,

Kelsey: Yeah. We call it the firm handshake.

Bernie: The firm handshake?

Kelsey: Right, you want to give somebody the firm handshake, so you're handing the person off.

Bernie: Great. And that's very important in this population. It can't just be a name and a number.

Kelsey: No, because for god's sake these are people who don't know what they ate today. How are they going to remember where they're supposed to go tomorrow? Or two days from now, you know.

The firm handshake could literally be visualized as two hands forming a link in the chain, a human to human connected chain of trust. Sometimes, more than a phone call was needed, a physical presence was required. Many participants told me that clients need to have someone go with them to access other services. In particular, nurses and others identified the need for 'accompaniment' of individuals to appointments. I came to understand that this could be a strategy for extending the chain of trust within the community.

Nurses developed relationships with other agency providers through formal and informal networks. I observed that on a regular basis most nurses participated in interagency activities. Emma states,

So like that [interagency] meeting, there are lots of times when you don't feel like going. But you go because that builds up relationships so they often ask us for help, but we can also ask them.....and it's just having relationships with the people, with the front line workers. That goes a long way. Yeah, so I think that's key too.

Although they often felt they didn't have time to do so, they recognized the benefits for their clients.

Liaising with Hospitals

All of the nurses in the primary health care centers expressed a desire for better linkages and liaison with hospitals. As one nurse said, going to emergency is 'when the whole thing falls apart' for her clients. She stated further, "And it falls apart. A lot of times. For a million reasons. It can be the personality, or it can be the state of emerg that day." In one center, the nurses expressed a desire to develop better liaison with hospitals and other agencies. One nurse stated,

I mean nobody's really making hospital visits. They do for people that are HIV positive because they are enrolled clients in the programs but we should be doing way more liaison with the hospitals and the jails.

There appeared to be few systemic links that facilitated the chain of trust between the hospital and the community. I observed that the only providers who actually cross this chasm are the paramedics who are both part of the formal acute care system and see the context of peoples' life on the street. However, paramedics only go one direction, leaving their patients at the emergency department entrance. In one center, a nurse expressed to me frustration over the difficulties she encountered in getting ambulance personnel to

actually take someone to hospital based on her assessment. She felt that people were being overlooked in their need for care. Although I observed interactions in shelters and on the street with ambulance personnel on a few occasions, there was insufficient data to reach any conclusions. However, I would highlight this as an area for future research.

Nurses working in the emergency department expressed their admiration, respect and value for the work done by nurses and physicians working in inner city agencies.

Betty an ED nurse said,

I think they're very open. When you phone them and you say, hi, it's [city] emerg calling. Do you guys have any beds tonight? Do you have any room? And they're very open, they're very helpful, they're very honest. They'll suggest, well, no, we don't have any place, but try the other places. I find them really helpful. I think the people on the street here are extraordinary. The people at the street level are extraordinary people, the street nurses, the clinics that are down there, I think they're truly extraordinary. And they're open to helping as best they can with the limited resources they've got.

Another nurse in the emergency room told me she was aware of a doctor who works with people in the inner city area and stated, "he should be canonized." While providers in emergency respected and admired practitioners working in the community, they had few connections with them.

In forging a link with hospitals, Emma shared with me her strategy of disrupting the negative chain of judgment that members of the health care team used. She said,

If we are referring to the outside, I mean, it's happened where I've been the one calling the emergency room. And we had a fellow, it was about three summers ago, who [had] HIV, starting meds for the first time, had a really low CD4 ended up with complications from the AZT because it can cause bone marrow suppression. His hemoglobin just dropped in his boots and he just showed up one day, like, so white he was yellow, short of breath, just standing there but did not want to go to hospital because he was always mistreated. I was the one, who ended up calling the emerg doc, and right away, he's well, how come I'm talking to the nurse, not to a doctor? I said, well right now I've got a man with a hemoglobin of 30. He needs to come in and I'm giving you a heads up. And I said,

now he's going to swear, you're all fuckin' assholes and idiots and he hates doctors, but that's just who he is and we love him. [laughs] And so the emergency room doctor actually laughed. The patient stayed there for a couple of days, got some transfusions and came out and said 'they treated me really well'. They even fed me. Well, you know. So it was just, and then he ended up, because it took a while for his bone marrow to kick back in so he had to go back a couple weeks later for a couple more transfusions and then it was arranged as an outpatient basis. But because he'd had such a positive experience it was no problem. Like he was, he had never kept an appointment here. We had just sort of dealt with him whenever he walked in, but he kept his appointment to go for his type and screen and then he kept his appointment to go back and get the transfusion. And that's where you're not allowing that chain to happen. Right away right off the bat saying, yes this is a problematic person but this is what's happening: this is where they're coming from. And we're fine with it (laughs) So hopefully you will be too.

Bernie: Right. So it's interrupting that chain so that they can get the care that they need in the emergency department or wherever. Not unlike kind of what happened, I mean on a much less dramatic case, yesterday. You know, having the physician phone

Emma: The physician phoned emerg, and... some people we can send up with a letter and we know that it's going to be fine, but there's some people we know if they've already had a bad experience, and it's not always the emergency room's fault, right? Some of these clients can be very difficult to manage, then we do some advocacy saying look, you know, this person needs to come in. This has to be dealt [with]. At least then they're prepared and they know what's coming through the door. And that in itself can go a ways and that they're okay well, you know, this person's difficult, and we know that they're going to be screaming because... And it's something that I keep in mind too when we've had to call the ambulance to come here, is how I present that patient is going to make the difference in that chain because then it's the ambulance people who are giving the report to the triage nurse.

Bernie: ...get the chain going.

Emma: Yeah. When I'm the one that when I'm the first domino, then I make sure that I'm trying to play the cards in that patient's favor.

Playing the cards in the client's favor or disrupting the negative chain of judgment helped others to focus on how ill the individual might be rather than focusing on behavior. It was a way of helping other providers to see the individual in context of their illnesses rather than in the context of homelessness or addiction. It was helping the other person to see

they were really sick rather than as difficult, maligning, or drug seeking. As described earlier, when people who are street involved go to the hospital, there is the potential for a negative chain of judgment to be created. For example, a paramedic might communicate to the nurse that this is a drug user, addict or alcoholic and one nurse may communicate this same message to another nurse.

An additional strategy that helped to disrupt the negative chain of judgment, used by nurses and others, was for the patient to be legitimized as an individual within the hospital context. This was described by participants as ‘vouching for patients.’ Legitimizing or vouching for people who are street involved was facilitated by being introduced, visited or accompanied by a respected community member. As mentioned previously, I was contacted by a nurse from acute care with many years of experience working in acute care and in emergency. She was interested in participating in the study because of her commitment to providing ethical care to people that are street involved.

Cheryl said,

I have to say that whenever you talk about certain people that are looking after or trying to integrate care of homeless into acute care, and you mention [Jack]...and I've been starting to mention the street nurses and there tends to be a little bit more respect associated with care of that client whenever you bring in people that have respect because of what they do. I looked after a client who was homeless and this poor man, he had a head injury. He fell on the ice and he just, he was in a real mess and he had lice everywhere. They were actually crawling out of his ears. He was just, it was really sad. And I had him and you know, I said, normally we don't shave the hair. But his hair was just matted and the neurosurgeon said, well, we're going to have to do this. And the guy came in who was [a minister], and I can't remember his name, at the time, you know, and he was just so wonderful. He was just like treating this guy, you know, hi [Pete, I don't even remember his name, because this was a long time ago], ...But you know, and it was just, I was just watching them. And they had a relationship. You know, you could tell it was there. And when he left, I kind of, because of what I'd heard, I was able to tie into my care that I was giving this guy and it made it better. And then I wrote on the care plan that this ...minister was actually coming to visit, and if there was any

concerns, you know, to go through him first. And that validated this guy's existence a little bit more.

Bernie: Well, and there's something else you said in there that I think is important, is that minister also helped you to know more about this man, about his life, or his experience, that gave you knowledge as well. So it isn't just necessarily the perceived prestige.

Cheryl: That's right. It's just helping to figure out where this guy's from....and it turned out that he'd actually had a head injury previous and so, you know, there was a whole bunch of other health issues involved with this guy presenting on the street anyway. You know? It wasn't just that he had a head injury and he was on a binge. He had a previous head injury that made him more susceptible to the amount of alcohol in his blood that made him more susceptible to falling on the ice because it was winter. So it was just like a domino.

Bernie: And so the minister helped to...

Cheryl: Bring that history.

In this example, a community member not only vouched for the person but also provided a life context to the staff that gave insights as to the history of this individual. Thus, such actions can serve to break the chain of judgment by generating a greater sense of empathy and potentially enhancing the provision of care.

Among those identified as having the status to legitimize patients were ministers, doctors and street nurses. Nurses identified that in transferring a patient to hospital, they felt that physicians had more status than nurses. Some participants noted that shelter workers and frontline agency staff had the least credibility. Nurses often had contact with people while in hospital. One nurse explained.

When I was street nursing I used to visit my clients up there all the time. And I would often stop to talk to the nurses sometimes because I knew them, sometimes because I was advocating again for the client or trying to just to intervene and make it so that it was comfortable enough for the client to stay until they got whatever treatment they need before they split but it's still a big role that somebody needs to play.

Many of the nurses who participated in this study echoed their desire to have more interaction and liaison when people known to the clinic were hospitalized.

In addition to the need to disrupt negative judgments and legitimize people within the system, there were concerns about ‘dumping people into the community.’ For example, nurses identified that lack of notice of release from prison for people requiring care in the community was problematic. Another situation in which clients were perceived to be ‘dumped into the community’ was when someone was discharged without adequate supports in place such as housing. As a social worker said, discharge to a shelter, is not a discharge plan.

Although I had heard this many times, I don’t think I fully appreciated this until one of the nurses told me that a woman who was homeless had suffered a serious head injury as a result of being attacked was being discharged to the shelter today. As we are talking, the nurse shakes her head and said to me staying at a shelter where they have to be mobile and up and about because the shelter is closed for part of the day is not a place to recover. Shelters often close for part of the day meaning that the person must be up and mobile. Not all shelters have meals or a place to stay during the day. She points out to me that you have to walk to get your meals. One shelter has a sick room where staff will make sure they get juice and food but it is still hard to maintain them there for any period of time. As we continue to speak, the nurse tells me she had tried to organize something in the community for the woman before discharge but was unable to do so because of the short notice that she was being released today. She said, “I don’t blame the discharge coordinator, this was her first day back and it was dropped on her desk.”

In reference to this same situation, another nurse said, that often we may get an “oh by the way phone call at the last minute.” We discussed that being discharged to a shelter was very different than being discharged to home where you can rest and convalesce in a safe place where you might have a support person to help with your meals.¹³² She went on to say, we need to be part of the health region, have a nametag and go into the hospital so this doesn’t happen.

¹³² Interestingly, during this same period of time, I had a friend who also suffered a head injury as the result of a fall. She had a close family member who stayed with her for several weeks preparing her meals and doing other domestic duties because my friend was so tired and spent most of the day sleeping.

This example highlights a number of things I heard from others. First, that there may be a lack of understanding of what the shelters can and are able to do. Second, it points to lack of continuity and the ability to plan discharge during hospitalization. Thus, there were concerns about linking individuals into the system, ensuring safe passage through the system and then ensuring they are properly connected to the community on discharge. In other words, there is a need for a persistent link that extends through a single emergency department visit or an entire hospitalization particularly for people who are homeless, experiencing addiction and mental health concerns because of the lack of stable housing and other supports. Kelsey, a social worker stated,

And I think one of things about a high-context culture is if people you know...and trust other people, it can go a long way. So if we can improve some of the relationships between community-based workers and hospital workers and health workers, they could then be like ambassadors to clients to say, oh but I did talk to so and so and we've worked this out, so when you go to the emergency room this is what we'll do, this is what's going to happen. They'll ask you these questions and you know.

Bernie: Mhm.

Kelsey: And even to have somebody do that, like you bring somebody in off the street and, you know, the first question they get asked is, well what medications are you on and what drugs are you...and a lot of people don't want to tell them. And if they could just have somebody there as a liaison to say, we need to know what drugs you're using and you kind of have to say everything because we have to know medically what to look for, right? And it's not to say you shouldn't be using them. It's that we need to know so that we can give you the best care. And if you're coming off of these drugs we need to...

From nurses and clients that I interviewed, I came to understand that hospitalization can be a key time for change as well as to put in place community resources. John, a man who quit drinking, made the decision to quit drinking when he was near death in hospital. As he said, something 'clicked.' He went from hospital straight to 'detox'. However, as

several people pointed out, treatment can be put in place in hospital but unless there is involvement of the community it won't necessarily stay in place.

Missing Linkages in Policy

Nurses expressed frustration when they were unable to link individuals to needed services. The missing linkages particularly point to areas for policy development, implementation and evaluation.

Linking to 'Detox' Services

A weak or missing link was to detoxification services. Nurses and other health care providers expressed the need for more 'detox' services. I repeatedly witnessed the inability of clients to gain timely access to support and services to withdrawal services such as 'detox'. For example,

One day a young man was standing in the door of the nurses' clinic room and asked for information about getting into detox. The look on his face as well as his demeanor was anxious and somewhat desperate. The nurse said I can fill out a referral and there may be a bed in six weeks or so. He said, "can you help get me in faster?" She said there are two ways to get in faster; by going through emergency or through another agency. There just aren't enough beds. If you don't get called in two weeks, we will have to fill it out the form again. He said, I can't wait. The nurse asked him if he wants a referral just in case. He says no, I can't wait a month. I don't know if I can wait a week. He turned around and left. The nurse did not fill out the form.

Similar scenarios occurred many times. One nurse who was fairly new to community work summed it up:

Ready for detox and you fill out the forms and you fax it and tell. You want to do the best for people who have decided that now's the time and I want to detox, [the best] would be to take them there, put them in a cab there right now. While they're ready.

Some nurses thought that the reorganization of 'detox' services had reduced rather than enhanced access and that there appeared to be a lack of beds. Some expressed a wish for beds that could be reserved for direct referral from their center.

When I was discussing the lack of detox services with one nurse, the nurse told me about a recent interaction with a nurse in [hospital] who said, she only has so many beds and she has to keep a bed open for "Sally who jumps off the bridge, that kind of situation" and that having someone go in and out repeatedly means a bed is not available to others in crisis. The nurse said, "I can understand what she is saying."

To me this spoke not only to a lack of beds but also to who is deserving of those beds. I persistently heard nurses and others indicate that clients often need to go through 'detox' and rehab many times before it clicks. Once is not enough. For those unable to access 'detox' services, physicians in both centers used a protocol of home 'detox' to assist clients to withdraw from substances in the community. However, without support, the client was often on their own to manage withdrawal except for their interaction with the clinic. For example, one nurse had repeated calls from a man who was withdrawing and then began drinking again at home. Others did not have families or homes to support them during withdrawal. An additional area where more access is needed, identified by participants, was in the area of rehabilitative services including support and follow-up post 'detox'.

Linking to Housing

A second missing link, identified by nurses and others, was to affordable and appropriate housing. Attempting to link individuals to housing was problematic because of the persistent lack of housing in both communities. While there was a desperate need

for housing of all kinds in both communities, it was a particular challenge to find 'wet' housing that was tolerant of ongoing drug or alcohol use. A social worker explains,

Yeah, and the other thing I was going to say is housing is a huge issue. We need more wet housing, we need more damp housing, we need more supported housing in general. That's affordable. And there's no reason we can't do that. Again, if you look at cost-saving issues, people who have stable secure housing do better. And we would save huge numbers of bed days. And the other thing is income security. People need to have a certain amount of income security and we can do that. I mean, it's always about who wants to put the money out of their pocket, right? So I think, yeah, like those are the basic things that we have to do as a larger community because health care and prognosis are extremely limited by income and housing. We've got to get to those basics; food, shelter, clothing, safety. And those should be our priorities. If we're looking at provincial and federal priorities, that should be our priority. We are one of the richest countries in the world. And we have no excuse to have so many people without access to adequate resources and manage just basic daily living

Bernie: Yeah, and I think one of the things I see is that we may have a centre like this which can make those links but you have to have something to link to.

Exactly. Yeah that's right. And housing and supported housing is huge. People who are using drugs and alcohol...like if we want to truly embrace the harm reduction approach, if we want to truly work to reduce morbidity and mortality and reduce costs from acute care, then we need to have damp housing and wet housing that's supported and staffed where people can have a safe environment....Well, and that would reduce people being held in jail....But again it's just a bed, right? It's not housing.....And you know, we're...one of the things that we do is we complain about the use of acute care services and emergency services and we create a system that only responds when people are in an emergent need. So if we want to reduce the need for acute care, then we have to have follow-up supports that provide the things acute care provides: food, shelter, clothing, support.

I discovered that some live-in rehabilitation programs had a policy that meant they would not accept individuals on methadone even if they were not using drugs. For those in recovery, there was a desperate need for housing that was affordable but outside of areas known for their drug trade. Often the only affordable and available housing was in a

hotel or apartment building known to be home to many people still using drugs. Thus, it becomes tough to break the cycle.

Linking to Welfare Policies

On several occasions, I heard, “oh, maybe you shouldn’t come tomorrow, it will be very quiet.” On one occasion, I was making plans to do an evening shift with a nurse. Overhearing our conversation, one of the front desk staff said, “Well it will be dead. It’s cheque day.” Cheque day happens once a month and is the day that everyone receives their social assistance cheque. ‘Cheque day’ is also known on the street as ‘Mardi Gras.’ I recall one man saying that on cheque day he buys a bottle of Southern Comfort and enjoys feeling the heat of it going down his throat and into his stomach. As he said this he got a satisfied smile on his face and it was clear this was one of his few pleasures in life. Will said,

You have your big Mardi Gras three day welfare times and you have the big 28 day kind of like survive time, right. You know, and people say, well, why do you blow all your money. I said because for 28 days I’m living, you know, picking butts off the street. And then that three days I’ve got money. Well, I’m going to treat myself.

Bernie: I’m going to live like a king.

Will: Yeah, exactly, right. Drink wine, go to have a meal, you know get a hotel room so I can sleep in a bed for a change. That’s the way it goes.

In the emergency department, nurses and others told me I should come on Thursday night or Friday after a ‘welfare Wednesday’ as they would be busy with the fall out of cheque day. Some providers suggested it would be better if they didn’t get all the money on the same day. These and other suggestions put forth by those participating in this study will be discussed further in the next chapter in relation to enhancing equity in policy.

Chapter 6

Enhancing Equity in Practice, Theory and Policy

The purpose of this chapter is to explore the implications of the insights gained from this study for enhancing equitable access in practice, theory and policy. An exploration of these insights is a strategy for providing suggestions to practitioners and policy makers, as well as to forge stronger links between practice, theory and policy to enhance ethical practice in nursing and ultimately to enhance access to health care for those who are street involved. Implications for education and research will be highlighted throughout the following discussion of practice, theory and policy.

ENHANCING EQUITY IN PRACTICE

The findings of this research are relevant to the everyday practice of nursing in a variety of settings. Health care interactions provide a multitude of opportunities for enhancing clients' self-esteem, building clients' capacity for decision-making, and linking individuals to other services and resources, as well as enhancing the health of individuals through harm reduction, health promotion, support and coordination of care. Within health care interactions, access to health care may be constrained or facilitated by the practice of nurses and other health care providers.

Developing Trust within Health Care Interactions

A primary ethical concern in health care interactions for those who are street involved was the desire to be listened to and treated with respect like a 'real person.' Perceived barriers to accessing health care included feeling overlooked, feeling prejudged, fears of being treated poorly and negative consequences. In particular, fear of being labeled and treated as a 'drug user' by those who use or were presumed to use

drugs was perceived to be a barrier to accessing health care services.¹³³ This is similar to other research in which individuals who were street involved described that being prejudged as a drug user acted as a significant barrier to accessing health care (Butters & Erickson, 2003; Carroll, 1996a, 1996b; McLaughlin & Long, 1996; Napravnik, Royce, Walter & Lim, 2000).

In research on health care providers' attitudes, drug use was more likely to elicit negative perceptions and attitudes among health care providers than homelessness or alcoholism (Carroll, 1996a, 1996b; Kee et al., 1999; McLaughlin & Long, 1996). In part, this might be understood as a reflection of societal attitudes in which illicit drug use is a highly charged moral issue. Negative attitudes can affect the quality of care when care is rationed on the basis of labels and stereotypical thinking. Furthermore, the profound effect of negative attitudes and behaviors on those experiencing low self esteem and feelings of low social worth, as well as previous experiences of abuse and trauma, must be recognized. Feelings of being stigmatized and discriminated against on the part of individuals accessing health care has been found to contribute to delays in seeking health care and can negatively affect their well being (Browne et al., 2002; Crockett & Gifford, 2004; Dinos et al., 2004; Gelberg et al., 2004; Kreiger, 1999; Stevens, 1992; Varcoe, 2004; Zickmund et al., 2003).

Fear of withdrawal, being in pain and fear of negative consequences were not identified in the literature reviewed for this study. These constitute important areas for assessment in nurse-client encounters, particularly in acute care settings. Within health

¹³³ I say presumed because many people felt they would be judged as an 'addict' even though they did not use drugs. I would note there was an association in being identified as someone from the street and using drugs.

care interactions, there are opportunities for nurses to identify and assess for possible withdrawal as well as to facilitate adequate pain management. Lack of knowledge and skill in working with people with addictions has been found to be a factor in providing access to quality health care (Gerace, Hughes & Spunt, 1995; Happell & Pinikahana, 2002; McLaughlin, McKenna & Leslie, 2000; Stadjuhar et al., 2001).

Of serious ethical concern, is the potential under treatment and inappropriate management of withdrawal from drugs and alcohol and management of pain in hospital. Simon, Dwyer and Goldfrank (1999) argue that practitioners have a primary obligation to provide care to patients and therefore must “balance fears of fostering an addiction with the risk of under treating a patient’s pain” (p. 362). Attention to managing withdrawal and pain can enhance access to health care and individuals are more able to follow through and complete treatment as a result. Within basic and graduate nursing education, opportunities to further develop nurses’ knowledge of addiction are needed so that nurses have the appropriate knowledge and skill to assess and intervene appropriately when caring for people with addictions.

Clinical experience with those who are homeless and experiencing addiction has been found to increase positive attitudes towards this group (Zrinyi & Bolagh, 2004; Kee et al., 1999; Minick et al., 1998). To gain such clinical experience, the idea of an inexperienced nurse buddying with an experienced nurse may be one strategy. Engaging nurses from different settings (e.g. street and emergency department) in joint educational and research activities. For example, a participatory action research project that brings nurses together to address enhancing access to health care for those who are street involved could be a meaningful and lasting strategy. Opportunities for joint education on

topics of shared interest and concern such as addictions, wound care, and pain management could act as a forum for nurses in different settings to engage in dialogue about their challenges and strategies in caring for those who are street involved.

Knowing that negative attitudes had been identified as a barrier in previous research, I searched for positive attitudes and experiences in the conduct of this project.¹³⁴ While individuals were able to recall positive experiences with individual nurses and hospitals, the general negativity and distrust towards accessing mainstream health care did not vary. In contrast, individuals were overwhelmingly positive about the care they received from nurses and other members of the interdisciplinary team in the primary health care centers. What is not clear is the degree to which feelings of being overlooked and feeling prejudged reflected feelings of low-self worth among individuals, dominant ideologies in health care and/or societal attitudes. In this study, there is evidence that suggests those who are street involved may be hypersensitive to negative attitudes, particularly lack of respect and judgments, and that they are hypervigilant in who they trust as a result of their life experiences. In this sense, they are not only more sensitive but more vulnerable than others to the negative effects of health care interactions. Additionally, these findings suggest that in the context of the emergency department, dominant ideologies such as the focus on medical curing (e.g. the need to fix people) and societal beliefs that people who use drugs are 'not taking personal responsibility,' may be contributing to perceived barriers.

¹³⁴ For example, I asked individuals in their interviews to tell me about their experiences in health care and when I heard predominantly negative experiences, I specifically asked about positive ones.

An important aspect of the findings is that individuals who are street involved often have fundamentally disrupted relationships of trust with individuals, institutions and social systems. I found that respect for humanity and accepting without judging were key aspects of developing trusting relationships. Listening and understanding persons within a life context were central to 'being in relationship' with the 'other.' Nurses, in this study, were hypervigilant in being aware of their responses to individual patients so as not to communicate judgments. Similarly, Liaschenko (1994) found that in working with patients they do not like, nurses drew on communication skills and "those cognitive and affective capacities which permit self-monitoring and self-evaluation" (p.86). She observed that listening to a patient's story gives us access to their world. In this research, because of a lack of trust, nurses often did not know an individual's story. Instead, nurses drew on an understanding of life context and assumed they didn't know or didn't need to know the particular story of an individual in order to connect with the humanity of the other. Nurses used the strategy of self-monitoring in an effort to ensure that judgments were not communicated and did not impact care.

Enacting Justice within Nursing Practice

The ability of nurses to convey respect and accept without judging people who are street involved suggests that the moral identity of nurses was constituted not only in their actions but also in their way of 'being' with others. Enacting their moral agency meant not only 'doing' the right thing but also 'being' in relation to others. Doane (2002) identified that the moral identity of nurses is a socially mediated process and that the development of moral identity is narrative, dialogical, relational and contextual in nature.

In this study, there is evidence that relational and contextual forces supported enactment of their moral agency.

As moral agents, the nurses in this study enacted the value of justice locally through their everyday practice. The Canadian Nurses Association Code of Ethics (2002), specifically states that nurses have a responsibility to advocate for fairness and inclusiveness in resource allocation including the support of primary health care initiatives. As well, nurses have a responsibility for being aware and seeking social change to address broader social concerns such as homelessness. The findings of respect and being nonjudgmental suggest that nurses were willing to tolerate and even correct inappropriate behaviors such as foul language or sexual overtures in order to ensure access to health care. There was a higher level of tolerance in the primary health care centers for those who might be seen as inappropriate, confrontational, demanding, difficult and even threatening, than that found in health care organizations more broadly. For example, most emergency departments have a visibly posted policy that foul language and inappropriate or abusive behavior will not be tolerated. These findings suggest that more exploration is needed to address questions such as the following: What ought practitioners be expected to tolerate in facilitating access to health care for those who are street involved? For example, did nurses in the primary health care centers go beyond what might be ethically expected when delivering health care or is there an erosion of tolerance in the current moral climate?¹³⁵ What level of tolerance ought to be

¹³⁵ The value of dignity within the Canadian Nurses Association Code of Ethics (2002) indicates that “nurses recognize and respect the inherent worth of each person and advocate for respectful treatment of all persons” (p. 13). It is not clear in the Code the degree to which respectful treatment must be provided in the face of verbal and physical aggression. One might certainly ask, “did these nurses go above and

ethically acceptable in health care organizations? What are other members of the public expected to tolerate when accessing health care?¹³⁶ This last question raises an important issue about the challenges for nurses working in acute care settings since they have responsibility to balance the risks and harms for all those who are accessing health care.

These findings suggest that nurses and others working with people who are street involved do so because of a strong ethical commitment to preserving the right of individuals to access health care including quality care. Among nurses and other team members, the underlying value that 'everyone is deserving' acted to preserve the right to access health care. In particular, individuals were seen as deserving because of their lack of access in the broader health care system. Jecker (1996) observes that negative judgments about a patient's social worth are never relevant to judging another's quality of life or as a basis for rationing of health care by professionals. The question for practitioners is whether or not the individual will benefit from care and whether or not the person is willing to participate in care (Jecker; Young, Fish, Browne, & Lawrie, 2002). Jecker observes further that decisions related to rationing of scarce resources are societal decisions or, in the absence of societal decisions, the purview of ethics committees and organizations rather than individual providers. Examination of regional health authority documents, in the regions where this research was conducted, affirmed that there was a

beyond the reasonable expectations for professional ethical behavior?" These findings suggest that norms of ethical behavior were different in the primary health care centers and the emergency department.

¹³⁶ In the data collected in the emergency room and in interviews with emergency department nurses, one rationale cited for the lack of tolerance of foul language, inappropriate and even abusive behaviors was the effect on others in the waiting room as well as concern for the safety of the public if there was the potential for violence.

commitment to improving the health of people who are street involved.¹³⁷ The question is the degree to which these commitments are seen to be relevant not only to specific programs but within the broader organization.

Nurses promoted the value of justice by advocating for fair resource allocation at the micro level on the basis of need rather than social criteria, such as ensuring that clients were treated fairly and without judgment when accessing care in emergency departments. A source of moral distress for nurses was when there was a perceived unfairness in resource allocation to particular individuals. As members of the health care team, nurses participated in resource allocation decision making that sought to ensure ongoing and continuing access to equitable health care through sharing continuity and care with other team members. When situations presented that required action at the meso or organizational level, nurses in their practice primarily worked through their manager to effect changes that would promote fair resource allocation. For example, when a client was banned from a 'wet shelter' and when individuals were banned from smoking in the same shelter the nurse communicated and worked through her manager to address this issue. The role and stance of the manager is critically important in supporting nurses to enact the value of justice in their practice.

These findings suggest that the value commitment of managers to an 'ethic of justice' is an important aspect of the context. For nurses to enact their commitment to justice, managers must listen and take seriously the concerns of nurses. Managers must critically assess concerns, not just in terms of organizational objectives, but also in terms

¹³⁷ For example, regional strategic plans had specific objectives related to the health of people who are street involved. Also, both health regions financially supported programs and services including the health centers.

of an ethical commitment to justice in health care for all members of the public. For managers, enacting their commitment to justice would include bringing concerns to the attention of those with overlapping and broader scopes of responsibility. However, findings by Storch et al. (2002) suggest that managers are constrained in their ability to enact such ethical standards because of conflicting loyalties. Conflicting loyalties to physicians, organizations and patients are a historical feature of ethical practice in nursing (Lamb, 2004). It is important to note that one of the features of the primary health care centers in this study was that, in some cases, they were at arms' length from the regional health authority, which I would suggest supported their ability to enact an ethical commitment to justice. Additionally, it is likely that the managers, like the staff, had a strong ethical commitment to the right of all individuals to access health care.

In this study, nurses recognized the need to address broader health and social concerns both within health care interactions and through their involvement in activities within the broader organization. First, nurses in practice consistently worked to link people with needed social support such as food, housing, and income. Although estimates vary, almost half of those eligible for government insurance in the United States may be uninsured due to beliefs that one is not eligible, a lack of knowledge or difficulty navigating organizational structures and requirements (Butters & Erickson, 2003; Gelberg et al., 1997; Hatton, 2001; Hwang & Gottlieb, 1999; Kreider & Nicholson, 1997). I cannot emphasize strongly enough the importance of health care interactions as an opportune time for health care providers to assist individuals to obtain needed assistance such as health care coverage and in doing so assisting individuals to develop knowledge, self-esteem and trust. Secondly, nurses participated in a variety of

community initiatives to effect social change. For example, some nurses were actively involved in community initiatives to promote harm reduction and the development of new harm reduction services. The practice of nurses in primary health care centers provides insight into the ways in which nurses in all settings can promote health and affect the broader determinants of health within health care interactions and within their respective health care organizations.

Some nurses in this study were supported by their organizations financially and in terms of release time from responsibilities to engage in community initiatives, research and professional development. This finding was in direct contrast to early findings in the 'Ethics in Action' study in which nurses in hospital financed their own professional development activities and had difficulty getting time off even without pay to attend committee meetings or professional development offerings (Rodney et al., 2002-2005). Nurses, in the primary health care centers, referred to professional development opportunities as both a tangible valuing of their work and as an antidote to burnout. In one example, the recognition of the outstanding work done by two nurses was a source of support that kept them going in spite of the specific challenges they faced. Enacting the value of justice requires that organizational support be available. However, it may be contrary to the goals of the organization to do so and the benefits may not be measurable in short term cost/outcome evaluations. These findings point to the important role of managers and organizations in recognizing and supporting the involvement of nurses in program development, research and educational opportunities. This includes the commitment of time and resource supports for nurses to enact their commitment to the value of justice.

A final observation is that enactment of the value of justice in practice by nurses was not necessarily undertaken through participation in professional association activities, media campaigns, letter writing or meeting with political representatives. Often nurses have been urged and even chastised to 'get political' (Chinn, 1992; Cohen et al., 1996; Grant, 1995; Pender, 1992; Porter O'Grady, 1997; Wakefield, 1999; Whitman, 1998). However, such calls to action are often framed within a governmental or societal context rather than a call to 'get political' within one's organization. While the work of nurses was highly political, it was enacted primarily within their organizational role rather than their professional or personal role.¹³⁸ The ability to respond to the call for political action at the individual, organizational and professional level may be difficult and even impossible for nurses who are feeling overburdened and strained in meeting daily obligations in their work setting as a result of shortages in nursing and reductions in resources (e.g. Rodney et al., 2002; Rodney and Street, 2004).¹³⁹ When I reflect on previous research with nurses in the current moral climate, it leads me to ask, "Is the right to health care eroding in the current ethical climate?" These findings suggest that the development of ethical climates within institutions is an important focus for further research (Corley & Goren, 1998; Olson, 1995; Rodney and Street, 2004).

¹³⁸ By professional role, I mean their professional role outside the organization such as involvement in professional association organizations such as the Canadian Nurses Association or their provincial professional associations. However, I would note that nurses did undertake activities to effect social change on their own time such as evening or weekends. However, there was usually reimbursement in terms of time back in their day time working schedule. Additionally, I did not investigate to any great extent their personal involvement in political activities except as they arose in their conversations with me.

¹³⁹ This is not to say that individual nurses may not be personally involved in initiatives that address issues such as homelessness through volunteer and other community activities. In fact, many nurses do volunteer work through their church and with other organizations in which they are actively involved in working to promote social change on issues of homelessness and lack of access to health care.

The nurses in this study described their work in promoting the value of justice as advocacy. Within nursing ethics, advocacy has been proposed as the moral foundation of nursing (Curtin, 1979; Gadow, 1990). However, multiple and conflicting notions of advocacy have plagued discussions of advocacy in nursing (Falk Rafael, 1995; Mallik, 1997; Martin, 1998). In this study, the role of nurses as advocates resonates with Gadow's (1990) work on existential advocacy. Gadow states,

The ideal which existential advocacy expresses is this: that individuals be assisted by nursing to authentically exercise their freedom of self-determination. By authentic is meant a way of reaching decisions which are truly one's own – decisions that express all that one believes important about oneself and the work, the entire complexity of one's values.

In the context of the findings of this study, advocacy in the form of listening, supporting, acting for and on behalf of individuals may be viewed as the most ethical thing for the nurse to do given the possibility that a client may face lack of knowledge, confidence or self-esteem to navigate the health care system. This type of advocacy is similar to findings of Falk Rafael (2001) in her study of empowerment and advocacy in public health nursing. Further conceptual work on advocacy in relation to ethical practice in nursing is needed.

ENHANCING EQUITY IN THEORY

The findings of this study provide an opportunity to reflect on theoretical perspectives in health care and nursing ethics presented in chapter 2. In this study, I was concerned with identifying theoretical perspectives in ethics that would illuminate ethical concerns in practice and assist nurses and others to be attentive and ethically responsive in their practice and in policy development to people who are street involved and to affecting conditions that mitigate inequities in access to health and health care. In this

section, I will reflect on key theoretical work in health care ethics (principlism, feminist and cross-cultural ethics), the linking of ethics to health policy and future directions for the development of nursing ethics. My intent is to provide a theoretical beginning for future work in this area.

Reflections on Principlism and Feminist Ethics

The findings of this research suggest the need for reflection on the principles of autonomy and justice in particular. In a study of the values, attitudes and beliefs towards end of life care among those who are homeless, Ratner, Bartels & Song (2004) found that considerations of autonomy and justice emerged as a dominant issue and extended beyond issues related to end of life care. Given the experiences and perceptions of people who are street involved in this study, the autonomous decision making capacity of individuals may be significantly compromised.¹⁴⁰ Individuals may have had limited opportunities to develop decision making capacity. In this study, nurses promoted autonomy of individuals within health care interactions and through their relationships with people by respecting choices and enhancing capacity for decision making. I would suggest for nurse participants in this study that autonomy was understood relationally and consistent with the work of Sherwin (1998). These findings suggest that in addition to the role of nurses in ensuring that the criteria of informed consent are met, opportunities to enhance decision-making capacity exist within health care interactions.

¹⁴⁰ I would note here that I am assuming competency has been established for an individual. However, competency does not equate with capacity. As Ratner, Bartels & Song (2004) observe, "A homeless person's capacity to make informed decisions may or may not be impaired by mental illness, intoxication, or delirium caused by physical illness. The physician must be able to carefully assess decisional capacity when serving patients who are homeless" (p. 1380).

When individuals made choices that were contrary to what providers perceived was in their best interest, nurses, working within a context of harm reduction, sought to minimize harm rather than abandon individuals on the basis that they were refusing care. In this regard, nurses drew on principles of nonmaleficence and beneficence. What will prevent harm in this situation? What is the best way to promote good? These findings provide insights into the way that nurses working with individuals balanced one principle against another in everyday practice. I think it is important to acknowledge that this was possible because of the organizational context in which choice, capacity for choice and reduction of harm was highly valued.

The findings of this study suggest that nurses drew on notions of justice that are more consistent with social and egalitarian notions of justice rather than distributive justice to ensure individuals were treated fairly and had access to a fair share of resources. Similarly, Ratner, Bartel and Song (2004) observed people who are homeless “viewed justice in terms of simply receiving basic health care offered with respect for them as human beings” (p. 1380). As discussed in chapter 1, principlism, as described by Beauchamp and Childress (2001) appears to be influenced by libertarian social values in that a primary concern is protection of individual liberties and freedoms. In contrast, egalitarian theories promote equity in access to health care on the basis of need and equality. In general, Canadians tend to support a more egalitarian system of health care where the principles of accessibility and universality are consistent with equal rights to health care on the basis of need not ability to pay (Pauly, 2004).

Daniels (1985, 2001), in an extension of John Rawl’s theory of justice to health policy, promotes an egalitarian concept of justice. In particular, Daniels (2001) argues for

a concept of justice that requires policymakers to be concerned not only with the distribution of health care resources but a recognition that health outcomes are affected by access to health care services and by social conditions (or social determinants of health). He states,

The fair equality principle assures access to high quality public education, early childhood interventions (including day care) aimed at eliminating class or race disadvantages, and universal coverage for appropriate health care (p. 6).

He argues that justice would be promoted by increasing access to services that impact the social determinants of health.¹⁴¹ Daniels (2001) argues that improvements in health status will be positively affected by increasing access to a broad range of integrated services that address conditions related to the social determinants of health such as housing, employment, and education. Health status is impacted both through direct service provision and by working in concert with other social services that support access to housing, income, and social support. It follows that a reorientation of health care services and intersectorial collaboration between health and other sectors is needed to impact the social conditions that affect health. Addressing inequities in health requires action aimed at addressing the conditions which contribute to poor health and removing barriers to accessing health care services. Drawing on egalitarian notions of justice, I would suggest that there is a moral basis for endorsing, supporting and implementing primary health care strategies that seek to address immediate health concerns as well as the determinants of health particularly for those experiencing social disadvantages.

¹⁴¹ Simply increasing access to medical care services has not been shown to improve health of populations (Daniels, 2001). Particularly because medical services (by this I mean access to physician care for injury and illness) do not seek to address underlying conditions of poor health.

Sherwin's work in feminist ethics (1992, 1998, 2002) provides important insights into what is needed in order to move such an agenda forward in the health policy arena. She argues that feminist relational understandings of personhood are not only superior to liberal individualistic notions of personhood (those which emphasize freedom of choice or personal choice) but "are *required* for an adequate ethics for public policy-making" (Sherwin, 2002, p. 277). She states

The questions that feminists raise involve more than violations of individual autonomy or failures of distributive justice among individuals in isolation, however. Feminists ask how different social *groups* are likely to be affected by the technologies in question. These are different questions, not alternative variations of the existing ones (p. 283)

She draws on Young (1990) as a resource for reconceptualizing justice in policy making. Young (1990) argues that the starting point for justice ought to begin with difference rather than distribution. However, as Sherwin observes, the challenge is to shift the moral orientation of policy makers from one of liberal individualism to relational notions of ethics and politics. She states,

Specifically, they require us to redefine the terms of autonomy and justice in ways that make clear the moral significance of considering the impact of policies on social groups as well as on individuals (p. 287).

Sherwin (2002) argues that beginning from reconceived notions of justice and autonomy, it is possible to broaden the scope of morally relevant aspects of policy making. She states,

If however, policy-makers can be persuaded to shift their moral and political framework from liberal individualist accounts of autonomy and justice to richer relational interpretations, they will be compelled to address a much broader range of moral questions. This requires them to reject conceptions of persons as pre-social in favor of relational accounts that view persons as products of society, inseparable from the complex social interactions in which they engage. The preferred account would make clear that the interest and identities of persons are

not independent of their social circumstances but are actually framed by them (p. 294).

Working from feminist notions of autonomy and justice, an understanding of the context in which health care is provided within health care interactions and in primary health care centers, can provide meaningful insights into potential policy implications for enhancing access to health care for those who are street involved.

I have focused heavily on the work of Daniels (2001) and Sherwin (1998, 2002) in providing alternative perspectives on autonomy and justice. I have chosen the work of Daniels (1985, 2001) because of his focus on equity in access to health care and because Beauchamp and Childress (2001) point to his work in their discussion of the principle of justice. Throughout my doctoral studies, I have found Sherwin's work to be especially compelling in illuminating broader socio-contextual issues within health care ethics. As Aroskar (1992) points out, and as was discussed in chapter 1, we are plagued by inconsistent and incommensurable notions of justice which she surmises have limited our focus on ethical concerns such as access to health care not only in nursing but more broadly. It is beyond the scope of this chapter to further examine notions of justice. However, this is important work that needs to continue. For me, the study of differing and competing conceptualizations of justice as a basis for policy and practice in enhancing access to health care for people who are street involved is an important aspect which I intend to pursue in my post-doctoral work.

Cross-Cultural Perspectives

Like feminist ethics, cross-cultural ethics, as a lens for examining Western based notions of culture and health, illuminates different understandings of autonomy and

justice in health care and provides a basis for cross-cultural dialogue. A cross-cultural lens illuminates the ethnocentricity of Western medicine by pointing to the strong values of individualism and personal responsibility that underpins Western approaches to ethics in health care (Stephenson, 1999). As Stephenson observes, a focus on individualism means we are concerned with rights of individuals and the responsibilities of groups to individuals rather than thinking in terms of the rights of groups and the responsibilities of society. He states,

Since culture is quintessentially a group concept with ramifications for individuals, then a cross-cultural medical ethics will of necessity have to move beyond the dimension of individual entitlements and rights and towards some way of addressing the rights of groups (p. 87).

For example, autonomy as conceptualized in a principled approach focuses on individual rights rather than group rights and societal responsibility. An interesting practical example that arises within the context of my research relates to a better understanding of the role of groups that have begun to emerge in society to protect the rights of intravenous drug users. Two examples are the Vancouver Association of Intravenous Drug Users (VANDU) who was responsible for the making of the movie, "Fix" and the Society for Living Intravenous Drug Users (SOLID) who brought the "Fix" to Victoria.

A cross-cultural approach to ethics would suggest that we need to understand autonomy within a cultural context. However, little is known about decision-making and development of decision-making capacity for those who are experiencing addiction and homelessness. For example, what do we know about the nature of decision making for someone with an active and consuming addiction? An additional area for future research is the perspective of those experiencing homelessness and addiction on a variety of

ethical issues. For example, as Song (2002) observes, we need to know more about the perspectives of those who are homeless, experiencing addiction and dying of HIV/AIDS on ethical issues such as end of life care.

A cross-cultural ethical perspective helps to highlight new relationships between personal responsibility and health. Anderson and Reimer Kirkham (1999), writing on cross-cultural ethics, state that health ought to be conceptualized as social responsibility rather than an individual responsibility. They state, “viewing health as a responsibility of the individual, or as located within static belief system – ‘the culture’ – will lead us in an entirely different direction than locating health within a web of social and political relationships” (p. 63). The focus on blaming an individual with an addiction for their problems or taking a moral view that it is a matter of personal responsibility can be placed into a more appropriate cultural context. In a cross-cultural approach, the conditions or context within which addiction and homelessness occurs and the associated social responsibilities can be illuminated.

Similar to the work of Daniels (2001) and Sherwin (1998, 2002), a cross-cultural view of health as defined above points to the importance of addressing the underlying conditions that affect health and the moral imperative to address such conditions. If we take the view that social conditions affect health we will work to reveal social injustices “located in histories of colonization, oppression, dehumanization, and depersonalization, wherever they may exist” (Anderson & Reimer Kirkham, 1999, p. 63). Anderson and Reimer Kirkham observe further that in order to illuminate social injustices, we need to expand health care ethics beyond concerns about individuals and their rights to address questions of social justice for groups that have been racialized, marginalized and

oppressed in society. It is not so much questions about just allocation of resources within health care but questions about the allocation of resources for health [e.g., to address the social determinants of health] and health care services (Anderson & Reimer Kirkham). I would suggest that both feminist and cross-cultural ethics are important areas for further exploration within nursing.

Trust in Health Care Ethics

Based on the findings of this study, trust as a normative concept in ethics is an important area for consideration and discussion in ethics. In this study, people who are street involved were often reluctant to access care because of a lack of trust. Although others (e.g. Browne et al., 2002; Stevens, 1992; Gelberg et al., 2004) have found there was a reluctance to access health care among marginalized groups as a result of negative experiences, the findings of this research suggest that it is more than negative experiences with individual providers. It is a lack of trust in systems that contributes to delays in accessing health care.

Throughout this research project, I continually examined literature in the field of health care ethics. Although I had specifically reviewed writing on trust in feminist ethics (e.g. Baier, 1986) in the context of other research projects, and was aware of work on trust as a normative concept in nursing (e.g. Peter & Morgan, 2001; Rodney, 1997; Rodney & Street, 2004), I did not choose to include these in my literature review for this project. In fact, I was fully immersed in data collection when I realized that trust was an important and central concept. I think I dismissed work on trust because of my bias that the concept of trust was not robust enough to capture and address concerns about the socio-political context. Thus, I viewed trust as being primarily confined to the nature of

proximal interpersonal relationships such as between nurse and individual, nurse to nurse, and nurse to manager.

Hall (2005) observes that trust in individual relationships is not only the result of knowledge of specific individuals but of preexisting concepts about professionals and organizations. He states, "once system trust is established, individual professionals do not have to earn their trust in each instance, and the breach of trust by one individual does not necessarily undermine trust in others" (p. 162). Hall suggests a three tiered model of trust in which trust in individuals is augmented by trust in an institution which is further augmented by trust in other institutions or in a social system.¹⁴² The findings of this study suggest that trust at the institutional or social system level is disrupted for those who are street involved and as a result interpersonal trust in individuals is affected and access to care is constrained. Reestablishing interpersonal trust is a means of rebuilding institutional and system level trust and necessary to facilitate access to care. Peter and Morgan (2001) suggest that an ethic of trust be explored as a basis for nursing ethics. Based on the findings of this study, I would agree that trust which is conceived broadly as interpersonal, institutional and systemic trust is be an important area for further exploration in nursing ethics.

ENHANCING EQUITY IN POLICY

Pal (2001) states that policies provide a direction to be taken in response to particular problems. Within every health care organization and at all governmental levels (regional, provincial, national) policies exist in the form of guidelines, laws, regulations

¹⁴² I would note that I did not discover this article by Hall (2005) until after I had completed the majority of my data analysis. I was struck by the levels of trust that he identified and that were consistent with the idea of different levels or links in the chain of trust.

and legislation (Blue et al., 1999). Policy is both the product and the process (Malone, 1999). Malone explains:

We do commonly think of policy as a course of action or guide to action, but we also regard it as a kind of public practice of deliberation in which various actors participate. So to speak of policy is to speak of both a social-political process and of the results of that process, which in turn are used to guide or regulate other processes or practices. Policy thus encompasses both means and ends. (p. 18).

Qualitative research has the potential to provide valuable information that will be of benefit in the policy process and in the development of policy tools used to achieve policy objectives (Rist, 2000).

In this section, my intent is to extend the insights for health policy identified in chapters 4 and 5. Based on the findings of this research, I would suggest that there are two potential contributions of this research for health policy. The first is related to the framing of policy concerns and tools for critical analysis in the policy process. The second contribution is the specific insights of participants for policy development at the micro, meso and macro levels of health care that would enhance access to health care for those who are street involved.

Framing Policy Problems

As Pal (2001) observes, “*specific policies are not an end in themselves but tools to be used to address concerns.*” He states further, “in this sense, policies are largely ‘instrumental’; that is they are not ends in themselves, or even good in themselves, but are [or] tools to tackle issues of concern to the political community” (Pal, p. 3). In formal policy making, the particular way that a problem or cluster of problems is defined limits the range of policy alternatives and instruments available to address the identified problem (Wharf & McKenzie, 1998). Values are integral to the framing of policy issues

and identified solutions (Kenny, 2002). Ethics, as a link between values and policy, is integral to the policy process (Pellegrino as cited in Bankowski, Barzelatto & Capron, 1989). According to Malone (1999),

policy, it seems reasonable to say, always has an irreducibly moral dimension insofar as it involves a decision about how to act toward affected others who are not involved (or only indirectly involved) in actually deciding what to do about an identified problem (p. 18).

A primary concern is when values and ideologies frame the issues in ways that perpetuate the concerns they purport to address. Based on the findings of this research, I would suggest a number of cautions in framing three specific policy issues: housing, utilization of emergency departments and disease specific policy initiatives.

Housing is essential to address the underlying foundations of ill health among those who are homeless or without adequate housing. Homelessness directs our gaze primarily to a lack of housing. While safe and stable housing is essential to the well-being of those experiencing marginalization, it is not adequate in and of itself as a sole response. Framing policy concerns primarily as homelessness can obscure other issues such as mental illness, HIV and hepatitis C. Stable housing, coupled with adequate health and social services is needed to address the complex concerns of those who are homeless, experiencing addiction and mental health concerns. Adequate income and social support are also important to maintaining housing. As well, there is a particular need for not just housing, but for particular kinds of housing. For example, there is a need for 'wet housing' in which individuals are not expected to be free of drugs or alcohol in order to maintain their housing.

Framing policy issues as an over utilization or inappropriate use of emergency room by those who are street involved requires caution for a number of reasons (Malone, 1996, 1998; Olsson & Hansagi, 2001). First, framing concerns as over utilization fails to recognize that the health care concerns of those who are homeless and experiencing substance use may be significant and that these individuals have fewer resources available to assist them in meeting health and social needs (Butters & Erickson, 2003). Second, it obscures the problem that many individuals lack a consistent source of care and they are viewed as 'difficult' and even 'undesirable' patients in the health care system (Gelberg et al., 1997; Jecker, 1996; Lewis, Andersen & Gelberg, 2003; Malone, 1996; Simon, Dwyer & Goldfrank, 1999; Wood & Valdez, 1991). Third, framing the issue as one of over utilization and inappropriate utilization can contribute to stereotypical thinking that all people who are street involved are frequent users of health care services. More likely it is a small number of individuals who are repeat and frequent visitors to the emergency department (Malone, 1996, 1998; Olsson & Hansagi, 2001). Lastly, it fails to recognize the reluctance and hesitancy of many people to access health care services, as well as the fact that some people who are street involved actually underutilize services (Butters & Erickson, 2003; Hatton, 2001; Hwang et al., 2001; Gelberg et al., 2004).

Frequent and repeated use may be better understood in light of socio-economic constraints in that emergency departments are no longer able to bridge gaps in social services or address complex health and social concerns of those who are homeless (Malone, 1996, 1998). Malone (1998) suggests that the problem of over utilization of emergency departments be reframed. She states,

If, rather than seeing the problem of ER overutilization solely as the result of lack of access to primary medical care, it is instead conceptualized in terms of a shift in the role of the hospital ED, a different set of clinical and policy approaches follows (p. 818).

If, as Malone (1998) observes, the ER can no longer be the 'almshouse' and provide services such as food, shelter, clothing and comfort, then we need to look at where such services can be provided and how connections can be forged between the hospital and other community agencies better suited to provide such services. The ability of nurse in hospital to identify and facilitate such linkages may be an area for future study. As Padgett et al. (1995) advises, policies aimed at decreasing emergency room usage should not be pursued until other sources of health care and support are firmly established. I would concur.

Third, in framing policy concerns it is important to recognize that HIV, homelessness, and mental health concerns overlap but are not necessarily mutually inclusive. Similarly, mental illness, addiction and homelessness often coexist but addiction and mental health concerns are certainly not limited to those that are homeless. It was not until I was near the end of my data collection that I began to think in terms of HIV/AIDS, hepatitis C or mental health as important areas for me to explore in relation to this research. In particular, hepatitis C, and HIV/AIDS represent medical categorizations of disease and within health care can become a defining label for a group of people who may or may not share much in common. A concern in defining the problems as HIV or hepatitis C reinforces the dominance of medically orientated values, which is reflected in allocation of research dollars and the focus of clinical practice.

A second concern is that people who are street involved are not a homogenous group (Begin et al., 1999; Hwang, 2001). For example, it was often pointed out to me that people who use cocaine are not like people who use heroine because of the effect of the drugs. Similarly, people who use alcohol often feared and did not associate with people who use drugs. This has significant implications for the development of drug withdrawal and treatment programs. Among those who are homeless, there is considerable diversity in age, gender and experience (Begin et al., 1999; Eberle et al., 2001; Hodnicki, 1990). Women, although fewer in number, are highly vulnerable and at increased risk for poor health. Youth may not feel comfortable accessing the same services as adults. For example, women and youth have often experienced trauma and abuse by men. Men, who compose the majority of those who are street involved, tend to be more isolated and have less access to other resources. The recognition of diversity in needs and experiences among those who are street involved has significant implications for the development of policy and programs. While services for all of those who are street involved are important, the need for youth services is particularly evident because of a general lack of services and the importance of prevention.

A Critical Lens for Policy

Based on the findings of this research and a review of the theoretical literature, a critical lens for policy that focuses on an examination of the implicit and explicit values inherent in policy is needed to excavate the way in that policies will affect those who are marginalized in society. A critical lens for policy that addresses difference, deservedness, discrimination and democracy in policy initiatives may assist in the illumination of issues that are often obscured for those who are street involved. Attention

to difference seeks to address the question of how differences among groups in society will be addressed by a particular policy initiative. Deservedness addresses implicit and explicit values in the process of policy development about what individuals or groups are construed as deserving. Questions of discrimination seek to illuminate whether or not those who are street involved will benefit or be further disadvantaged by a particular policy initiative. A fourth element of such a lens might be democracy; drawing attention to the need for thoughtful reflection and appropriate strategies for meaningful involvement of those who are street involved in policy. The development of a critical lens may be useful in all aspects of the policy process.¹⁴³ However, considerable work and much caution would be needed if one undertook to develop such a lens for policy.

Policy Insights

In the following section, I will discuss specific insights for policy at the micro, meso and macro level of health care. These insights are based on critical and recurrent themes that arose during data analysis in this project.

Primary Health Care Centers

The findings of this study suggest that primary health care centers are a critical link in facilitating access to health care for those who are street involved. Primary health care centers, through the delivery of integrated services, seek to address both inequities in health and removal of barriers to accessing health care. Lack of integration of services

¹⁴³ For example, access to health care in the current health care environment has taken on particular meanings including concern about equitable access to care for those in rural and remote settings (geographical access) and addressing the issue of waiting times for particular health care services. However, this is not the entire story of access to health care and as a current discourse has the potential to obscure the inequities in access to health care that have existed for some time as a result of discrimination and the rationing of health care resources to those who are considered less deserving. Furthermore, it is important to recognize that existing inequities in access for people who are street involved have likely been exacerbated by restraints in health care funding (Rodney & Varcoe, 2001; Varcoe & Rodney, 2002; Varcoe, Rodney & McCormick, 2003).

has been identified as a problem in meeting the needs of those who are homeless and experiencing addiction (Cousineau, 1997; Riley, Harding, Underwood & Carter, 2003; Sachs-Ericsson, Wise, Debrody, & Paniucki, 1999). There is preliminary evidence that suggests integrated delivery of services can promote access and enhance outcomes for those who are street involved (Cunningham et al., 2005; Gonzalez & Rosenheck, 2002; Rothbard, Min, Kuno, & Wong, 2004). The basic principles of primary health care programs include accessibility, appropriate skills and technology, health promotion, intersectorial collaboration and public participation (Canadian Nurses Association, 2003). The findings of this study provide direction and insight into a number of policy issues in the development and ongoing operation of primary health care centers.

In the context of this study, it should be noted that individuals may experience both interpersonal and systemic distrust that contributes to their reluctance to access health care. In addition, to the importance of the development of interpersonal relationships, the findings of this study suggest that attention to the physical environment in primary health care centers is an important consideration that can contribute to feelings of safety and trust. Street friendly primary health care centers are important in enhancing accessibility. Consideration should be given to waiting room aesthetics including color, music, the presence of resources, size, security personnel, access to TV and computer. All of these may add to the friendliness of the center. Another area of consideration is the opportunity for individuals to access a wide variety of services and resources within the primary health care center. For example, even the opportunity to use the bathroom can be an important feature that enhances accessibility. Ability to exchange needles, access fresh fruit or snacks, comfort measures such as foot soaks and clean socks

as well as drop-in programs that provide opportunities for recreation and interaction are other possibilities. Furthermore, programs of interest generated in conjunction with those using services can help to rebuild trust. However, adequate space is essential for offering such programs as well as ensuring space for meeting, groups and consultation. An important area of focus is engaging those who are street involved in the development of such initiatives as well as the integration of funding from a variety of sources to support identified initiatives.

Primary health care centers are particularly well suited to provide integrated health services and to link with other agencies to affect the social determinants of health and ultimately the health of those who are street involved. Accessibility will be enhanced by ensuring that the door to the center remains open to the street and the center is known for listening, addressing and coordinating responses to a broad range of individuals and concerns. This requires balancing the pressure to specialize in health care while maintaining the integrity of center as a point of access for a broad range of individuals. For example, if a clinic becomes known on the street as the 'HIV clinic', the 'Hep C clinic' or the 'Meth clinic', even though a broad range of health care services may be provided, many individuals may not go there because they do not define their primary concern as HIV, hepatitis C or do not wish to go on methadone. This situation is often exacerbated by the way in which funding of services is allocated and the lure of resources and research dollars for medically orientated specialization such as HIV and hepatitis C. For example, if pockets of money are dedicated to very specific kinds of services such as care of pregnant, or native women who are HIV positive, such a focus requires that individuals define themselves similarly in order to benefit from services. As well, short

term funding of specific initiatives are not amenable to developing longer term relationships of trust necessary to enhance knowledge, skills and capacity for those who are street involved. These are important policy issues that must be grappled with in the development of services at the policy level. Ethical analysis helps to illuminate such issues.

Access can be enhanced by the removal of structural barriers that limit the number of hours and days of services. It should be noted that many clinics are not open on weekends and have limited evening hours. If the clinic is not open, the only option may be to the emergency department. More research is needed to determine the effectiveness of primary health care centers in reducing utilization of emergency departments and the effectiveness and efficiency gained when individuals access a regular and consistent source of health care.

In this study, concerns related to geographical accessibility were identified. Some clients may fear violence, exposure or a return to drugs if they visit the center. This is particularly problematic if their primary trusting relationships are with providers at the center. First, it reinforces the need to establish linkages with other services and providers and, as professionals, to foster interpersonal relationships that facilitate referral along established lines of referrals as well to work to create new relationships and mechanisms for referral. Second, it is important to recognize that there is not one right but many right locations for service. The development of satellite centers has the potential to maintain the integrity of a small team of providers at the same time that services are offered in multiple convenient locations. However, the primary caution is that mechanisms and lines of referral need to be firmly established between centers.

Outreach by registered nurses was found to be central to the development of trusting relationships as well as providing access to a broader range of integrated services. In this study, the goal of outreach by nurses was to develop relationships of trust, to provide nursing care onsite and to link individuals with other providers and services. As demonstrated in this study, outreach has benefits both for individuals and providers. In a review of the literature on harm reduction, Hilton, Thompson, Moore Dempsey and Janzen (2001b) found evidence that outreach programs are effective in reaching those who use drugs, reducing the incidence of drug related harm and the spread of HIV. Hilton et al. (2001b) concluded that peer driven outreach programs are the most effective. According to Ng and McQuiston (2004), outreach is a critical first step in that clinicians and those who are homeless develop a relationship of trust with the goal of eventually linking the individual to treatment and services. These authors suggest that a continuous relationship model in which clinicians actually provide services is more effective than outreach aimed at linking people to services. Possible areas for expansion of outreach in primary health care centers include harm reduction based peer outreach workers and outreach workers able to accompany and support individuals to appointments.¹⁴⁴ Evaluation of different models of outreach in relation to specific program objectives is needed. Furthermore, particular ethical issues that arise in doing outreach, such as confidentiality, safety and degree of coercion used with individual clients, would benefit from specific attention.

¹⁴⁴ Peer outreach workers refer to individuals who have previously or are currently experiencing homelessness and/or substance use. They receive training and are usually paid for the work they do. They are viewed as effective because they are able to reach a broader group of people (Hilton et al., 2001b).

The presence of trusting relationships among integrated teams of providers facilitated access to health care. The physical proximity of providers as well as the presence of trust increased communication, consultation and referral. However, physical proximity such as being located in the same center is not sufficient. There must be a commitment to working as a team (inclusiveness and collaboration) as well as opportunities for the team to develop. A set of shared values as well as a present and supportive manager are central to the success of teams. This benefits both those accessing services and providers. Numerous authors have identified similar characteristics of effective multidisciplinary teams (e.g. Flanagan, 1998; Patterson & McMurray, 2003). There is some preliminary evidence that collaboration will enhance comprehensive care and improve patient outcomes (e.g. Sicotte, D'Amore, & Moreault, 2002; Way, Jones, Baskerville, & Busing, 2001).

The findings of this study suggest that a range of providers, beyond traditional health care providers such as doctors and nurses, can be extremely beneficial in promoting health and fully utilizing the skill of the most appropriate provider. For example, the presence of a pharmacist provides an added means of consultation, support and ongoing monitoring of medication regimes. In particular, the findings of this study point to the role of nurses as having a unique combination of knowledge and skill that makes the nurse well suited to be a first point of contact. Thus, physicians are more able to focus on their role in diagnosis and treatment. The unique contribution of the nurse is the combination of skills in physical assessment and management of common health care problems as well as the development of trusting relationships, education, monitoring, counseling and support in navigating complex health care systems. The effectiveness of

nurse practitioners in providing quality care and enhancing patient outcomes has been well established (e.g. Horrocks et al., 2002; Mitchell-DiCenso et al., 1996; Mundinger et al., 2000).

There are distinct advantages to having a nurse practitioner in terms of the ability to assess and treat health concerns. However, many of the benefits of the nursing presence are related to the nurse's ability to develop trusting relationships, to provide support, counseling, and education, and the knowledge and ability to connect clients with resources in the context of health care interactions. The ability of nurses to link and coordinate other health and social services is a particular strength on the health care team. Finnie and Nicolson (2002) observe that an added benefit of the nursing role is that it enhances opportunities for health promotion as well as harm reduction. Mistral and Hollingworth (2001) indicated that in addition to medication management, nurses provided health education, health promotion, harm reduction, and coordinated care. Also, the need for specialists in areas of mental health and chronic pain could be filled by individuals in a clinical nurse specialist role and provide alternative approaches to dealing with such concerns. The findings of this study suggest that nurses with a broad range of skills, including nurse practitioners and those with community health nursing experience, would make a valuable contribution to integrated teams in primary health care centers. While there is considerable support for the effectiveness of nurse practitioners, the importance of the role of registered nurses, particularly community health nurses, as members of a multidisciplinary team is an area for further exploration.

Interagency Linkages

This study found that both interpersonal and system trust was needed to facilitate access to health care between agencies. Providers in different agencies must know and trust each other at the same time that systems are put in place that support working together. It just can't just happen nor can it be left to good interpersonal relationships of providers. There must be mechanisms for coordination, consultation and referral among agencies. An area for further exploration and research are the linkages between nurses and others in primary health care centers with shelter workers, paramedics and front line workers in nonprofit agencies. Particular areas for exploration include the role of these individuals in facilitating access in conjunction with the primary health care center, as well as dealing with issues such as confidentiality, and differing goals and mandates within programs and organizations.

As demonstrated in this study, linking individuals to other agencies and services often requires the need for accompaniment and/or transportation. Accompaniment means that individuals are supported to keep appointments and assisted to follow through with plans of care. Although not a replacement for case coordination, accompaniment can provide an important link between services as well as enhancing the flow of communication between individuals and providers and provider to provider. The provision of transportation can also reduce barriers to accessing services. For example, a program that is dedicated to providing 'free' transportation for those who are street involved can assist in connecting individuals to agencies and services. This is an area for future exploration and development.

Linkages are needed between primary health care centers and acute care services. Based on the findings of this study, there is a need to assist individuals to navigate entry into the emergency department, to ensure safe passage through the hospital system and safe discharge into the community. One possibility is the development of a hospital liaison program in which individuals are accompanied or met in the emergency department by a nurse or other health care worker who is familiar with the street as well as the hospital. If admission is required, an interdisciplinary team from the community could assist in management of hospital care as well as discharge planning.

‘Detox’ services emerged as an important but missing link in this study. In this study, clients and nurses lost trust in the system to provide timely access to ‘detox.’ This has a profound impact on the decision of individuals to access ‘detox’ and the ability of nurses to facilitate access. For example, what is the point in completing forms when the opportunity to access ‘detox’ will be missed? Additionally, recognition that individuals often require more than one try to successfully complete a program is needed. What is clear is that the reorganization of ‘detox’ services and the mechanisms for referral to ‘detox’ are not well suited to the needs of those with addictions. This suggests an important area for client and provider input and for establishing mechanisms for feedback and discussion within regional health authorities. At a minimum, this would enhance understanding and identification of issues. Additionally, there is a need to explore sources of support for ‘home detox’ as well as adequate follow-up post ‘detox.’

Meso Level Policy: Expanding Harm Reduction

Central to establishing contact, and maintaining and developing trusting relationships with individuals were the principles and practice of harm reduction. Harm

reduction is most often defined as an approach or strategy aimed at reducing the costs and harms associated with drug use particularly the spread of HIV (Hilton et al., 2001b).

Gunn, White, Srinivasan (1998) state

harm reduction encompasses abstinence as a desirable goal, but recognizes that when abstinence is not possible, it is not ethical to ignore the other available means of reducing human suffering (p. 1191).

In this study, nurses interpreted harm reduction more broadly as a principle of minimizing harm in the context of caring for those who are street involved. It may be that nurses were drawing on the principle of nonmaleficence or beneficence as priority principles in practice. However, they located their descriptions of minimizing harm within the context of harm reduction. Additional exploration of the concept of minimizing harm within the context of caring for those who are street involved is needed.

The findings of this research suggest that there are potential benefits to be gained in expanding harm reduction approaches to the care of those who are street involved in emergency departments and hospitals. First, harm reduction can reduce the negative consequences of drug use. For example, there may be opportunities in the context of health care interactions in the emergency department to provide information about harm reduction strategies such as proper vein management.¹⁴⁵ Second, a harm reduction approach accepts drug use rather than ignoring, moralizing or condemning it (Canadian Harm Reduction Network, 2001). Third, harm reduction provides an opportunity to engage with individuals where they are at rather than expecting them to change or to feel the pressure to fix the other. Expansion of harm reduction approaches to care of

¹⁴⁵ One nurse, in the context of this study, working in an emergency department and after exposure to information about harm reduction, described a situation in providing care to a man with an addiction in which she taught him how to apply a tourniquet to facilitate injecting. Another nurse from acute care suggested we could show them where the sharps container is located so that they can dispose of needles.

individuals experiencing drug use may enhance access to health care by positively affecting health care providers' attitudes and providing a basis on which to build a relationship of trust. However, institutional commitment, support and policies need to be in place to assist practitioners implementing harm reduction strategies. Expanding harm reduction approaches to hospital programs and services has been successful in several settings (Young et al., 2002). Although such programs have not been rigorously evaluated, improvements in relationships with clients have been reported. This is an area for future research.

Communities are launching the four pillar approach as a local strategy to promote harm reduction. The four pillar approach includes attention to housing, policing, treatment services and health care as a coordinated approach to reducing the harms associated with drug use. In particular there is growing interest in expansion of harm reduction services such as needle exchanges and safe injection sites. For example, the first North American Safe injection Site has opened in Vancouver, B. C. (Wood et al., 2004a). While the findings of this study are consistent with expansion of harm reduction initiatives, there are also some cautions in that services need stable funding, should be offered on an ongoing basis and must be well linked to other services in the community. Increasing access to harm reduction services can also be viewed as a strategy for enhancing access to health care and other services. In the expansion of harm reduction approaches, I would also suggest that there is a need for assessment and communication to the public of the benefits to individuals and the community of adopting a harm reduction approach. Clearly, needle exchange programs, safe injection sites, and wet housing have benefits both to individuals and the community in reducing the transmission

of disease among those who use drugs, as well within the larger community.

Furthermore, providing safe environments for the use of drugs benefits both individuals and the community, such as ensuring safe disposal of equipment and monitoring for overdose (e.g. Wood et al., 2004b).

Enhancing Equity in Macro Policy

These findings suggest that primary health care centers and harm reduction services are more appropriate in providing quality, timely and relevant health care to those who are street involved than acute care services. Integrated teams of health care providers within a primary health care center are better equipped than isolated providers and emergency departments to address the complex health and social needs of individuals who are street involved. This view is consistent with previous research by Polizer et al., (2001). In particular, a major benefit, from an ethical perspective, is that both inequities in health and inequities in access to health care are addressed. I would suggest, as several participants did, that the benefits of integrated primary health care could likely be extended to care of the elderly and those with mental health problems who are experiencing complex and multifaceted concerns.

However, there are a number of challenges at the macro policy level in implementing primary health care initiatives. While primary health care reform has long been touted as an effective and efficient strategy for reform, it has also been misunderstood and conflated with primary care reform (access to physician services) or restricted to issues related to introduction of nurse practitioners by policy makers and others. For example, the Commission on the Future of Health Care in Canada (2002), which was a highly progressive report in most regards, fell significantly short in

recommending fully integrated primary health care centers in the final report. I would suggest that this was due, at least in part, to the difficulties of achieving intersectorial collaboration at the government level. Addressing inequities in health and access to health care through primary health care reform for those who are street involved would require access to services in health and other sectors.¹⁴⁶ Freund & Hawkins (2004) state,

There is a need to coordinate efforts of government bureaus and departments in order to address the complex issues facing persons who are addicted to drugs and end up on the streets. Housing alone or treatment alone does not help a large percentage of individuals who view life on the streets as their only option. It doesn't appear that the urban problem of homelessness and the public health problem of addiction will relent until our federal, state and county systems of service delivery coordinate their efforts to meet all identified needs, instead of compartmentalizing sets of human needs into separate departments and funding streams (p. 92).

Intersectorial collaboration among governments is essential to take coordinated action on issues of homelessness and addiction. The findings of this study suggest that not only is there a need for interagency linkages but a need for intersectorial collaboration particularly in relation to social services. Since housing, income, education and employment were persistent issues and areas in which lack of confidence and system distrust was high, intersectorial collaboration among different government ministries is critical and would enhance the ability of providers to connect clients with essential services that address broader aspects of health. A particular area of concern is the impact

¹⁴⁶ There are different approaches to how access to a broader range of services might be achieved. Aday et al. (1998) argue for expansion of existing health services. Alternatively, one might think about reorienting health services (particularly community services) to focus more on community development including promotive and preventative services. Access to a broader range of services can also be realized through creating better links between health and social services. The work of the Romanow Commission and discussions with Lillian Bayne, advisor to the Commission, have facilitated me in my understanding of the limits of addressing the social determinants of health within the defined health sector of government. Addressing the social determinants of health requires intersectorial collaboration among many government sectors including health and social services.

of provincial government policy in which welfare cheques are issued monthly rather than weekly or biweekly. This creates a situation that contributes to rather than ameliorates the problems. More exploration of the effects of this policy is needed.

Since Canada has a universal health insurance system most individuals, with a few exceptions, are eligible for health care coverage. During the period of data collection, many individuals presented to the primary health care centers without a valid health care card or indicated when seeing a nurse on outreach that they did not have a card. Often, they reported that their card and all their identification had been lost or stolen.¹⁴⁷ However, global clinic funding ensured that clients could access health care and, if possible, arrangements were made to obtain a card or social assistance so that coverage would be provided. Additionally, in the locations where this research was conducted there was a provincial pharmaceutical program that covered the cost of a broad range of drugs. If individuals had not applied for coverage, the cost of medications would not be covered. In some cases, organizational structures such as having a pharmacy associated with the primary health care center meant that the pharmacy would cover the cost of drugs until coverage could be obtained. This benefit was in addition to the benefits of having a pharmacist on the team. These findings are consistent with other Canadian research in which lack of a health care card, cost of premiums, transportation, child care, and pharmaceutical costs have been found to be barriers (Butters & Erickson, 2003; Hwang & Gottlieb, 1999; Williamson & Fast, 1999). In this study, additional financial barriers to accessing health care services identified included access to dental care, eye

¹⁴⁷ In order to get a health care card, an individual needs identification as well there is a cost for a replacement card. Often getting a card means phoning or visiting a Ministry of Health, which is an additional barrier.

care and medical equipment or supplies.¹⁴⁸ A new finding was that financial barriers, such as a decrease in social assistance payments, can act as a barrier to hospitalization. It is important to recognize that financial barriers to accessing health care still exist even when a system of public health insurance is in place.

In the United States, lack of health care coverage is a primary barrier to accessing health care (Barkin et al., 2003; Ensign & Panke, 2002; Freund, & Hawkins, 2004; Hatton, 2001; Hodnicki, 1990; McKinney, 2002). While Canadian citizens value and support maintaining universal access to health care, the tenets of Medicare in Canada are under threat (Pauly, 2004). The introduction of private for profit funding and delivery of services has the potential to restrict the availability of publicly funded services. For example, the introduction of additional user costs into the health care system would create new financial barriers for those who are living in poverty and who have limited financial resources. Thus, while we currently have a primarily publicly funded health care system, the subtle invasion of *for profit* health care will result in growing numbers of people who no longer have adequate health care coverage. In a for profit system of health care, lack of insurance will become a barrier to those without financial resources in accessing health care services (Pauly, 2004). Thus, creating a situation similar to that of the United States (U.S.) and generating moral concerns about inequities in access to health care on the basis of income (Caplan, Light & Daniels, 1999). While private for

¹⁴⁸ For example, Ensure was not covered. For people with HIV and undergoing treatment for Hepatitis C, Ensure is a quick and ready source of nutrition. One nurse related to me that when it was covered, it went out the back door as quick as it came in the front door; meaning it was sold on the street rather than consumed by the individual.

profit health care can be defended on the basis of choice, it would be at the expense of creating significant barriers to health care for those experiencing social disadvantage.¹⁴⁹

A final and important insight for policy that arises from this research project is the interest, willingness and incredible ability of participants to provide an articulate analysis of both the problems and solutions in addressing inequities in health and access to health care. Participants, both primary and secondary, actively sought out and were interested in talking to me, as a researcher, about their experiences in accessing health care. People on the street as well as health care providers had many suggestions about what might be done to improve access to health care. This observation points to the importance of public participation of those who are street involved and those providing services.

Strategies to enhance democratic processes and citizen governance seek to acknowledge and capitalize on public input and interest on issue specific policies (Abelson, 2002).

Abelson et al. (2002) in their recommendations state,

The key is to provide citizen users with adequate means for communicating their concerns about their care through accessible, easily identifiable channels (ie. They need to know where to go) (p. 18).

In this sense, the research and the researcher became a means of communicating individuals' concerns and their suggestions. It was particularly effective because the research was undertaken where people who are street involved live and work. As a researcher, I was an easily identifiable channel for communicating their concerns and suggestions for enhancing access to health care. This creates a significant moral obligation for me in continuing the work that has been started in this project.

¹⁴⁹ While some might argue that a system of publicly funded care would remain in place for those who need it, there is significant evidence that greater introduction of private for profit funding and delivery of health care would significantly erode a publicly funded system (Pauly, 2004).

Furthermore, it requires that one think creatively about strategies for meaningful participation of individuals who may be disenfranchised from society.¹⁵⁰ My experience in this project suggests that at a minimum one needs to go to their turf. I would suggest that individuals who are street involved are very willing to share their views and may even benefit from the affirmation of someone listening to their concerns. Success is possible if people are approached in a respectful and genuine manner through safe and legitimate channels. I would end by saying if we wish health care delivery to be successful and contribute to addressing inequities in health and health care, we are morally compelled to consult those we wish to benefit.

¹⁵⁰ In the context of this research, I observed that nurses were skillful in recognizing and eliciting feedback from participants within health care interactions and to communicate and initiate changes on the basis of client feedback. If an individual complained about services, nurses would listen and seek feedback on how things might be improved. In eliciting feedback, it became apparent that they were listening for trends. For example, a man in recovery expressed that it was difficult to pick up his medications in the same area where the needle exchange was located. The nurse immediately asked if he was feeling triggered by this. She wondered if installing a curtain might help. In an aside, the nurse told me she had heard similar things from other patients. The nurse took steps to have a curtain installed that would divide the medication area from the needle exchange, and she communicated this concern to other members of the health care team. Thus, in addition to individuals, nurses as well as other health care providers have a wealth of information about the problems and solutions in addressing access to health care.

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Appendix A

Verbal Recruitment Script for Agencies

I am conducting a study entitled Ethical Relations and Access to Health Care for At Risk Populations. My name is Bernie Pauly and I am a graduate student in the Department of Nursing at the University of Victoria. As a graduate student, I am required to conduct research as part of the requirements for a degree in nursing. It is being conducted under the supervision of Dr. Janet Storch.

The primary goal of my research is to learn from the nurses and clients about the effects of health care relations (both interpersonal and social) on access to health care and how access might be improved in the health care system for people experiencing poverty, homelessness and substance use. By health care relations, I mean interpersonal relationships and social relations (organizational, political, economical and historical influences which form the context within which care is provided).

Research of this type has the potential to

- 1) identify and generate new knowledge of factors that facilitate access to health care for underserved groups. New knowledge of barriers faced by marginalized groups in accessing health care in the current system of delivery also may be revealed.
- 2) provide knowledge of ethical health care relationships and strategies for enhancing ethical practice within health care relationships that will benefit other health care providers working with people experiencing poverty, homelessness and substance use.
- 3) provide insights for health policy development that could enhance the effectiveness, efficiency and equity of health care organization and delivery for people experiencing poverty, substance use and homelessness.

I would like to buddy with RN's in your agency working either regular or casual delivering primary health care to people experiencing homelessness, alcohol/drug use or poverty to understand health care relations. Participation of individual nurses is completely voluntary and informed consent would be obtained from nurses interested in participating. I would observe and informally interview the nurses during their work time. I would supplement my observations with qualitative interviews. Informal interviews with the nurses will be built into my observations when feasible – for example, during coffee breaks—and will be audiotaped whenever possible (with the nurses permission). Formal interviews will be conducted outside of work time and will be scheduled at a time and place convenient to the nurses. All names and identifying information including agency name will be removed from the data. The identify of the agency will be masked in any presentations or publications.

This research has received ethical approval from the University of Victoria and Vancouver Island Health Authority. However, if your agency is not in VIHA, I would need to obtain ethical approval for your region prior to beginning the study.

If you are interested in hearing more about the study or wish to participate, I would like to set up a face to face meeting with and members of your staff. Thank-you. I can be contacted at 472-0123 or bpaul@uvic.ca. You may also wish to contact my supervisor, Dr. Jan Storch at 721-7964.

Appendix B

A Nursing Research Study Access to Health Care

My name is Bernie Pauly.
I am a nurse doing a research study
about access to health care.

I want to learn about what might improve health care
for people who are homeless, poor or using substances.

I will be with the nurses and some of the other staff &
making notes of what I see and hear.

If you are seeing one of the nurses I am working with,
I will ask if you want to be part of this study.
It is your choice to have me present.
You may refuse to have me present at any time
and it will not affect your care.
I will not be keeping records of anyone's name
or the name of the health centre.

If you would like more information about the study
or if you have any questions or concerns about being part
of the study, please talk to me or to your nurse.

*Bernie Pauly, RN, MN,
University of Victoria (250 472-5405)
The Ethics of Access to Health Care for At Risk
Populations.*

Appendix C: Secondary Participant Information Pamphlet

A Nursing Research Study

This handout provides information for secondary participants (clients, families and other health care providers) about a study being conducted at this site by a graduate nurse researcher from the University of Victoria

Study Title: ***Ethical Relations and Access to Health care for At Risk Populations***

Student Researcher: Bernie Pauly, RN, MN
Student, UVic School of Nursing
(bpaul@uvic.ca)
(250) 472-5405

Supervisor: Jan Storch, RN, Ph.D
Professor, UVic School of Nursing
721-7964

1. WHAT IS THE RESEARCH STUDY ABOUT?

I am interested in learning from the nurses, clients and other health care providers about the effect of relationships and the environment on access to health care and to learn what might improve access to health care for people who are poor, homeless or use substances.

- This research will be conducted in several locations providing health services from January to December, 2004.
- This research is part of the requirements for a Ph.D in Nursing.

2. WHO IS PARTICIPATING IN THE RESEARCH?

During the study, I will be following a small number of nurses who agree to participate in my study. I will be with different nurses at different times of the day and on different days of the week.

I will be making notes of my observations of the nurses' actions and conversations with clients, family members and other staff. In the course of my observations of nursing activities over the six to twelve month period of the research, I will interact with other health care team members, patients/clients, and their families (secondary participants).

3. HOW MIGHT THIS STUDY AFFECT ME?

It is possible that you will become a secondary participant if you are talking to or being treated by one of the nurses I am observing. I will check with you to see if you agree to

having me present or if you would prefer not to have me around you or your family member. If you have any concerns about being observed, you can speak to me or to the nurse involved in your care. You may refuse to be observed or answer questions at any time, and you are free to change your mind about participating or not participating at any time.

- If you are a patient or a family member, your decision to participate or not participate **will not** affect the treatment or care you or your family member receives.
- If you are a health care team member, your decision to participate or not participate **will not** affect your employment or student status.
- Taking part in this study is voluntary

Since I will be following the nurse, there is no additional time required of you. There are no known risks or inconveniences for this kind of research. If you would like to share your health care experiences, you may request an interview.

4, **HOW WILL YOUR PRIVACY BE PROTECTED?**

- For patients/clients and family members who are too ill, or young to understand their right to refuse being observed. I will obtain consent from a family member, guardian, or caregiver to make notes if the patient/client is not able to consent. I will not make any notes about anyone who does not want to be involved or anyone who is too ill or young to understand their right to refuse observation and does not have a family member to provide or decline verbal consent.
- If you do not wish to be involved in the study, I will not make notes on any of the interactions that the nurse has with you. Confidentiality will be maintained by assigning each Site and each participant a code name. **I will not be keeping records of anyone's name or name of the site at any time.**
- The research information with identifying information (no names) will be kept locked in my office and will not be released to anyone except members of my supervisory committee.
- The research data without identifying information (no names and stripped of some specific details) will be used to write my Ph.D report. Presentations and publications, and any future research that I do.

If you would like more information about the study, feel free to speak with me.

If you have any concerns about being observed, you can speak to the researcher or the nurse participant

You have the right to request that I not include observations of nurses' interactions with you in the study.

This study is being conducted from January to December, 2004.

For more information, please contact:

Bernie Pauly
University of Victoria, Nursing Research Office
250 472-5405

Dr. Jan Storch, Faculty Supervisor
University of Victoria
250 721-7964

University of Victoria
Office of Research Services
250 472-4362

Handout Developed January, 2004

Appendix D
Ethical Relations and Access to Health Care
Registered Nurse/Health Provider Primary Participants
BACKGROUND DATA

Directions: These questions concern the backgrounds of those involved in this study. The responses to these questions will be used to help describe in a general way the nurses and other health care providers who participate in this research. As with the interview, your responses will be kept strictly confidential.

Please circle the appropriate number or fill in the blanks.

1. Are you...
 Female..... 1
 Male 2

2. In what year were you born? 19_____

3. What is your ethnicity? (please specify)

4. What is your basic education?
 Diploma (nursing)..... 1
 Diploma (other field).....2
 Baccalaureate (nursing)..... 3
 Baccalaureate (other field)..... 4

If basic education is in a field other than nursing, please specify

5. What additional degrees/certificates have you earned?
 Diploma..... 1
 Specialty certificate..... 2
 Baccalaureate (nursing)..... 3
 Baccalaureate (other field)..... 4
 Master's (nursing)..... 5
 Master's (other field) 6
 Other (please specify) _____

If your additional degrees are in a field other than nursing, please specify _____

6. How long have you worked as a Registered Nurse/Health Care Provider?
 Years_____ Months_____

7. Where are you currently employed?
 Community Health Care Center.....1
 Hospital.....2
 Community Agency.....3
 Other (please specify) _____
- 8 How long have you been employed at your present agency/hospital?
 Years_____ Months_____
- 9 What is your current employment status (e.g. full time, casual, .8, etc)

- 10 What is your current role/position?
 Staff nurse 1
 Nurse Practitioner.....2
 Primary Care nurse.....3
 Triage Nurse..... 4
 Primary Care Physician.....5
 Physician (specialist).....6
 Social Worker.....7
 Manager.....8 . .
 Other (please specify)..... _____
- 11 How long have you been employed in your current position?
 Years_____ Months_____

Appendix E

Ethical Relations and Access to Health Care
Client Participants
BACKGROUND INFORMATION

Directions: These questions concern the backgrounds of those involved in this study. The responses to these questions will be used to help describe in a general way the people who participate in this research. As with the interview, your responses will be kept strictly confidential.

Please circle the appropriate number or fill in the blanks.

- 1 Are you...
 - Female..... 1
 - Male 2

- 2 In what year were you born? 19_____

- 3 What is your cultural heritage? (please specify)

- 4 What is your highest level of education?
 - Elementary School.....1
 - Junior High.....2
 - High School Diploma... 3
 - College.....4
 - University..... 5

5. What additional degrees/certificates have you earned?
 - Diploma..... 1
 - Specialty certificate..... 2
 - University Degree.....3
 - Other (please specify) _____

What are your earned diplomas, degrees or certificates?

6. What is your current source of income? (e.g. social assistance, disability, panhandling, employment etc.?)

7. If employed, what is your current employment?
8. If employed, what is your current employment status (e.g. full time, casual, .8, etc)
-

9. Where do you currently live? (Circle all that apply)

Shelters1

Outdoors..... 2

Social Housing.....3

Your own place4

(e.g apartment or house)

Couch Surfing With Friends.....5

With family.....6

Hotel/Motel.....7

10. Do you have any mental health difficulties? Y N

11. Do you use street drugs? Y N

12. If yes, which ones and how frequently?

Appendix F

UNIVERSITY OF VICTORIA
OFFICE OF THE VICE-PRESIDENT, RESEARCH
HUMAN RESEARCH ETHICS COMMITTEE

*Primary Participant Consent Form
Nurses and Health Care Providers*

Ethical Relations and Access to Primary Health Care for At Risk Populations

I am inviting you to participate in a study I am conducting entitled Ethical Relations and Access to Health Care for At Risk Populations. My name is Bernie Pauly and I am a graduate student in the Department of Nursing at the University of Victoria. You may contact me if you have further questions by calling me directly at 472-5405. As a graduate student, I am required to conduct research as part of the requirements for a degree in nursing. It is being conducted under the supervision of Dr. Janet Storch. You may contact my supervisor at 721-7964.

The primary goal of my research is to learn from the nurses, clients and other health care providers about the effects of health care relations (both interpersonal and social) on access to health care and how access might be improved in the health care system for people experiencing poverty, homelessness and substance use. By health care relations, I mean interpersonal relationships and social relations (organizational, political, economical and historical influences which form the context within which care is provided).

Research of this type has the potential to

- 1) identify and generate new knowledge of factors that facilitate access to health care for underserved groups. New knowledge of barriers faced by marginalized groups in accessing health care in the current system of delivery also may be revealed.
- 2) provide knowledge of ethical health care relationships and strategies for enhancing ethical practice within health care relationships that will benefit other health care providers working with people experiencing poverty, homelessness and substance use.
- 3) provide insights for health policy development that could enhance the effectiveness, efficiency and equity of health care organization and delivery for people experiencing poverty, substance use and homelessness.

You are being asked to participate in this study because you are an RN or health care provider working either regular or casual delivering primary health care to people experiencing homelessness, alcohol/drug use or poverty and have expressed an interest in participating.

If you agree to participate in my research, I will observe and informally interview you during your work time. I will accompany you during your work day and will be taking field notes as I observe and talk with yourself and others. For nurses who are primary participants, the amount of time that I will accompany you will be determined as the research proceeds and in collaboration with you. I will supplement my observations with qualitative interviews. Informal interviews with yourself will be built into my observations when feasible – for example, during coffee breaks—and will be audiotaped whenever possible (with your permission). Formal interviews will be conducted outside of your work time and will be scheduled at a time and place convenient to you. One or two interviews may be scheduled with you, each lasting 1-2 hours. Formal interviews will be audiotaped and subsequently transcribed.

I do not know of any inconveniences or risks associated with the proposed research apart from the time required for interviews. While the exploration of the ethical issues encountered in practice may cause you some emotional discomfort, previous qualitative research conducted at University of Victoria by myself, my supervisor and others indicates that some may find the opportunity to talk about the issues in practice beneficial. Also, the insights generated from this study have the potential to inform policy development that could improve access to health care. If you or any participant appears distressed during the field work, I will remind you that you are free to not answer some questions, and free to withdraw from the study without any negative effects. If your distress is not alleviated by those reminders and by sensitivity on my part as an interviewer, I will make a recommendation for future follow-up (e.g. through employee health counseling). If any secondary participant who is a patient or family member appears distressed during the fieldwork, I will notify you or others involved in their care or a person responsible for overseeing care in your site. Furthermore, if I observe situations where I feel that I need to assist in my capacity as a registered nurse, I will offer to help—for example, by doing such things as calling for assistance, sitting with client. I would discuss any questions or concerns I have about clinical situations, directly with you. If follow-up is necessary, I would encourage you to seek assistance through the appropriate organizational channels or discuss it with the appropriate individuals within the organization. While there are no direct benefits of this research to you, the potential benefits of your participation in this research includes generating insights for other health care providers, administrators and policy makers that may improve access to health care for people experiencing poverty, substance use and homelessness

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study and do not want your data included, all attempts will be made to immediately destroy the data by:

1. Shredding any hard copies made of the data including transcripts and field notes
2. Erasing the audiotape or relevant segments.
3. Erasing the data from computers, floppy, disks, and CD;s

However, there may be instances, where it may not be possible to identify the source of specific data (for example in field notes).

To make sure that you are able to provide ongoing consent to participate in this research, I will be attending agency meetings to keep you informed throughout the course of the field work. I will also 'check in' with you weekly during the period of observation regarding any questions or concerns you may have regarding the research process. Research-related questions will be brought to my supervisor and/or dissertation committee and if necessary to the University of Victoria Office of Research Services. Procedures for voluntariness, confidentiality and security of data will be reviewed again at the commencement of your involvement. You will be required to sign and retain a copy of the consent form. Secondary participants will receive either an information sheet for secondary participants or a card with information regarding the name of the study and contact persons. Information sheets regarding the study will be made widely available at the study sites during the course of the study.

No data identifying or identifiable of individuals will be released to anyone outside the supervisory committee. However, you understand that complete anonymity within the observational sites cannot be assured. Your confidentiality and the confidentiality of the data will be protected by assigning each site, each participant (including yourself) a code name. Names of individuals or agencies will not be recorded in typed transcripts of field notes. Future reports and publications will 'mask biographical data' as necessary to preserve confidentiality. I will keep the data and I will be using it to compile my dissertation report for presentation to my supervisory committee. No data will be kept that identifies individuals or agencies. All data will be stored in a locked cabinet in my home office. Electronic data files will be accessible only to me via a password on my computer. Any secretary involved in transcription will sign a form promising that all data will be returned to me and will be kept confidential. You should be aware that one exception to confidentiality that could arise is if particular research data is subpoenaed for legal purposes, but that such subpoenas of research data are extremely rare. Only data directly requested by the court would be made available, and only individuals involved in the legal proceedings would have access to the data.

Other planned uses of this data include use for future presentations and publications and for possible secondary analysis in other related research projects. No data will be kept that identifies individuals or agencies, unless an individual or agency specifically requests that they be identified.

Data (which as been cleaned of identifiers) will be kept for a period of 15 years. Other data will be destroyed once the identifiers have been removed and the data checked for accuracy. When the data is destroyed, audiotapes will be erased, and transcripts and filed notes will be shredded and electronically erased.

It is anticipated that the results of this study will be shared with others in the following ways Dissemination will include presentation at local, regional, national and international

conferences in nursing, qualitative research health policy and ethics. Dissemination will also include presentation at educational seminars for students and health care professionals. In all reports and presentations, I will not be reporting site specific results but would provide insights based on what I am learning from all sites in the study.

In addition to being able to contact myself and my supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered prior to signing.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

FUTURE FOLLOW UP (OPTIONAL)

Name: _____

Preferred Mailing address: _____

Preferred e-mail address: _____

Preferred Telephone number: _____

Preferred fax number: _____

Do you wish a copy of the final report: Yes No

Do you wish a copy of future publications? (please note that this will mean that you will need to keep us up to date re your address etc. as it can take a few years to get publications complete)

 Yes No

Do you wish to be informed of future related research that I undertake?

 Yes No

Thank-you for your time and participation.

Appendix G

UNIVERSITY OF VICTORIA
 OFFICE OF THE VICE-PRESIDENT, RESEARCH
 HUMAN RESEARCH ETHICS COMMITTEE

***Primary Participant Consent Form
 Interview Only***

Ethical Relations and Access to Primary Health Care for At Risk Populations

I am inviting you to participate in a study I am conducting entitled Ethical Relations and Access to Health Care for At Risk Populations. My name is Bernie Pauly and I am a graduate student in the Department of Nursing at the University of Victoria. You may contact me if you have further questions by calling me directly at 472-5405. As a graduate student, I am required to conduct research as part of the requirements for a degree in nursing. My supervisor is Dr. Janet Storch. You may contact her at 721-7964.

I want to learn from the nurses and clients about the effects of health care relationships and the environment in which care is provided on access to health care. I would like to gain an understanding about what might be done improve access to health care for people who are homeless, poor or using substances. Doing this research may:

- help to identify factors that facilitate access as well as barriers to accessing care for those who are homeless, poor or using substances.
- provide information that will benefit other health care providers in developing good or ethical relationships with people experiencing poverty, homelessness and substance use.
- improve health care delivery for people experiencing poverty, substance use and homelessness.

I would like you to participate in this study because you are experiencing homelessness, alcohol/drug use or poverty or are working with people in these situations and have expressed an interest in participating.

If you would like to participate in my research, I will interview you at a time and place convenient to you. One or two interviews may be scheduled with you, each lasting 1-2 hours. Interviews will be tape recorded and then typed up word for word.

I do not know of any inconveniences or risks associated with the proposed research except for the time required for interviews.

If you appear distressed during the interview, I will let you know that you are free to not answer some questions, and free to withdraw from the study without any negative effects. If your distress is not alleviated by those reminders and by sensitivity on my part as an interviewer, I will share this with others involved in your care or a person responsible for overseeing care in your site.

While there are no direct benefits of this research to you, what I learn from this research may benefit other health care providers, administrators and policy makers and help to

improve access to health care for people experiencing poverty, substance use and homelessness

Participating in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study and do not want your interview included, it will be destroyed by:

1. Shredding any hard copies of the interview
2. Erasing all or a portion of the taping.
3. Erasing the interview from computers, floppy, disks, and CDs

I will not provide data that can identify you to anyone outside the supervisory committee. Your identity will be kept confidential by assigning you a code name and number. Names of individuals or agencies will not be recorded in typed transcripts of field notes. In all reports and publications information that could identify individuals will be altered or not included. I will keep the data and I will be using it to compile my dissertation report for presentation to my supervisory committee. No data will be kept that identifies individuals or agencies. All data will be stored in a locked cabinet in my home office. Electronic data files will be accessible only to me via a password on my computer. Any secretary involved in typing the interviews will sign a form promising that all data will be returned to me and will be kept confidential. You should be aware that one exception to confidentiality that could arise is if particular research data is subpoenaed for legal purposes, but that such subpoenas of research data are extremely rare. Only data directly requested by the court would be made available, and only individuals involved in the legal proceedings would have access to the data.

Other planned uses of this data include use for future presentations and publications and for use in other related research projects. No data will be kept that identifies individuals or agencies.

Interviews will be kept for a period of 15 years. Other data will be destroyed once the identifiers have been removed and the data checked for accuracy. When the data is destroyed, tape recordings will be erased, and interviews will be shredded and electronically erased.

It is anticipated that the results of this study will be shared with others through presentations at local, regional, national and international conferences and educational seminars in nursing, qualitative research, health policy and ethics.

In addition to being able to contact myself and my supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered prior to signing.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

FUTURE FOLLOW UP (OPTIONAL)

Name: _____

Preferred Mailing address: _____

Preferred e-mail address: _____

Preferred Telephone number: _____

Preferred fax number: _____

Do you wish a copy of the final report: Yes No

Do you wish a copy of future publications? (please note that this will mean that you will need to keep us up to date re your address etc. as it can take a few years to get publications complete)

 Yes No

Do you wish to be informed of future related research that I undertake?

 Yes No

Thank-you for your time and participation.

Appendix H

***Ethical Relations and Access to Health care for At Risk Populations
Script for Verbal Consent with Secondary Patient Participants***

1. Basic Information to be shared with all participants at the beginning of interactions with secondary participants:

I am a nurse researcher from the University of Victoria. As part of the requirements for a Ph.D in nursing, I am interested in learning about the effects of health care relations on access to health care and how access to health care services might be improved in other parts of the health care system. I will be observing the nurse as she is caring for you. If you do not wish me to be present, please tell your nurse or myself.

The following information will be put onto a small card for participants

Ethical Relations and Access to Health For At Risk Populations
Researcher: Bernie Pauly, 472-4606

If you would like more information about the study, please feel free to speak with me

If you have concerns, you can speak to me or to the nurse providing your care.

You have the right to request that I not include observations of nurse's interaction with you.

This research will be conducted from January to December, 2004

2. In anticipation of additional questions from potential secondary participants, the following questions and answers have been prepared:

What do I have to do? Do I have to answer questions or fill out a form?

There is no additional time expected of you and there are no known risks associated with this research to you or others. I will be observing you and the nurse so you do not need to answer any questions or fill out a form.

How long are you going to be observing the nurses?

I will be following several nurses at different times and on different days over the next 6 months. I will be making notes of my observations of the nurses' actions with you and conversations with you and others present.

What will happen if I say 'no'?

If you do not wish me to observe your interactions with the nurse, you may let me or your nurse know at anytime. If you decide not to participate it will not affect your care or the

care of others. Your willingness to have me present is your choice and you can change your mind at any time. You can ask me to leave and you can refuse to talk to me further.

Will you be using my name or writing about me?

I will not be keeping records of anyone's name or the name of the agency at any time. I will use a code name for individuals and agencies and that information will be kept locked in my office in a separate location from the other data and not released to anyone. The research information without code names and with specific details of your situation removed or altered will be used to write the final report, for future presentations and publications and in future related research.

If a client expresses an interest in talking about their health care experiences, as a result of my introduction or discussion, they will receive the following information.

If you would like to talk to me about your health care experiences, we could arrange a time and place convenient for you to share your experiences. However, this is not required of you and you may choose not to answer any questions and may withdraw at any time. You would be required to sign a consent form which tells you more about the study and your rights as a participant.