

Women's Experiences of Receiving a Diagnosis and Living With Hepatitis C

BY

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University of Victoria, 2008

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTER OF NURSING

In the Department of Human and Social Development

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ABSTRACT

This research explores the lived experiences of what it means to women when they receive a diagnosis of Hepatitis C (HCV). The approach to guide the conversations is hermeneutic phenomenology. Phenomenological text can have the effect of making one suddenly “see” something in a way that enriches one’s everyday understanding of women’s lived experiences (van Manen, 1997a). The intent is to share the lived experience knowledge, embedded in stories women have shared, with nurses and health care professionals. The hope is that, through these stories, health-care providers will develop insights and understanding which informs compassionate and sensitive care for women who have HCV. This study involved in-depth tape recorded conversations with nine women who have been diagnosed with HCV. The transcribed conversations were analyzed following the steps of a nursing Gadamerian based research method (Fleming, Gaidys & Robb, 2003). Analysis of the conversations occurred with the hermeneutic rule of movement from the whole to the part and back to the whole (Gadamer cited in Fleming et. al). Each of the participant’s stories are described followed by identification of shared experiences giving insight into the phenomena of receiving a diagnosis and living with HCV. Women described: shock and disbelief, a need for information on how to take care of themselves,

feeling they were treated like garbage, wondering how they could tell anyone they have this illness, receiving this diagnosis during a hugely fragile time, fears of infecting others, and concerns about being a mom with HCV. They relived past traumas of how they became infected by the virus.

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Acknowledgments

I would like to acknowledge those who have been steadfast in their support in my work on this thesis.

Dr. Bernie Pauly; thank you for sharing your enthusiasm for this research, from the very beginning, when the idea for coming to the question was first discussed. Your enthusiasm gave me the confidence to do this thesis. Your patience, encouragement, and wisdom has guided my academic progress.

Dr. Carol McDonald; thank you for your wisdom and expertise in a hermeneutical phenomenological approach.

My Family; my husband, Dwayne, for his steadfast support in all things. My three sons Matt, Dean and Jason. I love being your mom. Melanie and Tiffany, your partners, bring richness to our family. Our family is growing and Harleigh, our first grandson, will be born in May, 2011.

Ron and Dianne; my siblings, your belief in me has sustained me all my life.

Women Friends; to all my women friends who have walked with me, emailed me, talked with me, edited this thesis, and shared this entire journey with me. Thank you, Joan Wilson editor extraordinaire.

Registered Nurses Foundation of BC; Founders Grant assisted with funding this thesis.

AND

The nine participants; this work would not be possible without your candour, honesty, strength and sincerity. Your stories have touched me deeply.

Dedication

*This work is dedicated to all women, everywhere, who have
experienced living with Hepatitis C*

Chapter One

WOMEN'S EXPERIENCES OF RECEIVING A DIAGNOSIS AND LIVING WITH HEPATITIS C

Approaching The Question

Internationally, Hepatitis C (HCV) research has focused on the epidemiology of the virus and medical treatments of the disease. There has been limited systematic exploration of issues related to the meaning of the social or emotional dimensions of living with HCV (Hopwood & Southgate, 2003). The social impact of HCV on people's lives is considerable and the gender-specific impact on women has begun to be documented (Gifford, O'Brien, Bammer, Banwell & Stoope 2003; Banwell, Bammer, Gifford & O'Brien, 2005).

Issues and concerns such as stigmatization, discrimination, access to health services, changes in one's sense of identity, and difficulties forming intimate relationships remain as central themes in the lives of many people affected by HCV (Hepworth & Krug, 1999; Hopwood & Southgate, 2003; Paterson, Backmund, Hirsch & Yim, 2007). Roger, Jolley, Thompson, Lanigan & Crofts (1999) suggest that HCV affects quality of life on two levels: physiologically (for example nausea, fatigue and liver damage) and emotionally/socially (the burden of living with a stigmatizing illness with an uncertain prognosis). HCV is a highly stigmatizing health condition because of association with injection drug use (Richmond, Dunning & Desmond, 2004). Findings indicate patients with HCV are treated differently from other patients because health-care workers assume the former use illicit intravenous drugs (Treloar & Hopwood, 2004).

To reduce discriminatory or stigmatizing behaviour towards people who have HCV, strategies need to be developed that acknowledge the impact of nurses and other health-care professionals' clinical behaviour on people who have HCV. Treloar and Hopwood (2004) suggest

that health-care workers may reduce this negative social impact through appropriate and sensitive management at the time of diagnosis. In a small study by Grundy and Beeching (2004) all of the women interviewed had difficulty coming to terms with the diagnosis. This suggests there is considerable room for improvement of health care for women with HCV. Grundy and Beeching suggest improving provision of information at the time of diagnosis.

In the research, the experience of stigma has been identified as posing significant challenges for people who live with HCV, thus stimulating further inquiry into how nursing practice and policy can respond to identified health issues (Butt, Paterson & McGuinness, 2008; Crockett & Gifford, 2004; Gifford et al., 2003; Grundy & Beeching, 2004; Paterson et al., 2007; Zickmund, Ho, Masuda, Ippolito & LaBrecque, 2001). Goffman (1963, p. 3) defines stigma as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one.” Link and Phelan (2001) constructed a revised conceptualization of the term stigma. They explain that “stigma exists when elements of labeling, stereotyping, separating, status loss and discrimination occur in a power situation that allows these processes to unfold” (p. 382). Link and Phelan describe the components of this definition as follows: Labeling refers to the identification of human differences that matter socially whereby labels are assigned. Stereotyping is when the label links the person to a set of undesirable characteristics. One example would be associating HCV with dangerous illicit drug use. When people are labeled negatively, in the extreme situation, they can become thought of as non human. Status loss occurs when labeling and assigned undesirable characteristics leads to loss of status and discrimination. For example, the stigmatized illness may have less money dedicated for research or for adequate health care. These same authors observe that stigma occurs

when there are power differences and power is central to the social construction of stigma.

Previous research indicates that men and women experience the illness and diagnosis of HCV differently (Gifford et al., 2003; Grundy & Beeching, 2004; Butt et al., 2008; Crockett & Gifford, 2004; Zickmund et al., 2001). In women's narratives, feelings of shame, stigma and discrimination are contextualized in their stories (Crockett & Gifford). A striking feature of this study was that women had little opportunity to voice their feelings and concerns (Crockett & Gifford). They further explained that social stigma impacted negatively on access to healthcare, employment, and social support. In the Gifford et al. study, half of the 462 women who participated reported experiences of stigma and discrimination with health-care personnel.

In addition to reported experiences of stigma, when accessing health care, women felt they were not given adequate information or support upon diagnosis (Crockett & Gifford, 2004; Gifford et al., 2003). All women felt there were not enough services specifically for women living with HCV. Women felt they needed to talk about contraception, sex, pregnancy, and reproductive health (Crockett & Gifford; Gifford et al.). Health care that concentrates primarily on the medical aspects of HCV instead of a more holistic approach could explain why lower emphasis is placed on the social and emotional context of care surrounding HCV (Miers, 2002). Two main reasons Lawler (2009) identified for concentrating on the medical aspects of illness are, firstly, that dominant discourses have concealed the subjective in the search for objective and value-free knowledge. Secondly, medical research, which is powerfully masculinized, has found topics such as emotions and feelings to be troublesome.

Research Question

The overarching research question is: What are the lived experiences of women receiving a diagnosis of Hepatitis C? This research will attempt to explore and be open to what presents itself in the conversations of the women's experiences. What does it mean to a woman to come to a place of knowing one's diagnosis of Hepatitis C? The approach to exploring these experiences will draw on hermeneutical phenomenology.

The primary desire is to capture women's stories with the possibility of exploring and understanding the meaning of receiving a diagnosis of HCV. "To paraphrase Heidegger, the more important question is not: Can we do something with phenomenology? Rather, we should wonder: Can phenomenology, if we concern ourselves deeply with it, do something with us?" (cited in van Manen, 1997a, p. 45). The task of this hermeneutic phenomenological approach is to construct one possible interpretation of the nature of this lived experience.

Positioning Oneself as a Researcher

As a researcher I am a Caucasian woman who has benefited greatly from post-secondary education. I do recognize my present privileged position. I grew up in a home with a mom who was diagnosed with mental illness and addictions. She was not able to exercise her educational potential. Her five children went into foster care after she tried valiantly to raise them in dire, poverty-stricken conditions. In this era, there was no healthcare for women who had mental illness and addictions and my mom was unable to get help and medication until she was 50 years old. We then reunited and I developed some understanding of her lived experience, from her stories. It is from this perspective, and in humble appreciation of hearing those stories, that I approach this educational research endeavour.

In my present position, and for the past five years, I have worked as a Registered Nurse in

a Hepatitis Clinic. Prior to this position I worked casually in a street Outreach Health capacity for two years. Preceding these two positions my nursing experience was largely on a surgical unit and an intensive care unit (ICU). A colleague encouraged me to come to work with her in Outreach Health. As I developed a relationship with the clientele, whose home was the streets, I reflected back on many experiences I had while in ICU when these same people accessed health care. Some of these individuals were at the end of their lives when they were between 40 and 50 years old. Often there were no family members to hold their hands. They were sometimes discriminated against by the staff verbally during report, by restriction of visitors (their family were other people who lived on the street), and by withholding adequate pain medication because of their addictions. We would have a “patient” admitted and staff (which included myself) would identify them as “Hep C”, “HIV” or “street involved” and start double gloving. The belief was that additional infection control precautions were necessary to reduce the risk of contracting disease. This was accompanied by the desire to warn other nurses by putting red alert stickers on charts and identifying patients in shift reports as HCV positive. This created a false sense of security, based on the assumption that infection control guidelines needed to be stepped up only when patients are identified. Not all people disclose their HCV status and many people are completely unaware they have this virus.

When I took a position in the Viral Hepatitis Clinic I began meeting many of the people I had worked with at Outreach Health two years previously. I began to notice many of the women who came in wanted the time and the space to tell their story. This was often a time of transformation in their lives. They were getting stronger and taking care of their health needs. It seemed important that these women were sharing their stories. One woman actually said she

wished we could write her story down. I became increasingly interested in the intersecting experiences of stigma that women described. Women described living in poverty, their use of drugs, trauma, mental illness, and abuse. It was through these stories that I began to understand these women's lived experiences and had a glimpse of the meaning of those experiences. There was a growing awareness in me that health strategies and interventions were gender insensitive. It seemed it was not recognized women and men might need different approaches in education and support for HCV. Some women shared how they had been sexually abused as a child, became involved in the drug culture in their early teens, and had multiple abusive partners. The social implications of their illness could not be ignored.

I have encountered concerns in my practice where women did not receive adequate information or support upon diagnosis of HCV. Women who have specific difficulties with being HCV positive have many stories of complex oppression, trauma, poverty and/or abuse that they carry as a social identification, while adjusting to a medical diagnosis of HCV (Richmond et al., 2004). For example, I experienced a situation in which a woman was informed she had HCV and had no further follow-up for eight years. She was told it would be many years before she would have liver damage. She avoided hugging her grandchildren with worries that she may infect them with the virus. Another woman was notified by a letter that she was HCV positive and was informed to contact her family physician. She was not aware that she had been tested. Another woman was told that there was no follow-up nor was she eligible for HCV treatment until she was six months alcohol and drug abstinent. She was told she was not a treatment candidate. These examples suggest that the biological implications of HCV are often the focus of health services and ignore the emotional or social issues.

Mate (2008) writes about one woman's description of the first time she injected heroin. She said it felt like a warm, soft hug. This example is profoundly descriptive of a search for emotional comfort. Many of the women I meet in the Hepatitis Clinic are rebuilding fractured lives, entering healthier relationships, learning how to make a friend, and reconnecting with lost children. They are possibly taking care of themselves for the first time in their lives.

Significance of the Study

In telling woman's stories, my intent is to share with nursing and health care providers the lived experience wisdom embedded in these stories. The hope is that, through these stories, nurses and health care providers will develop insights and understanding that would inform compassionate and sensitive care for women who have HCV. A commitment from women's health services to HCV may see more women accessing treatment, support, and care (Crockett & Gifford, 2004). This would also assist in normalizing HCV in healthcare delivery as well as in the wider community (Crockett & Gifford). Women in these studies felt they had questions about breast feeding and sexual transmission of the virus which would be better addressed when accessing women's healthcare services. In this Australian study, staff from a local women's health centre were invited to participate in the focus group discussion. However, they declined saying HCV was not an issue amongst their client base. This revealed insight about HCV and the population it was perceived to affect (Crockett & Gifford).

I felt the stories I heard in everyday practice were snapshots of some of the lived experiences of women who are diagnosed with HCV. I have found when women tell their stories to a caring listener, this activity in itself values women's need to be heard and demonstrates the importance of inclusion and empowerment in their ability to effectively tell their story. Women's

health is not just about biological differences or reproductive health but also about the conditions of women's lives that affects their health status (Doyal, 1995). Nursing, as a practice, benefits from multiple ways of knowing (Munhall, 2007). While biomedical knowledge is valuable and one way of knowing, for nursing, this is not adequate (Lawler, 2009). Lawler explains that nursing is also concerned with an understanding of embodiment (the experience of the lived body). We have a need to share in and transmit that knowing to others, so that we reflect the concerns of nursing.

This thesis consists of five chapters. Chapter two reviews the literature on the background and epidemiology of HCV, HCV as a chronic illness, gender differences, women and HCV, and gaps in the literature. Chapter three outlines the use of hermeneutic phenomenology, my research approach, recruitment of participants, a feminist explanation, and ethical considerations for this research. Chapter four describes the findings, beginning with the individual stories of nine women who participated, and interpretation of the common or shared experiences of these participants. Chapter five returns to the literature and reviews the findings in relation to HCV as a chronic illness, mothering and HCV, and stigma related issues associated with this illness. This chapter concludes with nursing practice implications and clinical practice recommendations for people receiving a diagnosis of HCV.

Chapter Two

Literature Review

Background and Epidemiology

The enhanced Hepatitis strain surveillance system states HCV is one of the major causes of liver failure and transplant in the developed world (Public Health Canada, 2009). The HCV virus is transmitted through blood contact with someone infected with HCV. In Canada, drug use as a consequence of sharing needles, crack pipes, syringes, and other drug equipment, continues to be the predominant risk factor for HCV acquisition today. It is estimated 70-80% of all newly acquired HCV cases in Canada are associated with drug use (Public Health Canada). Buxton and Kraiden (2007) reported that in BC, the vast majority of new HCV infections (80-90%) are transmitted through using contaminated drug paraphernalia. Of the acute HCV cases, with known risk factor information, IDU (intravenous drug use) is associated with 63% of infections, 9% intranasal (drug use overall 70-80%), 14% sexual contact, 2% health care acquired (including blood transfusions, hemodialysis, surgery and dental surgery), and 8% other. Other includes occupational exposure to blood, household contact with HCV carriers, and incarceration without other risk factors (Public Health Canada). The prevalence of HCV among people who use drugs, but report they have never injected, is substantially higher than that for the general population. This may reflect non-injecting routes of transmission such as sharing intranasal straws (Tortu, Neaigus, McMahon & Hagen, 2001). Prior to 1990, a blood transfusion was a risk factor as blood products in Canada were not screened for the HCV antibody (Heathcote, Yim, Thai & Sherker, 2002). There are many people living with HCV today from this risk factor.

The World Health Organization estimates that 2-3 % of the world's populations

(approximately 123-170 million people) are infected with HCV. The majority of acute HCV infections in Canada occurs in individuals aged 15 to 44 (Public Health, Canada, 2009). The highest increase in reported rates of acute HCV infection was among females aged 15-24 years, with an increase of 114% between January 2006 and September 2008 (Public Health Canada). This could reflect testing bias. Buxton and Kraiden report that the rates of male infections are twice that of females, except in the 15 to 24 year old age group. There are a number of different populations affected by HCV. Due to immigration from countries such as Egypt, India, Somalia, Pakistan, Bangladesh, and Vietnam, with high HCV rates, there are increased HCV rates among immigrant and refugee populations (Sherman, 2007). Further, there are high rates among Aboriginal people with a reported rate of acute HCV, between 2004-2008, that was 5.5 times higher in Aboriginal people than non Aboriginal people (Public Health Canada). From Public Health Canada 2001 to 2009 statistics, of all those infected with HCV, 66% are male and 44% are female. The annual rate of reported HCV infections in BC is 57.1 per 100,000 in comparison to 40.0 per 100,000 overall in Canada (Public Health Canada). There is an estimated 43,000 chronically infected in BC, and an additional 20,000 people who remain unaware of their infection (Buxton & Kraiden, 2007).

Chronic versus Acute Illness

Approximately 15 to 40% of those who acquire HCV will spontaneously eradicate the virus on their own within six months (Palmer, 2004). The remaining 60 to 85% will progress to chronic HCV. This means the immune system has failed to clear the virus from the body. Palmer further explains, once a person is chronically infected the potential exists for liver damage and cirrhosis along with its complications, including liver failure and liver cancer. Typical HCV care

delivery in developed countries is provided in specialty liver or gastroenterology clinics (Zickmund et al., 2003). The focus is on the person's eligibility for treatment, assessment of liver damage, and the potential cure of the illness (Grundy & Beeching, 2004). However, the majority of people will live with the disease for decades because they are either ineligible for treatment or they find the side effects of treatment too debilitating (Richmond et al., 2004). A study by Paterson, Butt, McGuinness and Moffat (2006) found that people with chronic HCV constructed their disease as a chronic illness and the participants found the advice offered by health care professionals to be insufficient in assisting them to make self care decisions. The advice received was most often geared towards decisions about whether to have treatment rather than a focus on quality of life indicators specific to living with HCV as a chronic illness. The Paterson et al. study emphasizes the importance of understanding the experiences of living with HCV from a chronic illness perspective.

Gender Differences

Gender differentials in the social and personal experiences of ill health have been well documented for other chronic blood borne illnesses such as HIV (Zierler & Kreiger, 1997; World Health Organization (WHO, 2003). In the HIV/AIDS epidemic research, gender is defined as:

The array of societal beliefs, norms, customs and practices that define masculine and feminine attributes and behaviors - plays an integral role in determining an individual's vulnerability to infection, his or her ability to access care, support or treatment, and the ability to cope when infected or affected. (WHO, p. 5)

Gender stereotypes account for women having much less access than men to key resources such as education, land, income, credit, and employment. This significantly reduces the leverage they have in negotiating protection with their partners (WHO). WHO recommends, that in order to reduce gender inequalities, women and girls must be empowered by increasing their access to

economic and social resources which can then fundamentally change the economic and social dynamic of gender roles and relationships. In the long term this protects women, as well as men and families, in the HIV/AIDS epidemic (WHO).

Three gender-related differences between men and women, in their response to living with HCV, were identified in a study by Temple-Smith, Gifford and Stoove (2004). These researchers found that women were more likely to actively seek out help for their HCV, women went into greater detail in discussing their needs for information and social support, and finally, women's narratives reflected sensitivity to judgmental attitudes expressed toward them by health care professionals, family and friends. Women worried about people's attitudes towards them, while men defended themselves against these attitudes. Even for women who were physically well, HCV featured strongly in their everyday life. In this study, most men and women shared unsatisfactory experiences at the time of diagnosis. Research that focuses on men and women separately may give us further insight and understanding to develop gender sensitive health care approaches.

A study in Australia indicates support and care at the time of diagnosis is of utmost importance to women (Crockett & Gifford, 2004). Women also identified the need for women's health services to incorporate HCV as a key issue, so that their sexual and reproductive health issues could be addressed in a gender responsive manner. Women's concerns appear to result in worries about perceived infectivity, social acceptance, and their internal feelings of being contaminated (Grundy & Beeching, 2004). There is ambiguity on the issues around the risks of transmission of HCV. Women often receive conflicting and inaccurate information about these risks.

Women and HCV Risk

This thesis is not examining the risks of acquiring HCV. However, some knowledge of the risks give an understanding of the complex issues women navigate and what contributes to young women becoming infected with this virus. The increased reported rate of infection in younger women, compared to their male peers, may reflect an earlier introduction to injection drug use (IDU) and a social structure that may inhibit young women's ability to negotiate safer drug use and sexual behaviours (Public Health Canada, 2006). Young women are sought after by older males as potential sex workers and are often injected by more experienced males after the males inject themselves (Bourgois, Prince & Moss, 2004). The women participants in this study indicated that this is often an issue of control in the relationship. The man exerts control over the drug supply which makes them feel the woman will not leave them. Young women who inject drugs usually treat male control as a natural fact of gender relations (Bourgois et al.).

One Canadian study by O'Connell et al. (2005) also reported that gender dynamics among those who use injection drugs are such that men often control the administration of drugs. Because of these dynamics, women may not learn to inject or may defer to men even if they know how to inject themselves. These researchers found that women who require assistance with injecting are at greater risk of both HIV and HCV infection, even after adjusting for other confounding factors. In relation to the risk of contracting HIV and HCV, the social research clearly indicates that gender related factors put women at greater risk (Zierler & Kreiger, 1997; O'Connell et al.; Bourgois et al., 2004). A number of qualitative studies indicate that the social nature of injecting drug use is complex and that power relations between men and women are mirrored in injecting social networks (Marsh, Loxley, Hawks & Quigley, 1995; Bourgois et al.;

O'Connell et al.). Women are often on the bottom of the social hierarchy when it comes to injecting networks, as well as turn a blind eye to sharing risks in order to demonstrate trust and love to their partners (Barnard, 1993; Bourgois et al.). Sexual transmission of HCV is considered low risk at 3%. However, when sexual transmission is thought to have taken place, it is more likely to have spread from male to female (Heathcote et al., 2002). The virus can be transmitted when there are no precautions taken during traumatic sexual intercourse, even with minute amounts of bleeding, or by exposure to blood tinged saliva (Heathcote et al.).

Women, HCV, Stigma and Discrimination

In 2001, a study in Australia identified that new HCV infections in young women outnumbered those of men (Crockett & Gifford, 2004). This study interviewed 25 women and the results painted a complex picture of the ways in which stigma, lack of knowledge, poverty, and social disadvantage contributed to the negative experiences of living with HCV. It is clear that stigma poses substantial challenges for women living with HCV, their social networks, and the health care provided. HCV may be a symptom of larger societal issues.

Women arrive at the Hepatitis Clinic blaming themselves for becoming infected. The stigma and discrimination faced by people with HCV is a secondary, or underlying epidemic, just as threatening as HCV itself (Richmond et al., 2004). In the case of HCV, the label is a perceived stereotype of involvement in injection drug use for many people, and the virus is the 'mark of social disgrace' (Richmond et al.). Participants described how health professionals were unable to respond with compassion to people with HCV due to underlying negative attitudes to illicit drug use. Incidents described in the health care setting were doubly distressing because these professionals are often turned to for assistance in dealing with problems experienced in other

settings. It is important to understand the meaning attached to the experience from the individual's perspective (Richmond et al.; Crofts, Louie, & Loff, 1997; Sgorbini, O'Brien & Jackson, 2008). Most respondents stated their experiences of stigma and discrimination had substantial personal implications. However, in one study only 11% of the 37 incidents of stigma and discrimination were reported to any authority (Crofts, et al.). None of the 11% reported led to any action under the various Australian discrimination acts. Each support group, approached by the researchers in this study, were aware of many more cases of stigma and/or discrimination which were not reported. Some people declined to be interviewed for fear it would exacerbate their situation.

The van de Mortel (2004) study explains nurses and other health care professionals often discriminate by: assigning labels to medical histories and flagging the person's HCV status, placing persons at the end of the surgery list, and by overusing protective barriers such as double gloving when caring for persons with HCV. These behaviours are influenced by a lack of understanding of HCV and infection control practices. However, if nurses treated all blood and body fluids as potentially infectious, their risk of contracting HCV would be reduced and nurses could ensure people were cared for equally and respectfully (Richmond et al., 2004). Another study by van de Mortel (2002), developed to determine health care workers' knowledge of HCV and attitudes towards persons with HCV, found 83% of people with HCV experienced substantial discrimination as a result of their illness. However, 88% of the health care worker respondents reported they did not treat persons with HCV differently than other patients. This leads one to wonder if people's lived experiences could better convey understanding to health care providers of what behaviours feel stigmatizing and distressing to them?

To further demonstrate experiences of stigma and discrimination when accessing healthcare, a study on incarcerated women who have HCV raises many issues (Sered & Horton-Hawk, 2008). In addition to health concerns, women described lives repeatedly disrupted by sexual and physical violence, homelessness, joblessness, loss of their children, and fragmented medical care. Rather than the health care experiences promoting healing, such experiences were a part of the fragmentation of their lives. Women described healthcare histories where they had to beg for treatment, hide information about themselves, and depend upon people who were more powerful than they to receive care. Women's pain was ignored, their experiences of childhood abuse were not acknowledged, and their sense of self was shattered. Their needs were not seen in the full context of their lives and they were often treated in different facilities and programs. When women are released from prison and seek healthcare from the Hepatitis Clinic, nurses question why they have difficulties with compliance and with attending their appointments.

Gaps in the Literature

There is a beginning foundation of qualitative studies from Great Britain and Australia on the lived experiences of women who have HCV. This literature's rich descriptions of women's experiences of living with a diagnosis of HCV and accessing healthcare provide support for this thesis. Canadian studies are also beginning to document people's health care experiences when diagnosed with HCV (Butt, 2008; Butt et al., 2008; Paterson et al., 2007). These studies assist in developing an understanding of the health care experiences in the Canadian population. Women with HCV represent a minority in research reports (Zucker, 2005). Little has been reported in Canada about the impact of living with HCV, the experience of diagnosis, and the meaning of this experience from women's perspectives. This study will help develop an understanding of

what those issues may be for local Canadian women.

Further qualitative research describing Canadian women's complex lived experiences and prioritized health care issues is essential. Further education among primary health care professionals is required. Research that focuses specifically on women's embodied experiences of living with a stigmatizing illness may help to inform health care providers, who may then provide more gender sensitive and appropriate care to women.

Chapter Three

A Hermeneutic Phenomenological Approach to Inquiry

The approach chosen for this study is a hermeneutic phenomenological process. “As a philosophy, phenomenology is our hope for understanding in this world” (Munhall, 2007, p. 205). If nurses can understand the meanings of individual’s events and experiences, those individuals can be approached in ways that reflect the many ways of being (Munhall). Would we, as nurses, be different with patients when we have a greater understanding of the meanings of their lived experience? How would this internal understanding and change manifest itself in practice and caring for women who have Hepatitis C? The focus of this research was to be open to what presented itself in the conversations with women participants, with a sincere attempt to be open to the unique surprises embedded in the meanings of those lived experiences. van Manen (1997a, p. 12) states:

Hermeneutical phenomenological research is a search for the fullness of living, for the ways a woman possibly can experience the world as a woman, for what it is to be a woman....So phenomenological research has, as its ultimate aim, the fulfillment of our human nature: to become more fully who we are.

van Manen draws upon the philosophers Heidegger and Husserl whose understandings of phenomenology and hermeneutics will be explained more fully later in this paper.

van Manen (1997a) states if there is one word that aptly characterizes phenomenology itself, then this word is thoughtfulness. “In the works of the great phenomenologists, thoughtfulness is described as a mindful, a heeding, a caring attunement (Heidegger, 1962)- a heedful mindful wondering about the project of life, of living, of what it means to live a life” (cited in van Manen, p.12). Phenomenology aims at gaining a deeper understanding of the very nature of what makes something what it is (van Manen). For example phenomenology does

not ask whether something actually happened or how frequently it tends to happen, it asks what is the experience of being diagnosed with, and living with, an illness such as HCV? Nursing phenomenological perspectives aim to enhance understanding through reflective awareness, describing human experiences more fully, processing and interpreting experience, and explicating meaning in experience (Lauterbach, 2007). Lauterbach explains phenomenology seeks to explicate personal meanings as well as uncover the hidden meanings of the experience. This only becomes apparent through in-depth personal journaling and reflection on the topic.

van Manen (1997a) views phenomenology as a philosophy of being as well as practice. “We tend to get a certain satisfaction out of grasping at a conceptual or “theoretical” level the basic ideas of phenomenology, even though a real understanding of phenomenology can only be accomplished by “actively doing it” (van Manen, p. 8). A “...major focus of phenomenological inquiry is understanding meaning of some “thing”, some experience, something that is human so that we can better understand the meaning of being human,...” (Munhall, 2007, p. 153). “A good phenomenological text has the effect of making us suddenly "see" something in a manner that enriches our understanding of everyday life experience” (van Manen, 1997b, p. 345). Heidegger often used the metaphor of “coming to a clearing in the woods” as a way of understanding an enlightened interpretation of the world (cited in Conroy, 2003). A concept van Manen utilizes, that further describes and expands upon Heidegger’s metaphor, is one of epiphany, which will be described further under key concepts.

Key Concepts and Assumptions

Husserl first introduced phenomenology as the idea that subjectivity expands and enriches the perceptions and understandings of phenomena (Munhall, 2007). Munhall states it is this

perspective that is both essential and desirable. Phenomenology, as a philosophical research tradition, was developed as an alternative to the prevailing empirically based positivist paradigm (McConnell-Henry, Chapman & Francis, 2009). Originating from the Greek word "phaenesthai", which means "to show itself", a phenomenon might be considered anything that presents itself and phenomenology is the study of phenomena (McConnell-Henry et al.).

There are many key concepts that underpin phenomenology as a philosophy. Only a few will be described in this paper. These concepts reflect the inevitability of subjectivity in any understanding or description of reality (Munhall, 2007). The concept of *consciousness* is the experience of existence in the world through the body (Munhall). Munhall explains the world is knowable only through the subjectivity of being in the world. Being is constantly interpreting the meaning of things even when unaware this is happening. A Heideggerian explanation is: one is born into a world that pre-existed and takes on meanings from the past, interacts with the world in one's presence, and projects what one will do and be in the future (Conroy, 2003). One is always in relation with others, thus one's understanding and interpretation of the world is co-constituted and synergistic (Conroy). Hermeneutic phenomenology is a theoretical approach that reminds us that what something means depends upon the social context in which it was originally created, as well as the context within which it is subsequently interpreted (Patton, 2002).

The concept of *embodiment* explains that consciousness allows awareness of being in the world and the world is experienced through the body (Munhall, 2007). Meanings associated with certain life experiences can be understood through embodied approaches such as hermeneutic phenomenology. When phenomenology evokes particular images that call forth vividness and

brings into presence relevant embodied aspects of the experience, one can reflect on the meaning this brings about (van Manen, 1997b). van Manen explains it is through language and text that conceptual definitions are stated and felt or experiential understanding evolves. In this manner the felt understandings that lie beyond language come within reach. The evoked images can inform and by informing leave an effect. When this happens Gadamer describes it "...as language touching the soul or as Bachelard puts it, the reverberations bring about a change of being, of our personhood" (cited in van Manen, p. 365).

The concept of *natural attitude* explains that the teachings about the world as it is experienced and interpreted by preceding generations are handed down (Munhall, 2007). This teaches about reality in the process. The teachings then become assumptions, or unquestioned meanings, about the phenomena. Both the perception and the physiological alterations connected to a life change are often the result of a disruption of the natural attitude. The perception also varies depending on the context of the situation. When the aim of phenomenology is to describe the lived experience, it can be the person's own perception, or another's perception, of that lived experience. Munhall explains it is interpretation of the experience from the individual's unique perception of an event that is critical. The reality to learn from, or to be concerned about, is the experience as the individual perceives it (Munhall).

The concept of *epiphany* refers to the sudden perception or intuitive grasp of the life meaning of something (Munhall, 2007). "This experience is so strong or striking that it may stir us at the core of one's being" (van Manen, 1997b, p. 365). Gadamer (cited in van Manen) says when this happens it becomes a new being in one's language and reverberates so that it is then incorporated into one's being as a reader.

The process of reflection, experiential outreach nursing, listening to women's stories, writing graduate nursing papers, and coming to the question for this thesis has led me on a personal experience of consciousness, embodiment, natural attitude, and epiphany. This moved me to experience, reflectively, meaning in my own life. Women's stories put into words that which gave me some understanding and helped me to come to that "clearing in the woods". How, indeed, does one go forward when all that one knows, or one's natural attitude about one's own body and health, is deeply shaken? How does one manage this change and loss so one can rebuild one's life? These questions have led me on a quest to understand further the meanings of women's lived experience, when accessing care and support, for an illness that carries medical and social implications.

Husserl and Heidegger Approaches

There are two main types or approaches to phenomenology: Husserl's transcendental phenomenology and Heidegger's hermeneutic phenomenology. The primary differences are in how the findings are generated and in how the findings are used to support professional knowledge (Lopez & Willis, 2004). Phenomenology is not something that can be defined or interpreted as one thing. If we believe all our voices express multiple ways of approaching research then we respect varying interpretations of method (Munhall, 2007). van Manen (1997a) views phenomenology as a philosophy of being as well as practice. It is from this perspective that I, as a novice researcher, will endeavour to give a view of experiential understanding by questioning lived experience through reflective writing. Through the use of reflexivity, subjectivity in research can be transformed from a problem to an opportunity (Finlay, 2002).

Edmund Husserl is generally acknowledged as the founding father of phenomenology.

Husserl suggested that phenomena cannot be separated from the experience of them, therefore, the way to access the phenomena is through pre-reflective descriptions of them, in the person's own words (cited in Beck, 1994). Thus he talks of "lived experiences", a phrase which has become the catchphrase of the phenomenological method (cited in Beck). Husserlian or descriptive or transcendental phenomenology believes the researcher must shed all prior knowledge to grasp the essential lived experiences of those studied (cited in Lopez & Willis, 2004). It advocates that the researcher not conduct a prior literature review and not have specific research questions. Another assumption of descriptive phenomenology is that people have commonalities in their experiences. These must be identified and it is these common meanings that represents the true nature of the phenomena studied (Lopez & Willis). Husserl's philosophy was firmly within the framework of a traditional scientific approach with its associated assumptions of objectivity and neutrality (Fleming et al., 2003). These authors further explain that Husserl stated in order to understand the nature of phenomena all prejudice must be eliminated through the reduction of the phenomena to variables. These variables can then be objectively measured. This was prized within the positivist world. Husserl advocated for the use of phenomenological bracketing. He believed in order to expose the true essence of the lived experience it was first necessary for preconceived ideas to be put aside (McConnell-Henry et al., 2009).

Heidegger modified and built on Husserl's work. Heidegger's ideas comprise the interpretive or the hermeneutic research tradition (cited in Lopez & Willis, 2004). Heidegger articulated "being" or "*Dasein*" (translated as "human being"). *Dasein* refers to how one exists in a world where there is interdependence between self, others, and society (Conroy, 2003). Conroy

explains one exists amid a world of shared meanings and understandings in a social context. Meanings are not constructed as individual thinkers for one is always in relation with others. Understanding and interpretation of the world is co-constituted and synergistic. *Dasein* is not static and it cannot be measured objectively. For many philosophical hermeneutic thinkers, including Heidegger and Gadamer, the ontological is primary (Annells, 1996). Meaning lies in the individual's transaction with a situation, such that the situation and the individual constitute each other (Annells). Fundamentally, the meaning of being is subject to the context of that being but meaning always exists. *Dasein* is the entity that allows humans to wonder about their own existence and to question the meaning of their being in the world (McConnell-Henry et al., 2009). In other words, a person constructs reality from experiences of being in the world. Once immersed in a relationship or a conversation with another, it becomes impossible to maintain a bracketed stance. Heidegger's message was there is no understanding from a purely objective position but always from within the context of involvement in the world (cited in McConnell-Henry et al.).

Gadamer followed Heidegger. Gadamer (1976) emphasized that our past and our history influence our understanding and this is a positive condition for knowledge and understanding: "But it seems to me there can be no doubt that the great horizon of the past, out of which our culture and our present live, influences us in everything we want, hope for, or fear in the future" (Gadamer, p. 8-9). Gadamer explains the productivity of the hermeneutical circle, as a process of understanding lived experience developed by Heidegger, is dependent upon our prejudices or preunderstandings that constitute our being. Gadamer puts these prejudices in a more favourable light when he says: "Prejudices are biases of our openness to the

world” (Gadamer, p. 9). Here the meaning of prejudices is more aligned with the word preunderstanding (Fleming et al., 2003). “Gadamer considered it is only through one’s preunderstandings that understanding is possible” (cited in Fleming et al., p. 119).

Hermeneutics goes beyond description of core concepts and essences to look for meanings embedded in common life practices (Munhall, 2007). These meanings can be gathered from participant’s stories with a focus on what they experience rather than what they consciously know. A central principle of Heidegger’s thought is an individual’s realities are influenced by the world in which they live and humans cannot abstract themselves from their world (cited in Lopez & Willis, 2004). For example, in a study pertaining to living with a stigmatizing illness, the interpretive phenomenologist would be sure to encourage the participant, in a conversation, to describe interactions, relations to others, experiences of the body, and lived experiences in the context of daily life. Another concept important to interpretive inquiry is situated freedom (Lopez & Willis). That is, people are free to choose but not absolutely as it depends upon certain conditions of their lives. This is in direct opposition to descriptive phenomenology. Another assumption underlying interpretive phenomenology is knowledge and experiences of the researcher are valuable guides to inquiry and, in fact, make the inquiry a meaningful undertaking (Lopez & Willis). For example, personal and clinical experience has determined research is needed in the area of women’s lived experiences when diagnosed with HCV. The researcher has a responsibility to self-reflect and be aware of biases and assumptions. However, the interpretive research will be a blend of the meanings articulated by both the participants and the researcher. There can be no one true meaning produced by the conversations but the findings must be logical, plausible, and reflective of the realities of the participants (Annells, 1996).

Munhall (2007) believes nursing requires an understanding of various lived experiences. This understanding arises from people telling their experiences of life events. Munhall explains people reach out and beg to be understood and many practitioners in mental health believe feeling understood is essential to health. The inquiry process of hermeneutic phenomenology aims to identify and provide an understanding of a variety of constructions that exist about a phenomenon (Annells, 1996). The interpretation is open to re-interpretation (Annells). Particular benefits cited in the literature from the use of Heideggerian phenomenology from Annells are:

...the revelation of shared meanings, the illustration of uniqueness and diversity, the provision of multiple interpretations of the phenomenon, the unveiling of practices, the seeing of new ways of Being, commitment to understanding, the presentation of evocative, animating and compelling narrative, the aim of keeping the dialogue open and portraying the voices of the informants in their daily struggles, and in their struggles over time. (p. 79)

Annells notes how these comments, in the literature, have come from different continents and this could represent a global awareness of the positive gains to nursing, through this approach to inquiry.

My Research Approach

Allen (1995) argues that a clear distinction between phenomenology and hermeneutical phenomenology does not exist. Fleming et al. (2003) acknowledges there is much debate and different views in the literature on hermeneutics and phenomenology. These authors say there is not one phenomenology or one hermeneutic. My approach is based on Gadamerian philosophy and grounded in van Manen's descriptive and interpretive approach. My understanding is phenomenological research seeks to understand how individuals perceive and make sense of their lived experience (Annells, 1996). This assumes we make sense of lived experience according to its personal significance for us. The writings in this study do not yield absolute

truths and, at best, we gain an occasional glimpse of the meaning of human existence (van Manen, 2002). van Manen explains no interpretation is ever complete and no insight beyond challenge. The hope is this research will bring about an intensified awareness of the phenomenon studied and the reader may see or hear what the researcher overlooked or forgot (van Manen). The word hermeneutic is derived from the Greek word *hermeneou* which suggests that it is “bringing to understanding particulars where the process involves language” (Leonard cited in Annells). Heidegger believed understanding was possible because of relationships, along with an awareness of one’s being and belonging to the world (Fleming et al.). Hermeneutics has a primary focus on understanding and Gadamer (2004) states “Understanding and interpretation are indissolubly bound up in each other” (p. 400). Gadamer understood hermeneutics as a co-creation between the researcher and the participants, through a hermeneutic circle of conversation, readings, reflective writing, and interpretations. The search is towards understanding the experience from a particular philosophical perspective, such as feminist, as well as the horizons of the participants and the researcher (Lavery, 2003). It is the historical, social, and biographical location of both the participants, the transcribed conversations, and the researcher, where interpretation emerges (Allen). Hence, I discuss where I am situated as a researcher. This influences my interpretation and understanding.

I have not returned to the participants for validation of the interpretation of these conversations or text, a decision supported by Gadamerian informed hermeneutics. To return to the participants for validation of the interpretation would suggest that there is a ‘correct’ interpretation, originating from the participant. The interpretation of the transcribed conversations, even by the same researcher, always produces new meaning or new

understandings (Allen, 1995). Allen explains that knowledge is produced and not discovered and this knowledge is an interpretation or understanding of the phenomena explored. This study reflects the interpretations co-created by myself with the participants, through conversations, transcribing the conversations, reflexive journaling, actively constructing interpretations of the experience from the transcribed conversations, while simultaneously questioning possibilities and how those interpretations came about. From this process, shared experiences and new understandings of those experiences emerged. With this new understanding, one perspective on the meaning of the lived experience of receiving a HCV diagnosis and living with this illness is described.

Once my proposal was accepted by the Supervisory Committee, the approach to this inquiry began with obtaining ethical approval through the University of Victoria and the Health Authority. Following this I began the recruitment for participants as outlined in my ethics proposal. Underpinning the recruitment, and guided by my research approach, I utilized a guide by Fleming et al. (2003). This approach identified steps, guided by Gadamer's philosophical concepts that may be utilized as a guide for nurse researchers when using a hermeneutical phenomenological approach to inquiry. Fleming et al. have outlined one approach for hermeneutic phenomenology and I have chosen their steps to guide my research. The steps are: identification of preunderstandings, gaining understanding through dialogue with participants, and gaining understanding through dialogue with text.

Identification of Preunderstandings

The process of identifying preunderstandings began during reflection on my experiences as a nurse and how I came to explore the question identified in this research proposal. The literature

search and my own clinical practice have influenced my understanding of what women's concerns might be, their experiences, and what might be helpful for nurses to better understand. I was aware, in this research, there may be other concerns, other understandings, and new meanings. It was imperative it not be literature identified or previous stories that guided my analysis but the ideas women themselves brought forward in the conversations. It was helpful to keep a research journal and document my own thoughts, ideas, interpretations, feelings, and preparation as I moved through the research steps. Some journal notes as I prepared how to approach the first conversation are:

This is the first time I have worked with a hermeneutical phenomenology approach. As I study and read about this approach I reflect on my nursing experiences. I realize that rarely do I have an in-depth conversation armed with a list of questions. I wonder how I can put this nurse in me, that gathers information, away so that I can be open to, not only the person's experience, but to what might be important to them. I know that gathering demographic information will set the tone for me leading the conversation. It is a comfortable, more in control space for me to be. I had to let this go. I approached my first conversation feeling unarmed without a backup plan. If the conversation got way off track I had to consciously prepare myself that off track was OK. What is off track to me might be the space that reveals the unexpected.

I dialogued with my supervisor and committee member throughout the entire process.

This has helped not only to refine the question and develop the approach, but also to understand better how to identify and address challenges in research. It has helped me to question, for example, the language utilized and the assumptions or judgments embedded within how one describes people. Although there were shared experiences and themes generated, I also prioritized capturing the unique and individual experiences that bring meaning to women's lives. My ability to understand and be open before, during, and after the conversations depended on an awareness of my own life experiences and stories heard thus far. Some preunderstandings I

became aware of through journaling and reflection were intertwined with my own experiences as a daughter, a woman, a mother, and a nurse. Gadamer (2004) describes this awareness:

Rather, a person trying to understand a text is prepared for it to tell him something. That is why a hermeneutically trained consciousness must be, from the start, sensitive to the text's alterity. But this kind of sensitivity involves neither "neutrality" with respect to content nor the extinction of one's self, but the foregrounding and appropriation of one's own fore-meanings and prejudices. The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own worth against one's own fore-meanings. (p. 271-2)

Indeed the topic was chosen and the question developed from my own experiences as a nurse working with people who have been diagnosed with HCV. Following the conversations with participants, I remembered not only stories told to me in my nursing practice, but I also reflected upon my own health care experiences. At times, I felt caught up in these experiences especially if they were emotionally close to my heart. For example, a diagnosis of breast cancer was given to me on my cell phone, in the middle of my work day, on a Friday. It was during these times that I had to reflect, journal, and attempt to explicate what this person was telling me in their situated context. My own experiences would cloud or influence what I was hearing. I also brought the dominant medical knowledge, which is an integral part of my nursing education and experience, to these conversations. It was here I often struggled to remain open to women's experiences. It was opening myself to the embodied experiences and the invisible work that nurses do that resonated and brought me to that 'clearing in the woods' or the 'fusion of the horizons'. It was here that understanding developed and my greatest learning often occurred. However, understanding came only with recognition of biases or preunderstandings. Gadamer (2004) uses the concept of horizon to speak of how understanding takes place. The horizon is explained as"the range of vision that includes everything that can be seen from a particular

vantage point” (Gadamer, p. 301). This understanding is formed by both the personal and socio-cultural experiences and interpretations of the participants and myself. As we participated in the hermeneutical conversation our horizons could be transformed. Gadamer says “understanding begins....when something addresses us” (Gadamer, p. 298). Many of the conversations helped me to reexamine my preunderstandings of HCV treatment and how care is provided.

Gaining Understanding Through the Hermeneutic Conversation

Fleming, drawing on the work of Gadamer, suggests “that understanding may only be possible through dialogue, with researchers being open to the opinion of the other” (Fleming et al., 2003, p. 117). Fleming further explains that a conversation between a researcher and a participant is an acceptable way of achieving understanding about the phenomenon of interest. Gadamer tells us “understanding will appear through the fusion of the horizons of the participant and the researcher. Horizon is the field of vision, which includes and comprises everything that can be seen from one perspective” (cited in Fleming et al., p. 117). It is through conversation we will reach a shared understanding. Gadamer refers to the idea of developing understanding as the hermeneutic circle (cited in Fleming et al.). For this research I had conversations with nine women.

I began each conversation with the open-ended request and a question: Tell me about your experiences of receiving a Hepatitis C diagnosis. What were your feelings and experiences around that? The question was worded somewhat differently each time because I did not bring a list of questions to the conversation. I felt this would help me to be open to what the person was saying and that my next question would be taken from their lead. I purposely left ‘my list’ of questions in a folder not visible to me as I knew a list of questions was a place of comfort and

control for me. Throughout my readings I became cognizant that I must be able to hear what the person is moving away from and where the participant is going (Munhall, 2007). I attempted to verify interpretations throughout the conversations and encourage rich and descriptive dialogue. My supervisor reviewed the first two transcripts and gave me feedback on my interviewing skills. Through this process, I was able to recognize where I had asked questions that were out of context with what the person was talking about and what open-ended questions would be more helpful. The emphasis was on awareness of nonverbal communication and sensitivity to what meaning the person was communicating. Data analysis began during the conversations as I wondered what nonverbal expressions and pauses in the conversation meant. There were parts where I did not know, in the moment, where a descriptive experience was going. I prepared myself by reading Gadamer (2004), van Manen (1997, 2002), Munhall (2007), Cohen, Kahn and Steeves (2000) and a variety of other hermeneutical phenomenological studies. I attempted to follow Cohen, Kahn and Steeves words of wisdom:

A basic premise of the hermeneutic phenomenological method is that a driving force of human consciousness is to make sense of experience. In other words, the understanding people have of their world and life situation and the meaning they have made of this is usually contained in the narratives or stories they tell, first to themselves to make sense of their own experience; then to family, friends, and other social actors in their lives;...and hence the natural focus of inquiry is aimed at understanding the meaning of human experience. (p. 59-60)

Gaining Understanding Through Dialogue With Text

“Analysis of the conversation with the participants should occur with the hermeneutic rule of movement from the whole to the part and back to the whole (Gadamer cited in Fleming et al., 2003, p. 118). I began this process by listening to all of the tape recorded conversations. I transcribed seven of the nine conversations. The two which were done by a transcriptionist I

listened to and reviewed in order to verify accuracy. I immersed myself in listening to the taped conversations and reading the transcribed words while making notes in the margins. I examined each conversation, on its own, prior to looking at the whole of the nine conversations. Fleming et al. outlines four steps I followed in this stage: (1) Examine all the texts to understand the overall meaning of the text as a whole. (2) Next, investigate each sentence or section to expose its meaning to understand the subject matter. This stage helped to identify themes and these themes should be challenged by, and in turn, challenge the researcher's preunderstandings. During and following each conversation I paid attention to what made me feel uncomfortable. What perspectives challenged how I normally viewed those ideas. I reflected upon, questioned, and wondered what the meaning or possibilities for meaning were. (3) Each section of the conversation was then related to the meaning of the whole text. The hermeneutical circle was only fully experienced when the movement back to the whole was included. (4) After the first four conversations, I identified passages that seemed to be representative of the shared understandings that are identified through the research. After reviewing all nine conversations individually, I then focused on the whole of all the shared meanings. Immediately following each conversation, I reflected upon the conversation, the words, the gestures, the pauses, the language used, and the emotions demonstrated. I jotted down journal ideas, thoughts, feelings and observations that might be relevant from the nonverbal communication that occurred during the conversations. These are my field notes and part of data collection. Vocal intonations, physical expressions and gestures, that are not audible on the tape, were recorded in the field notes and later incorporated into the transcribed notes. After the conversations were transcribed verbatim, I consulted with my supervisor and committee member, who have expertise in qualitative research

and hermeneutic interpretive phenomenology. We discussed my approach, how to delve deeper into the descriptions of the participant's experiences, and how to stay with the data. The hermeneutic circle, as a process, is aimed at enhancing understanding, relating parts to wholes, and wholes to parts (Patton, 2002). Within the circular process, narratives are examined simultaneously, never losing sight of each participant's story and context (Patton). I continuously immersed myself in the transcribed conversations.

The field notes and the transcripts were a means to consider the original conversations through a different lens (Phillips, 2007). Phillips explains the fusion of horizons, which occurs between the researcher and the transcripts, is not the same as from the original conversation. This process of reflection is another hermeneutic layer. However, one must be aware that reflection on the transcripts and the conversations themselves are different. "Both events expand our horizons and as a result, understanding is expanded" (Phillips, p. 93). When listening to the transcriptions and reading the written words I would reflect back on the actual conversations. Something new would present itself that had not drawn my attention during the conversation. This would then shift my understanding. For example, a voice would get very quiet and the meaning of this had an impact on me in a different way when hearing it through the audio-tape.

Recruitment of Participants

I recruited participants through third-party agencies which provide services to women with HCV. Agencies such as Outreach Health, Living Positive, and two other Hepatitis Clinics were approached and they agreed to assist with recruitment. Following a verbal presentation by me to the managers of these agencies about this study, they enthusiastically supported the study and provided me with letters of support. A poster (Appendix A) describing the study, as well as a

letter of invitation (Appendix G) was provided to the Living Positive and Hepatitis clinics. The women were given the sample open-ended questions which would be explored in the invitation to participate mailed to them. These agencies mailed out the letters and the poster to approximately 80 women who have HCV or who had been treated for HCV. To ensure agencies were not aware of who responded, interested individuals were asked to contact me directly. In addition, I placed a small advertisement in the provincial newsletter named the Hep C Bull. Potential participants were asked to make contact with me, the researcher, by telephone or email, to ask further questions or to arrange a meeting for a full explanation. The arrangement with Outreach Health, which is a street health clinic, was for me, the researcher, to attend Outreach Health on two specified dates, to see if there were any participants who might wish to participate on a walk-in basis. Within two weeks, following the mail-out of the letter of invitation, I had received responses from twenty women who were interested in booking a time to meet and have a conversation. I also had affirmation from the editor of the Hep C Bull, stating their support of this study. They said they appreciated the subject of the thesis. Of the participants who responded, three were outside the two hour travel time I had stipulated. Although they were aware this was the case, they wanted to let me know that they supported and were very interested in the study topic. After email conversation with them, they indicated they would like to be participants if this research was repeated in their area. One of the twenty women who responded had been a patient at our clinic in the past six months. According to the ethical guidelines for this study, participants could not be a patient at the clinic where I am employed or must have been discharged from our clinic. Four participants had been patients at this clinic more than two years ago and were considered discharged. Two of those four participants attended our clinic more than

five years ago which was prior to my employment there. As this is a Master's thesis, with limited resources, we (my supervisor and myself) decided nine participants would be the maximum I could manage for this study. I booked nine conversations and then, if others wished to be on a wait list, I took their contact information.

When the potential participants made contact by phone, I answered any questions they had and we made arrangements to meet at a private comfortable space of their choosing. I met four of the women in their homes and five of the conversations took place in a booked private room at the local library on a date and time convenient to the participants. We spent the first fifteen minutes prior to turning the tape recorder on, reading and reviewing the consent and ensuring their questions were answered before signing. Once the consent was signed, I asked permission to turn on the tape and all of the participants agreed readily. During the consent process I emphasized that my approach and hope was that we would discuss what was most important to them in their experiences of receiving a diagnosis and living with HCV.

Description of Participants

The method of selecting participants for this study was purposeful sampling. The purpose was to recruit participants who are HCV positive, have a rich experience of the selected topic, and were willing to talk with the researcher (Patton, 2002). This yielded in-depth understanding of women's experience of receiving a diagnosis and living with HCV. Participants who joined the study had the ability and willingness to communicate their experience to others, through a tape-recorded interview, and were over the age of nineteen. I did not collect demographic information. The approach, compatible with a hermeneutical inquiry, of this study was to begin with open-ended questions and encourage the conversation to be participant-led. However, all of

the women shared information about their employment, age, and whether they were mothers within the conversations. All of the participants were Caucasian women over the age of 35. Three were on income assistance, three were retired, and three were employed. Eight of the nine participants were mothers. Five were single parents at the time of their diagnosis.

Establishing Trustworthiness

Interpretation is an unending process and readers of the study make the final interpretation. Evaluation of hermeneutic interpretive phenomenology research considers whether one's concern has been answered (Crist & Tanner, 2003). Interpretations submitted through a rigorous process can then broaden possibilities for nursing knowledge and research (Crist & Tanner). Trustworthiness criteria applicable to a Gadamerian research process has been explained by Lincoln and Guba (cited in Fleming et al., 2003). The conversations began with a broad open-ended question. This meets the criteria for this type of study. Seven of the nine conversations were transcribed by the researcher which facilitated full immersion in working with the data. Throughout the analysis of the findings, it is documented how the researcher moved from the parts to the whole in the hermeneutic circle of understanding. Writing about the meaning of the data, followed by discussion with the researcher's supervisor and committee member, then rewriting validates returning to the data repeatedly. In the findings, the researcher has faithfully represented the text by providing that text with every opportunity to read its truths (Geanellos, 2000). The use of direct quotes in the findings demonstrates credibility. "Which meaning is chosen to represent the text depends on the interpreter, their orientation toward the phenomenon of interest (ideological perspective and focus), preunderstandings, the questions asked and answers sought, and other contextual data obtained throughout the research" (Geanellos, p. 118).

These concepts have been explained in positioning myself as a researcher, my approach, identification of my situated context, and my preunderstandings. No single interpretation ever exhausts the meaning of the text and hermeneutic understandings are multiple and continually evolving (Geanellos). Readers will interpret research findings from their own horizons (Bollnow cited in Fleming et al.). “For Gadamer (1990), understanding can only be achieved by consensus of the whole and the parts of the text” (cited in Fleming et al., p. 119). I have attempted to provide details of the how this process was accomplished in the description of the approach to this study, as well as development of the findings, by providing sufficient direct quotes from the texts, personal reflections, and how the common experiences emerged from the individual stories.

This study set out to describe the experiences of nine women who have received a HCV diagnosis and the meanings of those experiences. It is congruent with the chosen methodology that the women who chose to participate were only those who felt a deep insightful connection with the study’s topic of interest. The conversations are within a cultural and time specific snapshot of those nine lives. Other times, other cultures, countries or socio-economic backgrounds have not been included. Younger women may have different shared experiences and concerns. Women who access healthcare through Outreach Health may have different experiences than those in this study. It could be considered a limitation that these women are not represented in this study. Hermeneutics challenges the assertion that an interpretation can ever be absolutely true (Patton, 2002). “It must remain only and always an interpretation” (Patton, p. 114). The analysis is one perspective, from the researcher’s understanding in conversation, with these nine participants.

The experiences of women who have contracted the virus from injection drug use, blood transfusions, or from unknown causes is not represented fully. Nor can the experiences or themes discussed be generalized to other women who have HCV. The stories told are representative only of individual women, told from their own unique context and perspective, within this unique conversation. Another conversation at a different time may reveal different concerns and issues with the same group of participants. In addition, every time the transcripts of the conversations were read, new insights would emerge. The interpretation is from the researcher's own unique view, forging a horizon of understanding, with some of the participants' experiences. Heidegger reminds the researcher first that meaning is always in the context of something, one's humanity, one's personal situation, or the particular practices adopted by a certain group (Johnson, 2000). Also, the stance that the researcher takes in relation to the conversation, the types of questions asked, how the researcher interprets the text, and the language the researcher chooses to use all varies and influences what is emphasized or deemed important. One cannot recreate the stories, the audience, or the feelings felt when the stories are told. This supports Heidegger's view that the standpoint of humans is to always be involved in the practical world of experience. Heidegger calls this temporality; the way humans have of relating to others in the world (cited in Johnson, 2000). Therefore, the things humans encounter in the world do not exist out there in a detached manner, waiting to be discovered, or investigated. They are all part of an interconnected world of human beings in the world (Johnson). The stories, as told by the women in this study, have the potential for multiple possibilities.

Feminist Landscape

Feminist Research Approach

While this research was informed primarily by hermeneutic phenomenology, the focus on women's experience with HCV made it important to consider a feminist perspective in the conduct of the research. In this section an overview of the feminist perspectives drawn on for this research will be discussed. DeVault (1999) describes some of the rationale of this approach as follows: The aim of much feminist research is to reveal the diversity of actual women's lives and to understand some of what it is that has made so much of those lives invisible. What makes an approach feminist is a commitment to finding women and their concerns, and in doing so, provide a fuller account of the phenomena of interest by including them. She further explains that researchers can utilize this approach for women who share experiences that are meaningful to them. However, commitment to inclusion requires considering women whose experiences are different as well.

Secondly, De Vault (1999) maintains that a feminist approach minimize harm and control in the research process. I am a white, middle-class woman pursuing graduate education and in a position of privilege. I am aware that this places me in a potentially dominant power-over situation. My hope is the hermeneutic phenomenological approach honours the wisdom and diverse lived experiential knowledge shared in this research approach, that this is a conversation shared, and we learn from each other. Finally, De Vault says feminism will seek an approach that will support research of value to women. This value must be reflected in praxis that changes women's lives or the systems of social organization that control women.

Why is a Feminist Perspective Important to this Research

hooks (2000) describes how the feminist movement urged women to no longer see themselves and their bodies as the property of men. "Feminist thinking helped us to unlearn

female self hatred” (hooks, p. 14). She explains women knew they had been socialized by patriarchal thinking to see themselves as inferior to men. This type of sexist thinking made women judge each other harshly and without compassion. She believes much of the class power held by elite groups of women in our society has been at the expense of poor women. It is not a matter of joining the ranks of the patriarchal system that will bring justice to all women. Feminist thinkers did not foresee the assault on welfare and how single mothers would be blamed for being poor and demonized (hooks). hooks clearly describes there is no single path to feminism and people need feminist theory that speaks directly to their lives. “Feminism encourages all of us to courageously examine our lives from the standpoint of gender, race and class so that we can accurately understand our position within the imperialist white supremacist capitalist patriarchy” (hooks, p. 116). For years, feminists held the assumption that gender was the only factor determining their status. As privileged women gained access to economic power similar to their male counterparts, society began seeing this as a positive sign for all women. In reality these changes rarely had gains for the poor and the working class (hooks). The working class and the poor did not feel they had made gains when they realized that working outside the home did not mean they shared the work of the home with their partners.

Oppression in women’s lives is so pervasive, well established, and internalized, that it can remain invisible (Sherwin, 1992). A feminist perspective can draw attention to the barriers of oppression. Women and children make up the majority of the poor in the developed world (Sherwin). In the first year after divorce the average standard of living for men rises by 42% and for women and their children it falls by 73% (Weitzman cited in Sherwin). Women not only experience economic disadvantage, injustice exists within personal relationships. Sherwin

explains that women experience the double burden of working outside and inside the home. A perpetual sense of guilt is fostered as they struggle to earn an income and become role models for their children, are challenged to find affordable child care, and criticized for not spending enough time with their children. Sherwin further explains how women's roles in the bedroom, the kitchen, the hospital, the classroom, and the boardroom also call on them to be sensitive and nurturing. Furthermore, these nurturing roles are not recognized as 'work'.

Sherwin (1992) states feminist changes required to eliminate sexist oppression are deep and difficult to imagine situated in a patriarchal culture. Feminism would need to dismantle the numerous practices that make up patriarchy, work towards a world free from abuse, a world where women and children are not forced into poverty, where women have control of their reproductive lives, and a world where women are themselves nurtured and not the only ones responsible for nurturing others (Sherwin).

Ethical Considerations

The ethical recommendations, from Patton (2002), were utilized to develop the following guidelines. Particular attention was given to informed consent, confidentiality, and the researcher-participant relationship. The Tri Council guidelines for ethics in research were reviewed and incorporated into the ethics protocol for this study. According to the Tri Council Policy Statement for Ethical Conduct (2005) this research qualified as minimal risk. The definition of minimal risk is as follows:

If potential subjects can reasonably be expected to regard the possibility and magnitude of possible harms implied by participation in the research to be no greater than those encountered by the subject in those aspects of his or her everyday life that relate to the research, then the research can be regarded as within the range of minimal risk.

Consent

Initial approval of the proposal was received from the researcher's supervisor, Dr. Bernie Pauly, and the thesis committee member Dr. Carol McDonald. Ethical approval from the University Of Victoria and the Health Authority was obtained. Signed and informed consent was obtained after information about the nature and purpose of the study had been explained. During the consent process some of the participants wished to have the consent (Appendix C) read to them. I followed the guidelines I had proposed in the ethics application by putting the written consent on the table between us and reading through it, pausing for any questions. This was beneficial to those participants who found it overwhelming to read a three page consent due to sight issues or reading ability. In the consent process information that describes situations where there is child abuse or neglect must be reported according to our professional standards. This was verbally discussed during the consenting process and each participant indicated understanding by initialing this portion of the consent. In addition, participants were offered the choice of withdrawing from the study at any time and could request that all or part of the information shared be excluded from analysis and publication.

Because of the evolving nature of this inquiry, the consent was free, informed and ongoing (Polit & Beck, 2004). Commitment to ongoing consent was reflected in seeking permission, following the conversation process, especially when there was difficult and emotional information shared. The consent included the following options: use of the tape and transcript to be cited in written documentations or presentations of the researcher with all identifying information removed. The transcript is only to be used for the purposes of this research project.

The tapes will be shredded once the defense of the thesis is completed. A copy of the signed consent was left with each participant.

Researcher Participant Relationship

Following the consent process, I had an in-depth audio taped conversation about the study topic lasting about one hour. After turning the audio tape off we would have a further fifteen minute conversation. This was often a time participants shared, in-depth, about something close to their heart. Several of the participants indicated they had a need for more information about their liver disease and I sent them books in the mail in follow-up.

There is also the ethical challenge of how hard to push for information during the conversations. There must be a balance of the value of the potential response against the potential distress for the participant (Patton, 2002). If either the participant was struggling or I sensed it was an uncomfortable place for this person, I asked the participant to be a partner in the decision about how deeply to pursue the matter. The conversations were participant led and I did not pursue any matters that were deeply personal. Participants could choose not to answer questions of a sensitive nature at any time. I also utilized my nursing experience to be caring and sensitive to the experiences they were sharing. I drew on my interpersonal relational skills from working as a nurse in a Hepatitis clinic as well as my Outreach nursing experience.

Although there were at times emotional experiences shared, it was also an opportunity to share with a caring listener who was interested in learning from their experiences. The women in this study experienced some emotional distress related to discussing the impact of living with a stigmatizing diagnosis. However the participants were encouraged to discuss only what they were comfortable with and wished to share. Women expressed that they hoped what they shared

would make a difference in nurses and health care providers understanding of this lived experience. They said they appreciated the opportunity to talk about what it was like to receive a HCV diagnosis. Most of the conversations ended with a hug. One participant said she is not sure that anyone cares but she believes that I (the researcher) care. My contact information was left with all of the participants and I offered to provide them with a summary of the study's findings in May of 2011 when I anticipated completion of this thesis. All of the participants were interested in obtaining a copy of this summary. Explanations were provided about accessing counseling. Most of the participants had accessed counseling support services on their own as part of their healing process of living with a diagnosis of HCV. Six of the participants were currently, or in the recent past, accessing counseling and support through services such as Living Positive, their employment programs, and referral through their family physician. The three participants presently not accessing these services felt they did not wish to at this time. They gave reasons such as life was good now and they knew how to access services if the need arose.

I made every attempt to develop a trusting relationship with participants, by being respectful, mindful and open to women's experiences and individual responses. Prior to each conversation we had an initial telephone call that was initiated by the participant. We had a brief discussion about the letter of invitation and then decided upon a mutually agreeable safe and private space to meet. I also called the participant the evening before the scheduled conversation and asked them if they were still interested in meeting. This gave them the opportunity to decline meeting with me if they had second thoughts.

An ethical commitment revolves around the researcher making every attempt to be transparent in showing how they arrived at the interpretation and how the researcher comes to a

new and deeper understanding. Hermeneutical research requires the researcher to be prepared for deepening of self understanding with a commitment to reflective journaling throughout the process.

Participants were offered travel and phone call expense reimbursements upon presentation of receipts, as well as compensation of a \$20 gift certificate to a store of their choosing. During the initial telephone contact I asked the participant which store they would like a gift certificate from. I felt it was important that it be accessible and their choice. Participants did not give me receipts for telephone calls or travel expenses. I offered and they declined saying it was no big deal. If I knew they had some travel or phone expenses I added five dollars to the gift certificate, to ensure this was adequately reimbursed. None of the participants had childcare expenses.

Confidentiality

Interviews were tape recorded and transcribed with identifying information kept separate from the tape recording and transcription. All identifying information was removed in the transcribed data to respect the confidentiality of the participants. Some participants chose a pseudonym to use and I chose one for those who were not interested in choosing themselves. The tape recorded interviews were kept in a locked cabinet in the office of the researcher, with the key kept by the researcher, and data available only to those directly involved in the project. Those directly involved in the project are the University of Victoria supervisor and supervisory committee, myself as a Masters student and the transcriptionist. The transcriptionist signed a contract of confidentiality (Appendix D). The transcriptionist typed two of the nine conversations and I transcribed the remaining seven. All computer documentation was on a computer with limited and coded identity access. This computer was kept in the researcher's locked office. The

tapes will be shredded once the defense of the thesis project is completed. A summary of the thesis may be shared with nurses and agencies who work with women who have HCV and with the participants themselves. The knowledge gained may also be presented to students in health care programs.

Chapter Four

Gaining Understanding Through Conversations

We'll find that as we begin to commit ourselves to this practice, as we begin to have a sense of celebrating the aspects of ourselves that we found so impossible before, something will shift in us. Something will shift permanently in us. Our ancient habitual patterns will begin to soften, and we'll begin to see the faces and hear the words of people who are talking to us.

(Chodron, 2008, p. 47)

Conversations With the Participants: The Centre of the Circle

To preserve the integrity of the individual conversations or stories, I have chosen to discuss and reflect on each conversation separately. Each story has contributed a unique perspective to the whole. Within each conversation I have attempted to be open to the possibilities and understand some of what is going on for one person at one particular place and time. Following discussion of each story I have next attempted to explore what I have interpreted, through these nine voices, as the shared experiences of receiving a diagnosis and living with Hepatitis C. Each story begins with a pseudonym for the participant and a title that emphasizes a particular important aspect of the individual conversation.

Ann: Abandoned

Ann called me the same day that she received her letter of invitation in the mail to participate in this study. When she answered the door she had a firm handshake and made eye contact. As the first participant, Anne's exuberance and willingness to share fostered my sense of confidence and the importance of doing this project. I began with one open-ended question and she took the lead for the rest of the conversation. It was somewhat of a whirlwind to be carried along with her obvious enjoyment of this conversation. She was honest, open, and unsure at times.

Ann received her HCV diagnosis shortly after being diagnosed with another chronic illness. A routine blood test indicated her liver was inflamed and she had some physical symptoms:

I could not figure out what the hell, just itchy all the time, and it is not a good sign I understand. But anyways, the bottom line is I went to my doctor and they do the test. (He said) Why do you think you need this test-well I have tattoos, I have pierced ears, I used to use drugs intravenously, my ex-husband has it, and what else, and I had a blood transfusion. That is more than enough reason, so we tested me and it came back positive, and ya I was quite angry, not at my doctor, but I was angry that I even had this and how long have I had it, and I guess there is no way of really telling, or what gave it to me.

She was angry when she heard she had HCV. After receiving the diagnosis from a specialist she described as cavalier, she goes on to say:

But to go back to this doctor, I really felt abandoned through that whole process because my doctor really did not know....So the whole thing was like, not that it is their concern as to what I am doing, but there was very little compassion shown and you know the weight thing kept coming up and yes you do not need to tell me I am overweight. I am pretty well sure I know about that and there are other things I need to fix but right now we need to do something about this Hep C. I need to know more about it. So the information I got from the specialist was crap, to be honest.

When Ann received treatment, she had a similar experience with lack of information. She states:

I did the Pegatron thing and ya, it did make me pretty ill, but I mean, you know I had to fight a lot of colds and a lot of stuff and I dealt with this doctor's office, this specialist's office, that talked to me about the Pegatron, and what it could do. But you know, when you are first taking this crap you've got a lot of questions and when I phoned in I got nothing but attitude from both her and this doctor. Basically, it is not our business; go ask your own doctor. My own doctor doesn't know shit about Hep C...but it is like going to the diabetic centre versus my own doctor. I will go to the diabetic centre if I have any questions because they are there for it.

Ann feels she did not receive adequate support and information and felt she was treated quite badly with her treatment and care. When Ann is describing how she was treated, she utilizes nonverbal reinforcement of her words, by waving her hand dismissively through the air. Ann's

anger was not directed towards the doctor who told her the HCV diagnosis. However, her anger is directed towards the specialist she was referred to for education, treatment, and support. She may feel angry because instead of support, she experienced abandonment and possibly felt somewhat judged.

Abandonment describes a fear that you will be left alone to deal with these difficulties when you are feeling least equipped to do so. Abandonment is the feeling Ann describes when no one cares, when she is told the many things that are wrong with her, and given the treatment plan. She casually mentions “the weight thing” and I sense that her medical diagnostic experiences did not acknowledge her feelings, as she was repetitively told she was overweight during the course of her education, treatment, and support for the HCV. I wonder if she felt judged and blamed for acquiring HCV and being overweight. This would explain her anger and sense of abandonment as she began to navigate learning how to manage multiple complex health issues.

In contrast to her HCV diagnostic and care experiences, when she speaks of her diabetes experience, she sits taller, speaks with a sense of confidence in her self-knowledge and management of her diabetes, and feels ongoing holistic support. The following passage demonstrates the chronic illness support that was helpful for Ann.

They (diabetic nursing support) helped me out when I was going through depression. My doctor couldn't help me out. This summer I was trying to find a job and like I had been traumatized (by a previous job experience) and I was just crying at Drano commercials. I mean I couldn't keep my stuff together and I went over there and she helped me through three months of that, and then I got into therapy but she helped me through the hard part. She (diabetic nursing support) said we don't care, come over anytime you want. Ya, they are not just stuck with the diabetic thing.

She has multiple ongoing chronic health issues including diabetes and HCV. In addition, to managing several chronic illnesses, she was experiencing multiple intersecting issues in her life such as the loss of employment. Having her emotional being acknowledged and recognized was an important aspect of her healing and integral to her care.

When one is diagnosed with HCV a common diagnostic test ordered is a liver biopsy to assess the extent of liver fibrosis or damage from the virus. This test also reveals if there are concomitant factors such as Autoimmune Hepatitis.

You know what, I have been to (name of hospital) a few times and I have had the horror stories. I think also, that gets generated by who you are, what you are doing, and what level of discomfort you are at, of course. But when I went in for that liver biopsy and they rolled me in I was pretty terrified because I knew what they were going to do and so I just, there was a doctor and a nurse holding my hand. I'm not scared about needles but this is my liver okay, and she held my hand and I said to the doctor, I tell you what I got 20 bucks, I will give it to you if you can get it right the first time....they just treated me great.

It is interesting to note that Ann was terrified of having the liver biopsy. However, this is the experience she describes as being amazing and positive. She said "They were amazing in there." I was left wondering how being wheeled into a cold procedure room, in anticipation of having a six inch needle inserted into one's liver, could evoke positive feelings? I assumed this is usually an experience that is quite frightening. Ann has also just described anger that was compounded by a recent experience of feeling abandoned by her physician. In contrast, the connections the physician and nurse made with her contributed to making the liver biopsy a positive experience. They spoke with her, held her hand, and she could joke around with them. Telling a joke and laughing was possibly a way that she could release her fear and stress and feel a moment of distraction. I believe she also felt cared for. Following the biopsy Ann says "I would not be as frightened the second time going in but I would want somebody there..." The human to human

contact and interaction were critical factors during Ann's diagnostic liver biopsy experience and in her feelings now in anticipation of future procedures she may need to have.

Ann mentions several times that ongoing information would be helpful for her in managing the HCV:

Let me have more understanding. I am not an idiot. I just want to understand my disease so I know that if I am doing something that is really, really wrong that I can knock it off right away or something like that, whatever... Ya more knowledge, doctors need to be more forthcoming. They need to admit when they don't know what's going on. You know, I mean, I don't know if we can ever change that but if they don't know, don't just say well it's one of those things, it's part of the virus. I don't want to hear it's part of the virus unless it is part of the virus, you know. Or don't be so quick to knock it off like, oh you must have a fatty liver because that makes your ALT go up. That's fine but explain to me how it works, like is there any information that can explain to me how that works and again, I refer back to the diabetic centre.

Ann would like a place to go to for accurate ongoing information about HCV as a chronic illness, similar to the diabetes centre she attends. When HCV care is accessed under an acute care, treatment only, model of care, people's chronic illness care needs are often not met. "It is chronic and you fight it and half the time you do not know what you are fighting. Like what symptom is going to come up next. When should I be worried if I notice something, right?" It would be helpful for Ann to have a centre of knowledge and expertise that she could access when she has worries about her health.

In addition to the above described information needs, Ann talks about her concerns of transmitting the virus to other people. When she learned she had HCV one of her first concerns was about her daughter:

I am going to call my daughter because I do not know, like you know, you are always bandaging your kid from stuff, right...I do not call up anywhere and make an appointment without first letting the nurse know that I am a Hep C patient. That is the first thing out of my mouth.

The most poignant time in our conversation was when Ann explains what worry about transmitting the virus means in her everyday life when she goes for a job interview:

And so I applied for it and I shook their hand and I left and you know what it just really bothered me. I got in the car and I looked at my hand to make sure I had no cuts and I went, now this does not make you any different than anyone else. You shouldn't be doing that, like that should not be an issue unless you have a gaping gash on your hand in which case you really can't go to a place like that anyways. Well because you know that you, I could easily transmit my disease to someone that way and I do not want to do that but you are self-conscious about it.

Ann has an internal message telling her that touching could infect others. Although, she knows this is not true, she thinks about it and is consciously aware of the HCV, when she touches someone. She has an acute awareness that she has a virus that could potentially be passed on to others.

Shifting to look at the whole of Ann's story, there are many examples where Ann talks about what information she might like or need. She would like information about the illness and the risks of transmission. HCV is potentially infectious although not easily transmitted. She is not completely sure of how HCV transmits. She states "I do not know how it transmits." This statement clearly indicated a knowledge deficit. The significance of this was demonstrated after the tape was turned off, when Ann asked if HCV was transmitted by saliva, and if it was OK to give her daughter a kiss? I sent her two books following our conversation so she would have access to accurate information. Given the level of nervousness and possible intimidation some people feel when speaking with a specialist, as a nurse it has many times been evident to me that one can remember very little of what was said, or one can feel there is not enough time to answer one's questions. Another possibility, which I thought of during this conversation, was that asking a question such as, "Can I give my daughter a kiss?" may seem like an insignificant question to

ask a specialist. I reflected back to Ann's first concerns upon hearing she may have HCV. She wondered if in the many ways a mother cares for her child that she could have infected her daughter. I also cannot help but wonder that during the diagnostic experience that was described as abandonment, along with feelings of being judged and blamed, that it might be intimidating to ask a question where you expose yourself as a mother who possibly infected her child?

Joan: Suffering Revisited

Joan and I had our first interaction on the phone, when she contacted me to participate in this study. She was soft spoken and wondered if she might have something interesting to share. She indicated that her preference was to meet in her home. There are parts of the conversation with Joan that are inaudible because she has a soft, gentle voice and at times during the conversation, she was whispering and sometimes crying. The way Joan tells parts of her story signifies the depth of the burden she silently carried, deeply buried.

The actual experience of receiving her HCV diagnosis is one of shock:

I'm thinking it's a mistake, it's a big mistake. And I was called in by my doctor...and he said you know you've got Hepatitis C, you know. What have you been up to? I immediately related it to a sexually transmitted disease. That was in my head. Of course, it made me absolutely sick. There could be no possible way.

For Joan, it put her whole being into question, imagining that only a certain lifestyle or a certain kind of person could have brought about a diagnosis such as this. Overall, receiving this diagnosis had a profound impact on Joan's life and self perception. The emotional impact seemed far more arduous than the physical implications of the illness. She shared with me how it brought to the surface memories of a very painful experience from many years ago. As a result of an abortion Joan received a HCV tainted blood transfusion. She relived this experience following her diagnosis and talks about her sadness and guilt:

Then when the Hepatitis happened I thought it was punishment for what I had done. The doctor gave me pills (to bring on contractions) and I only took some of them, and then it was about a month later, way too late for an abortion, that the contractions came. I have to admit that I cried almost daily.

Joan cried daily for six months and was only able to come to terms with her memories after receiving counseling. The diagnosis of HCV is a constant reminder of the circumstances surrounding the transfusion and infection with the virus.

In the conversation, she can only speak about the abortion that resulted in receiving a HCV infected blood transfusion in tearful whispers. She has interpreted the affliction as punishment for past sins. What is profound about the whole conversation is the multiple intertwined layers of guilt, grief, abuse and resilience. Following Joan's whispered description of having the abortion she ended with "He (husband) left me anyways." She had to live with what had happened, as well as go to work to raise her young family as a single parent. "And um, I certainly wasn't an angel, I was a single mom. I was working quite hard to maintain ourselves because the settlement from the divorce was slow and complicated and not good." Given that Joan only took a portion of the pills to stimulate contractions, and it was a month later that the actual abortion resulted, I found myself wondering whether this was more properly a miscarriage, and whether such a distinction would have proven helpful to Joan in reducing some of the guilt she has carried through the years. Or is this my heart wishing to help Joan? However, Joan believes that she aborted this baby.

Once Joan received the diagnosis she told her volunteer colleagues at the foodbank:

They said that is fine, just wear your gloves and work in the back. They were really good about it. Here I am serving street people living under a bridge and they have to be protected from me. I found it fairly comical. No, it's not comical; ironious I guess.

Joan's diagnosis triggered a complete re-examination of her perception of herself or being. Her embodied experience of receiving a physical diagnosis is what gives us access to this lived experience. This was her self-realization, of the possibilities of her character, when she was asked to wear gloves and work in the back, once her volunteer colleagues were told about her diagnosis. Receiving a HCV diagnosis was a turning point, or a time to reflect on her values, and how she now sees things. I had a sense that adversity had created an inner being that had more substance and authenticity.

“And uh, over a period of far too long, I was feeling this sadness, this sadness I was carrying. Couldn't handle the sadness I was carrying.” Joan described a pervasive sadness that, upon reflection, she realized had been a part of her for an incredibly long time. It is possible that Joan has not really had an opportunity to grieve the loss of her baby or take a rest from her emotional burdens. Joan whispered very quietly when talking about her sadness. The whispering, lowering of her head, and slumped shoulders was symbolic of what continues to be a burdensome secret.

I thought it helpful to utilize a metaphor to describe the emotional burden. A woman, and a mother, carries much with her on this journey called life. Imagine the babies carried first in one's uterus and then on one's back and hips. The bags and bags of food one carries into one's home to nourish oneself and those one cares for; books and toys, or any manner of objects, which occupy one's family and work day. One can set these physical burdens aside and rest for awhile at the end of the day. However, the intangible things are not easily disposed of (O'Brien, T. 2009). Feelings, secrets, sorrows, sadness, memories of the contractions, the what ifs.... are just as heavy upon one's shoulders. I imagined Joan with a heavy, yet invisible, backpack on her

shoulders. She was sleeping with it, waking up with it, and carrying it every minute of every day. Joan's sadness became raw and real again resurfacing with the HCV diagnosis. However, it also opened the possibilities to share this heavy burden with loved ones. "And at that time I didn't even tell anyone. I didn't even tell my sister." She has now shared her story with loved ones, easing the weight of the emotional backpack so she can take a rest. The Hepatitis diagnosis has opened the doorway for her to share her loss with her now adult children and her sister.

Joan has not been able to access compensation associated with receiving tainted blood. I asked her to tell me what it was like to try and get compensation. Joan has not mentioned to any health care professionals that she ever received a blood transfusion. It is through hearing her whole story that one is able to understand the context of this experience:

It brought it all back (the abortion). There were times I couldn't answer the phone. I sent for the forms, that you have to fill out. So I did all of that. Apparently if I had only made a statement to anybody, the doctors or hospital admissions, about a transfusion, it would have been written down. But I never thought of it because I had it so buried, I didn't want to think about the contractions, the fear and the...I had...young children. I didn't deal well with that. I couldn't speak to anybody. There was no evidence, no records left. But my husband was there. But they said, oh no it can't be your husband. Even though he is not my husband any longer. The evidence just wasn't satisfying them at all. And up to this date I don't know if I will ever get compensation, I have no idea.

An overarching meaning or understanding I sensed from hearing Joan's whole story was her experience of being a changed person inside herself as a result of the diagnosis. She describes how she sees things differently now and she would be "somebody that wouldn't judge." A widely used definition of compassion is "that it reflects a deep awareness of the suffering of another, coupled with the wish to relieve it" (Chochinov, 2007, p. 186). Her previous normal self perception was not one of a person that others would need to be protected from. Her use of the word 'ironious' stresses the absurdity of the situation. This may have had a

significant impact on the development of what she describes as a different kind of compassion. This compassion is demonstrated at the end of the taped conversation when it is Joan's wish that someone could talk to her. She wishes to be a non-judgmental person someone could share a secret with. She believes this would be helpful to others who may be burdened with secrets deemed shameful by societal values. I sense that Joan developed a deeper understanding of her depth of compassion and her own possibilities which she feels is more true to herself.

After the tape was turned off, Joan described her volunteer work in care homes. She does not describe it as work but as joy. She describes how people's eyes light up, the music brings joy to the expression on their faces, they sit taller, make eye contact with those around them, and one person's fingers tap to the music on the arm of their wheelchair. The whole atmosphere of the home is transformed. As Joan describes this experience there is a sparkle in her eyes, she leans forward, speaks louder, is energized, and smiles. Joan is not magnanimous in her descriptions. However, she rather humbly describes her volunteer endeavours as bringing far more joy to herself than she could have asked for or imagined. She has re-engaged with her community following the HCV diagnosis which had triggered reliving a particularly traumatic period in her life.

Cathy: Treat People Like People

Cathy told her story utilizing descriptive and emotional language. The impact of receiving the diagnosis was significant for all of the participants so far and Cathy describes what this was like for her when she arrives at the physician's office to get the results:

I am sitting across from his desk and he goes, well they came back. He said you have Hepatitis C. And I am lookin at him. I didn't hear him say that, did I? And I thought it can't be right. By that time I had heard about it (HCV) and I knew more about it. I said, Oh my god. he might as well have told me I had cancer. It felt like this sledge hammer

between my eyes. I knew it was contagious. And I remember I was out with a group of women once...and this woman walked in the restaurant past us. One of the girls said, did you see that woman? I said, ya. She's got Hepatitis C. And everyone went, oh my god, and I thought geez, well you don't want to have that.

She further states "oh my god, now I am one of those women, it is like leprosy." While she was experiencing this emotional reaction and the meaning it had for her in her sexual relationship, the physician delivering the news was completely oblivious to her experience of being hit by a sledge hammer with this diagnosis. Cathy expresses few concerns about the physical or medical aspects of the illness. The feelings described are almost completely located within her relationships and her socio-cultural understanding of having this virus. She heard the words through the lens of her previous social exposure to Hepatitis C and stigma. Her fears of being discarded by her new partner were unfounded in reality.

Cathy then describes a traumatic situation, during a breast biopsy, under a local anesthetic. She had to return to the hospital, by bus, to give a blood sample because the physician doing the biopsy had poked himself. Cathy was shaken to the core and devastated at the possibility of infecting another person with her blood. She describes this experience:

Covered in my blood into him (the physician poked himself with a needle that was being used to stitch Cathy post biopsy). I said oh my god, I was so upset, I said I'll be right there so I got on the bus, went back down and I was still unthawing. I had to wait to get into the hospital to give blood. I talked to this woman, a counsellor, before I went in because I was crying and all upset. I want to know if he is going to be OK and what his results were. She said that is a privacy thing, we can't tell you that. I'll never know if I gave it to him or not. They can't even tell me if he didn't get it or not.

When Cathy arrives at the laboratory to give a blood sample she describes what her experience was like:

Yes I tell everyone that touches me that that I have Hep C. I always make sure they know. This woman would not look at me, she would not speak to me, she wouldn't acknowledge anything about me. I said, gee I'm kinda sore, I'm having trouble gettin

my sweater off, I'm sorry, I'm kinda sore. She just treated me like CRAP (emphasis). Like I was a prostitute off the street. I don't know whether in her mind Hep C, drug addict, or what the 'hell' she was thinkin. I totally felt like I was this disgusting person that she didn't even want to touch and she just had to do it for her job.....And I just felt terrible about myself.

The lab technician does not make eye contact or assist Cathy with removing her sweater. The lack of eye contact or a reassuring touch, at such a vulnerable time was the most emotionally descriptive experience shared in this conversation. Cathy described getting infected by the virus and many significant events in her life. However, this experience had a profound impact on her and was evident in the hurt, anger, and tears expressed.

One of the most ordinary experiences one can have is to look at another person or to be looked upon. There are many types of looks such as the hostile look, the loving look, or the intimate look (van Manen, 2002). Cathy's descriptive encounter of 'not being looked at' gave her a feeling of being a non person. It is true that a look, or in this situation the avoidance of being visually acknowledged, can evoke significant feelings of stigma. It is not so much what one does but also what one does not do. Cathy was in a vulnerable state when she returned to the hospital to have her blood drawn. She had just experienced a breast biopsy under a local anesthetic.

Cathy described the experience of having her breast frozen to remove a suspicious lump. During this procedure she is so diaphoretic that she is concerned she could be electrocuted by the cauterizing wires. She is sweating profusely from the stress of the procedure. "They had to cut right down to the rib wall, they had to pry it open" in order to remove the lump. However, it is during the above quoted passage, about the fear of infecting another person, that Cathy becomes emotional and starts to cry. She goes home following the breast biopsy and is called to come back to the hospital to provide a blood sample. While still frozen she has to walk to the bus stop,

sit on a hard bench, wait for a bus, ride to the hospital with multiple stops on the bus, and then walk from the bus stop to the lab. She is sore and feels it when the bus driver steps on the brakes and every little bump in the road pulsates through her body. Cathy has had a traumatizing local breast biopsy procedure, the results of which are still pending. This is the kind of day Cathy has experienced when she arrives at the lab to give a blood sample.

In the midst of Cathy's descriptive story, I was drawn into the inner hermeneutical circle. I imagined this experience and got caught up in the powerful images of vulnerability that her account provoked. Cathy describes how vulnerable she felt hooked up to wires not knowing if they could electrocute her. She was soaked in sweat which evokes the images of how physically taxing this was on her body. Having experienced a breast biopsy myself, I knew not just the physical experience but the inner agony such a procedure induces and the fear what the results might bring. It is like having a tight rubber band strapped around your chest and one finds it difficult to breathe because the band will barely move. I watched Cathy breathing wondering if she felt this same experience as she described what happened. I was not sure where her descriptive experience was leading. I was surprised when Cathy became more emotionally involved, as her story unfolded, about having her blood drawn. The blood draw was a moment when she most needed a reassuring look and a touch and possibly someone to say, "This is not your fault and we are going to help you get through this."

As I stepped back to the perimeter of the circle to look at this situation, I imagined going about one's day at work, focusing on the tasks at hand, and not really seeing the people one is poking, or turning, or the multitude of tasks health care professionals perform daily. I know I have done this. This is not a matter of time constraints, staff shortages, or lack of equipment. It

requires awareness and understanding that can be more deeply appreciated through lived experience stories. I wonder if this descriptive lived experience of a blood draw could be told in every university and college where health care professionals are educated. What could we learn from this? The impact of this story on students could be pivotal if, during their education, the way in which they impact vulnerable persons were highlighted. I am not able to discern whether the lab technician was truly just going about her daily tasks or whether she felt this way about people who have Hepatitis C. Either situation is a possibility. The value or understanding is seeing it through Cathy's eyes.

I felt bad. But I tell you this has certainly taught me, boy. This has taught me. I'm a better person. Because I don't do that to people. Totally because now, you know, I don't look down on prostitutes or drug addicts. I have a child who is actually a drug addict so I've been dealing with that for years. I treat people like people. Even these people begging on the street, I always make eye contact with them. If I don't have money I say I am sorry. I notice people just keep their eyes straight and walk right by. Or mmmhhhh don't bother me, you piece of trash, kind of attitude, you know. But because of the experiences I've had and the way I got treated, totally unjustly, I thought wow I know what they feel like to be treated less than a person.

I found the above passage a powerful message of understanding from Cathy's perspective. She felt she was treated unjustly. I wonder that there would ever be any kind of situation that would warrant or condone this type of treatment. She describes what she witnesses in everyday life when she walks down the street. She demonstrates what one human can do for another with true compassion. A kind nod or a look of acknowledgement can uplift the spirit and help another to feel they are a part of this experience we call life. I reflected on this passage, in the moment, during our conversation, and again when listening to and reading the words. This resonated with me because I was curious about the language Cathy utilized in her description. She said she treats people like people. What does this mean? She was courageous enough to

share her vulnerability and this created openness in our conversation. This helped take me to an understanding of how this has helped her to communicate from a more genuine place. She treats people as she hopes to be treated, because we all come from a place of vulnerability at different times in our lives. This is a look into another's eyes with understanding and with the recognition of one's own vulnerabilities.

Cathy's description of when the lab technician drew her blood was an epiphanal moment. "When such experiences emerge in ways that disrupt or permit significant transformation of people's lives, one may rightly use the word epiphanal" (Denzin cited in Hepworth & Krug, 1999, p. 240). This experience produced changes and a re-examination in how she views and interacts with people who others might look down upon.

Dee "A Shock, ya!"

A letter. What is the meaning of a letter in the mail? There are letters that cause one to be curious and wonder, what news will this reveal? A letter can be saved, re-read and carried about. Different letters mean different things and most of us have some memories of getting a letter in the mail, looking at the stamp, how it was addressed, and turning it over to examine it from all angles; wondering what it is about. One might tuck it away, to relish every moment of reading it later; when curled up on the living room sofa with a cup of tea. If it is handwritten, the style of the writing can bring back memories of who that person is. While searching through the closet one day I found a box of letters that my mom had written over the years and for some reason I had saved them in a shoe box. Time stopped as I became lost in the memories of reading them, once more, many years later. I transported myself back to the time when they were handwritten.

Dee received one of those puzzling letters twenty years ago, by registered mail, and wondered what news it would reveal. She knew it was from the Red Cross blood services prior to going to the post office to pick it up. She wondered if they were notifying her of her blood group. This all seemed so official. So she tucked it away to open later. She drove home, walked into the house and sat down at the kitchen table. Again, wondering, as she carefully opened the end of the envelope careful not to tear the letter inside. She pulled the piece of paper out and unfolded it. Right there in black and white, with her name stamped at the top was the news that she had tested positive for Hepatitis C. Dee describes the experience of opening this letter. “And I’m sitting there by myself reading it, and I’m like Holy Pete how did this happen?” It seems somewhat ironic that she received the virus through a blood transfusion and that when she went to be a blood donor a few years later, she discovered this diagnosis. “Twice a year I would go and donate, and then in the mail, came this nice little letter. And that’s how I found out.” “A shock, ya!”

Twenty years later, Dee brought her letter in to share while participating in this conversation. We sat down at the table and Dee had her hand on a letter-sized envelope, ready to pull it out from her purse. I could sense that what she had to share was very important to her. The envelope was worn as though the letter had been taken out many times to read. She laid the letter on the table between us pushing it towards me, waiting for me to initiate the conversation. My first question was to ask how she had found out about her diagnosis. And she responded by gesturing and turning the letter towards me so that I could read it. The letter is dated 1991, has her name on it, and informs her that she has tested positive for Hepatitis C. Dee puts her finger on the sentence where it actually states Hepatitis C. It looks rubbed and a bit smudged as though

someone has read this many times, following this one sentence with their finger. Dee has completed treatment, successfully cleared the virus, and has also received compensation. Her primary concern is when she is around her grandchild and she bleeds for any reason. She says “I wonder if it is ever going to be totally totally gone. Like can it come back again?” Her final thoughts at the end of the conversation are “I don’t know, just receiving that letter in the mail was such a shock.” An interesting contrast given the research question: for some participants, there was personal contact but it was extremely negative and for Dee it was the most impersonal way she could be told she had HCV.

Toni: Very Lonely Diagnosis

Toni learned about her diagnosis of HCV when she was sick with liver disease. The virus had caused significant damage. She started treatment with Interferon and Ribavirin and experienced profound psychiatric side effects. In addition to psychiatric effects this treatment can have debilitating side effects similar to chemotherapy. Toni experienced dark and depressive thoughts and wrote in her journal throughout treatment. She brought this journal to our conversation to share an intense glimpse of this period in her life.

I would get up and I would stand at the kitchen window, waiting for my coffee, and I would cry. The tears would just come. I was crying all the time for nothing. So then, I was getting very impatient, I would be rude to people in the stores if I didn’t get what I wanted right away. I would be swearing at them. I plotted revenge against my neighbors and I planned suicide. And I just, I had no problems in doing that. And mmmm. Everyday I would stand at the window and cry.

Tony was in a situation that was life threatening. “It was scary, very scary. I wasn’t scared myself, at the time. I was thinking this is OK, this is what I have to do....And I had no qualms about it.” She was also looking for support and companionship when she asked her nurse if there were any local support groups she could join.

Yeah so women can get together. Like, I say, I don't want to tell anybody. Out in the public, that's my conception anyways, when you hear someone has hepatitis C they're a dirty drug addict, they use a needle. I have told my nurse and I don't care how you contracted hepatitis C, I will sit with anyone for as long as it takes if they need someone to talk to..... Well yeah, I felt so alone. I only had my partner to talk to about it and he passed away. I never told him about the thoughts of suicide that I had. I never told anyone that.... People would email me and then when I did get up I would check my email. I will always have a computer and email. It was my window to the world. It's a lonely experience, very lonely diagnosis. I don't know what the nurse's reason for discouraging me from going to a support group was. mmm I don't know, it's in the wrong part of town. There's some of the wrong type of people hanging around there. But I had no-one to talk to.

Tony was profoundly lonely with her dark thoughts. She was grappling with this impatient, medication induced, suicidal personality suddenly thrust upon her. Her thinking became tortuous with no control over the dark thoughts. Tony laid her journal on the table between us knowing that it contained a story that was scary and lonely. I wrestle with my thoughts and my own understandings on the meaning this had for Tony. Looking at the parts of this conversation Tony described her tears and suicidal thoughts. However exploring the whole of the conversation I have a sense of intense and scary loneliness. I imagine her standing at her window in despair, wondering who this person is. This is a descriptive metaphor of her loneliness, looking from inside herself to the outside world, tears streaming down her face, wondering who she can connect with to share this anguish. As social human beings shared experiences can bring meaning to all that we are. Sharing can help us better understand our health struggles to better help ourselves. There was a support group in Tony's community. However, her health care provider recommended that she not attend.

I am wrestling with the concept of loneliness that Tony describes. Illness can be a solitary battle and it is a common experience that people seek out others with similar afflictions. Tony understood that the nurse had the best of intentions when she advised her not to join the support

group. However, it reinforced her social experience that Hepatitis C was a stigmatizing illness. The only group was located in the “wrong part of town” which alluded to the possibility that she needed protection from seeking out companionship there. It raised questions for her about what kind of people hang out in the wrong part of town. It is possible the nurse advised her not to go to the local support group for safety reasons. As I thought about this I may have given her the same advice. It is also possible the support group was a viable safe option. What prejudices do we as nurses bring to the advice we give? The result was the only person she could seek out for support was the nurse. Tony wanted and desperately needed peer support. This story is an exemplar for me to examine and explore my own preconceived understandings, of how one might be assigning people to certain groups. This exacerbates the stigmatization and loneliness of this illness.

After we turned the tape off (the conversation had come to a natural conclusion) Tony talked about how she felt as though she had leprosy and was sent to an island. She felt all by herself because she did not even fit in with others who had the same illness. She truly believes she has much in common from living with the illness and going through treatment. She wishes to reach out to support other women now. Tony’s experience is an illustration, in helping me to understand possibilities, of how to approach access to support groups. We can trust that women will find support in multiple, creative and unique ways without predetermining who fits what sort of social peer group. I would like to conclude with Tony’s perspective: “....until this moment I have never been able to sit down with someone that has Hep C, and talk to them, and say how did you get through it?” She would like to give back and be a support person for others with HCV.

A woman's support group would have been a helpful resource for her during this time. This need continues today for her. She has heard about someone who has HCV and does not want to talk about it either. "She didn't want anyone to know. If she has that outlook, the same as I've had, there is something in common here." Toni is telling us that this experience has been very isolating for her. She would like the opportunity to try to understand her experience better by discussing it with someone who is living with HCV.

Toni said she did not experience stigma. However, she hesitated about telling people about her HCV. "But in the beginning I didn't want to tell anybody, I didn't want to tell my friends.....Because of the connotation of Hep C. Right away, they would think you are a drug addict." She believes she did not experience stigma because the first question people would ask was how she got the virus. She felt a blood transfusion exonerated her from the stigma that someone else might experience if they were infected from less socially acceptable sources. Toni could feel this when people asked her how she got the virus and she wondered how it would feel to carry the burden of blaming oneself, in addition to managing the debilitating psychiatric effects, she experienced. There is a powerful theme emerging in the data about whether there are deserving and undeserving victims of HCV.

Sherri: Mark of Death

Sherri described her experience of coming to know her diagnosis of HCV as crushing. She refers to it as a death sentence. She learned of the diagnosis during a vulnerable period in her life when she was in a recovery program. This was during a time when she was beginning to feel like she was pulling things together. She was recovering from alcoholism and trying to leave an

abusive relationship. She received the news over the phone, with no follow up information or support:

And so I went and had the blood work done and they called me on the phone....I don't remember today how long it took. But they phoned me and said, you tested positive for Hep C and that's it, just right over the phone. Have a nice day. It was crushing, it was crushing because the other part of my story is that I'm a recovered alcoholic....I found out about the Hep C and I was so proud that I had made it....And I thought the worst was behind me....So when that call came the relationship with this fellow was also abusive and bad. When that call came I thought it was a death sentence, well I knew it was a potential death sentence.

Sherri almost relapsed with alcohol use and felt suicidal. She had no information on how it might be transmitted. Her first worries were about her grandchildren and she relied on her cousin, who was quite knowledgeable about medical issues, for information about the virus.

When Sherri received her diagnosis of HCV she did not have any physical manifestations of the illness. People present with a range of no symptoms to vague feelings of fatigue or itchiness. They may have swollen legs and a distended abdomen, which can be a sign of severe liver failure. Some people can have very few symptoms and have severe liver disease with this virus. However, this diagnosis had a profound impact on her self identity:

I literally, kind of, crawled out of that house on my hands and knees scraping my way through the door. Like that's how difficult it was for me. A lot of it, from my point of view, was tied up around the Hep C and what was I going to do. Look at me now. I'm a complete failure. Mark of death, great big mark of death.

It is as though she had an inside voice telling her she really did not deserve to get well. "So I stayed in this abusive unhealthy relationship because I thought I'll never get anybody else, I'll never be able to be in a happy safe, you know, relationship." Sherri was enmeshed in an abusive relationship, both socially and financially. She feared loss of financial support and doubted her abilities to look after herself, or to move into a healthy relationship in the future.

The importance of women's voices, and the context of their experience, cannot be underestimated. Many women are conditioned that they are responsible for making the relationship work. When it does not, it adds to a long list of failures, from society's expectations, of a woman. Sherri's description of leaving this relationship gives a mental image of how grueling it was. She utilizes a descriptive metaphor to communicate what was happening in social reality (Rudge, 2009). Crawling her way through the door is her embodied experience in the context and complexities of her lived experience. It is not possible to separate the HCV diagnosis, the family of origin issues, the addiction illness, the abusive relationship, and her social and cultural experiences of being a woman into categories. They are multi-layered and inter-connected.

During the conversation Sherri mentioned her son's death casually. I was not sure if this was a place that she wanted to go. She then mentioned it again and said her son had died of an overdose. She moved lower in her seat, her voice was quieter and she lost her train of thought. It was evident that this was a painful topic and I let it go where Sherri wanted it to go. I did not ask any questions and instead gave her the opportunity to change the subject or to talk about her son. Sherri returned to talking about Hepatitis. Towards the end of the conversation Sherri initiated conversation about the circumstances surrounding her son's death. Reflecting on this part of the conversation I wondered how this related to the whole of the experience of receiving a diagnosis of HCV. Sherri booked herself into treatment and explains why and what this meant for her:

For me it was not about my alcoholism because I was no longer drinking. All the other women, my cohorts, it was about their disease. For me it was about the emotional crash that I had relative to stopping drinking and coming to the realization of my whole life pattern, and then this illness and what was I going to do, right. And that saved my life.Treatment was safe, it was just women and it wasn't men as well and there was some wonderful counselors there.

Sherri needed a safe place for emotional healing. She was stopping to reevaluate all that was going on in her life. The HCV diagnosis triggered a huge crash for her. People who have experienced trauma and violence in their life need to feel safe and respected, to begin healing. She says “treatment was huge for me. I had come to a place where I was either going to drink again or I was going to commit suicide. My mother was, umm, an attempted suicide addict.” Sherri did not have the coping skills to manage everything in her life. Treatment helped her to develop the tools to learn how to look after herself. I sense that HCV is a social illness that is symbolic for Sherri, in her regrets and also in her accomplishments. She has learned to live with the illness just as she has equipped herself to manage her alcoholism, her family of origin issues, and coming to understand herself as a woman and a mother. I wonder about the common emerging shared experiences the women have expressed so far. It is not just about receiving a diagnosis. It is about the complex intersecting areas of their lives. It is about learning to have compassion for oneself.

One of Sherri’s concerns upon hearing the diagnosis was whether she could infect her close friends, children, and grand children.

Having people for dinner, just an awareness. I get hyper-vigilant about it, probably. And then it goes away and I don’t think about it. I have close friends, my sponsor in AA is a close friend. Mostly women friends, my sisters and everyone, they don’t treat me different. They don’t clean up after me. I don’t see a change in them. Like I’ll go to my friend, her home, and we’ll have coffee, and they’ve got young children. I know it’s ridiculous but I’ll wash my cup right away and put it in the sink. Or when the kids (grand children) are around I think I’ve got to make sure if I’ve got any cuts that everything is bandaged up. Chances are probably nothing. It is still that....

She recognizes that she is hyper-vigilant about the transmission risks. Sherri thinks about HCV at least weekly. Possibly, because women are often caregivers for their grandchildren and cook for family and friends, they think about HCV and infection risks more often. HCV affects what she

does. I thought possibly, with enough information and support, it would ease the anxiety women feel in transmitting the virus through casual care giving tasks. Possibly, for some this might be the situation. However Sherri's experience is different. She feels the need to be hyper-vigilant despite awareness of all of the medical transmission risks. It may be she is not really sure how she acquired the virus. Medicine does not have all the answers and she has internalized the responsibility to be hyper-vigilant. This could be, what I might term, a mother's instinct. It is often thought of as excessive or needless worry and is vague and unscientific. I wonder about the possibility that women should be encouraged to value and follow their instincts. During the conversation my thoughts were to reassure Sherri and to share with her the statistics of transmission risks. Reflecting back on this conversation, and all of the other conversations, I wonder if the fear of infecting others is a woman's or mother's instinct to protect others, especially their children and grandchildren? I think it means that, in addition to accurate information, we respect the instincts people have about their own illness.

My experience, as a woman and a mother, is that we often take on the health of the family as a moral obligation and we judge ourselves harshly when we do not meet those expectations. We often take personal responsibility and feel it reflects upon us, as a mother, when our children are sick. As female caregivers, do we expect or hope that we can nurture and heal all things, especially our children? In reality this is often an unrealistic expectation.

Sherri's son had health issues and when our children enter the medical diagnostic cascade, especially with a mental health or addiction issue, questions are inevitably directed to the mother. The search is on for genetic as well as prenatal exposures to environmental teratogenic toxins. Socio-cultural issues, such as single parenting and family dynamics, are

documented as social history that may be contributory to the child's illness. Sherri says she would change things if she could go back. I am not sure what the regrets were but she would change how she raised her children. She was a single parent and a student. Today, she has met her education goals and raised a family in addition to working outside the home. I wonder how, as a society, we will be able to find a realistic balance of our expectations and roles of women? Unrealistic societal expectations are an additional burden that women internalize. Layered on this are multiple levels of stigma, which is a further reflection of societal judgments.

Mary: A Comedy Routine of Getting a Diagnosis

Mary's primary concern was about the difficulty of navigating the medical system and obtaining the care and treatment she needed. She utilizes the language of a comedy routine as a metaphor. She believes no one would believe this actually happened and it could be acted out as a spoof or a farce to illustrate the bizarre nature of her experience. In reality, her faith and trust in health care is deeply shaken.

Well, to be honest with you I had a horrible experience because I was sick for awhile. And it probably took 3.5 years to figure out what was wrong with me....I went to the doctor and said something isn't right. He said you should stop eating salt and you should wear stockings....I felt so bad....My ultrasound also showed that my spleen was enlarged and so was my liver and nobody gave me the results.

When we sat down to talk Mary was keen to share her experience. She talked quickly and throughout the conversation she continually questioned the loss of her test results, the delays, the spilling of her 24 hour urine, and the feeling she was kept in the dark every step of the diagnostic journey. No one contacted her or followed up on her care. She raises intelligent and valid concerns about the barriers to treatment and care for those who have HCV.

Mary was feeling unwell and her illness was progressively impacting her ability to carry out her usual activities.

Now I'm going home and I'm so tired that I have to sleep for 40 minutes. I could ride two horses and by the third I'm so freaking tired. Like I run four horses in a weekend, three days in a row, and I could keep riding them.

She is normally a vibrant, high-energy person and she was not able to ride her horses. She describes this as a "horrible experience" because she was so unwell. She felt lost with disjointed and fractured care. Her test results were either lost or did not warrant further investigation. When the nurse from the liver clinic assisted by navigating the system and maintaining communication with her, she felt cared for. It took approximately five years before she was able to access treatment for HCV. This is considerable for someone who is clearly symptomatic.

There are multiple references, throughout her conversation, about what may be termed as reverse discrimination. Over a period of three and a half years she describes being grilled "...asked me these thousands of questions and of course I don't fit in the hepatitis thing. I don't drink, never did drugs or nothing, don't smoke, so ah that's not it." Mary's experience may perpetuate the discrediting profile of people with HCV that exists within society. For her, the medical system was only prepared to test her for HCV if she fit an at-risk profile. Mary's experience reinforced her own perceptions of what type of lifestyle leads to HCV infection. She was told repeatedly by health care professionals what kind of behaviour warrants testing for this virus. However, there are multiple ways of acquiring the virus. Some people do not know how they acquired it.

Once Mary's diagnosis is determined, a clinic nurse becomes an advocate and navigates the system with her. Mary's words are "She would phone and check on you to see how you were.

All this, like just, just you know care (with a soft emphasis). She was the best and I think without people like her, nobody else gave a crap....She deserves a medal....She was phenomenal.” This conversation draws attention to nursing work that is not readily visible. Nurse’s work and the participant’s experience is brought to light within this conversation. This part can only be understood by looking at the whole of Mary’s story. Mary describes her experience of treatment for HCV with the drugs Interferon and Ribavirin.

Yeah and I actually didn’t lose a lot of hair until I was almost done and then my hair started to fall out, a lot. I braided it into this little tiny braid. It was like a Ninja. My little Chinese braid...I can imagine how easy it is to get sunk into a hole because everyday it’s crappy. Unless you make your own uncrappiness. But it’s gonna be crappy. I don’t think there’s any other way to look at it. And I don’t think people understand, you know. I mean they understand people who have chemo because you have cancer, but they don’t understand. I mean your hair falls out and you look grey. And I think there’s a stigma to it, Hepatitis C. That you’re some drug addict from whatever, you’ve done something stupid or whatever.

Mary only shared her diagnosis with close family. She explains what many women in this study described as lack of understanding about the medical and social implications of HCV and treatment. I wonder that by comparing HCV treatment to cancer chemotherapy she is emphasizing the social acceptance and empathy generated by a diagnosis of cancer, in comparison to the lack of understanding and empathy when one has HCV? Although she had no risk factors, she still felt silenced because of the associations of drug use with HCV and felt people would just think she had done something. This stigma is a reflection of our societal values.

Mary’s conversation is significant in that she wonders how people with multiple health issues such as addictions, poverty, and mental health challenges can access care. “Like, I say I would hate to be the typical Hepatitis C person because (pause) how do they get anything done?”

She thinks that “nine times out of ten, what are they, they’re drug addicts or something or they’ve had some issues of something or whatever, like they’re those types of people that are (pause) you know what I mean.” I sense that this is compassion and Mary cares. She came to have this conversation to raise awareness of these challenges. She recognizes the systemic challenges, she experienced, as barriers to accessing her health care. She just cannot imagine how much more difficult it is to access care when you have additional social challenges. I believe she sincerely wishes to bring awareness to this illness and the challenges in accessing care, support, education, and treatment. She took the opportunity to try and make a difference by adding her voice to this collection of experiences.

There is a powerful theme emerging, from most of the conversations, about societal judgements and deservedness of care. For example, some people are labeled fairly and some unfairly; depending on how you have acquired the virus, one deserves more or less compassionate or respectful care. However, it is the labeling and societal expectations that are the issues and not the source of acquiring the virus. This stigma is a reflection of our societal values. People are not deserving of stigma. We must challenge this stigma from a health care perspective.

Kari: The Middle of the Earth Fell

Kari’s experience, of actually receiving the diagnosis of HCV, was not a surprise or a shock. When I met Kari on the phone she was talkative and excited about sharing her story. We met to have this conversation in her home. She talked very quickly and seems to have come to terms with many of the issues in her life. She has found a healthy balance looking after her

health with complementary therapies and enjoying her property. However, it was a complex difficult journey to regain her health. Kari explains:

ummmm. Well basically it (HCV diagnosis) was probably one of the things that helped to turn that switch to quit drinking. Yup. I was really mixed up then, I wasn't diagnosed with bipolar then and everything kind of melded into one time. I was going through menopause and I was really depressed and I was doing drugs and I was drinking and I was... and and I had been diagnosed with Hep C. So I'm not sure what kicked in or made the decision to quit drinking. Menopause made everything kick in all at once. Holy Moly. When I was having my periods all my life I wouldn't even notice it. It was just 3 days out of my life, just like another 3 days, there was no PMS, no nothing. Then all of a sudden it was like the middle of the earth fell.

Kari feels that she lived her life in the manic phase of her bipolar illness for many years. She said she was carefree and unaware of the health implications of alcohol, HCV, and drug use. It was during the complexities of crashing into a state of depression, learning she was HCV positive, and her diagnosis with bipolar illness that she decided to get help. Everything happened all at once and how she interacted with the world, as she knew it, was falling apart. Kari then accessed health care services for HCV treatment and "...that one doctor told me I didn't have any liver cells LEFT (said loudly) to regenerate and showed me a picture of it and showed me it was completely scar tissue." It was at this time in her life, in the midst of numerous health issues, that she started the Interferon and Ribavirin treatment for her HCV.

I was, I was not very good about doing those shots in my stomach but that's because there was my head space; was not very good at the time. I was living in the middle of nowhere. I wish I could have come in and got those shots in the office.

The treatment can exacerbate depression and most people with cirrhosis have significant side effects. This includes extreme fatigue, headaches and weight loss. She was isolated and struggled with giving herself the weekly injections.

Today, Kari has found her own path to wellness and she demonstrates resilience and insight in managing her care. Throughout the whole of her story she discusses the changes she has made and how she has incorporated a healthy lifestyle into her self care.

All of a sudden I was going to the mental health and addiction, somebody helped me get in there. And that was to do with drugs and I started to go to a counsellor there and it just hit me one day and I thought, you know what, I just want to quit drinking but then to try and get into the women's centre, because that is where I wanted to go...I'm ready now. I might not be ready next week.

Kari then explains what nonjudgmental, compassionate care meant for her when she accessed alternative Reiki care:

Yup, well when I started going there (Reiki) I was still doing drugs and I know the person who does Reiki, she can read your mind. So I would have to tell her, no matter what, and she would just say well don't feel guilty. Just stop again. So I would stop again....

Because of the cirrhosis, Kari's chance of clearing the virus would be in the range of 15-20%. The treatment regime compromised her confidence in her ability to look after herself. Kari blamed herself for not "giving the shots good enough" and for not being in a healthy enough space to be successful. There is not a quick fix for complex medical and social health issues. Again, I question the acute care model of treatment and cure which predominates in care models for those living with HCV. With lived experience stories, one can gain an understanding of what individuals' needs for care are and what is most important at various times in their lives. Kari's story has given me a perspective and understanding I was completely unaware of at the time. Because some people do not want anything to disqualify them from accessing the treatment, they may not share some information as they wish to just get on the treatment. With a chronic illness model of care, treatment is just one option of managing care. Kari was managing three different illnesses concurrently, each one impacting the other. She was on treatment for

HCV only a short time. The treatment was not working for her and she was considered a *non responder*. If one does not have a viral response to treatment it is considered failed and one is a *non responder*; if one does respond, but the virus comes back, one is termed a *relapser*; and if one responds and the virus continues to be negative six months following treatment, one is considered a *sustained responder*. Medical language is cruel and harsh.

Nancy: An Untouching Hospital Experience

Nancy experienced receiving the diagnosis of HCV during a time when she was vulnerable, residing in a recovery facility, and on a Friday afternoon. There was minimal support and information to help her navigate the troubled feelings churning up inside when she received this diagnosis with a lonely weekend ahead. She was told she had HCV over the phone with no follow-up and describes it as: “ummmmm actually the doctor gave it to me on the telephone, on a Friday afternoon, nobody to make contact with, no information. I thought this is like a death sentence.” Her voice then became quiet and she turned her head as though sharing a secret she wanted no one to overhear. I could hear the despair that Nancy felt, as a daughter, in her belief that she had disappointed her dad.

...because your family wants to be there for you but you're also this walking disease. It's very hard for them to follow, you know.... OK and they are like (sigh) not my daughter. ...It was really hard for my dad to accept that. (Her voice was too quiet to hear the next comment).

The essence of Nancy's message is that she possibly views her drug addiction and recovery as a personal choice and somehow a character flaw. Her hospital experience reinforces this internalized belief. I wonder if addictions could be approached as a health issue instead of in a punitive blaming manner.

Most of Nancy's conversation centered on her negative hospital experience. She describes her experience during an admission for surgery. While talking about this experience Nancy grimaces and looks like she has been punched in the stomach.

I told them I have hepatitis C at the interview. With that diagnosis everything was horrible for me. I told them I no longer have Hep C, I went through the treatment and everything. Well, I had to have surgery and I got upstairs and they couldn't do me right away. I told the guy uhhhh, they couldn't find a vein. I have no veins anyways. I never did, OK. I have really bad veins. You're going to have trouble. And he said I see you have Hepatitis C here on your report. And I said no I don't. I went through the program. He said oh yes you do....Do you know what he did? He said turn your neck, you know, you should be used to this. And I was just like....Yeah that is exactly what he said. And he actually put something in my neck and then I was out. That's because they had a lineup of people waiting and I just felt like a can of meat on an assembly. It was very upsetting. Because as soon as they knew I had Hep C, ...the most disregard is in that hospital.

Nancy continues to share more of her experience and what it means to her:

But when you're thinking how much that whole thing (treatment for HCV) costs to health care to be cured and nobody regards you as cured at all. They don't. There's nothing more to say, there's nothing more to say after two years, you don't really know and nobody treats you like...and before you want the treatment you want that soooo bad cause you think that that's going to fix everything. It's going to fix you being tired or whatever, or you know, constantly sicker.

Feelings of hurt and vulnerability are contextualized in this experience and this has impacted negatively on her access to health care. Nancy is feeling stressed as she contemplates accessing care for any other health concerns. The two negative experiences described are: an interaction with the anaesthetist and a separate incident with the recovery room nurse. The experience with the anaesthetist occurred following repeated statements from staff about her poor veins.

Throughout her hospital stay, Nancy felt the nonverbal message that she had damaged all her veins through drug use. She felt she had to defend her veins. She genetically does have poor veins and she inherited this from her mom. No one really believes her. Immediately following the experience with the anaesthetist Nancy wakes up in the recovery room.

I did get the interview before the surgery, I did say I had Hepatitis C, I had treatment. I don't want to be treated like some drug user. So what did they do? Then when I woke up out of surgery, the nurse was so rude, she was like you're drug seeking. I was how can you be drug seeking when you just woke up and you're in frickin' pain. You wouldn't even have it together to do that. She said I don't know anybody that needs that much.

The nurse accuses her of drug seeking because she is having pain. It is as though the HCV diagnosis is haunting her throughout this hospital experience. With this diagnosis Nancy feels she was blamed for ruining her veins and assumed to be drug seeking. Nancy has a powerful message for all health care professionals when she tells me:

It's just so associated with dirt...Some people get around it though. I know one lady who has it (emphasis) and she was telling me about how she just kind of shuts up about it. I don't know. I don't know. I just think the whole experience at(names the hospital), it was the most rude hospital, the most untouching hospital that I've ever been through.

Nancy is not sure that she supports the approach of nondisclosure of HCV status. However, she certainly understands that it is a viable option, considering the way one is treated when disclosing. The language she uses in describing the hospital is poignant and I immediately have a sense of how abandoned and uncared for she felt during an especially vulnerable time. One is completely powerless when approaching a surgery. Her last feelings and thoughts, prior to being anaesthetized, are of disrespect and insults. She then awakes to her experience with the recovery room nurse.

Nancy had completed the therapy for the HCV which many consider is comparable to going through a six to twelve month course of chemotherapy. Brain fog, depression, anger, joint aches, and blurred vision are only some of the most common side effects people manage daily. The goal is a sustained viral response (SVR). This means no evidence of the virus detectable six months following treatment. A SVR is the standard medical measurement of what we call a "soft

cure.” Nancy did respond to treatment from this biological perspective. However, she does not feel cured. She continues to feel very much infected from her social health care experiences, following treatment.

Following this conversation, on my drive home, I reflected on our conversation and I felt increasingly disturbed. I was nodding my head as I drove and wondered what message Nancy had been trying to communicate to me. However, the unease was not only related to the graphic descriptions of her hospital experience. Nancy questioned a health care system that treats people like this. She is not convinced we can manage to convince colleagues to treat people with respect. What hope does she have in avoiding another demoralizing exposure, as a social outcast, in future interactions as a patient? At a time when support is crucial, a stigmatizing experience can compel people to keep their Hepatitis status a secret. The social stigma attached to this illness reduced Nancy to despair and made her feel her life was disgusting in the eyes of her health care world.

I have a sense that Nancy feels *I just do not get it*. She may be right. Understanding is not necessarily just empathy or compassion. How can I know what it feels like to be red-flagged with a stigmatizing illness when one walk through the hospital doors? The negative social meanings attached to a diagnosis of HCV have been a powerful influence, for not only social exclusion, but also a barrier for Nancy in accessing health care. For future health care needs, she feels compelled to go to another town, rather than risk exposing herself to another stigmatizing experience. This story weighs heavily on my heart.

I believe there was a subconscious part of me that thought there must be some biological or physical improvement when you actually eradicate the virus long term. Nancy recognized this

in the question I posed. Her story is an exemplar of the psychosocial implications of this illness.

I know you're looking for the medical part but it's just not that, it is just devastating with the other part of it..... And I mean why are they treating me. I mean why are they treating me? I mean, it is two years after that it should be gone, gone because it's such a stigmatism. It should be gone, it should be not available to the public.

This is Nancy's response to my questions asking if clearing the virus had changed her in any way. Clearing the virus did not 'cure' the social implications of this illness and did not close the door to a past she feels has marginalized her in many aspects of her life. Nancy states "well it's not really closed, is it?" She feels the Hepatitis virus has marked her socially for life. It is unfortunate that health care experiences will further silence and disconnect women. I wonder that a diagnosis of HCV could facilitate access to counseling and social support services in women's communities? Could the social components be recognized as an essential component of health care.. "I think maybe it is smarter to just keep your mouth shut. That is real life." Earlier in the conversation Nancy was not convinced that nondisclosure was the right thing to do. She is changing her mind. Unfortunately, this is the reality of healthcare experiences like Nancy has described. The social implication of having an illness that is associated with illicit drug use has been significant for Nancy.

Nancy's hope is that telling her story will possibly make a difference. "Maybe somebody has something really grabbing, and you could be on it, and say this is what happened. Because it is a really harsh reality, a horrible thing. I don't know." Nancy's story illustrates the need to break the silence and prevent further marginalization and stigmatization. Nancy has a story that is 'really grabbing' and I feel gratitude that she has partnered with me to break the silence surrounding this lived experience she carries as an inside wound.

Forging the Horizons Through the Shared Experiences

Resonance With the Researcher

The process of coming to understand shared experiences has been guided by the hermeneutic circle of understanding (Gadamer cited in Fleming et al., 2003). By examining the parts of each conversation within the context of the whole of that conversation, I next looked at each of the conversations as a part of the whole nine conversations. Moving back and forth, from the parts to the whole, I attempted to incorporate a portion of the participant's horizon of experience into my own. Questioning and correcting, writing and rewriting, I developed new understandings.

The experience of having nine conversations with women who have received a diagnosis of HCV has revealed both surprises and expected experiences. When I encountered expected findings, or issues that supported my own preunderstanding, the experience resonated in a way significantly different from reading about these experiences in the literature. The women took me right there in their stories, into the midst of what it is like to fear infecting your child, the heartache of losing a child, and being a mom living with HCV. As a daughter, I witnessed my own mom's struggles with addiction and mental illness. I thought of her when some of the participants talked about their recovery and what they wished they could have done differently. I reflected upon the social roles and expectations we internalize as women and as mothers. And at times I knew, or had this overwhelming sense of greater understanding, that I did not have the language to express. It was that sense of coming to a 'clearing in the woods' and how differently your world looks when you step into that space. This is the imagery I summoned as I wrote about the findings.

The conversations also revealed surprises, experiences, and perspectives that made me feel uncomfortable. I developed an entirely different understanding of ‘cure’ once I was able to set the medical definition aside and hear what a lived experience of cure might mean. With further in-depth reflection, I was able to gain insight which I believe will help me practice nursing with greater sensitivity and understanding. Women experienced trauma when receiving a diagnosis and often experienced trauma in other areas of their lives. To hear how some health care experiences produced further trauma, instead of healing, was deeply concerning.

Understanding the social implications of the illness are just as important, and for some more important, as eradicating the virus biologically. What deeply resonated was the societal values and stigma reflected in these conversations. This understanding is important knowledge that can contribute to the body of nursing knowledge and praxis. It was with a grateful heart that I joined these women, for a brief moment, in their journey with HCV. I witnessed a glimpse of what it means to receive a diagnosis of and to live with HCV.

Their perspectives, heartfelt sharing, and the language they used to express themselves has now become a part of who I am. The pauses during the conversations and repeating some fragment of the sentence would give them time to gather their thoughts. This also gave me time to reflect, during the conversation, about what the pause meant and what they might be emphasizing as they searched for the right words. The expression on their faces and their posture as their memories surfaced, communicated the emotion attached to their words as did the look when they made eye contact about something that was important to them and, especially, the compassion and understanding in their demeanour when they talked about struggles others might have. Sometimes words were crafted so that complex meanings could be communicated; words

such as an *'untouching hospital'* or *'ironious'* or *'uncrappiness'* to better describe the emotion attached to their experiences.

My hope was to retain the richness and integrity of each voice within the collective whole of the findings. I was concerned that important things may get left behind. It is at this point that I realize that much will get left behind and it is impossible to capture everything. This thesis will reflect some of the participants' meaning from their stories and some of my own experiences of listening, learning, reflecting upon, and making my own personal meanings. Their stories have enhanced my own understanding of the context in which I view of the system I work in and enriched the way I practice what I do as a nurse. My hope is this knowledge and understanding will enrich the practice of other health care providers as well.

The women all expressed feelings of shared gratitude in contributing to the collective voice of this thesis. They felt it was an opportunity to share and to be heard. Their hope is that it makes a difference and health care providers will better understand women's lived experiences when diagnosed and living with HCV. One participant said she hoped there would be something 'really grabbing' that would communicate what it feels like to experience stigma. She hopes that health care providers will develop an understanding of the trauma experienced. Although there were difficult and emotional experiences shared, for all of us, it was an opportunity to further open the possibilities of understanding the complex socio-cultural intricacies, of receiving and living with a diagnosis of HCV.

Throughout the process of analyzing the nine conversations, shared experiences emerged. I now summarize what some of those are. While all the participants shared the experience of receiving a HCV diagnosis there were also shared experiences of: shock and disbelief,

wondering ‘how do I take care of myself?’, they were treated like garbage, described untouching experiences while feeling untouchable, they wanted to keep the diagnosis a secret, it was a hugely fragile time in their lives, they had fears of infecting others, and they spoke of being a mom with HCV.

Shock and Disbelief

A shared experience was the shock of receiving a HCV diagnosis. Four participants utilized descriptors to explain this with terms such as “it felt like a sledge hammer between my eyes”, “shock, ya”, it’s a mistake, a big mistake”, “Mark of death, great big mark of death” and “I felt like a victim with the grim reaper there.” These are strong terms that highlight the gravity of receiving a diagnosis of HCV. For these participants the fear of death was very real upon hearing the diagnosis. They wondered if their liver could fail suddenly. However, when reviewing the entire context of the conversations, as a whole, there is another aspect to this fear. There is a palpable sense of participants feeling contagious and a fear of being socially ostracized. This is possibly a social mark of death in addition to the fear of physical demise. To help me further understand this, I returned to each of the transcripts where participants had spoken about their fear of death. They worried about telling their partners and their families. There were concerns about being social outcasts amongst their peers and in the everyday work they do as volunteers.

In addition to the shock, seven of the participants received their diagnosis over the phone or in a cavalier manner with no follow-up. They described cavalier as lack of understanding the gravity of hearing this news. When one participant attempted to explain to the physician how devastating this news was he said “well that’s the way it goes.” The shock of diagnosis was

associated with a fear of their mortality in addition to a fear of social rejection. They were concerned about how they would be seen and accepted in their social roles as a daughter, a mom, a partner, and a volunteer. They were distressed at the possibility that they would be assigned labels and would be judged. Some women compared the diagnosis to leprosy or HIV as these illnesses are known to carry stigmatizing labels.

How Do I Care For Myself?

Some questions participants had centered around how to care for themselves, what treatment was available, how to access information, whether they really were ‘cured’, and what symptoms to watch for and be concerned about. Only two of the participants received information and support about HCV when receiving their diagnosis from their family physician. Important information about sexual transmission and counseling and support on how to talk to partners or family members were identified needs. One participant learned about treatment options many years later when she accidentally overheard it on a television show. Another participant said, “In order to get help for this you have to be really aggressive, it’s no more assertive, you have to be aggressive to get the help that you need to get any questions answered...Every time I think about it I get angry.” She continues with “...like the specialist said to me there is nothing really more we can do for you because you have had Pegatron treatment and there is nothing new. That’s kind of dismissive.” Eight of the participants expressed a need and an interest in ongoing support for social and/or medical health information supports. It was important to them to know more and have access to modalities such as massage, Reiki, stress management, peer support groups, and diet education. All of the women were referred to specialty liver clinics and, although this met some of their acute treatment medical needs, there

were many identified areas of information and support that would be better managed with a chronic illness approach.

The participants' experiences illustrate the multiple ways of knowing and managing their illness. Although the participants identified areas of need in managing their illness they also identified strengths. They shared that there is much that one can do to live a balanced and healthier life with this illness. One participant described HCV as a 'crappy disease' and you have to make your own 'uncrappiness'. Going outside for exercise relieved the fatigue associated with treatment. Receiving a diagnosis of HCV was instrumental in accessing support for counseling. Six participants sought counseling support connected with advocacy support groups in the community, or accessed treatment for addictions when they were diagnosed.

Participants described many ways that they were looking after themselves. One participant described self care: she is living her life and her partner built her a treehouse. The treehouse was an important and a wonderful surprise. It is a concept that helps me understand the holistic care that has helped this woman get well. It is a similar analogy to when one goes to their cave to regenerate. A cave reminds me of a masculine concept and a treehouse, in the forest, is a gentle and nature inspired concept. She explains that she feels she is in a healthy space right now. She found the right balance of alternative care and self nurturing that helped her attain health. I wonder that each of us should have a treehouse to escape to. It is no wonder that this participant looked so vibrant and healthy. She says "Life is actually quite grand. It worked out good."

There is a plethora of myths and a need for participants to know which reliable internet sites they could access.

It is scary because there are people, a lot of it is American, although I am sure there are Canadian sites as well. But if you, once you are shocked and you have Hep C they have

on there this did this for me and I can even have a few beers every now and then. Are you out of your mind? That sort of thing.

All of the participants identified ongoing needs for information about transmission risks, had questions about how their livers should best be monitored, wished to know what and when new treatments were available, wanted to understand how their livers function, needed information on how to manage chronic symptoms, and expressed interest in community social or peer support services.

Treat You Like Garbage

Nancy's experience resonates and delivers the message that our society presently lacks compassion and understanding about injection drug use. From a number of these conversations, the women who used to inject drugs or injected one time feel haunted by their pasts and want to avoid the labels such as drug user. There are many comments throughout the conversations about how they are made to feel like a drug user when disclosing their HCV status. "I don't want to be treated like some drug user." I wonder about the many women who continue to struggle with the double stigma of HCV and continuing drug use. An issue to explore is our own internal labels produced from the values, understandings, and the beliefs of health care deservedness that are products of the society we live in. There are many stereotypes about the kind of people who get HCV and who deserves care.

Within every conversation the women came to know their diagnosis from a perspective of their own perception of what kind of woman becomes infected with HCV. These perceptions are deeply embedded within societal values of who is more or less deserving of: health care dollars, compassion, housing, understanding, or acknowledgment as a valuable person. Some of these internalized societal values are reflected in the women's thoughts and feelings around being

diagnosed with this virus. They expressed feelings like: “Look at me now. I’m a complete failure”, “I thought, great everybody’s going to think I’m a drug addict, like a needle user and I’m not”, “Oh my god, now I am one of those women”, “You mention Hep C they immediately think drug addict”, “It’s just so associated with dirt”, “There’s a stigma to it, Hep C, that you’re some drug addict, you’ve done something stupid”, “I didn’t ask for it. If I’d a been a drug user or something”, “When you hear someone has Hep C, they’re a dirty drug addict, they use a needle.” These statements are in every conversation, whether the participants acquired the virus from illicit drug use, blood transfusions, or unknown causes. The participants saw themselves apart from those who use drugs and it was important to avoid being labeled. People are not deserving of stigma and they cope with it by responding to stigma and try to avoid being labeled.

The experience of stigma when accessing health care was described in profoundly painful language. Most of the participants were in a vulnerable state when accessing care. It was a time when they needed reassurance, acceptance, and a feeling that they would be cared for. It was interesting to hear how Joan did not feel that she had been stigmatized. She was told to work in the back of the food bank and to wear gloves when she disclosed her HCV diagnosis. She thought this was normal and that the people she was serving did need to be protected from her. Joan accepts that it is normal to be treated like this. I wonder if some people become socialized to stigmatizing practice and this then becomes the norm. People no longer consider the practice as stigmatizing including those who are stigmatized. It is also possible that people do not have accurate information and believe that HCV is transmitted through casual contact.

There were descriptions of reverse stigma from medical professionals. Mary had difficulty accessing the necessary tests, because she did not have the social risk factors for HCV.

An especially traumatizing experience was shared by Cathy when the lab technician would not help her take her sweater off or acknowledge her as a person. One is more vulnerable when accessing health care, having diagnostic tests, and having surgery. It is during these more vulnerable states that one needs extra reassurance and care. It seems with increased vulnerability the experience of stigma was more traumatizing, as with Cathy and Nancy's experiences. Nancy continues to be so distressed by her stigmatizing surgical experience that she will not be able to return to this health care facility in the future. This is a barrier in her access to health care.

In addition, to stigmatizing hospital experiences, one participant experienced discrimination at her work place.

It is, it is you work all of your life, you come from that end of life to this end of life and you think I'll be able to go back to work and they treat you like garbage and you can't go back to work. I was there for a year and a half and I worked eighty hours a week. I worked twenty one hours a day one time and it was still marked on my record as Hepatitis C.

This participant does not feel valued and utilizes language that is descriptive of the societal values of being discarded and treated like garbage. A health care professional accessed her records, disclosed her HCV status to her employer, and she lost her job. She felt so silenced that she was not able to exert her legal rights to confidentiality and act on the job discrimination she experienced. This participant no longer has HCV as she completed treatment with a successful biological outcome. There was no recognition of this biological 'cure'. We tell people they are cured when they have no virus six months following completion of treatment. I thought possibly the employer had concerns the HCV could be transmitted on the job although she informed them she no longer had the virus. However, even if this participant continued to have the virus, it is discriminatory practice for her to lose her job. In my practice area I have heard several accounts

of people who have HCV, losing their job if they are food handlers. There continues to be myths about the risks and mode of transmitting this virus. I wrote in my journal notes, following this conversation, about feeling increasingly disturbed by the urgency of this message. She felt someone needs to know about the discrimination she experienced in her employment. Additionally she had worries that she would be exposed to even further discrimination if she put forth complaints. She felt powerless to give voice to her experiences and did not submit a complaint.

For many of the participants, receiving the diagnosis changed how they saw themselves as a woman in their social and sexual realm of being. Several of the participants brought a preconceived idea of what kind of woman would have HCV. They had developed their judgments from previous socio-cultural experiences. With past exposure to stigmatizing experiences they had formed a fear of being labeled and talked about. One participant states “Now I am one of those women, it is like leprosy.” Or “Hep C is like telling people you have AIDS.” They described their feelings in comparison to other known stigmatized illnesses. Through social experiences prejudices may be formed which may then be turned inwardly and have an impact on how one sees oneself as a woman living with HCV.

The salient factor that emerges from this socialized stigma is a wish to keep the diagnosis a secret. All of the participants disclosed to health care professionals because they felt an obligation to protect others. They knew it was contagious. However, they did not receive the information on what this means in their daily life, in preparing food, in sexual relationships, and in caring for children. One participant described herself as a “walking disease” and understood that under those circumstances it would be difficult for her family to accept this. Another

participant wondered how she would be able to escape the abusive situation she was living in now that she had this mark of disgrace. Most of the participants had concerns about being treated like someone who has addictions. Their socialized experience was that these type of women deserve to be treated badly, were not welcome in some social circles, and that women who use illicit drugs are less deserving of nonjudgmental compassionate care.

And going through the whole thing and having surgery and you think, that they think, you don't deserve a knee replacement or a spinal surgery cause you're just a junkie, whatever. I mean I've never been to the hospital for an OD or drugs or needles, that kind of thing, ummm.

Following this I said to the participant "...well this is my perspective, even if you are using drugs you still deserve good care. If you need a knee replacement you still need to have that care in a respectful manner."

The participant went on to say:

The same thing happened to my girlfriend. She said, you know you're right. You know what, I went to the hospital and they treated me like garbage. She's down to about 80 pounds. And I know she doesn't do drugs. I know it. I know her and we both just lost a child. Just to be attacked like that.

Throughout many of the conversations, there was an underlying message of self blaming for making a lifestyle choice that caused them to be infected with a socially unacceptable contagious disease. "I haven't lived a good life, I really haven't. I was doing the best I can, I messed up early, big time." There was a sense that, somehow, one has to earn back the right to have non-stigmatizing care and how one earns this is by changing one's lifestyle and making choices that are socially acceptable. Changes like no longer using illicit drugs and recovery from addiction. When they continued to be stigmatized and treated badly, all of the hard work they had done in recovering from their illness of past additions was not recognized or supported. It was as

though they continued to be punished. The women who had acquired the virus through a blood transfusion felt they had to defend themselves or they too would be socially ostracized for past deeds.

But as it was leading up to that he kept saying to me well you should try drugs, right. I said no I am not into that. I have enough problems already. One night he came home and he had some cocaine with him and he said just try this. I was getting really depressed and hopeless about our relationship; as he was going this way...He cooked up this cocaine, he cooked the needle for 15 minutes, in the rubbing alcohol and everything, said it was going to be safe, no problem. I don't like needles at all. I was like oh god ya. But I'm tellin you I never even felt that; he was so good at it...So he injected me, then he injected himself. I am sittin there.

This participant's husband then injected her twice more until her heart was pounding and she thought she might die. I continue to reflect on these described experiences wondering how, not only from a health care delivery perspective, but also from a societal perspective we attribute blame to certain illnesses and deem them less deserving of care. This described experience helps one to understand the vulnerability for women in acquiring HCV. This is discordant with the stigma and blame associated with drug use and personal responsibility for the disease. The factors that lead to use of illicit drugs are not of one's choosing. Stigma is unfair to all, not just some. I wonder if one could shift the paradigm to understanding addictions as an illness, instead of a behavior that requires punishment, we would be able to better care for those who most need a compassionate healthcare system. The participants also described examples when they felt cared for. A reassuring word, holding of a hand, or a follow-up telephone call are examples they described. Care that takes only seconds or minutes made a difference in their health care experience.

Untouchable and 'Untouching'

All of the women's stories have a powerful theme of *untouching* or being untouchable. There was a continuum of being untouchable, being afraid of touching, to a description of the whole institution portrayed as untouching. This untouching experience was more than precautionary measures related to the fear of infecting other people. Possibly there was an internalized sense of feeling contaminated. Ann felt self-conscious about shaking someone's hand. It bothered her even though she knew she had no cuts and was not putting them at risk. One participant said "As for the Hep C, I wear a medical alert because I do not want anybody touching me with their bare hands, in case, right." As humans we have a need for touching. Does this mean that she feels touching is no longer an option for her because of this virus? What is more concerning is that this woman has been through the entire cascade of medical diagnosis, as well as treatment through a specialty clinic, and she continues to feel this way. This reveals a gap in the social and emotional care a woman needs and deserves. There is a gaping gap in the societal values that stigmatize those vulnerable and in need of care. I wonder where the compassion can be found in our values to reach out and touch people so that they feel cared for.

Cathy describes how the lab technician would not touch her to assist in removing her sweater. She was in pain from her recent biopsy and expressed how she was having difficulty taking her sweater off. Cathy said "Yes I tell everyone that touches me that I have Hep C...I totally felt like I was this disgusting person that she didn't even want to touch and she just had to do it for her job." Nancy describes the hospital as the "...most rude hospital, the most untouching hospital that I've ever been through." When one goes to the hospital, a reassuring touch is powerful nonverbal communication that can provide comfort and trust. Human touch is essential for normal development and we have a lifelong need of touch for a sense of well being. It is a

universal experience: a warm hug, the love expressed by the squeeze of a friend's hand, or a nurse's gentle touch on your arm. Nancy's choice of the words 'untouching hospital' resonates and describes abandonment of the human caring she needed in her health care experience and did not receive. I sense that 'untouching' means uncaring. Are our societal values reflected in feeling untouchable and experiencing an untouchable hospital? Does this mean that one feels relegated to the margins, *othered*, and not deserving of respectful care? I believe the feelings of being untouchable and the 'untouching' hospital experience are a reflection of our society's deep roots of who is more or less deserving of care.

Keeping Secrets

Regardless of how all nine participants acquired the virus they described being secretive about their diagnosis and treatment. Women only shared their diagnosis with their immediate family and with health care professionals when necessary. They described feeling alone and isolated. When on treatment the isolation becomes exacerbated. This is possibly because of the psychiatric side effects of depression and suicide ideation in addition to feeling so unwell. A participant says "I am not ashamed to say I have diabetes. It is not one of those things I like to have but under no circumstances are they going to hear Hep C come out of my mouth."

One participant was concerned that if she disclosed her diagnosis of HCV she would be refused as a tenant:

Well when I moved in here I thought, should I say anything? They wanted to know if I had any health issues and just for a second I thought, should I say anything? Then I thought, no, they are not going to get it. Because my feeling and the way I've been when you mention Hep C they immediately think drug addict; that's where they go. Right away you can see the change. It is like 'OH'. They're suspicious of me and thinking.

The words above summarize what many of the women's concerns were. They do not want to

be thought of as previously using illicit drugs and they have very real concerns. There is not only a stigma in health care but employment and housing are also impacted by stigma. Women are impacted in multiple aspects of their life by stigma.

This participant felt she needed to prove to her landlord that she was reliable and dependable before she could risk disclosing. Another participant explains “I think maybe it is smarter to keep your mouth shut. That is real life.” All of the participants had some aspect of secretiveness to this illness. I wondered about the meaning of a secret illness. The internal feeling of being an outcast is exacerbated. It is difficult to find others to learn from and lean on. One participant’s window to the world was her computer. Many may enjoy the anonymity and this type of networking is valuable in numerous ways. However, I sense in many of the conversations there is the loss of human to human social contact and sharing that many people find helpful. Once Joan shared her backpack of secrets with family members, she was better able to access the supports necessary to become healthier in all aspects of her life. I have a sense that one of the compelling reasons the women participated in this study is to give voice to an illness that they feel the societal pressures to keep a secret. Secretiveness is part of the response to stigma. They have experienced what it feels like to be stigmatized. It is never justified or deserving.

It Was a Hugely Fragile Time

The diagnosis was given to many of the participants when they were experiencing other relational or health challenges. Seven participants were concurrently managing issues such as a new diabetes diagnosis, loss of employment, treatment for addictions, residing in abusive relationships, learning about a bipolar diagnosis, helping children with serious health issues, or reliving the past traumatic experience of an abortion. The diagnosis was an additional medical

and social burden experienced with no additional support. Some participants described family of origin dysfunction that they felt left them vulnerable and less equipped to manage their lives. Two participants shared how they felt suicidal. The coping tools they relied on were from parents, who themselves had alcoholism, mental illness or sexually abusive situations they were trying to cope with when raising these participants who were their daughters. The participants felt they had a crumbling foundation of coping skills to draw on. It is not just about the HCV diagnosis. It is about what is going on in one's life socially, relationally, and medically. Family of origin issues were an additional layer of challenges that some participants had to relearn how to manage so that they could survive. When listening to many of the conversations, I had an overwhelming sense of this vast array of interrelated complexities many of the women lived with and managed on a daily basis. One participant described her experience when hearing her diagnosis as "Oh it was a hugely fragile time. Yes it did a couple of things. It made me think of picking up a drink again, like right away, immediately." With this realization, I could better understand their resiliency and ability to learn, grow, adapt and build their own inner resources. I could also appreciate that learning about their diagnosis was often during a fragile time in their lives.

Treat People Like People

The participants demonstrated a new found compassion from their own lived experiences. This compassion was evident when they expressed a wish to support others by listening and reaching out to people who live on the street. Many of the participants had a profound sense of understanding and compassion for those marginalized by society. One participant felt compelled to reach out to those whose home is the street in a human to human way by making eye contact

and acknowledging them. “I treat people like people.” These women came forward to share their experience with the hope that it may make a difference in decreasing the barriers in access to care for those with multiple health challenges. They have joined their collective voices to name what they see as injustices, stigma, and discrimination. This is an act of resilience and compassion. They wish for their experience to make a difference for someone else. Possibly if policy makers become aware of the lived experience of receiving a HCV diagnosis by a letter in the mail someone will not have to experience this impersonal shock. Participants did not want to hear this news in a letter or over the phone. They wished to be told by a knowledgeable person, in a compassionate manner, with an understanding of the impact this diagnosis had on their lives.

All of the participants readily shared the health care experiences that they found caring and phenomenal. This was of great value; to know what is especially meaningful is just as important to create awareness and affirmation as those experiences described as discriminatory or *‘untouching’*. Nurses and health care professionals would be touched to hear these positive testimonials. This increases my awareness of how a look, or a touch, or a phone call, has an impact on care. When one hears a health care experience described in the context of how one felt cared for, it becomes a powerful and meaningful image. As I reflect on the value of hearing these testimonials, I wonder how I incorporate these moments of care into interactions with people not simply as a component of one’s daily work or an additional task to incorporate, but more an attunement or sensitivity to what a person might need at that moment. This requires an openness or understanding to what people might be experiencing. As I reflect further I believe it requires a shift in one’s own presence or being. This is the sense I am gathering from these positive interactions described by the women.

Fear of Infecting Others

The fear of infecting others is intertwined with how the participants saw themselves as women and mothers. All of the participants had worries about passing the virus to others. There was a predominant concern, as mothers and grandmothers, of infecting family members through care giving activities such as wound care or meal preparation. All but one of the participants were mothers. Even this participant raises concerns about infecting others through using a razor or when getting a pedicure. She felt the spa professionals were not diligent enough in their precautions and chose not to have pedicures or manicures because of this. She is vigilant about warning others if she cuts herself. The participants carried a daily awareness and worry of the possibility of exposing children to the virus. Dee has cleared the virus with treatment. However, she continues to be cautious around her grandchild because she believes she can never be too cautious or be sure that the virus is really gone.

From my journal notes following the conversation with Ann, I wrote that she demonstrated a tough demeanour throughout much of our conversation. Once we turned the tape off she seemed vulnerable and unsure. Her most pressing question was whether it was OK to kiss her daughter. She questioned whether the risk was zero. This fear was intense and women were emotional when describing potential situations where they might transmit the virus to others. Cathy continues to feel despair regarding the exposure of a health care professional to a needle poke. Another participant had concerns about serving food and these concerns were reinforced when she was told to wear gloves and work in the back of the kitchen. What is the meaning behind the fear of infecting others? Perhaps it is because mothers and grandmothers have a protective instinct in their caregiving roles. It is onerous when there is a need to protect family

and loved ones from oneself. It is a burden the women carry as part of this illness. Throughout the conversations, women were not sure of the risks of transmission specific to HCV. Two of the participants were not sure how they acquired the virus supporting the concept that one can never be too careful. All of the participants felt a strong desire to protect others.

Mothers in this study also had concerns of transmitting the virus in their caregiving roles of cooking, hugging, kissing and tending to wounds. One woman described how, if she accidentally cut herself when preparing food, she would throw all of the food in the garbage and start over. There was a sense that one needed to be hyper-vigilant, even when common sense indicated that the transmission risks were very low.

Being a Mom With HCV

Eight of the nine participants were mothers. All eight worried about transmitting the virus to their children or grandchildren. They felt their bodies could potentially infect others. The mothering role often includes taking care of loved one's wounds and serving food. Possibly there is the perceived possibility of greater risk of transmission of the virus because of this close contact. When speaking of their children, some of the participants felt they had not lived up to their own expectations of motherhood.

I've always been supportive of him (son). I've felt guilty actually cause of the way I was so messed up raising him, probably didn't help anything. I've always been there for him, tried to do the best I could. It is like you are told to dig a ditch and you're given a teaspoon to do it. You do the best you can but it's going to take you a long time. The person who has the backhoe is a lot better equipped, obviously. Well now I do have equipment. I learned and have more skills. But back then I did the best I could with what I had, but it wasn't good enough.

This participant did not feel equipped for her mothering role. She described multiple family of origin issues such as sexual abuse and mental illness. It took time for her to learn and access

appropriate support to develop the skills for mothering. Five of the participants in this study were single parents and worked outside the home to support their children.

ummmm. It is one more thing I would change if I could go back. Things I would change in how I raise my kids. There again I have to say because I was a student and a single mother when I first sobered up, for the first four years of my sobriety, including when I was told I had Hep C.

Well I am on my own. I mean I can't be sick for a year and not work sort of thing. So the whole thing was like, not that it is their concern as to what I am doing, but there was very little compassion shown...

But at the time I didn't know that I had contracted anything. I was working full time. It was grueling work. Demanding, heavy lifting, go go go, always by the clock...One day, you know, a couple of weeks went by, and this girl said to me, you know you look yellow. I said really. She said ya, even the whites of your eyes are yellow.

The participants who were single parents had additional burdens of working inside and outside the home. They had to put their own health issues aside because the demands of their social and work roles were overwhelming.

Four of the participants had experienced the loss of a child. During the taped conversation they shared some of their concerns about their lifestyle and that they would do things differently. Acquiring HCV may have intensified their feelings of responsibility for the loss of their child. It is possibly connected to the social expectations of what a mom should be. Some of these participants did not know how they had acquired HCV for sure, yet they still felt a sense of remorse. I felt this topic was very close to the heart for the participants who gave me a brief glimpse of this pain they carried. They alluded to this pain during the taped conversation and shared more once the tape was turned off. Five of the participants who were moms also had to navigate the challenges of fractured relationships with the partners and fathers of their

children. They then raised the children as single parents. Further conversation would be required to explore this sensitive issue.

I now reflect and wonder at the magnitude and capacity of the women who so graciously shared a sensitive part of their being and lived experience. Gadamer (2004) explains that one's horizon is as far as one can understand or see. The process of understanding is a fusion of horizons. Collectively we are ten participants. Each has brought greater understanding to this lived experience which has contributed to a fusion of our horizons. It has been more than I could have asked for or imagined. The understanding continues to reverberate daily as I carry with me, and reflect anew on, each of their shared experiences.

Chapter Five

Expanding the Horizon, Findings in Relation to the Literature

Hepatitis C as a Chronic Illness

What is the meaning of a diagnosis of Hepatitis C? One can no longer take one's body for granted as the diagnosis is a constant reminder of something (Hayne, 2002). "Like a curse it stains my existence" (Hayne, p. 184). Women were able to access medical information, eventually, for physical assessment, treatment and monitoring. However, the participants in this study have identified a number of areas that increase the burdens of living with HCV. There is very little research on women's experience of receiving a diagnosis of HCV. One recent study documented that the social consequences of living with HCV may be more significant and have a greater impact than clinical markers of the disease (Murphy & Fitzpatrick, 2011). This should be emphasized in understanding this illness. These authors also wondered if "when patients leave us after receiving a diagnosis of Hepatitis C do we really understand the impact" (p. 49). Harris (2005, p. 4) argued that the "biomedical model is flawed in its attitude towards chronic illness....Necessary for the attainment of this goal are ongoing models of care that take into account the experiential nature of illness and the social context of the individual." Biomedicine has generated valuable knowledge, however it is partial.

Chronic illness is considered long term and perhaps permanent. The onset of chronic illness is not only physical but also an assault on one's sense of identity (Bury, 1991). Bury describes this experience as a 'biographical disruption'. This idea brings into focus the meaning of the illness, the setting in which it occurs and includes an assessment of the resources available to the person to live with and manage the illness. Bury distinguishes between two types of

meaning pertaining to chronic illness. That meaning lies in the consequences of the illness in the person's everyday life and secondly that meaning may be seen in terms of its significance.

Different conditions carry with it different connotations. These differences may have a profound influence in how people regard themselves and in how they believe others might see them.

Disclosing depends not only on the physical aspects of the illness but also the social contexts. A study by Sutton and Treloar (2007) found participant's experiences were well described by a chronic illness model. Wellness and illness were perceived not just by physical experiences of ill health but also by the social implications of living with a stigmatizing virus. The women in my study described feeling 'dirty' and felt aware of their illness even when they were feeling well. This indicates similar findings to the Sutton and Treloar study. This points to the importance of social factors in the management of HCV as a chronic illness. The participants had ongoing questions, concerns, and health care monitoring needs that would better be addressed from a chronic illness perspective. Even the participants who were considered 'cured' had concerns about whether the virus might return, long term side effects from the treatment for HCV, and ongoing issues of feeling labeled and socially ostracized.

Much research has ignored biological differences while paying little attention to women's emotional and social circumstances (Doyal, 1995). Women in my study have shared their experiences so that health care providers might understand better what it is like to receive this diagnosis and live with HCV. When developing the proposal for this study it was indicated that further research is needed so that nurses and health care providers might be sensitive to the gendered, social, and medical needs of those receiving a HCV diagnosis.

Mothering and Female Identity

Thetford's (2004) study indicates that motherhood remains a central identity for women. Mothers are portrayed as self sacrificing, caring, virtuous and nurturing (Wearing cited in Thetford). Women with Hepatitis C may be assumed to expose their children to harm through transmitting the virus in their care giving roles (Thetford). It is assumed or thought they are poor role models with either present or past addictions.

Employment, age, race, other health problems, economic status, family of origin issues, and addictions all influence the degree to which Hepatitis C may influence a woman's ability to meet the ideals of motherhood (Thetford, 2004). Common multiple stigmas include being female, Black, an offender, homeless and/or a sex worker (Lloyd, 2010). Research also indicates that women who use illicit drugs, either currently or in the past, may be more stigmatized than men, especially if they are mothers or mothers-to-be (Simpson & McNulty, 2008).

Women not only experience economic disadvantage, injustice exists within personal relationships. Women and children make up the majority of the poor in the developed world (Sherwin, 1992). In the first year after divorce, the average standard of living for men rises by 42% while for women and their children it falls by 73% (Weitzman cited in Sherwin). Sherwin explains that women experience the double burden of working outside and inside the home. Historically, the expected and appropriate roles for women include caring for children and the family as well as being dependent financially on men (Lumby, 2009; Doyal, 1995). A perpetual sense of guilt is fostered as they struggle to earn an income and become role models for their children, are challenged to find affordable child care, and criticized for not spending enough time with their children (Lumby). Five of the participants were single parents working inside and outside the home. These women had multiple roles to fulfill and they struggled to meet those

expectations even when they were sick and unwell. Their economic, social, and emotional resources were inadequate as they continued mothering and working outside the home. The work outside the home they often do is physically challenging and leaves little energy for the full time mothering roles required of them at the end of the paid work day. They described work days that were grueling with hard physical work. They would go to work when they were unwell. Women are socialized to take care of their families and this is not a bad value except when they are not able to care for themselves (Walker, 2009). As a result of the significant challenges of single parenting mothers often stay in relationships that are unhealthy and are at increased risk of acquiring Hepatitis C.

There are multiple layers of socialized issues that put women at greater risk of Hepatitis C. According to the women's stories described in Mate (2008) many women who use injection drugs are severely abused, dislocated, and powerless. "The drug addict is today's scapegoat....we banish her to the margins of society" (Mate, p. 266). Mate summarizes that as a society we have failed to honour family and community life, failed to protect children, and refused to grant justice to Aboriginal people. We see our "vindictiveness toward those who have already suffered more than most of us can imagine" (Mate, p. 266). Mate further explains how each unit of our society reflects something of the whole. Until we see the complexities and the context of drug addiction as an issue of societal responsibility, health care providers and members of our society will continue to lay blame and further distance those most in need of healing and acceptance.

Lumby (2009) explains how historically women have experienced control socially and medically. "The body was not only controlled by medical surveillance, it was also disciplined through social expectations. Social status was determined by the way in which individuals

controlled their lives, habits, and bodies and this was particularly so for women” (Lumby, p. 115). Participants in another study wondered that society and the media needs to address some of the societal issues, such as poverty and drug addiction that lead to HCV infection, rather than blame, discriminate and judge (Butt et al., 2008). It is clear from the conversations with women in this study, in addition to other published studies, that interventions to reduce stigma will require individual, structural and systemic changes (Butt et al.). A focus on the social factors that contribute to poor health among women could help identify what is causing illness, if we wish to prevent illness (Walters, 2004; Doyal, 1995). The western expectation is that doctors will diagnose and treat the disease. When there is no obvious disease, or categorical reason to test for a particular disease, there is the risk that the illness will be labeled as psychosomatic (Lumby, 2009). Women are often labeled as anxious, fatigued, or neurotic prior to even doing investigations for symptoms reported. It is possible Mary’s experience was deemed hormonal or female with the advice to wear stockings and reduce her salt intake considered adequate treatment and advice. One such role is the stereotyping of women as ordinary tired mothers, despite their deteriorating physical health (Lumby). Mood disorders such as anxiety and depression are still represented by females in the media by pharmaceutical advertisements (Lumby; Doyal). A study, with HIV positive women, indicated “profiling women as bad or nice determined whether a diagnosis of HIV infection was even considered to explain a set of signs and symptoms” (Sandelowski, Lambe & Barroso, 2004). Socially advantaged, middle class women were more likely to suffer from delayed diagnosis (Sandelowski et al.). It is difficult to surmise or extrapolate Mary’s story to these assumptions. However, one does wonder why it was

so challenging, and took five years, for her to access treatment, when she was obviously so unwell.

Complexities and Nuances of Women's Lives

According to a Public Health Canada (2006) report, single working mothers have higher rates of chronic illness, score substantially higher on distress scales, and are three times more likely to consult a health care practitioner for mental and emotional health reasons. According to Statistics Canada, working single mothers put in an average 75 hour work week when paid and unpaid hours are accounted for (Public Health Canada). The findings also indicate that children who are poorly supervised and live in poverty are at higher risk of engaging in behaviours that lead to HIV/AIDS and Hepatitis C. Researchers such as Hertzman (1994) note that health impacted by low socioeconomic status accumulates over the life span and are passed on inter-generationally. Scott, Varghese and McGrath (2010) found that childhood adversity increases susceptibility to mental illness later in life. These authors also state that it is important to work with all of the adversities from a holistic aspect. The more adversities there are, the greater the risk of mental illness. This literature expands the understanding in the context of some of the participant's lives in my study. They spoke of intergenerational mental health, addiction, and abuse issues they struggled with. They carried the burdens of their own children's illnesses and deaths. They talked about not having the tools to support and raise their families as single parents. They spoke of being forced to have an abortion or their spouse would leave them to support and raise the family. They shared that their paid work was "grueling, demanding, heavy lifting, go go go, always by the clock." They told stories about being injected with illicit drugs by their partners in an attempt to save the relationship.

A gendered analysis best explores the complexities and nuances of women's lives to better understand the health impacts in their everyday lives (Reid, 2002; Doyal, 1995).

“Women's health involves the interplay of social, individual, and biological factors and is experienced within the physical, emotional, intellectual, social and spiritual dimensions” (Reid, p. 3). Explanations that do not include gender and social patterning of disease do not adequately represent women's health (Krieger & Zierler, 1995). For example many studies do not measure or consider women's domestic and caring roles. The fields of psychology, sociology, and anthropology suggest that women and men have different life experiences and have different resources for dealing with threats to their health (Macintyre & Hunt, 1997). A biomedical model is inadequate for identifying key health issues for women as it does not include gendered experiences, diversity, and the multiple roles that women fulfill in society (Doyal, 1995; Orme & Naidoo cited in Reid). A gendered understanding of socioeconomic status and health yields a fuller perspective of women's health (Reid). The main causes of the feminization of poverty are labour inequities, marriage breakdown, and motherhood (National Council of Welfare, 2007). Poverty rates among single parent families are unacceptably high and there have been staggering losses in welfare rates across Canada (National Council of Welfare). The most fundamental feature of women's lives is their responsibility for home, family, and household labour. Caring for and caring about others is a central feature of these activities wherever in the world they are carried out (Doyal). Doyal explains that millions of women around the world do the ‘emotional housework’ of managing the family's social health. “It is the least visible of their labours but may well be a major burden” (Doyal, p. 46). Doyal wonders who is looking after women's needs.

Domestic work is open ended and there is no end to the working day, making it difficult for women to separate rest from work (Doyal).

Women know that illicit drugs, tobacco, and a poor diet are hazards to their health. These practices reflect ways of coping with depression, deprivation, heavy workloads, uncertainty and lack of support (Walters, 2004; Doyal, 1995). Blaming the victim, or focusing on individual behavior, diverts attention from fundamental social inequities that cause poor health for marginalized women (Labonte, 1994). This is a power-over system. Power, with respect, tries to understand the context of people's lives and how they view the world (Labonte). Violence against women has also been a defining issue in the feminist movement for the past thirty years. All women are at risk of violence and this is one of the extreme power imbalances that exist in some gender relations (Walters; Doyal). Women are less likely to be employed full time, are more likely to be in caring roles, their views are more likely to be devalued, and they are less likely to occupy top positions in society (Walters; Doyal). In addition, with cuts to public services, there are fewer supports for women in their domestic and caring roles (Walters). This discussion cannot adequately discuss these issues. I mention them so we can understand the broad landscape of socio-cultural gender issues involved when women speak of their lived experiences. Many of the participants in my study internalized the societal value of blaming themselves and women for illnesses like HCV or addictions. Whereas the illness is a result of women finding themselves in circumstances that are increasingly difficult to manage with inadequate social supports (Doyal). It is difficult to see or understand the complex interplay of poverty, intergenerational health challenges, single parenting, women's social and work roles, and how they impact health. However, the women's stories, in my study, reflected all of these

issues in the context of, not only acquiring an illness such as HCV, but also living with the social and medical implications of this disease.

Epidemic: Social Silencing of Hepatitis

The initial literature review revealed a number of studies where stigma was an additional burden for women particularly (Butt, 2008; Paterson et al., 2007; Richmond et al., 2004; Crockett & Gifford, 2004; Sered & Horton-Hawk, 2008; Grundy & Beeching, 2004). Hepatitis C is often called a silent epidemic (Turkington, 1998). This is because many people are not aware they have the virus and it can lie hidden without producing symptoms for many years (Heathcote et al., 2002). However, of considerable concern is the social silencing of Hepatitis C due to stigma. Those most in need of social peer support feel silenced at the time of diagnosis, during treatment, and while living with Hepatitis C as a chronic illness. Individuals are viewed as having made poor choices and are seen as having chosen to engage in illicit and dangerous behaviours that resulted in contracting a contagious illness (Astone-Twerell, Strauss & Munoz-Plaza, 2006). These authors also explained that people who contracted the virus through drug use and continue to use drugs have a double stigma that causes social isolation as well as increased barriers to accessing HCV education, testing, and medical care and support. This double stigma occurs most commonly among people who use drugs when they are accessing support for their addictions. Two of the participants in this study received the HCV diagnosis while in recovery. Receiving the diagnosis with no information or support, at a particularly vulnerable time in their lives, was an additional burden. This put them at greater risk of relapse and one woman thought of suicide. The time of diagnosis was especially traumatic for most of the participants. It is imperative that women are heard in developing health care services that better meet social and

medical needs. My study indicates that current practices and societal blaming values exacerbate and perpetuate the epidemic of silence.

Stigmatizing experiences further silence those living with the illness. One participant states “I think maybe it is smarter to just keep your mouth shut. That is real life.” She believes Hepatitis C has marked her for life. A Hepatitis C diagnosis represents another means by which IDU can become visible, through medical records and treatment (Thetford, 2004). There is an assumption that people with Hepatitis C are, or have used illicit drugs, with blame for acquiring the disease, and putting other people at risk of infection (Lloyd, 2010). Butt et al. (2008) interviewed 26 people with chronic Hepatitis C in British Columbia. Participants described the the stigma they felt was associated with HCV. One person described how he “wasn’t well liked” when using drugs but when he acquired HCV he was treated “like I was a lower lowlife than before” (p, 211). The stigma and silencing revealed in my study further isolated women and created barriers in access to health care. They described it as a “very lonely diagnosis” and all of the participants were secretive about this diagnosis and the connotations of this label. This is a response to society’s stigmatization of this illness. As a result it was difficult to access peer support. Stigmatizing health care experiences will drive the illness further underground.

The literature indicates there are cultural fears that those who are infected with HCV are irresponsible, blamed for acquiring the virus, and have no regard for the safety of others (Sandelowski et al., 2004). My study demonstrates all of the participants were hyper-vigilant in protecting others and readily disclosed to protect anyone who touched them. One participant weighed the risks of disclosing to her landlord wondering if she would be refused as a tenant. She worried that possibly she would have an emergency and the landlord could be exposed to her

body fluids. It caused her great stress mitigating the effects of potential discrimination with the remote and unlikely risks of infecting another. One of the greatest burdens of the illness demonstrated in this study was women's concern and fear of transmitting the virus to others.

A US task force believes it is imperative that there be a coordinated response to the HCV crisis and have dubbed it "The Secret Epidemic" (Webb, 2010). They mean that many of those infected with the virus are unaware and programs need to be created for prevention, screening, and treatment. The women in this study have delivered a clear message. The social implications of the illness increase the burden of living with this illness and the secret component of the epidemic is the stigma that silences. This created barriers for women in accessing social and emotional support.

The most common report of stigma, with people who have HCV, is the withdrawal of care, support or services by health care practitioners (Butt, et al., 2008). However, the literature and segments of society continue to blame and actually believe there are benefits to stigmatizing and blaming. A conference of researchers discussed the impact of stigma on public health and the following dichotomy, related to stigma, is the personal communication reported at this conference. "There's an upbeat side to stigmatization, however, that often goes unnoticed. Collective decisions to stigmatize some behaviors, such as smoking cigarettes and using illicit drugs, actually benefit public health....What's more, encounters with stigmas may inspire some people to overcome society's obstacle and achieve more than they might have otherwise" (Bower, 2001). Yet within this article they also state that stigma-related fears hinder recovery and deter people from seeking treatment. People who experience stigma and

discrimination are at increased risk of a loss of social standing, are at increased risk of living in poverty, and receive poor or no medical care (Bower).

'Untouching' and the Embodied Experience of Touch

There is historical merit to the word '*untouching*' that Nancy utilizes in describing her experience. In Hinduism untouchables are those people who are outcasts and not accepted in general society. Despite outward signs of normalcy, untouchables cannot hide their status, and it is as though they have a scarlet tattoo on their forehead (O'Neill, 2003). Unfortunately, this description echoes Nancy's feelings and hospital experience. However, there is another possible interpretation of the language she uses in describing the hospital as *untouching*. DeVault (1999) explains that words available often do not fit the experiences that women may try to communicate. Possibly the lack of fit between women's lives and the words available for describing experiences present difficulties for self expression of a lived experience (DeVault). Nancy has constructed a word to help convey an experience in which she felt not only uncared for, but also marginalized, stigmatized, and a social outcast. A word that describes her embodied health care experience. She felt *untouchable* by the uncaring or *untouching* hospital experience. The word *untouching* symbolizes both the embodied experience, of feeling her body was *untouchable*, as well as the social or emotional need to feel cared for when vulnerable. One is vulnerable when sharing personal information that commonly evokes judgment, blame, and rejection. People are required to share their diagnosis of HCV when accessing health care and this further increases their vulnerability because of the risk of exposure to stigmatizing attitudes.

A medical diagnosis puts us in touch with our corporeality giving a heightened sense that we have a body (Hayne, 2002). The mind is embodied in the access to experience of the body

and the researcher must contemplate the connectedness of embodiment with experience (Munhall, 2007). Body intelligence is what gives us access to experiencing phenomena and we negotiate this experience in how we understand or perceive what is happening in our bodies (Munhall). In my study the women not only had a virus enter their body and, for some, cause physical damage but their whole perception of self was altered by the experience. The women's embodiment was severely threatened (Munhall). Their perceptions of being touched by another human were significantly altered. Although most of the participants knew and understood the risk of transmitting the virus was through blood to blood risk factors, this did not change how they felt about their bodies after receiving the diagnosis. Women were constantly aware that their body had the potential to infect others. It was an altered sense of their being and how they perceived themselves following diagnosis. "The diagnosis is not simply a medical condition but, in the eyes of others, it may define our very being. Now this label will determine how we will be judged and viewed" (Hayne, p. 193). One participant explains how this felt "oh my god, now I am one of those women, it is like leprosy."

The embodied concept of feeling untouchable was a powerful theme. To understand this from a social perspective the concept of *Othering* will be explored further. Othering is interpreted relationally by Canales (2000). "The self is only known through Others, and how Others are 'marked' and 'named' depends on the role taking of the self" (p. 18). According to Canales there are two processes of Othering: exclusionary and inclusionary. When the former occurs, in the context of health care delivery, the consequences are people feel oppressed and alienated. Opportunities for health promotion and restoration are then decreased.. This type of Othering exists within the context of power over relationships. The participants were relegated to

a different category of person following their diagnosis based on social constructions of what kind of woman has HCV. In contrast Canales describes Inclusionary Othering as a “process that attempts to utilize power within relationships for transformation and coalition building” (p. 19). When a person is able to take the role of another and attempt to view the world from the other’s perspective, they can begin to understand the meaning of the other’s world (Canales). There were many examples of Inclusionary Othering described by the participants. One example is Cathy’s description of compassion for people whose home was the street. Canales believes transformative relationships cannot develop without the Inclusionary Othering process. When nurses are able to better understand the role of the Other, however the Other is defined, their actions will be less directed by prejudices and stereotypes.

Inclusionary Othering is conceptualized as a process that also occurs within the context of power relationships. The difference between Exclusionary Othering and Inclusionary Othering relates to how power is used, by whom, and with what consequences. Inclusionary Othering practices attempt to use power to create transformative relationships in which the consequences are consciousness raising, sense of community shared power, and inclusion (Canales, p. 25).

Reading Canales perspectives, following my conversations with participants, not only expands the boundaries of my understanding, it provides an approach that can effect change at all levels of health and nursing care.

Stigma

Stigma, as a social process, is reflected throughout the women’s stories and emerged as a major facet of the experience of being diagnosed with HCV for women in this study. They described being treated like garbage, feeling like a non person, being untouchable, and wanting to keep this illness a secret. The women felt they were blamed through internalized felt stigma. In some of the stories, illness was constructed as preventable, behaviours such as illicit drug use

were identified, and these behaviours drew on existing social constructions of 'other'. Some people may avoid testing or disclosing their status because of stigma which can lead to further spread of a contagious disease (Benoit, Shumka & Barlee, 2010). This results in limiting access to necessary treatment, care, and support for the illness. Benoit et al. explains that stigma does not affect or impact everyone in the same way.

Those who face serious health concerns, and at the same time are subject to multiple stigmas by virtue of their age, sex, gender, sexual orientation, race, ethnicity, socioeconomic or other social determinants, are less able to access key resources and therefore differentially positioned to buffer themselves against the damaging impact of interacting stigmas (p. 5).

The women participating in this study, who were especially vulnerable to stigma, had intersecting vulnerabilities that placed them at greater risk of stigma, and were less empowered to respond or fight back against discrimination and stigma experienced. They feared being labeled and stereotyped and were more vulnerable when accessing health care because of the power over situation. They had less power in society because of their gender and fewer financial resources. Link and Phelan explain how stigma places people at a social disadvantage with respect to the resources of knowledge, money, prestige, and the power connections needed in order to adopt protective strategies. Poverty, single parenting, mental health issues, addictions, stigma, and overwhelming work loads are some of the intersecting issues, described in this study, that contributed to the participants having fewer resources to protect themselves from the damaging impact of interacting stigmas. Stigma is all encompassing and the associated stress puts people at further risk to develop other illnesses (Link & Phelan, 2006). The clinical course of the stigmatized illness itself may be worsened as well as the ability to work or lead a normal social life (Link & Phelan). They described loss of employment, dread of accessing needed

health care, and fear of being rejected as a tenant. They described lack of peer support because many wish to keep this illness a secret. The women were aware of the stereotypes that might be attributed to them resulting in a continuum of loss of self esteem and, in one situation, feeling like a non person.

Nursing Practice Implications

The general public consistently views nurses as compassionate and ethical professionals. The Canadian Nurses Association (2009) position statement on determinants of health recognizes the value of health research that deepens understanding of the impact of various determinants of health on the health status of individuals and populations. How does this hermeneutic phenomenological process contribute to nursing and knowledge development? Listening and sharing, articulating our authentic experiences with people, and claiming what we and the people we work with believe to be essential to health is the core of nursing knowledge development (Munhall, 2007). Phenomenological text can have the effect of making us suddenly ‘see’ something in a way that enriches our understanding of everyday life experience (van Manen, 1997a). Boyd (2001) explains it well when she says access to truth is a problem of access to human subjectivity.

Trauma Informed Care

Crotty suggests that nursing studies should offer pragmatic suggestions to improve the quality of life for people (cited in Munhall, 2007). Nursing has unique and important access to this knowledge development, in the everyday experiential care that is nurse’s work. However, “much of nurse’s business is like women’s business--it is taken for granted, it is stories, it is grounded in experiential knowing, and it has been silenced in a patriarchal world” (Lawler, 2009,

p. 49). Dominant emphasis has been on biomedical interventions guided by a disease based model (Walters, 2004). However, if we focus on gender, we must redefine how we understand and approach healthcare. Nursing can take a role in fighting stigmatizing behaviors, labeling, and blaming. We must first examine and become aware of how we might be taking up a stigmatizing attitude because stigma causes trauma. The more vulnerable women were when accessing healthcare, the greater stigma experiences affected them. It became a significant experiential trauma. This was possibly a greater burden than the illness itself. Women, in this study, said it is important that they feel safe and respected so they could heal. Thinking with the data about the human conditions experienced in this study is important nursing work. Thinking with the data is not the same as making recommendations to policy makers. This thinking can change the minds and culture of clinicians who will make specific changes in policy and practice (Cohen et al., 2000). Nursing can take a leadership role in research that describes these human conditions from lived experience inquiry. This is where the potential exists to shift approach and attitudes to care provided.

For example, it is clear from many of the women's experiences in this study that they were coming from places of trauma. Receiving the diagnosis was traumatizing and the women utilized strong language to communicate their experiences. If we wish to understand health in the context of women's lives, we must make space to hear the stories that tell us what those experiences are. When we care for women who have HCV, we must approach them with the possibilities that they have experienced previous trauma. Fallot and Harris (2006) have outlined one approach to trauma informed care. Some of the principles encompassed in this care are: symptoms of trauma are understood not just as complaints but as attempts to cope; treatment recognizes women's

vulnerabilities and their strengths; services are based on the principles of safety, voice and choice; peer support can be life saving; trauma services are ethnically, racially, spiritually and gender relevant to the individual; and finally trauma services are coordinated across multiple service systems. Often women cycle in and out of these various service systems without receiving appropriate services. Nursing services must do their part and we cannot let this continue. Linda Rosenberg (2011), from the National Council for Community Behavioral Healthcare, has posted a letter challenging all social and health care services to implement trauma informed care. She asks that we simply ask those we care for “What happened to you?” and not “What’s wrong with you?” She asks all of us who work in health care to send her stories of lives we have touched and transformed so that they can be shared. This will communicate to the world how we are making a difference.

Clinical Practice Recommendations

The experience of a diagnosis of HCV is a powerful experience that brings to the fore issues of stigma and mental health issues in addition to medical concerns. Testing for HCV is complex and involves multiple steps before a diagnosis can be made. Currently there are no formal pre and post test counseling guidelines or policy for HCV testing in Canada (Canadian Aids Treatment and Information Exchange). We need clinical guidelines that address the way that a diagnosis is managed. For example, receiving a diagnosis in person in a compassionate knowledgeable manner would be appropriate instead of over the phone or by a letter in the mail.

The implications of my study indicates that further research is needed so that guidelines can be enacted to provide information that is sensitive to the gendered social and medical needs of those receiving a HCV diagnosis. Research is needed on men’s experiences of receiving a

diagnosis of HCV so nurses and health care providers can understand what gendered approaches might be beneficial for their health care. Further research is indicated on what types of experiences are considered stigmatizing when people access health care. Health care providers can then develop insight and awareness on what types of experiences are considered stigmatizing. This study raises many questions and asks us to examine everyday practice and policy as health care professionals.

Summary

The participants have courageously shared what their experiences of receiving a diagnosis and living with Hepatitis C means in their everyday life. The women in this study have told us that safe, non-judgmental, respectful care, and a space to hear their stories, is central to their health care experiences. As health care professionals we need to understand the implications and meaning for women when they receive a diagnosis of Hepatitis C. Readers will develop their own understanding and interpretations. The hope is these nine stories will help nurses and health care professionals develop understanding that informs compassionate and sensitive care when working with women who have Hepatitis C.

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Appendix A
Recruitment Advertisement

ATTENTION WOMEN WHO HAVE HEPATITIS C

**WE WANT TO HEAR YOUR STORY
WOMEN'S PERSPECTIVES ARE VERY IMPORTANT IN GUIDING HEALTHCARE**

Would you like to participate in a research project? I am a graduate nursing student at the University of Victoria and I am interested in having conversations with women who have (or had) Hepatitis C.

Who can participate?

**ANY WOMAN 19 YEARS OLD AND OVER WHO HAS RECEIVED A
DIAGNOSIS OF HEPATITIS C**

What will I be asked to do?

**SPEND 1-2 HOURS HAVING A CONVERSATION WITH DONNA
(RESEARCHER) IN A PRIVATE CONFIDENTIAL SPACE**

Some questions explored are:

- 1) Tell me about your experience when receiving a diagnosis of Hepatitis C?
- 2) Tell me about your health concerns and living with Hepatitis C?
- 3) What supports, information or services would be beneficial to you?

If I am interested what should I do?

If you are interested in participating or would like further details, please contact Donna at:
250-870-1902 or donnazuk@uvic.ca

All Information is Completely Confidential

Taking part in this study is voluntary

You can stop anytime

Access to services will not be affected

Appendix B

Proposed Open Ended Conversation Questions

Open Ended Conversational Questions:

1. Tell me about your experience of being diagnosed with Hepatitis C.
2. Can you describe any feelings or symptoms related to HCV you are presently experiencing?
3. Prompts and further questions will be guided by each individual's response. The conversation will be led by the participant and what they believe is most important to share. Some further potential prompts or questions are below.
4. Tell me about your experience of being told you have HCV.
5. Has being diagnosed with HCV changed your life in any way?
6. Is there anything you believe is unique to women living with HCV?
7. Tell me about what you may have experienced as challenging living with HCV.
8. Tell me about anything that you may have experienced that is positive about living with HCV or are there any ways that life has gotten better for you since you were diagnosed.
9. Have you had any experiences of stigma and if yes could you describe what that was like and means to you.
10. A final question will be: is there anything else I should have asked to help understand what it is like living with Hepatitis C?

Appendix C
Informed Consent
Lived Experiences of Women Receiving a Hepatitis C Diagnosis

Title of Research Study: Lived Experiences of Women Receiving a Hepatitis C Diagnosis

Primary Investigator: Donna Zukowski is a graduate student in the department of Nursing at the University of Victoria. You may contact her if you have further questions by phone: 250-870-1902 or email: donnazuk@uvic.ca. As a graduate student I am required to conduct research as part of the requirements for a degree in the Master's of Nursing Advanced Practice Leadership.

Supervisor: Dr. Bernie Pauly at 1-250- 472-5915 or email: bpaul@uvic.ca

University of Victoria Research Ethics Board: 1-250-472-4545 or email: ethics@uvic.ca

Interior Health Ethics Board Contact: 250-870-4602 or email: ann.ferguson@interiorhealth.ca

You may contact any of the above contacts if you have any questions or to verify this study. In the case of any study related harm, or if you wish to verify this study, or find out what your rights as a research participant are, you may contact my supervisor Dr. Bernie Pauly or the Interior Health research ethics contact at the above contact phone or email contacts.

Access to health care services will not be affected in any way by participation in this study.

What is this study about? I, as the researcher, wish to talk to you about “What are your lived experiences of receiving a diagnosis of Hepatitis C?”

Why am I asking these questions? Research of this type is important because women's stories can assist health care workers to understand these lived experiences and develop new understandings of the effects of being diagnosed and living with an illness such as hepatitis C. Potentially this study may reveal other concerns you may have. This may provide further knowledge and understanding; especially for healthcare workers who work with women who have hepatitis C. Understanding the context and the lived experiences will add to a small but growing data base of literature on women's healthcare experiences.

You are being asked to participate in this study because it is believed women's stories and descriptions of living with Hepatitis C and their access to healthcare is valuable. There will be 4-8 participants recruited from Kamloops, Vernon and Kelowna.

What will you be asked to do if you take part in this study? If you call me or email me I will explain to you what this study is about and share with you the contents of this consent. If you agree to voluntarily participate in this research, your participation will include meeting with me, the investigator, once for one to two hours for an audio taped conversation. I will ask you to choose a place that is comfortable and private such as booking meeting space in a private room in the library near by. If we are at Outreach Urban Health we can meet in a private office onsite. The beginning of the meeting will involve explaining the study and answering all of your questions. I anticipate this will take about 15 minutes, however, it is most important to take

whatever time is required to fully understand the study. There will be an opportunity for you to read this consent and verbally tell the investigator your understanding of the study. Or you can choose to have me, the investigator, read this consent to you. I will answer any questions you may have. This will be followed by an in-depth taped conversation on the study's topic. You are free to decline answering any or all questions at any time. You are encouraged to only answer and share information that you are comfortable sharing. At any point if you wish to withdraw information already shared it will be erased from the audio tape.

Confidentiality: In terms of protecting your confidentiality I will not reveal your identity to anyone. Any questions such as your age, relationship status, education, or stories you share, will be kept confidential. All identifying information, including the geographical location of this study, will be removed. Your taped conversation will be coded with a number so as to maintain confidentiality and not reveal your identity. I will ask you to use a "nick name", of your choosing, to further help maintain confidentiality during the taped conversation. During and after the study all written and taped information will be kept in a locked file cabinet in my locked private office. The key is kept with me. No one has access to this office except myself. One list, of your contact information, will be kept by me for the purposes of communication with you. This list will be kept in a locked drawer separate from the transcribed data and shredded 2 weeks following our conversation.

No information will be kept on Interior Health computers or in their offices. Information will also be kept on my personal laptop that has a security code to access it. This laptop is kept in my locked personal office. Your confidentiality and the confidentiality of the data will be protected by restricting the audiotapes and transcribed data to be available only to myself, my primary supervisor and my committee (if requested). Interviews will be transcribed by a paid transcriptionist; who will also uphold the ethics of confidentiality and sign a contract. Confidentiality will be upheld if research findings are shared in any publications or presentations.

All paper information will be shredded and computer information deleted once my thesis is completed. I anticipate finishing the thesis in the spring of 2011.

What will the information be used for? Your information will be used to write my thesis for my Master in Nursing degree. A summary of the important themes identified in our conversation will be shared with nurses and students who work with women who have hepatitis C. I will share this information with you if you wish this. All identifying information will be removed prior to writing the thesis so no one will be able to identify you. The data will be of use to me personally in my studies as well as contribute to scientific knowledge. When my thesis is completed the final document will be kept in the University of Victoria and will be accessible to faculty and students. Sections of the thesis may be published in scientific journals/books or publicly presented while adhering to the ethics of anonymity and confidentiality. I may distribute a summary report to the service providers from where you were recruited to participate in this study.

Reimbursement: Participation in this study may cause some inconvenience to you, including the time commitment as outlined above. There may be costs associated with travel, phone calls or childcare and these will be refunded by me, the investigator. You will be given a \$20 gift certificate to a store of your choosing. The anticipated conversation time is a maximum of 1-2 hours. At any point you can withdraw and ask to not include what you have shared with no obligation to return the gift certificate. It is important for you to know that it is unethical to provide undue compensation or inducements to research participants. If you agree to be a participant in this study this form of compensation must not be coercive. If you would not otherwise choose to participate if the compensation was not offered, then you should decline. All of your expenses will be paid to you even if you choose to withdraw at any time. It is estimated that gas costs could be approximately \$10 and taxi fare \$30. Childcare costs will be refunded at a rate of \$8 per hour for a total of the anticipated three hours to cover the interview and travel time. I ask that you provide receipts for expenses. Any information shared up to the point of withdrawal will only be used with your written permission.

Potential Risks: There are some potential risks to you by participating in this research and they include emotional or psychological responses when discussing personal experiences. Potential risks are related to the possibility of becoming upset, feeling anger or feeling fatigued from reliving past experiences that were unpleasant. To prevent or deal with these risks the following steps will be taken:

1. If you experience fatigue or any unease during the interview you may end the interview, reschedule at your convenience, or call me at the number provided if you decide you do not wish to meet.
2. You will also be provided with the names and phone numbers of support services for counseling that are available to you that are not associated with this study.
3. If any information is shared that involves abuse of minors it is the legal and professional responsibility of the researcher to report this to the appropriate authorities. This is one area of confidentiality that legally cannot be honoured. **Initial your understanding of this legal requirement ____**
4. Participation in this study may cause you some inconvenience including the time commitment required. To facilitate minimal disruption to your schedule I am flexible to the timing and location of the conversation. I am hopeful that the benefits of sharing your personal experiences will counter the inconvenience associated with participation.
5. The researcher may have a future relationship to potential participants. If your family Physician refers you to the Kelowna Hepatitis Clinic, where the researcher is presently employed, the researcher will ensure that a colleague is your primary Nurse, if this is your preference. This colleague will have no knowledge of your participation in this study. In this study I am in the role of a graduate student conducting research and not in the role of a nurse.
6. It is possible the investigator or their supervisor could become ill and not be able to continue the study. If this happens every effort will be made to notify participants that the study may be terminated.

Potential Benefits: The potential benefits of your participation in this research include the opportunity to share your story with someone interested and concerned. You may learn more about your condition through self-reflection or through direct interaction with the researcher. You may derive satisfaction that information you provide may help others with similar problems. Potentially this research will reveal concerns specific to women; giving further understanding and knowledge for nurses who work with this population. The data will add to a small but growing database of literature on women's healthcare experiences and related unique needs. The primary benefit concerns the advancement of knowledge which can be used to promote human health and welfare in the long run. There may also be no benefit realized from participation in this study.

Participation and withdrawal: 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 your data will only be used if you give written permission at the time of withdrawal to use the data. If you decide to enter the study and to withdraw at any time during the interview there will be no penalty or loss of benefits to which you were otherwise entitled. Any expenses you have incurred for transportation and/or childcare will be paid to you. We ask that you provide receipts for expenses. In no way does signing this form waive your legal rights nor relieve the investigator, sponsors or involved institutions from their legal and professional responsibility. If any information becomes available that may affect your willingness to continue in this study you will be informed of it at once.

Study Results: You can obtain a copy of a summary of the findings from this study by contacting me, the investigator, at 250-870-1902 or donnazuk@uvic.ca any time after May/2011.

Your signature below indicates that you are withdrawing part way through the study **and you wish for your data to be included in the research.**

Name of Participant (printed)

Signature

Date

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 by the researchers.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>

<hr/> <i>Name of Participant</i> <i>Withdraw data (Optional)</i>		<hr/> <i>Signature</i>		<hr/> <i>Date</i>
<hr/> <i>Name of Participant</i>		<hr/> <i>Signature</i>		<hr/> <i>Date</i>
<hr/> <i>Witness</i>		<hr/> <i>Signature</i>		<hr/> <i>Date</i>

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix D

Contract for Transcription of Interview Tapes

You have agreed to be a transcriptionist in a study entitled *Women's Experiences of Living with Hepatitis C* that is being conducted by Donna Zukowski. Donna Zukowski is a graduate student in the department of Human and Social development at the University of Victoria and you may contact her if you have further questions at 250-870-1902 by phone or email: donnazuk@uvic.ca. As a graduate student, I am required to conduct research as part of the requirements for a degree in the Masters of Nursing Advanced Practice Leadership program. **You may contact my Supervisor as follows:** Dr. Bernie Pauly at 250-472-5915 or email: bpaul@uvic.ca

In addition to being able to contact the investigator and the 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 at 250-472-4545.

This contract for transcription of interview tapes constitutes an agreement between Donna Zukowski, principle investigator, and _____, transcriptionist. In agreeing to this contract, I _____ agree to the following:

- ♣ Audiotapes are to be transcribed verbatim, and in detail, according to the formal instructions of the principle investigator.
- ♣ As the transcriptionist, I will maintain the confidentiality and privacy of the participants. I will repeat no part of the participant dialogue and if I am aware of the identity of participants, I will not reveal this information to anyone. As soon as I become aware of the participant's identity I will stop the tape and notify the researcher. The researcher will then transcribe this taped interview ensuring removal of all identifying information.
- ♣ The audiotapes and hard copies of the data, when not being actively used by me for transcription, will be kept in a locked filing cabinet supplied to me by the principle investigator.
- ♣ Once the tapes and transcriptions are returned to the principle investigator, I will erase all computer files pertaining to this study/research.
- ♣ Payment will be made upon completion of transcripts at a rate of \$20.00 per hour of work. It is expected that each hour of tape will require three to four hours of transcription time.

Your signature below indicates that you understand the above contract conditions and that you have had an opportunity to have your questions answered by the researcher.

Appendix F
Letter of Introduction to Recruitment Sites
DRAFT

Donna Zukowski
790 Anders Road
Kelowna, BC V1Z 1J9
donnazuk@uvic.ca
250-870-1902 (cell)
250-769-3256 (home)

XXXX
Manager

Dear XXX

I am currently enrolled in the University of Victoria's Master in Nursing Leadership program. I am preparing to complete the thesis component of this graduate degree. I work in the area of hepatitis care and treatment. Women's experiences of diagnosis and living with hepatitis C is an area I am interested in exploring further. The primary desire of this thesis is to capture women's stories with the possibility of describing the meaning of receiving a diagnosis of hepatitis C.

I would like to have a conversation with women and recruit participants from your health care program. I will provide a poster for recruitment as well as a script for the person who may distribute these posters. I ask that the posters be placed in the area where other pamphlets and information is made available in your clinic. I will have an in-depth conversation with each participant; at a time and place that is convenient for them. Full consent will be obtained as per ethics requirements and confidentiality maintained. It will be up to the participant to make contact with me and no one in your clinic will be aware of who the participants are.

I have obtained approval from the Interior Health Ethics Board as well as from the University of Victoria's Ethics Board to conduct this study.

After completion of this thesis I hope to summarize the findings and share them with health care providers and students entering the health care profession who work with women who have hepatitis C.

Thank you for your assistance and please do not hesitate to contact me at the above email or phone numbers and I will be more than happy to answer any questions of provide more details.

Sincerely
Donna Zukowski

APPENDIX G
Letter of Invitation Mailout

September 2, 2010

Letter of Invitation:

The agency is sending invitations out and I, the researcher, do not know which individuals this notice is being sent to.

This is a letter of information about a study that I as a Masters Nursing student am conducting in your area. I am the principal Investigator and my name is Donna Zukowski RN, BScN. I am at the University of Victoria, in the Advanced Nursing Practice Leadership Masters program. Conducting this research study will contribute to completion of a thesis towards a Masters in Nursing degree.

I am interested in speaking with women who have Hepatitis C. We need to hear women's stories, as their perspectives are very important in guiding health care.

You are being asked to participate in this study because it is believed women's stories and descriptions of living with Hepatitis C and their access to healthcare is valuable.

If you agree to participate you will be asked some questions such as:

1. Tell me about your experience of being diagnosed with Hepatitis C.
2. Has being diagnosed with Hepatitis C changed your life in any way?
3. Is there anything you believe is unique to women when living with Hepatitis C?
4. Tell me about what is most important to you in your healthcare and Hepatitis C.

The whole conversation will take from 1-2 hours and will be led by you, the participant, in a casual conversational manner. The information gathered will be used to write a thesis as well as shared with nurses and health care workers who work with people who have Hepatitis C. The findings may also contribute to educational presentations for students going into the healthcare field. All results will be combined into a summary report; which will not include any identifying information. All information shared will be kept in the strictest of confidentiality so no one will know whose story or information it is. The place participants live will not be shared. You can withdraw from the study at any time and you can decide what information you would like to share about your health and Hepatitis C. If you decide to meet with me we would meet at a mutually agreed upon location that is private so we could have a confidential conversation; such as private space at the library. If you contact me I will give you more information and discuss what is involved in the consent process on the phone. You can then decide if you are interested in meeting to have a conversation about this topic.

I will not have any of your contact information unless you decide to contact me and are interested in participating in this study. I do not know whom this letter was mailed to as only the clinic where you have received care for your hepatitis has this information and they must keep it confidential.

It is your choice whether to call me for more information or whether to give me your contact information. I will keep any information you share completely confidential; if you choose to participate in this study. The clinic where you receive or have received care will not know whether you decide to participate or whether you even contact me.

If you choose to participate in this study or choose not to your access to healthcare will not be affected in any way.

My supervisor is Dr. Bernie Pauly and you may contact her at any time to verify this study or if you have any questions. You may also contact the University of Victoria Research Ethics Board or the Interior Health Ethics Research Board to verify this study.

Supervisor:

Bernie Pauly RN, PhD

Associate Professor

School of Nursing, Center For Addictions Research BC

Mailing Address: University of Victoria, Box 1700 STN CSC

Victoria, BC, Canada V8W 2Y2

bpaul@uvic.ca

University of Victoria Research Ethics Board: 1-250-472-4545 or email: ethics@uvic.ca

Interior Health Ethics Board Contact: 250-870-4602 or email: ann.ferguson@interiorhealth.ca

I would like to have a conversation with you if you are interested in sharing your experiences on this topic.

Any expenses such as phone calls, bus fare, gas costs or childcare will be refunded to you; by myself. It is estimated that gas costs could be approximately \$10 and taxi fare \$30. Childcare costs will be refunded at a rate of \$8 per hour for a total of the anticipated three hours to cover the interview and travel time. I ask that you provide receipts for expenses. I will also be providing you with an honorarium for your time. The honorarium and expenses refunded in no way obligate you to participate in this study and you may withdraw at any point.

I will provide you with further details during the consent process if you are interested and have information to share about your experience of being diagnosed or any aspects of living with hepatitis C. If you are interested would you please contact me within two weeks of receiving this letter. Any date we would set up to meet would be at your convenience.

If you would like more information about this study please contact Donna Zukowski at 250-870-1902 or donnazuk@uvic.ca

Thank you

Sincerely

Donna Zukowski RN BScN