

The Experience of Feeling Understood for Nurses with Disabilities

by

Kara Lee Schick Makaroff  
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Supervisor: Dr. Deborah Thoun Northrup

### ABSTRACT

The purpose of this research was to explore the experience of feeling understood for five nurses with disabilities. Guided by Parse's theory of human becoming, a descriptive exploratory methodology was used to answer the research question: What is the meaning of the experience of feeling understood for nurses with disabilities? A process of analysis-synthesis revealed three research themes. When interpreted in the language of the researcher and linked, the themes are: *Acquiescence-non acquiescence of shifting capabilities with prospects give rise to serenity-anguish while bonds of security-insecurity surface with candour-concealment amid tentative assistance as buoyant conviction wavers amid fervour with fright*. When interpreted in the language of the theory, feeling understood is conceptualized as: powering of imaging valuing amid connecting-separating with revealing-concealing. Findings were then discussed in light of relevant literature, and suggestions for nursing practice, education, research, and policy were offered.

Supervisor: Dr. Deborah Thoun Northrup (School of Nursing, Faculty of Human & Social Development)

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Dedication

In memory of those in my family who passed away in the last year:

Grandpa Beiber

Giacomo

Grandpa Eliason.

This thesis is dedicated to

my parents,

Vi and Richard Schick,

and to my siblings,

Julie, Daniel, and Andrea Schick,

who were the first ones with whom I knew what it was like to feel understood.

I cannot imagine my world without you.

## *Chapter 1- Introduction and Background*

Research related to the phenomenon of concern of feeling understood for nurses with disabilities is relevant and timely as health care organizations across Canada are currently struggling with the compounding issues of recruitment, retention, financial strain, and efficiency. To date, no research related to this phenomenon has been conducted with nurses with disabilities. However, the Canadian Nursing Advisory Committee (CNAC) (2002) reported that the incidence of absenteeism among nurses because of injury and illness is eighty percent higher than the average statistic in Canada's full-time labour force (Canadian Labour & Business Centre, 2002). Such diverse issues of absenteeism, retention, occupational health, policy, or even the complexity of disabilities are, however, not the primary focus of this research. Rather, it is the experiences of nurses with disabilities and their perspectives of feeling understood that comprise this research inquiry.

With increasing absenteeism and disability, numerous authors (McLeod & Spée, 2003; Mitchell, 2001; Wharf & McKenzie, 1998) suggest that policy may provide capacity to be responsive to the experiences of individuals when developed with more involvement from practitioners and service users. While policy is not an end in and of itself (Cheek & Gibson, 1997), it may provide a framework of opportunity through which individuals' experiences can be acknowledged. Significantly, there is virtually no evidence of participation in policy development from nurses with disabilities (B.C. Government & Service Employers' Union, 2002; "B.C. Government to Disband", 2002; B.C. Human Rights Commission, 1998, 2000; Human Rights Research & Education Centre, 2004; Joanis, 2001; Revised Statutes of British Columbia, 1996; The B.C. Human Rights Coalition, 2003). However, when informed by a different understanding of the experiences of nurses with disabilities, health professionals who practice with this population may choose to prepare job sites, recruit, and retain nurses in different ways; in short, they may participate in different policy decisions. With new understanding, policies that honour and reflect the experiences of nurses with disabilities may be enacted and developed. Such an evolution may considerably affect future directions in health care policy development.

Honouring the experiences of people is a needed shift in health care, nursing practice, and development of policy (McLeod & Spée, 2003; Mitchell, 2001). A lack of understanding related to human experience has perpetuated the tendency toward objectification of individuals with disabilities. Traditionally, such objectification in practice is embedded in the dominant bio-medical model of health care delivery, within goals of efficiency and effectiveness, and sustained by societal and cultural influences. However, when human experiences are included, the continuous dynamic dialogue between nursing practice, theory, knowledge, and policy can broaden.

For most persons, feeling understood is an experience that brings a sense of comfort and belonging. A greater understanding of the phenomenon of feeling understood may enhance insight about other experiences such as quality of life and work satisfaction for nurses with disabilities. Further, Jonas-Simpson (1998, 2001) suggested that new knowledge of feeling understood “may create a transformational shift in knowing and provide nurses with insights for new possibilities in being with persons and families in the nurse-person process” (2001, p. 229).

The specific phenomenon of concern in this nursing study is the human health experience of feeling understood. This study differentiates between feeling understood and being understood, a distinction that was not generally recognized or discussed within the body of literature on this topic. Rather, the literature frequently used the term feeling understood interchangeably with being understood. The phrase “not feeling understood” was also used synonymously in the literature with not being understood, feeling misunderstood, or being misunderstood (Abrams, 1988; Allen & Thompson, 1984; Baker & Daigle, 2000; Black, 1991; Carlson, Ottenbreit, St. Pierre & Bultz, 2001; Carroll et al., 2000; D’Avanzo, 1992; Feitel, 1968; Gray et al., 1999; Gray, Fitch, Davis & Phillips, 1997; Howell, 1998; Jan & Smith, 1998; Jonas-Simpson, 1998, 2001; Murray, Holmes, Bellavia, Griffin & Dolderman, 2002; Peltz, 1992; Pocock, 1997; Reis & Shaver, 1988; Stallard, Velleman & Baldwin, 2001; Sullins, 1992; van der Kolk, 2002, Van Kaam, 1958).

In Jonas-Simpson’s (1998, 2001) phenomenological inquiry of feeling understood, she considered her participants’ relationships with others who “understood”, “were understanding”, or “were not understanding”. Jonas-Simpson’s distinction of the

phenomenon of concern differs from this study in the sense that feeling understood is *not* considered to be the same as understanding or being understood. In this study the phenomenon of concern is regarded from the person's articulation of her/his *perspective* of feeling understood by others or her/his self. The concept of being understood or engaging with those who understand implies that the other person may correctly, rightly, or accurately interpret what you are saying. Such conceptualization is epistemologically rooted in an objective view of what constitutes knowledge and lived experiences. It is inconsistent with the human science perspective underpinning this study and further developed later, that dissolves the objective-subjective duality into a view of persons as indivisible.

Moncrieff (1999) also discussed feeling understood as having "accurate insight into the person's rationale for choices" (p. 61). Conversely, in the conceptualization of feeling understood purported in this study, the focus is on the individual and her/his perception of feeling understood rather than on another person's correct or incorrect interpretations. Dickson (1991) also made a distinction between feeling understood and being understood. He explained that he chose to study feeling understood as opposed to being understood because, " 'being understood' seemed to imply an objective state, one determined by looking from the outside. I can 'be' understood without realizing it" (p. 48). Dickson's discussion of the phenomenon of concern closely aligns with the conceptualization of feeling understood in this research. Thus, in this study, the research question is, What is the meaning of the experience of feeling understood for nurses with disabilities?

#### *Why is this Research Important to me?*

I have discovered that personal experiences of nurses with disabilities are significant from first hand experience with the topic; I am a nurse with a disability. Although I have not chosen my own personal experiences as the focus of this study, they bear heavily on my insights related to the phenomenon of feeling understood. Therefore, I purport the disbelief in value-free research (Denzin & Lincoln, 2000), recognizing that I am approaching this topic as an "insider" (Creswell, 1998) informed by my own values. I agree with Creswell that researchers bring their biases and values to a project. When it

comes to Creswell's view that there is not room for insiders to research areas in which they have a vested interest, I disagree. I believe that the only way in which I can (first) approach the world, other people, and my work in nursing research, is through my own personal beliefs, experiences, and understandings. Therefore, infinite room is available for researchers to study areas in which they are deeply involved. For it is only as insiders that we know the universe. This view is consistent with the indivisible ontology and interpretive epistemology that underpins this study and shall be discussed in other sections of my study.

Society, culture, politics, and stigma, all features of our world, add to the complexity of disability. Nursing practices, including the practices of nurses with disabilities, are also affected by such influences. As a nurse who has cared for persons with disabilities (Linton, 1998), a colleague who has worked with other nurses who have disabilities, and a nurse who has an invisible disability, I have experienced frustration with co-staff, as well as with myself, when work has been slowed because "normal" work processes and speed have been interrupted. With political, economic, and organizational goals of efficiency incorporated within the majority of clinical settings (Armstrong et al., 2002; Campbell, 2000; Fuller, 1998), a common belief is that disability disrupts productivity. I have also experienced disappointment caring for individuals with disabilities because their altered abilities could not be "fixed" or "cured".

Ironically, I have experienced this frustration even though I also live with a disability. I am aware of my personal prejudice towards people with disabilities. I fear being labeled as "one of them"; yet, consider myself a part of this community. My personal choices have frequently been disregarded when my care has been planned by health care professionals. Yet, I have also done the same to my patients. This discrepancy in my life has alerted me to the obligation for nurses in practice, including myself, to honour individuals as they express the meaning of their experiences and make choices that will inform and direct their care.

In early consideration of this thesis topic, many nurse colleagues encouraged me to use autoethnographic, narrative, or autobiographic methodologies because of my personal experiences, or to use phenomenology to specifically address the essence of individuals' lived experiences. I gave these options considerable thought and even began

studying one method in particular. However, it was my decision to write with the intent of contributing to nursing science that led me to ascribe to nursing's theoretical underpinnings and subsequently to the methodology chosen for this study. The methodologies identified above would not contain ontological, epistemological, or theoretical congruence with a nursing science perspective within an indivisible multidimensional reality (see Principle 1 in Parse, 1981, 1987, 1998).

In initial formulation of this study, I discovered that the experiences of individuals with disabilities were rarely explored in scholarly literature. Studies of individuals' experiences of receiving assistance (Lillesto, 1997; Morris, 1995) contended that health care personnel focussed on the aspect of an individual that is disabled alone, neglecting to address them as whole individuals. Participants in Lillesto's and Morris' studies reported feelings of violation, lack of control regarding choice over required assistance, humiliation, embarrassment, and "feeling misunderstood". This finding identifies that a shift is needed with regard to the education of health care professionals. Sadly, many health care professionals, including nurses, do not even realize that the receiver of their care may perceive their actions as a violation because education in the biomedical culture has routinized daily actions, which in turn have been internalized by health care professionals.

During early consideration of this study, I initially only found three studies that examined the experiences of nurses with disabilities (Brewer & Nelms, 1998; Kimpson, 1995; Pohl & Winland-Brown, 1992). These articles discussed nurses' similar reports of financial stress, organizational influences, illness, and challenges in their quality of life and work. First, Pohl and Winland-Brown explored how nurse administrators could create caring environments for nurses to return to work. While the authors' recommendations were consistent with their organization's goals of recruitment and retention, their suggestions were not consistent with their stated obligation to address issues of betterment or quality of life for the nurses involved. Second, Kimpson wrote autobiographically in consideration of organizational influences, as she assessed power, representation, and authorship in relation to her personal experiences of feeling that the academy did not value her experiential learning as a nurse with a chronic illness returning to university. And third, Brewer and Nelms conducted a phenomenological study that

described recovering nurses' experiences of living with the negative label, "impaired", and the consequences of this on their employment, their relationships, and their lives.

When I read these articles, it was the disability aspect of this study that intimidated me because I knew virtually nothing of the disability movement, literature, or politics outside of my own experiences. I also recognized that I did not like to be labeled or referred to as "disabled" despite the fact that the university, government, and my health care providers clearly guided me within this categorization. Wendell's (1996) writing informed me that I was not alone in my personal struggles of being labeled as disabled. Wendell analyzed the complexities of defining who is disabled, cognizant that definitions are powerful rules that impact social policies, political groups, organizational forms, stereotypes, and ultimately impact individuals with disabilities, creating both positive and negative consequences. She further noted that there is a pragmatic need for definitions but that defining people for administrative purposes to meet organizational requirements objectifies their experience and "deforms" their lives. After reading Wendell, I began to ponder the contribution that health professionals in practice could make to the quality of life for nurses with disabilities if they were cognizant of nurses' experiences, specifically that of feeling understood (Jonas-Simpson, 1998, 2001).

Initial literature searches revealed the paucity of research on the lived experiences of nurses with disabilities. Thus, I expanded my search to consider the population of nurses with disabilities. Three main categories within this population were identified and they included:

- #1. nurse recruitment and retention (Agnew, 2000; "Back Injury", 2002; Canadian Nursing Advisory Committee, 2002; Cornwall, 2003; Colella, DeNisi & Varma, 1997; Dinsdale, 2000; "Exclusion Zones", 1995; Hernandez & Keys, 2000; Maheady, 2004; Nemeth, 1995; "Occupational Safety", 2002; Ponak & Morris, 1998; Porter, 2004; Restifo, 2001; "Safety to Practice", 2003; Sloane, 1998a, 1998b; Smith, 1992; Tammelleo, 1993; Thomas, 2000; Tuttas, 2002; Wallis, 2004; Winland-Brown & Pohl, 1990),
- #2. nurses with substance use (Beckstead, 2002; Brewer & Nelms, 1998; Chiu & Wilson, 1996; Champagne, Havens & Swenson, 1987; Finke, Williams & Stanley, 1996; Green, 1984; Hood & Duphorne, 1995; Hutchinson, 1987; Jensen, 1996; Lillibridge,

Cox & Cross, 2002; Penny, 1986; Smardon, 1998; Swenson, Havens & Champagne, 1987a, 1987b, 1989; “The Indiana State”, 2003; Torkelson, Anderson & McDaniel, 1996; Trinkoff, Eaton & Anthony, 1991; Wennerstrom & Rooda, 1996; West, 2003; Wheeler, 1992), and

- #3. nursing students with disabilities (Arndt, 2004; Carroll, 2004; Champagne, Havens & Swenson, 1984; Christensen, 1998; Colon, 1997; Helms & Weiler, 1993; Konur, 2002; Letizia, 1995; Magilvy & Mitchell, 1995; Maheady, 1999; Marks, 2000; Moore, 2004; Mueller, 1997; Murphy & Brennan, 1998; Persaud & Leedom, 2002; Selekman, 2002; Sowers & Smith, 2002, 2004a, 2004b; Watson, 1995; Weatherby & Moran, 1989; Wood, 1998).

These bodies of literature are reviewed thoroughly in chapter four of this study.

#### *Why is this Topic Important to Nursing Science?*

Through the study of the human experience of feeling understood, located within a basic human science nursing theory, I intend to make a contribution to nursing knowledge. I did not use theoretical concepts from other disciplines to guide my masters in nursing, policy and practice thesis. Rather, I created it as a nursing study. As Schoenhofer (1993) explained, “nurse scholars ... have the social responsibility for developing knowledge of the content of the discipline of nursing, and practitioners of nursing have a similar responsibility to base their service on knowledge of the discipline” (p. 60). However, many nurses and nurse scholars are unclear about what constitutes knowledge within the discipline.

Within nursing discourse, distinction has been made between nursing as a basic or applied science (Cody, 1995; Cody & Mitchell, 1992; Donaldson & Crowley, 1978; Johnson, 1991; Oldnall, 1995). Many scholars and nurses support nursing as an applied science (Packard & Polifroni, 1999; Polifroni & Welch, 1999), thereby drawing on other disciplines, such as sociology, economics, and education, as a means to guide its research, practice, philosophy, frameworks, et cetera. When considered an applied science, nursing does not define for itself a “phenomenon of concern”, that is, phenomenon related to nursing’s epistemic foci (Kim, 1997). Rather, nursing’s foci of concern are delineated by other disciplines. Historically, nursing began as an applied

science. Monks, nuns, and nurturers drew on religious inspiration, traditional healing practices, and early bio-medical knowledge. But with nursing's articulation of its specific phenomenon of concern in the mid to late twentieth century, basic nursing science began generating original knowledge specifically in alignment with its phenomenon of concern (Barrett, 1992, 2002; Fawcett, 2001; Northrup, 1992).

Distinction between nursing as an applied (academic) science and as a basic (academic) science rests primarily in acceptance or rejection of study that contributes to the discipline's phenomenon of concern. The term phenomenon of concern is referred to directly by Parse (1997a) as "the core focus of a discipline [that] is stated at a philosophical level of abstraction so as to encompass all manifestations of the phenomenon with the discipline" (p. 74). Recognition of nursing's phenomenon of concern provides a unique field of inquiry further clarifying nursing as a discipline, "characterized by a unique perspective, a distinct way of viewing all phenomena, which ultimately defines the limits and nature of its inquiry" (Donaldson & Crowley, 1978, p. 113).

Parse defines nursing's central phenomenon of concern as person-universe-health (Parse, 1992). She explains, "of particular interest is the wholeness or health of human beings, recognizing that they are in continuous interaction with their environments" (Fawcett, 1993a, p. 152). However, other nurse theorists identify the discipline's distinguishing phenomenon of concern quite differently depending upon their epistemological and ontological perspectives. For example, some theorists and nurses include the concept of "nursing" within the phenomena of concern (Fawcett, 1984, 1997). Yet this inclusion brings debate as to whether or not study of nursing is tautological, as Conway (as cited in Fawcett, 1993a) explains, "nursing represents the discipline or the profession and is not an appropriate metaparadigm concept" (p. 3).

Parse's articulation of person-universe-health is explicitly advanced as nursing's phenomenon of concern and nursing science as a distinct body of knowledge in this study. The specific focus of inquiry in this research was the experience of feeling understood. The phenomenon of feeling understood is important to the discipline of nursing because feeling understood involves a process of living one's values as one chooses among options in life. Living one's values is health from Parse's perspective.

Deeper understanding and knowledge regarding feeling understood may then provide insight into lived experiences and ways in which we appreciate, comprehend, and co-create reality.

This study of feeling understood is guided by a basic science nursing theory. Within nursing science, the field of nursing has been organized into various paradigms (Fawcett, 1993a, 1993b; Hall, 1981; Huch, 1995; Newman, 1992, 1997; Parse, 1981, 1987). A paradigm, also referred to by Parse (1997a) as a worldview, “organizes ideas, perspectives and systems for knowing about reality” (Kramer, 1997, p. 67). Cody (1997) further explains that in relation to the discipline of nursing, a paradigm is a position “from which one may construct a philosophical perspective of the phenomena of concern to nursing” (p. 4). One articulation of nursing paradigms is posited by Parse as the simultaneity and totality paradigms (Cody, 1995; Parse, 1987; Parse, Coyne & Smith, 1985).

Within the totality paradigm, a human being is “a biopsychosocioculturalspiritual being who can be understood by studying the parts, yet is more than the sum of parts. The person is separate from the changing environment, but interacts continuously with it” (Barrett, 2002, p, 52). Currently, the totality paradigm is the dominant perspective, grounded in the natural sciences. From this perspective, a person or aspects of a person can be measured, reduced, manipulated, isolated, objectified, and controlled. Nursing, from the totality paradigm, is advanced as an applied science (Benner, 1983; Cody, 1995; Dreyfus & Dreyfus, 1996; Packard & Polifroni, 1999; Polifroni & Packard, 1999; Schlotfeld, 1989; Visintainer, 1986).

Within the simultaneity paradigm a human is an open being who is greater than and different from the sum of parts, interacting reciprocally and simultaneously with the world, where health is an unfolding experienced process (Cody, 1995, 1999; Parse, 1987). Viewed as an indivisible or an irreducible whole (Parse, 2002), the human is further considered “an indivisible being recognized through patterns” (Parse, 1998, p. 4). The simultaneity paradigm is situated within a human science perspective (Parse, 1981), a term frequently used in nursing literature, but rarely defined or discussed. Nursing, from this paradigm, is conceptualized as a basic human science (Parse, 1998).

Numerous authors concur that generation of knowledge located within the totality and simultaneity perspectives constitutes nursing knowledge, or more clearly, knowledge *of* rather than knowledge *for* or *about* nursing (Barrett, 1992, 2002; Benner, 1983; Dreyfus & Dreyfus, 1996; Fawcett, 2001; Northrup, 1992; Packard & Polifroni, 1999; Parse, 1996b; Polifroni & Packard, 1999; Schlotfeld, 1989; Visintainer, 1986). Indeed, Cody (1994) argues that “research using the theory base of another discipline contributes to the theory base of that discipline, not nursing’s” (p. 99). Further, he suggests that it is the “nurse’s ethical responsibility to utilize the knowledge base of her or his discipline” (1997, p. 4). This knowledge base includes both nursing and non-nursing science since the discipline “encompasses all that nursing is and all that nurses do, overlaps with other disciplines, and is more than the theory and research base. The discipline of nursing requires knowledge and methods other than nursing science ...” (Cody, as cited in Daly et al., 1997, p. 12). While the discipline of nursing is greater than its science (Cody, 1997; Northrup et al., 2004), nursing knowledge, generated within the totality and simultaneity perspectives, will broaden when nurses are rooted in nursing theory for the maturation of its science (Huch, 2001). Nursing science has the opportunity to expand when nurses are educated within their own specialized body of knowledge, providing further direction for graduate students and scholars to advance the complex discipline of nursing itself.

Parse’s theory of human becoming is the theory chosen to guide this study of feeling understood. This basic nursing theory was chosen because it provided new insight and language that reflected many of my own values and beliefs. My hope is that knowledge creation from this research may contribute to nursing science, expand knowledge related to feeling understood, and advance the development and implementation of policies. It is my contention that the findings of this study have broad appeal to a diverse range of persons associated with disabilities. These include persons living with disabilities, health professionals in practice with persons living with disabilities or with colleagues who have disabilities, and administrators in a number of realms including nursing, education, legislation, human resources, professional bodies/union, and health care policy development and implementation. In the following chapter, the theoretical nursing perspective that underpins this study is further explored.

## *Chapter 2 - Theoretical Nursing Perspective*

### *Nursing as a Human Science*

Human science has emerged in the world of science as significantly dissimilar to the dominant ideology associated with the traditional form of scientific inquiry, the natural sciences. In health, and specifically nursing, there is significant resistance to accepting an alternative to a natural science medical model. The term human science is widely used in nursing literature; however, definitions vary leading to both confusion and suspicion of the human science paradigm.

The natural science tradition (aligned with the totality paradigm in nursing) is situated in a positivistic perspective that assumes “the natural world has an independent existence which is governed by laws discovered by research” (Oldnall, 1995, p. 608). In the natural sciences explanations regarding “human meanings and behaviour are used to manipulate people – to alter their views, their will, and their actions – and this clearly poses a serious threat to the practices of honouring human freedom and respective human dignity” (Cody & Mitchell, 2002, p. 8). However, society in general refers to this linear and causal perspective as logical or rational because a natural science perspective has been accepted as the order of humanity.

The overarching epistemology of the natural sciences is an object–subject duality, postulating that “objective observation and measurement lead to truth” (Cody & Mitchell, 2002, p. 11). A subjective or personal stance is considered as something to be mastered and controlled, and with regards to research, to be completely separated so as to not affect the objective data. Many practitioners, quantitative and qualitative researchers, and scholars in nursing engage in practice from this paradigm. Some have chosen the natural science perspective purposefully whereas others do so unwittingly because it is the acceptable discourse in the world around them.

One of the features that differs across the natural and human science paradigms “is the value placed on subjective data versus objective data, with obvious implications for the type of research deemed most valuable with each” (Malinski, 2002, p. 15). Human science is pre-dominantly concerned with explicating truths about language and the human world (Cody & Mitchell, 2002). The human science belief system supports and

values an understanding of “life as it is humanly lived” (Cody & Mitchell, 1992, p. 54), human freedom, dignity, multidimensionality, and illumination (Cody & Mitchell, 1992, 2002). Harmonizing with the human science paradigm in nursing shifts the object–subject duality to a position that incorporates both subject and object into “a unitary perspective that values whole persons and the whole of human experience as the proper concerns of nursing science” (Cody & Mitchell, 2002, p. 11).

Human science dates back to Vico and Dilthey, the first philosophers to challenge the assumptions of the natural sciences. Vico was the first person to differentiate between natural and human science subsequent to scientific achievements by Galileo, Newton, and other scientists and philosophers such as Descartes in the 17<sup>th</sup> century (Cody & Mitchell, 2002). From the perspective of the latter group of scientists, scientific inquiry was firmly establishing empiricism broadly, and rationalism more specifically, situating the natural sciences as the predominant modes of pursuing scientific knowledge. Although this philosophical view of science was still in conception in the 17<sup>th</sup> century, it firmly remains to this day as the benchmark of Western thought (Northrup, 2003). However, Vico offered a diverging philosophical view of science and knowledge. Dating back to Vico’s publications 250 years ago, the primary goal of incorporating the human science perspective is to understand the meaning of life and what being human represents, for the benefit of humankind (Cody & Mitchell, 2002; Parse, 1998).

The philosopher Dilthey continued Vico’s work with human science into the 18<sup>th</sup> century. Parse (2001a) cites Dilthey’s explanation that the human sciences

illuminate meanings, values, and relationships to gain understanding of human experiences. The ontological base of a research tradition that focuses on discovering the meaning of humanly lived phenomena is acausal, reflecting the idea that humans cocreate experiences in mutual process with the universe. (p. 2)

Mitchell and Cody (1992) further explain that Dilthey purported creation of concepts, methods, and theories distinct from the natural sciences and aligning with the human science perspective.

The discipline of nursing has taken up the human science perspective in varying ways. Some nurse theorists (Newman, 1992, 1997; Parse, 1981, 1998; Rogers, 1992) have followed Dilthey’s suggestion and designed concepts, methods, and theories in agreement with a human science perspective. Cody and Mitchell (2002) stated that the

human science tradition “provides a basis for methods of research and practice for a sizeable minority of scholars in nursing” (p. 4). The use of human science nursing in practice facilitates learning to “care for people in a context in which a primary value is honouring and upholding individuals’ and groups’ rights to think, feel, and act out of their own lived experiences in relation to health and quality of life” (Cody & Mitchell, 2002, p. 8). Whereas some nurses use the term “human science” in collaboration with a distinct nursing research method, others use it as a broad term referring to disciplines that focus on human beings, such as psychology, biology, and anthropology (Cody & Mitchell, 1992).

Parse’s theory of human becoming is grounded in a human science perspective and is consistent with the philosophical foundation of this paradigm on an ontological, epistemological, and methodological level (Malinski, 2002). The following table (Mitchell & Cody, 1992, p. 56) clearly articulates both ontological and epistemological features of the human science paradigm. Mitchell and Cody drew upon works by Dilthey and Giorgi to create this synopsis.

The tradition of human science in nursing has grown in the last decade, but so has resistance. While health disciplines, including medicine, “are turning to the study of lived experience, nursing on the whole may be turning away” (Cody & Mitchell, 2002, p. 4). Much of nursing remains grounded in scientific realism and as a result, education regarding and exposure to the human sciences is generally ignored. Tolerance of human science nursing is limited and is “largely excluded from the greater portion of funding, policy decision, curriculum, and practice in healthcare organizations” (Cody & Mitchell, 2002, p. 7). In such circumstances, nurses will face growing challenges to practice according to a human science paradigm where the dominant natural science perspective governs (Cody & Mitchell, 2002; McLeod & Spée, 2003; Mitchell, 2001). Cody & Mitchell purport that “human science nursing only happens when individual nurses choose to make a commitment and then choose to act accordingly” (2002, p. 11). However, the process of learning and practicing human science nursing take years of learning and mentorship and is often challenged by a health care system which operates from a natural science philosophy of care. It may be too easy to suggest that one may choose the perspective and simply live accordingly.

Table 1.

*Ontology and Epistemology of the Human Science Paradigm*

Ontology	Epistemology
<ul style="list-style-type: none"> <li>• Human beings are unitary wholes in continuous interrelationship with their dynamic, temporal, historical, cultural worlds.</li>   <li>• Human experience is preeminent and fundamental and reality is the whole complex of what is experienced and elaborated in thinking, feeling, and willing.</li>   <li>• Human beings are intentional, free-willed beings who actively participate in life continuously.</li>   <li>• The researcher is inextricably involved with any phenomenon investigated.</li> </ul>	<ul style="list-style-type: none"> <li>• Research and practice focus on the coherent experience of the person's meanings, relations, values, patterns, and themes.</li>   <li>• Lived experience is the basic empirical datum, as gleaned from the participant's description free of comparison to objective realities or predefined norms.</li>   <li>• The person's coparticipation in generating knowledge of lived experience is respected, and no more fundamental reference than what is disclosed by the person is sought.</li>   <li>• The researcher seeks knowledge and understanding of lived experience and is cognizant of the other's lived reality as a unitary whole.</li> </ul>

(Mitchell & Cody, 1992, p. 56)

*Historical Snapshot of Parse's Theory of Human Becoming*

In 1981 Rosemarie Rizzo Parse's theory was introduced as *Man-living-health: A theory of nursing*. This theory was published at a time when nursing was emerging as a scientific discipline with formalized theories and models, articulating its phenomenon of concern, and therefore, propelling nursing as a basic science. Parse predominantly drew on works by Heidegger, Merleau-Ponty, Sartre, and Rogers in the development of the ontology of her theory (Parse, 1998). In 1987 Parse developed practice and research methodologies consistent with the theory. The title of Parse's theory was renamed in 1992 as the theory of human becoming when the 1990 dictionary definition of "man" no

longer referred to mankind. Parse's articulation of nursing's metaparadigm (or phenomenon of concern) also reflected the change of terminology, therefore evolving from man-living-health to the human-universe-health process. In 1998 Parse's original work as a nursing theory developed into a school of thought: "a theoretical point of view held by a community of scholars" (Parse, 1997, p. 74).

Today, human becoming continues to provide "a framework to guide nurses and others in research on lived experiences in practice that honours personal beliefs about health and quality of life" (Parse, 1998, p. x). The significance of the theory is ensconced within the human science perspective of how a person as an indivisible being experiences health. Health is considered a lived experience, constantly in flux, and a co-creation with others and the universe. Further, the individual is considered the expert on her/his health (Parse, 1994a) and the goal of nursing is quality of life (Parse, 1992) as defined by the person, not the nurse. The focus is on the individual's participation and connectedness with the universe in cocreating health. The person and universe, which includes other people, cannot be separated, reflecting the indivisible nature of the human-universe-health process.

Parse's theory of human becoming contains specific assumptions, principles, and concepts. These aspects will be identified and discussed along with Parse's practice methodology and the theory's internal consistency.

### *Assumptions*

In human becoming, the assumptions are clearly articulated, providing the foundation for the theory situated in the human sciences (Parse, 1998). The assumptions address the human, becoming, and human becoming, "all written at a philosophical level of discourse" (Parse, 1992, p. 37). The nine assumptions about the human and becoming were created from a synthesis of Roger's science and principles from existential phenomenology (Parse, 1992, 1998). These philosophical assumptions are intertwined making it impossible to separate them (Fawcett, 1993a). The assumptions, along with the principles, construct the specific ontology (philosophical assumptions and principles) of Parse's theory (Parse, 1998).

The first four assumptions articulate “the human as an open being in mutual process with the universe, cocreating patterns of relating with others” (Parse, 1992, p. 37). The following five assumptions relating to becoming, articulate “health as a process of becoming, experienced by the person, coconstituted through the human-universe mutual process, and incarnated as patterns of relating value priorities” (Parse, 1992, p. 37).

The nine assumptions are as follows:

1. The human is coexisting while coconstituting rhythmical patterns with the universe.
2. The human is an open being, freely choosing meaning in situation, bearing responsibility for decisions.
3. The human is a living unity continuously coconstituting patterns of relating.
4. The human is transcending multidimensionally with the possibles.
5. Becoming is an open process, experienced by the human.
6. Becoming is a rhythmically coconstituting human-universe process.
7. Becoming is the human’s pattern of relating value priorities.
8. Becoming is an intersubjective process of transcending with the possibles.
9. Becoming is human evolving. (Parse, 1999b, p. 5-6)

These assumptions are then synthesized into three assumptions about human becoming (Parse, 1985, 1998). They are:

1. Human becoming is freely choosing personal meaning in situation in the intersubjective process of relating value priorities.
2. Human becoming is cocreating rhythmical patterns of relating in open process with the universe.
3. Human becoming is cotranscending multidimensionally with the emerging possibles. (Parse, 1999b, p. 6)

### *Principles*

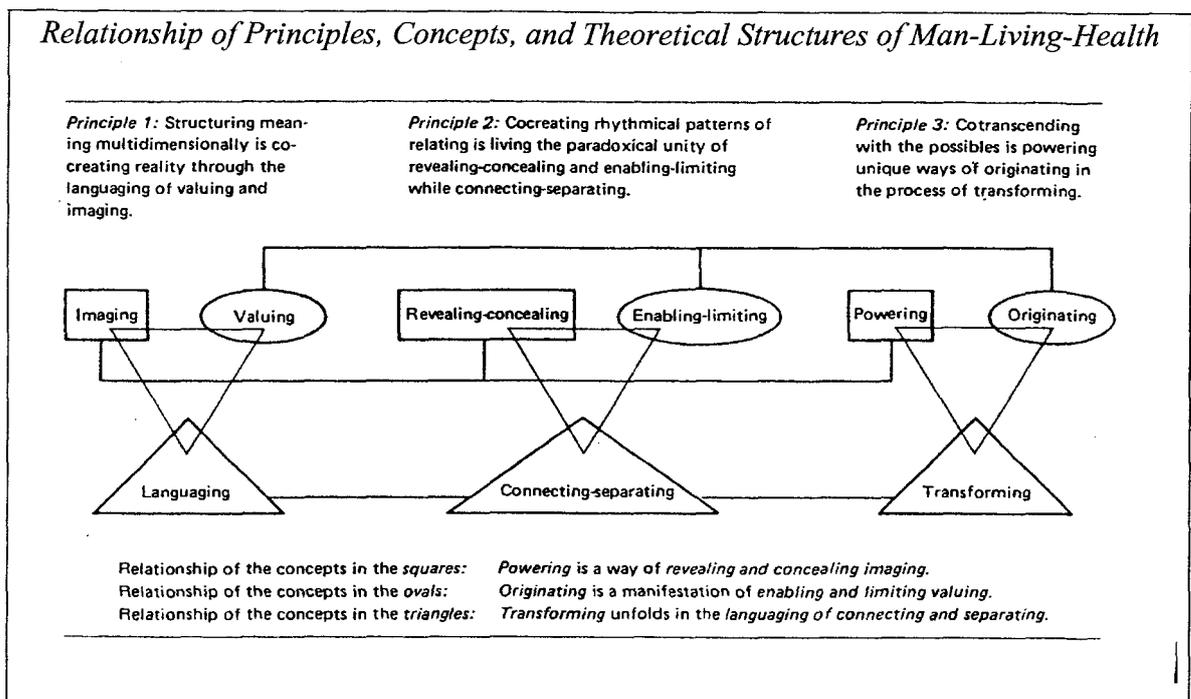
The principles in the theory of human becoming derive from the philosophical assumptions and “incarnate the beliefs articulated in the assumptions” (Parse, 1992, p. 37). Similarly, they are written at a theoretical level of abstraction for the purpose of theory creation (Parse, 1992, 1999a). Parse (1998) articulates that the term “theory” specifically refers to the principles in human becoming. From the principles, three dominant themes have emerged: meaning, rhythmicity, and co-transcendence (Parse, 1981, 1987, 1998). The principles are as follows:

- Principle 1. Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging.
- Principle 2. Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating.
- Principle 3. Cotranscending with the possibles is powering unique ways of originating in the process of transforming. (Parse, 1981, p. 69)

*Concepts*

As previously discussed, the main concept in this theoretical nursing perspective is human becoming. However, the theory is rich with additional concepts that are languaged in unique ways. These concepts will be discussed in relation to the three principles listed above. Table two (Parse, 1981, p. 69) below further identifies the relationship between principles, concepts, and theoretical structures of the theory of human becoming.

Table 2.



(Parse, 1981, p. 69)

*Principle one*

Principle one states, “structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging” (Parse, 1981, p. 42). The major theme of principle one is *meaning* and it relates to both “the linguistic and imagined content of something and the interpretation that one gives to something. It arises with the human-universe process and refers to ultimate meaning or purpose in life and the meaning moments of everyday living” (Parse, 1998, p. 29). A person constructs meaning or significance by choosing options from the universe, similar to speaking and moving, thereby displaying the beliefs that are lived both explicitly and tacitly at the same time (Parse, 1992). Meanings also change continuously as an individual grows more complex and as diverse images point to new values and expression through language. Principle one addresses how a person constructs the meaning of her/his lived experiences in multiple realms all-at-once, therefore cocreating reality (Pilkingon & Millar, 1999). Principle one addresses three concepts: imaging, valuing, and languaging.

*Imaging*, the first concept of meaning, refers to personal knowing (Parse, 1992, 1998). Such knowledge exists at the explicit and tacit realms all-at-once and contributes to the co-creation of reality (Parse, 1981, 1992, 1998). Parse suggests that personal knowledge of reality is constructed through reflective-prereflective imaging, explicitly and tacitly all-at-once (Parse, 1981, 1992, 1998). Whereas explicit knowing is logically articulated and reflected upon critically, tacit knowing is prearticulate, prereflective, and acritical (Parse, 1981, 1992, 1998). “Tacit knowing is quiet and vague and lies hidden from reflective awareness, somewhat anonymous” (Parse, 1998, p. 36). Explicit and tacit knowing continuously evolves as new experiences, found in the meaning moments of day-to-day living, simultaneously reshape personal knowledge. Through imaging, an individual pictures, symbolizes, or realizes experiences and events (Parse, 1981, 1992, 1998). Imaging may also entail aspects of personal questioning and searching for answers in life (Parse, 1981). Another example Parse (1990b) offers is regarding imaging as creative imagining, which is picturing “what a situation ‘might be like’ if lived in a particular way” (Parse, 1990b, p. 138).

*Valuing*, the second concept of meaning, refers to an individual’s process of confirming cherished beliefs or priorities, which reflect a personal worldview (Parse,

1981, 1992, 1998). A value is something that signifies meaning. Valuing is giving meaning to multidimensional experiences as a way in which a person creates reality (Parse, 1992). “The term multidimensional refers to the explicit-tacit knowings of the was, is, and will-be that humans live all-at-once with the predecessors, contemporaries, and successors at many realms of the universe” (Parse, 1999a, p. 3). Valuing is evident in choosing, prizing, or acting to confirm a cherished priority (Parse, 1981, 1992, 1998; Wang, 1999). For example, in a study on struggling in change for persons at end of life (Hutchings, 2003), valuing was portrayed when participant’s said or did not say what they had cherished or longed for in reviewing their life experiences. Participant’s described places, things, and persons that highly ranked in significance for them.

*Languaging*, the third concept of meaning, refers to the way a person constructs and represents her/his own personal structure of reality (Parse, 1992). Languaging is an expression of valued images through symbols such as posture, speech, voice, gaze, touch, and movement by which individuals express unique realities (Parse, 1981, 1992, 1998). Paradoxical examples of languaging include moving-being still and speaking-being silent (Parse, 1992, 1994b, 1998). Both of these paradoxes symbolize further expression of personal meaning. The concept of languaging reflects the “interconnectedness of humans and the universe from generation to generation” (Parse, 1992, p. 37). For example, oral myths and ritualistic ceremonies that include song and dance are created to identify cultural notions that are valued (Kelley, 1999). Such traditions are cocreated and passed on between generations while “unique realities are also structured by each individual” (Parse, 1998, p.39).

#### *Principle two*

Principle two states, “cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating” (Parse, 1981, p. 50). Principle two addresses cocreated rhythmical patterns of relating that are evident in daily life experiences as identifiable manifestations of human becoming (Parse, 1998). This principle focuses on the relational aspects of human becoming. The major theme of principle two is *rhythmicity*. Rhythmicity is acknowledged as a cadent or something ordered (Parse, 1981). Such cadence or

rhythmical patterns in relating are paradoxical by nature. The idea of living *paradox* (Parse, 1994b) is a fundamental concept in human becoming.

Parse's theory is unique in that it considers paradoxes inherent in being a human (Parse, 1999a). Paradoxes are considered one phenomenon with two dimensions (Parse, 1998). Paradoxes appear to be opposite. Yet, these rhythmical patterns are not opposites but are rather indivisible, with two sides of the same rhythm simultaneously present (Parse, 1992, 1998). In the moment, one side of the rhythm is in the foreground, while the other side of the rhythm is in the background (Parse, 1998). These paradoxical dimensions fluctuate and the rhythmical patterns shift. Such rhythmicity is reflected in a variety of patterns that arise within change (Parse, 1992). Paradoxes are not regarded as problems needing to be solved or eliminated. Rather, "they are flowing rhythms lived with an unrepeatable changing process that is unpredictable. This means that no moment can ever be the same as it was. The human is mystery" (Parse, 2002, p. 48). Principle two addresses three concepts: revealing-concealing, enabling-limiting, connecting-separating. These concepts represent paradoxical patterns, two sides of a rhythm which coexist simultaneously.

*Revealing-concealing*, the first concept in rhythmicity, is "a paradoxical rhythm in the pattern of relating with others" (Parse, 1992, p. 38). As an individual discloses or reveals a part of her or himself to another person, she/he also hides or conceals other aspects. Revealing-concealing can also be considered as disclosing-not disclosing which occurs all-at-once (Parse, 1992, 1998). The notion of human as mystery is fundamental to the paradoxical rhythm of revealing-concealing (Parse, 1992). Within the notion of mystery is an acknowledgement of the unexplainable that is inherent in human becoming (Parse, 1998). There always remains more to a person than they can reveal, simultaneously leaving areas that are concealed (Parse, 1992, 1998). In disclosing to others, one knows oneself more fully. But one can never completely reveal oneself to another because one can never fully know all that there is to know about oneself. There is always mystery.

*Enabling-limiting*, the second concept in rhythmicity, is also considered "a rhythmical pattern of relating" (Parse, 1992, p. 38). Inherent within the choice of decisions, there are an infinite number of opportunities and restrictions in what is chosen

and what is not chosen (Parse, 1992, 1998). As one moves in a particular direction, there comes inherent opportunities that are enabling, as well as simultaneous limitations including limited movement in another direction. For example, a nurse with a “recognized” disability chooses not to pursue short or long-term disability options available to her/him. Rather, the nurse decides to keep working whenever she/he can physically do so. In this decision, the nurse is enabled to stay within the work force, maintain contact with work colleagues, and potentially provide greater financial support than disability monies would provide. However, she/he may also be restricted in how her/his disability may limit the amount she/he is able to work, time available for resting or health care she/he may need, and may potentially provide lesser financial support than disability monies would have provided. Therefore, “one is enabled-limited by all choices” (Parse, 1992, p. 38). Within the theme of rhythmicity, enabling-limiting is also closely associated with the simultaneous disclosing-not disclosing aspects inherent in the paradox of revealing-concealing (Zanotti & Bournes, 1999).

*Connecting-separating*, the third concept in rhythmicity, represents “a rhythmical process of moving together and moving apart” (Parse, 1992, p. 38). A process of moving together with one phenomenon, moves away from other phenomenon at the same time (Parse, 1992). Connecting-separating is being with and apart from others, ideas, objects, and situations in the was, is, and will be all-at-once (Parse, 1981, 1992, 1998). Bunkers (1999b) further articulates that this concept “involves choosing at multidimensional levels to participate in engaging-disengaging with others in the universe” (p. 248). For example, when two or more people come together and connect, they are all-at-once separating from others (Parse, 1998). “In closeness, there is also distance, and in distance, there is a closeness. This is a continuous cadent process and a feature of human becoming” (Parse, 1998, p. 45)

### *Principle three*

Principle three states, “cotranscending with the possibles is powering unique ways of originating in the process of transforming” (Parse, 1981, p. 55). The major theme of principle three is *co-transcendence*. Co-transcendence purports that a person transcends the actual with intentional hopes and dreams through pushing-resisting, thereby creating

original perspectives of viewing the familiar and the unfamiliar (Parse, 1992, 1998). This principle means that a person moves beyond what is familiar to them, also known as “what is”, towards the unfamiliar, “what will be”, in the process of seeing newness in a situation. Co-transcendence or moving beyond to new ways of being (Cody, Bunkers & Mitchell, 2001) encompasses a personal shift from where one is now, to where one might be. A person lives with others and continuously cocreates new possibilities that arise from contextual situations from which options are chosen. Contextual situations are present from prior choices and cocreate other possibilities. Therefore, an individual constantly creates ways of becoming while cotranscending with the possibles (Parse, 1998). Principle three addresses three concepts: powering, originating, and transforming.

*Powering*, the first concept in co-transcendence, is “the pushing-resisting rhythm in all human-human and human-universe interrelationships” (Parse, 1992, p. 38). Powering is considered an energizing force that creates moving beyond the moment (Parse, 1992, 1998). For example, powering is experienced by a person when pushing-resisting rhythms are altered and conflicts emerge. Conflicts or tensions potentially rise when an individual struggles with issues, other people, hopes, et cetera in the process of changing from what she/he is to what she/he is not yet. The person involved in conflict encounters the possibility to clarify views, examine the worldviews of others, and make choices with others to move beyond the moment to a new way of pushing-resisting (Parse, 1992). Conflict is not regarded as a negative force, but as a natural process that surfaces in every human relationship. Powering is evident in the ways a person changes or chooses to persevere as when they reach beyond the moment with her/his cherished plans, hopes, and dreams (Parse, 1981).

*Originating*, the second concept in co-transcendence, “means creating anew, generating unique ways of living which surface through interconnections with people and projects” (Parse, 1992, p. 38). The way in which interconnections are lived out by a person reveals her/his uniqueness through expression of oneself (Parse, 1992). A person is unique and irreplaceable in intimate relationships or creative projects (Parse, 1992). Each person has her/his own way of interacting with people and projects. The ways in which she/he lives these connections also reveals how she/he seeks to be like others, yet all-at-once, not be like others (Parse, 1998). Originating also includes the process of

unfolding, which is creating new ways of living (Allchin-Petardi, 1999). In summary, Parse (1998) explains, “originating is inventing new ways of conforming-not conforming in the certainty-uncertainty of living” (p. 49).

And lastly, *transforming*, the third concept in co-transcendence, is a “shifting of views of the familiar as different light is shed on what is known” (Parse, 1992, p. 39). A changing of one’s familiar perspectives occurs as one looks at a situation, issue, person, tension, et cetera in a different way. Transforming is further considered the changing of change (Parse, 1998), shifting the familiar to the unfamiliar and the unfamiliar to the familiar all-at-once. It is “linked to the continuous changes in life that accompany changing views of one’s life situation” (Zanotti & Bournes, 1999, p. 111). Transforming is self-initiated and includes creative shifting to a different vantage point (Kelley, 1999). Change is ongoing in the human-universe process and is recognized by changing diversity. “Changing diversity is rhythmically lived as experience melts into experience and different priorities arise” (Parse, 1992, p. 39). Different priorities arise with transcendent movement beyond the now. “This movement is all-at-once struggling and leaping beyond, cocreating diverse patterns with new meaning. This new meaning stretches the possibilities of the moment” (Parse, 1999c, p. 76).

The previously discussed three theoretical principles and corresponding concepts will be further applied in relation to this study’s research findings in chapter six, *Discussion of Findings*.

### *Practice Methodology*

Parse’s practice methodology (1987) was developed to guide human becoming theory-based practice. Again, the goal in practice is quality of life as defined by the individual or family. The goal in research is to elicit descriptions from the participant’s perspective about the phenomenon of concern being studied. In both the goals of practice and research, the person is honoured and considered the expert (Parse, 1994a). Although it is quite simplistic to verbally articulate or write such goals, it is an entirely other matter to follow them in practice. While there may be room in some areas of practice to follow through with participants’ decisions, more often than not the health care system does not openly welcome participants to direct their care. Traditional nurse’s charts, discharge

protocols, ethics applications, professional bodies' standards of practice, et cetera may all ignore the need to honour quality of life from the person's perspective. The challenges inherent within theory-based practice from a human science tradition are tremendous within contemporary health care systems (Bunkers, 1999a; Cody et al., 2001; Coker & Schreiber, 1990; Laschinger & Duff, 1991; Mayberry, 1991; McLeod & Spée, 2003; Milton, 2001; Mitchell, 2001; Nagle & Mitchell, 1991; Northrup & Cody, 1998; Parker, 2001).

Yet, consideration must be given to question why many nurses speak of having difficulty integrating nursing theory into their practice. Could it stem back to how theory was introduced and taught in their nursing education? Were theory and practice distanced from each other, taught as separate rather than intricate components? Were theories from other disciplines promoted over nursing theory? In the work place, is nursing theory acknowledged and discussed? Is theory recognised as an influence for nurse scholars but not for bedside nurses? Do senior nurses discourage recently graduated nurses from implementing theory into their practice? Is theory regarded as insignificant by nurse leaders, while emphasis is directed at practice? Questions such as these must be scrutinized to further enlighten understanding of connections, or lack thereof, between nursing theory and practice.

Returning to Parse' theory, the belief that persons are coauthors of their health underpins this practice methodology. There are three dimensions and processes. Each will be identified and then discussed. First, "illuminating meaning is shedding light through uncovering the what was, is, and will be, as it is appearing now. It happens in explicating what is. Explicating is a process of making clear what is appearing now through languaging" (Parse, 1992, p. 39). The nurse practicing from Parse' theory is dramatically different from one engaged in traditional nursing practice. The nurse does not offer advice nor act according to a predetermined care plan. Rather, the nurse lives the practice methodology through *true presence* with individuals and their families (Parse, 1990b). "True presence is a special way of 'being with' in which the nurse bears witness to the person's or family's own living of value priorities" (Parse, 1992, p. 40). True presence purports that each individual knows within themselves "the way" and it will be different for each person. The nurse in true presence attends to individuals as they

explicate significant moments in their lives and potentially view the familiar from unique perspectives.

Despite nursing's reputation for caring for people, living true presence remains a significant challenge. Specifically, there are many factors that objectify patients and demand efficiency. As previously discussed, these factors may include lack of respect towards individual's unique experiences, the dominant bio-medical model, the political, economic, and organizational goals of efficiency (Armstrong et al., 2002), or the varying definitions of "disability" (Wendell, 1996). However, theory-based knowledge, generated from a human science perspective in general and a human becoming viewpoint in particular, offers a way of ushering nursing to a place of practice where the lived experiences of people are honoured and esteemed. Once true presence becomes the pre-eminent focus of practice, nurses can create ways of being with others that herald the possibility of a new practice free from objectification and particularization of human beings.

Second, "synchronizing rhythms happens in dwelling with the pitch, yaw, and roll of the interhuman cadence. Dwelling with is giving self over to the flow of the struggle in connecting-separating" (Parse, 1992, p. 39). The nurse in true presence remains with the individual or family as they express and live the highs, lows, and unevenness of their present situation. The nurse does not try to "fix", label, or diagnose rhythms but rather, "goes with the flow". And third, "mobilizing transcendence happens in moving beyond the meaning moment to what is not yet. Moving beyond is propelling toward the possibles in transforming" (Parse, 1992, p. 40). Again in true presence, the nurse and individual or family move beyond towards dreams and possibilities that have surfaced in the process of being with each other.

Nurses who adhere to a theory-based practice, such as Parse's practice methodology, will act in a fashion that stems from their individual understanding of that particular theory. These actions manifest as a "value-laden practice" (Northrup, 2003, p. 41). How one nurse practices in accordance with Parse's philosophical assumptions, principles, and practice methodology will differ from another nurse's practice. In relation to this thesis, Parse's theory guided my research decisions. This study could also be considered theory-guided research. Parse's theory was a framework from which I based

my research decisions, interacted with my participants, conducted my analysis, considered future policy development, et cetera. Each reader of this project may also interpret this value-laden research project differently.

### *Internal Consistency*

In analysis of Parse's theory of human becoming, it is appropriate to question whether or not there is internal consistency because critique and evaluation of scholarly work is inherent in the development of new knowledge within a discipline (Parse, 2001a; Parse et al., 1985). Internal consistency is a marker by which review of a theory's maturity, scope of applicability, congruence, and usefulness is considered and regarded as necessary from academic and practice perspectives. As foundational nursing knowledge is critically challenged, depth, growth, and evolution to the discipline's unique body of knowledge will be added.

Parse's theory is consistent with the conceptual and philosophical underpinnings of human science. Human becoming is also consonant with human science as Vico and Dilthey initially expressed Logical congruence is also present in Parse's deduction from Roger's science of unitary human beings and from existential phenomenology (Fawcett, 1993a). From such philosophical foundations, Parse derived the assumptions, principles, concepts, theoretical structures, and propositions. "Each assumption interrelates three foundational concepts, each principle three of Man-Living-Health's concepts, and each theoretical structure a concept from each principle" (Lee & Schumacher, 1989, p. 180).

The language is also internally consistent within the theory. Similar to the challenges in learning a foreign language, one is required to spend time, practice, and discipline in learning the verbiage of human becoming theory. The concepts, goals, and language are not those used in everyday medical and healthcare life mostly because they reflect the simultaneity paradigm which is not the dominant discourse of our society. Normative language would be inconsistent with the theory. Therefore, labels and terms such as "roles", "health difficulties", "normal / abnormal", "expert nurse", "interventions", et cetera that are used in everyday speech, do not align with human becoming (Cody, 1995). However, this poses certain difficulties for transition towards a human science perspective of persons because the dominant language used in health care

settings is incommensurate with such a viewpoint. There may indeed be no clear answer to this challenge except to begin by questioning the language we easily overlook. Practicing from a position that honours individuals' perspectives may also propel nursing language in a new direction that is congruent with such a practice. As Cody and Mitchell (1992) explain, "when the focus of inquiry is humanly lived experience, a unitary phenomenon in the human science tradition, the language and concepts used must be congruent with this focus" (p. 61).

While there is internal consistency within Parse's theory, to be clear, it is not the intent of this study to test or critique the theory. The basic beliefs within the theory including the assumption of mutual human beings in process with the universe align with my own values. This study will not set out to test such assumptions (Mitchell, 2002). Rather, research that is guided by the theory "is meant to enhance the theoretical foundation or the description contained in the principles and concepts of the human becoming theory" (Mitchell, 2002, p. 529). Another significant reason for choosing human becoming is that the theory focuses on understanding human experiences. Such focus aligns with the purpose of this research that was to explore the experience of feeling understood for nurses with disabilities. In the following chapter, this study's methodological decisions are further discussed.

### Chapter 3 - Methodology

#### *Science Versus Sciencing*

Traditionally, science is considered investigative, providing theoretical accounts of phenomena and information gleaned from its procedure (Anderson, Anderson, & Glanze, 1994; *Webster's II New Riverside Dictionary*, 1984). Conventionally defined as a product, science pursues the achievement of absolute truth (Parse, 2001a). Science consists of a formal process of inquiry directed towards the study of "x" for the purpose of knowledge generation. "Simply, the word science means to know" (King, 1997, p. 24). The generation of knowledge is typically considered in an objectivist paradigm. The production of knowledge is regarded as words on a page, research, facts, et cetera, and as something separate from us as humans. From the natural science perspective, knowledge is applied rather than lived.

Parse (1997a) defines science as "the theoretical explanation of the subject of inquiry and the methodological process of attaining knowledge in a discipline; thus science is both a product and a process" (p. 74) and is reached through "creative conceptualizations and formal inquiry" (p. 75). Parse's definition explicates the recognition of science as something more than a product. The process of science relates to the term *sciencing*. Parse draws on White's (1938) work to explicate sciencing as coming to know, an ongoing process of inquiry. Knowing is considered perspectival and everchanging; therefore, absolute truths are not sought (Parse, 2001a). "Science-as-process, rather than product, is rooted in the belief that there are multiple realities and multiple truths about human experience and health" (Mitchell, 1999, p. 189). Sciencing is situated in the human sciences with a foundation in living knowledge (Mitchell). There are four assumptions which further explicate sciencing:

1. To question is to reach beyond what is with what is possible.
2. A question in itself incarnates the questioner's attitudes, beliefs, and style and points to personal projects.
3. Both questions and answers are set with the boundaries of the questioner's understanding of the phenomenon.
4. The questioning process and the answers are intersubjective. (Parse, 2001a, p. 2)

The term *sciencing* is addressed because of its usefulness in consideration of research that examines human experiences (Parse, 2001a), including the phenomenon of feeling understood. Congruent methodologies are used to explore the meaning of lived experiences described by the individuals living them (Parse, 2001a).

### *Descriptive Exploratory Methodology*

The qualitative approach and research design chosen to guide this inquiry was the descriptive exploratory methodology advanced by Parse (2001a; Parse et al., 1985). Chosen for its ontological and epistemological congruence, this human science methodology seeks to explore the meaning of an event for a group of people who share the experience (Parse, 2001a; Parse et al.). This methodology arose from the descriptive method. “Although [the descriptive] method had its origins in the social sciences, a discipline-specific theoretical perspective, such as a theory of nursing, can be used as a conceptual framework to guide the research study” (Parse, 2001a, p. 57). This use of a methodology that originated in the social sciences, and appropriating it along with a nursing theory (knowledge *of* nursing), displays an example of drawing on knowledge from another discipline (knowledge *for* nursing) therefore incorporating both nursing and non-nursing science in a research endeavour (Barrett, 1992, 2002; Benner, 1983; Cody, 1994, 1997; Dreyfus & Dreyfus, 1996; Fawcett, 2001; Northrup, 1992; Northrup et al., 2004; Packard & Polifroni, 1999; Polifroni & Packard, 1999; Schlotfeld, 1989; Visintainer, 1986).

The processes for the descriptive exploratory methodology are:

1. Planning a coherent design to ensure scientific merit.
2. Specifying the participant group.
3. Planning for the protection of participants' rights.
4. Gathering data....
5. Analyzing-synthesizing data....
6. Discussing findings in light of the disciplinary perspective guiding the study.
7. Recommending further research. (Parse, 2001a, p. 58-59)

Several Parse scholars have continued to use the descriptive exploratory methodology considering phenomenon such as not having ones own home (Baumann, 1995), being an elder in Nepal (Jonas, 1992), and quality of life for persons living with

Alzheimer's disease (Parse, 1996a, 2001b). This previous research provides direction for future studies, such as this project, that used this design.

The descriptive exploratory methodology proposes that the research objectives evolve from the conceptual framework. Questions used for data gathering derive from the objectives and data analysis is also conducted in consideration of the objectives (Jonas, 1992). The logistics of this study will be explained along with consideration of issues related to participant selection, ethics, and rigor.

### *Objectives and research questions.*

The central research question, from a descriptive exploratory methodology, searches to understand the lived experience of health (Parse et al., 1985). This study was intended to answer the research question, What is the meaning of the experience of feeling understood for nurses with disabilities? A traditional study within the natural sciences would seek to disprove a hypothesis. On the other hand, a focal research question is pursued within the human science tradition.

The three objectives in this study arose from three themes specific to the theory of human becoming: meaning, rhythmicity, and co-transcendence (Parse, 1981, 1987) that are represented in the assumptions and principles. The objectives similarly addressed the phenomenon of concern in relation to meaning, patterns of relating, and moving beyond.

The following questions served to guide the participant interviews. Each research objective directed exploration through dialogue. Each interview began with one or two questions from the first objective with subsequent questions directed from the participants' responses. Therefore, all of the following questions were not necessarily asked. Care was taken to clarify and deepen participant's narratives as appropriate in each individual discussion.

The objectives and subsequent interview questions for my study were:

Objective 1: To describe the meaning of feeling understood for nurses with disabilities through dialogue.

- Can you tell me about your experiences of feeling understood?
- What is the experience of feeling understood like for you?

- How would you describe it?

- (or) Describe the experience of feeling understood.
- What contributes to an experience of feeling understood?
  - What may diminish an experience of feeling understood?
- What is the meaning of feeling understood for you?
- Can you describe a situation in which you experienced feeling understood?

Objective 2: To describe patterns of relating within the experience of feeling understood for nurses with disabilities.

- How has your experience of feeling understood affected your relationships with your family, friends, (co-workers), and care-givers?
- What is most important to you?
- How has your experience of feeling understood been influenced by your work life?

Objective 3: To describe personal hopes, concerns, possibilities, and visions of what might be in relation to feeling understood for nurses with disabilities.

- What are your hopes about feeling understood?
- What are your concerns about feeling understood?
- What are some of your dreams and visions of possibility regarding feeling understood?
- What would your ideal look like?

#### *Participants.*

Participants for this study self-identified as nurses with disabilities. For the purpose of this research, the disabilities accounted for included long-term or recurring physical, mental, psychiatric, sensory, or learning disabilities, disfigurement, and past or present drug or alcohol dependence (Canadian Human Rights Tribunal, 2002; Department of Justice Canada, 1995, 2002). Criteria for qualifying as a nurse with a disability in this research stipulated that both the nurse and the employer/union must have agreed that the nurse qualified as disabled in employment by reason of disability

(Department of Justice Canada, 1995). These criteria included: 1) nurses who have taken a short-term leave from practice before returning to work, 2) nurses whose functional limitations due to disability have been accommodated in their current workplace or job (Department of Justice Canada, 1995), and 3) nurses who have left nursing practice due to disability. All participants in this study identified that their employers/unions considered them to be living with disabilities. Employer recognition of disability was also required for all of the participants to receive either short / long term disability or a workers' compensation board claim (see table 5 – Profile of Participants).

It is recognized that the prescribed criteria for participation in this study may have excluded individuals who viewed themselves as having a disability but their employer/union did not recognize their disability within policies. The significant issue of who is “included” and “excluded” within disability definitions, policies, income assistance, et cetera remains as a looming area of ongoing debate (for example, see Kimpson, 1995). From a theoretical perspective that aligns with Parse's theory of human becoming, criteria created by others do not pre-determine whether or not disabilities are “legitimate”. Undeniably, many individuals who are not formally recognized within disability criteria have considerable health challenges, and therefore may have potentially even greater economic challenges (Morris, 1995, 2000) because they are disregarded and left without supports. Yet, the participant criteria for this thesis were stipulated solely to facilitate discussion in relation to policies that recognize particular health challenges as disabilities. Although casual relationships were not the focus of this study, official acknowledgement of disability (or lack thereof) are acknowledged as potential influences for persons' experiences of feeling understood.

Participants were adults living in greater Victoria, B. C., Canada, who had been through an accredited nursing education program to become a registered nurse. Participants who were a part of this population self-selected, meaning they responded and volunteered to share their experiences in relation to this study. Participants were not restricted by race, age, or gender. Participants were those who could describe the experience of feeling understood through words, symbols, photographs, poetry, and art (Baumann, 1993; Parse, 1999b). For purposes of this study however, participants were asked to volunteer to participate in a dialogue with the researcher. While they could have

shared poetry, photographs (e.g. of themselves prior to their disability) et cetera, the common mode of description was dialogue.

The first recruitment advertisement was placed in a local newspaper, the *Monday Magazine*, inviting participation in this study (see Appendix A). Another recruitment strategy used was word-of-mouth conversation (also known as snowball sampling) through my nurse colleagues, many of whom knew nurses with disabilities. Through word-of-mouth, nurses interested in the study were directed to the newspaper advertisement. The first advertisement was also distributed to my nurse colleagues via e-mail. Many of my colleagues chose to forward this e-mail on to potential participants, including long-term disability groups. After a month and a half of advertising, no participants had volunteered. I decided to revise the invitation (see Appendix B) and place a second advertisement in a local health authority newsletter. There was an immediate response from many nurses interested in participating.

Participants included those who responded of their own free will and agreed to participate in a face to face, taped interview. The sample included five nurses who agreed to be interviewed. This number of participants was considered more than enough when using a descriptive exploratory methodology (Parse, 1987, 2001a) because this qualitative inquiry sought rich, thick data due to the complex nature of the topic. Interviews were anticipated to take 30-60 minutes. If the participant wished, interviews were greater or less in duration. However, the interviews with the participants ranged between 45 minutes and two hours and fifteen minutes. One interview was conducted with each participant. A second follow-up interview was necessary for only one participant with the purpose of clarifying previously gathered data.

Participant involvement only involved the time required for interviews. Participants were not shown their transcripts or analysis of their interview unless specifically requested. None of the participants requested to review their transcript or analysis of their interview. Member checking (Janesick, 2000) was not adhered to because the practice was considered philosophically inconsistent with the theoretical underpinnings of this study. Member checking, frequently used in qualitative research yet grounded in the natural sciences, supports a verifiable reality. However, from a human

science perspective, reality will be different for each individual, as will interpretation and analysis.

#### *Data.*

Interviews were conducted face to face between researcher and participant where the participants shared specific information related to the objectives of the study (Parse et al., 1985). The verbal and non-verbal communication of the participant was considered “data” according to the descriptive exploratory methodology. The interview questions were open-ended and only included questions purposefully directed towards uncovering depth, attribute, and meaning related to the lived experience of feeling understood. The descriptions provided by each individual participant set the direction of the interview while the researcher engaged in true presence.

Participants determined sites of interviews since their health challenges could have been influential factors. Interviews were conducted in predetermined places, including coffee shops and university offices, and at a location and time convenient for both people. Prior to each interview, I spent time alone journaling in preparation. I repeated this process after each interview and noted particularly interesting points from the interview. During the course of 15 days, six interviews were completed including two in one day. All interviews were audio taped and transcribed verbatim.

After each interview, I mailed participants a card thanking them for their participation in this study. During the interviews many of the participants expressed a sense of gratitude at the opportunity to share their experiences of feeling understood while living with a disability. Many commented on the rare experience of having another listen to them.

#### *Ethics.*

My research was approved through the University of Victoria Human Research Ethics Committee (HREC) (see Appendix C). An application for Ethical Review of Human Research was submitted using guidelines for application provided by the university. Topics of consideration in this application included potential risks and benefits, confidentiality, anonymity, ongoing consent, and storage and destruction of

data. A request was not completed for the use of deception in the conduct of human research. Permission from HREC was required before this research could be conducted.

A consent form (see Appendix D) was given to each participant, identifying the purpose of the study, the time and nature of the questions involved, assurance of confidentiality, anonymity, and the right to withdraw without repercussions (Parse, 2001a). Consent forms were required to be signed by each participant. In the event that a person was unable to sign, verbal consent would have been obtained and documented (Parse, 2001a).

Participants were informed of the potential risks, benefits, and inconveniences to them as a result of involvement in the study. The only known inconvenience was the time associated with participation in an interview. The potential for emotional or physical responses was minimal, however it was possible in the discussion of personal experiences. Potential risks were related to the possibility of becoming upset, feeling fatigued, and/or experiencing physical pain when engaged in the interview. To prevent or deal with these risks, the consent form explained to the participant that if they experienced any fatigue, pain, or unease during the interview, they could end the interview and reschedule at their convenience. Participants were also given the researcher's telephone number and e-mail address if they wished to discuss concerns that lingered after the interview. None of participants contacted the researcher after their interviews. The researcher was also prepared to provide names and phone numbers of support services available to participants if requested or thought to be appropriate by the researcher.

All data included in this research was confidential. Participants were referred to only in pseudonyms and transcripts were numbered (Baumann, 1993). Interviews were transcribed by a paid transcriptionist who also upheld ethics of confidentiality and signed a contract (see Appendix E). Transcripts were coded, used in analysis, and were available to the supervisor and committee only through the researcher while the study was in progress. Transcribed data will be kept for the possibility of secondary analysis because this research is potentially the first of a series of studies with the phenomenon of feeling understood and with nurses who have disabilities. The researcher kept one list of participants' names, addresses, phone numbers, e-mail address (if applicable), and codes

for purposes of communication with participants. This list was kept in a separate location from the transcribed data. Tapes and transcripts, were kept in a locked cabinet. Tapes were erased upon completion of analysis and the file containing the list of participants was destroyed at the end of the study.

*Data analysis: Analysis-synthesis.*

The researcher analyzed data by searching for major themes regarding the phenomenon of concern (Baumann, 1993; Parse et al., 1985). I listened to the tapes multiple times while reading and re-reading the transcripts. Analysis-synthesis, a method used with descriptive exploratory studies, involves “a process of separating the themes according to the major elements in the objectives, examining these elements, and constructing a unified description of the phenomenon as lived by the subjects” (Parse et al., p. 94). Although computer assisted qualitative data analysis software is increasingly being used in research (Bringer, Johnston & Brackenridge, 2004), a computer program was not used as a means of analysis. Analysis-synthesis could not have been conducted by a computer analysis program because such software focuses on identifying or counting identical words and phrases versus identifying conceptual similarities. The identified themes and unified descriptions were then transformed from the language of the participants to a higher level of discourse aligning with science in the discipline, that is, in the language of the researcher (Baumann; Parse, 2001a; Parse et al.). The answers to the research question constitute the findings which were then considered with regards to the theory of human becoming (Parse, 1996a).

Analysis-synthesis results in an articulation of a unified description of the phenomenon of concern that answers the main research question for the study. One of the most persistently asked questions regarding such findings relates to generalizability (Janesick, 2000). “Generalizability refers to the degree to which the findings are applicable to other populations or samples” (Ryan & Bernard, 2000, p. 786). In this thesis, the findings are not considered generalizable to other individuals’ experiences of feeling understood, even if they are also nurses with disabilities. This standpoint stems from a theoretical perspective that posits it is impossible to predict persons’ experiences (Bournes, 1997). The goal of analysis-synthesis for this research was to provide a unified

description of the experience of feeling understood that represented the participants in this study. The participants' experiences were unique to themselves. However, the major themes in analysis-synthesis represented similar patterns of experiences that the participants shared. Other people in similar or different populations than nurses with disabilities may share these experiences of feeling understood, but they are not presumed to do so.

Although findings of this study are not considered generalizable, they can inform practice. For example, recognition of these five individuals' experiences of feeling understood may provide further insight for a diverse range of persons associated with disabilities. These include persons living with disabilities, health professionals in practice with persons living with disabilities or with colleagues who have disabilities, and administrators in a number of realms including nursing, education, legislation, human resources, professional bodies/union, and health care policy development and implementation. In turn, these findings may potentially influence the quality of work life for nurses with disabilities who choose to remain in or return to the practice of nursing. The development of policy related to nurses with disabilities may also be practiced in a new way that is informed by what a few members of this population have experienced. Exploration of feeling understood may further provide knowledge for nurses and others who daily work alongside colleagues and patients who may express a longing to feel understood. The new knowledge about feeling understood surfacing from this study "may create a transformational shift in knowing and provide nurses with insights for new possibilities in being with persons and families in the nurse-person process" (Jonas-Simpson, 2001, p. 222). When we understand differently, we *are* different. Furthermore, knowledge generated from these findings may serve as insight into lived experiences and ways we understand reality. And while there may be many other possibilities of how this research may inform nursing, the practice methodology and theoretical foundation for this study may be used by all nurses in all areas of practice.

### *Rigor.*

Critique of scholarly work is inherent in the academy and is required within all disciplines that are advancing their scientific base (Parse, 2001a; Parse et al., 1985),

including nursing. Critical appraisal is considered “the art of analyzing and judging the worth of a work in light of a set of criteria related to correspondence and logical coherence” (Parse, 1993, p. 163). However, different criteria are required for different types of research. For example, criteria for evaluation should reflect the assumptions of the research approach being used (Parse et al.), whether inquiry is quantitative, qualitative, natural or human science, totality or simultaneity, or otherwise.

Within qualitative research, many different terms are used to address critique. Words such as goodness (Emden & Sandelowski, 1998), rigor (Janesick, 2000; Sandelowski, 1986; 1993), credibility (Denzin & Lincoln, 2000; Janesick), transferability, dependability, confirmability (Denzin & Lincoln), validity (Creswell & Miller, 2000), et cetera are used in critical appraisal, and at times used interchangeably, potentially adding confusion. Criteria for this research was chosen to align with the basic assumptions within human science and an ontology of indivisible multidimensionality, thus providing a foundation for the theory of human becoming. Therefore, critique based on objective measurements, such as validity or dependability, were inconsistent with the conceptual framework.

A compatible form of critique adds to internal consistency or rigor as congruence is maintained methodologically, epistemologically, and ontologically (Parse, 2001a). Two appropriate frameworks aligned with the theory of human becoming (Burns, 1989; Parse et al., 1985) and this study used Parse’s (2001a) criteria for appraisal which expands Parse, Coyne and Smith’s (1985) original work. Parse (2001a; Parse et al., 1985) established criteria as a means of examining the substance and clarity in published qualitative research. Substance is considered as soundness, comprehensiveness of the presentation of phenomenon, accuracy of evidence, and semantic consistency. Clarity is evident with a logical flow of ideas, appropriate grammatical vocabulary, and technical precision. Substance and clarity should be seen throughout the research process and text.

While substance and clarity are examined through the criteria for approval of rigor (as outlined below in table 3), these may be problematic terms in light of Parse’s theory and the pursuit of semantic and theoretical consistency within this research. For example, because “logic” is considered to be a tenant of empiricism and rationalism, how will “logic” be determined in human science research? Who is granted the power to judge

the accuracy of evidence? Although questions such as these may not have clear answers, for the sake of this study, authority for considering substance, clarity, and rigor will be granted to the thesis committee.

The interface between a research text and the reviewer is guided by specific criteria (Parse, 2001a). These criteria for qualitative research include four dimensions of the processes of research: conceptual, ethical, methodological, and interpretive. The following table was created by Parse (2001a, p. 245) and identifies criteria for appraisal of qualitative research. This study has adhered to the following criteria in both conception and critique.

Table 3.

<i>Criteria for Appraisal of Qualitative Research: Conceptual, Ethical, Methodological, and Interpretive Dimensions</i>	
<i>Conception</i>	<ul style="list-style-type: none"> <li>- How does the phenomenon under study relate to the phenomenon of concern to the discipline?</li> <li>- How does discipline-specific knowledge underpin the frame of reference?</li> <li>- How does the research question flow from the frame of reference?</li> </ul>
<i>Ethical</i>	<ul style="list-style-type: none"> <li>- How does the plan of study meet standards of scientific merit?</li> <li>- How does the study contribute to unique discipline-specific knowledge?</li> <li>- How are participants' rights protected?</li> <li>- How does the researcher treat the data in light of accuracy and authenticity?</li> <li>- Are the credentials and experience of the researcher adequate for conduction of the study?</li> </ul>
<i>Methodological</i>	<ul style="list-style-type: none"> <li>- Is the method identified correctly?</li> <li>- Are participants, the text, or the art forms appropriate for the method?</li> <li>- Is the participant selection process appropriate for the method?</li> <li>- Is the data-gathering process appropriate for the method?</li> <li>- Is the data analysis-synthesis process appropriate for the method?</li> <li>- How does the researcher show conceptual shifts in levels of abstraction?</li> <li>- How do the abstract statements evolve from the participants' descriptions, the text, or the artforms?</li> </ul>

<i>Interpretive</i>	<ul style="list-style-type: none"> <li>- Is the path of inquiry easily identifiable?</li> <li>- Is the path of inquiry logical from question to findings?</li> <li>- How do the interpretive statements correspond to the findings?</li> <li>- To what extent are the findings interpreted in light of the conceptualization of the study?</li> <li>- How do heuristic implications reflect an accurate interpretation of the findings?</li> <li>- How are the interpretations woven with theory, research, and, when appropriate, practice?</li> </ul>
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(Parse, 2001a, p. 245)

The substance and clarity of this study will be reviewed using the criteria for appraisal articulated by Parse (2001a) in the above table.

### *Review of Methodological Rigor*

#### *Conceptual.*

The phenomenon of concern that was studied in this project was the experience of feeling understood. This phenomenon was considered within the population of nurses with disabilities. The topic of feeling understood is significant within the discipline of nursing because it relates to the phenomenon of concern within nursing, which is advanced in this study as the person-universe-health process (Parse, 1992, 1998, 1999b). This process is further considered as humans living health. Similarly, feeling understood involves individuals living out their health values as they chose among the unfolding options in life. From the theory of human becoming, living one's values is considered an expression of health (Cody, 1995).

The discipline-specific knowledge that guided this study from beginning to end was Parse's basic nursing theory. The research question for this study was, What is the meaning of the experience of feeling understood for nurses with disabilities? The frame of reference or ontology underlying this research question aligns with the theoretical perspective and assumptions of human beings as indivisible, unpredictable, and everchanging in mutual process with the universe (Mitchell & Cody, 1992; Parse, 2004).

Such ontology is consonant with the pursuit of research to study humanly lived experiences with people as they live them day-to-day (Mitchell, 2002; Mitchell & Cody).

*Ethical.*

The plan of study met standards of scientific merit by presenting the research process in a manner that was semantically consistent. This consistency encompassed the research from its description of discipline-specific theoretical perspective to its discussion of findings. The plan of study also rigorously attended to the descriptive exploratory methodology (Parse, 2001a; Parse et al., 1985). This project contributed by adding to nursing's unique body of knowledge through the use of nursing theory-guided research. Thus, this study advanced nursing knowledge about the experience of feeling understood for nurses with disabilities. The findings from this research were also interpreted in light of the theoretical underpinnings (see chapter six).

This study was reviewed and accepted by the Human Research Ethics Committee at the University of Victoria. As previously discussed in this chapter under the heading *Ethics*, participants' rights were protected through adherence with confidentiality and anonymity. All participants signed the form of consent (see Appendix D) and were informed of their rights to withdraw without repercussion and any time. Participant interviews were transcribed by a paid transcriptionist who signed a consent form (see Appendix E) and upheld ethics of confidentiality.

The findings from this study reflected the participants' descriptions of their experiences of feeling understood. The research findings are presented in a manner that reveals accuracy and authenticity to the reader. For example, in chapter five, each theme is presented in the language used by the participants. Direct quotes from each participant are then provided to present the reader with substantive data depicting how the themes are a synthesis of the major statements from each participant interview. Each theme is then interpreted in the language of the researcher and discussed in greater detail in chapter six.

The conduct of this study is adequate in relation to the credentials and experience of the researcher. The researcher is a graduate student who has completed graduate level courses in qualitative research, along with all other class requirements for a degree in a

masters of nursing, policy and practice program. This study has also been conducted under close guidance by a thesis supervisor and considered by a thesis committee.

*Methodological.*

The method and methodology chosen for this study were described earlier in this chapter. The descriptive exploratory methodology is considered appropriate for human science research (Parse, 2001a). Participants were chosen to be within the population of nurses with disabilities. This population is appropriate for inquiry with the chosen methodology because nurses who share the experience of living with disabilities could explore the meaning of feeling understood (Parse, 2001a; Parse et al.). The research question, interview questions, and study objectives were derived from the theoretical perspective and the three theoretical themes of meaning, rhythmicity, and co-transcendence (Parse, 1981, 1987, 1998). A total of five participants volunteered to describe their experiences of the phenomenon of concern. This is an adequate sample because there is no set participant sample size required for this methodology (Parse, 2001a). Most participants heard of the study through the revised advertisement in the local health authority newsletter (Appendix B).

Data was gathered through taped, face to face interviews to facilitate description of the phenomenon from the perspective of the individual living the experience. Participant descriptions related to the phenomenon of feeling understood and the research objectives were linked to the three theoretical themes of meaning, patterns of relating, and co-transcendence (Cody et al., 2001; Parse, 1981, 1987, 1998). Themes within the data were likened to recurrent melodies within participant stories. In this manner, identification and coherence of the path of inquiry from the research question to the findings is expressed.

The data analysis-synthesis process is congruent with a descriptive exploratory methodology (Parse, 2001a; Parse et al., 1985). This process was followed and described fully in chapter five. Connection between the themes in the language of the participants and reinterpretation in the language of the researcher is identified and described in chapter six and table six.

*Interpretive.*

The three research themes composed the findings of this study and answered the research question. The themes are theoretically interpreted according to the principles and concepts within Parse's theory (Parse, 1981, 1992, 1998) (see chapter six). Discussion of these theoretical interpretive statements includes examples of direct quotes from participant descriptions. Findings are further discussed in relation to the relevant literature. Heuristic implications are considered in the final chapter in suggestions stemming from this research towards nursing practice, education, research, and policy (see chapter seven).

In the following chapter, the relevant literature related to this study will be reviewed. Bodies of reviewed literature will include the population of nurses with disabilities, the phenomenon of feeling understood, and policy in relation to nurses with disabilities who lived greater Victoria, B. C., Canada.

#### *Chapter 4 - Literature review*

Currently, there is neither scholarly nor non-academic literature addressing the phenomenon of feeling understood among the population of nurses with disabilities. There is, however, literature that addresses sub-components of this inquiry. While the following literature review includes hundreds of articles, it is not assumed to be completely exhaustive on either the population of nurses with disabilities nor on the phenomenon of feeling understood.

The majority of this literature review was conducted through the literature database, ISI Web of Science (Thompson ISI, n.d.). The Web of Science database was employed after CINAHL (Cumulative Index of Nursing and Allied Health Literature) and MEDLINE (database for medicine and related areas) provided only a few articles on nurses with disabilities and feeling understood. Web of Science accesses and compiles citation databases, which are comprised of multidisciplinary databases of bibliographic information collected from thousands of scholastic journals. Once an article of interest is found on the database, Web of Science provides an option of viewing related records of literature that are biographically linked to the primary search.

The process of reviewing literature through the Web of Science directed my exploration that first addressed the population of nurses with disabilities. A growing number of articles on nurses with disabilities surround the popular “crisis” issue of nurse recruitment and retention. The web of related records explained that the population of nurses who use substances were also considered nurses with disabilities when they have enrolled in or completed a rehabilitative program. Nurses who use substances are increasingly being researched and these studies constitute the majority of the literature on nurses with disabilities. Another growing area in the literature explored the topic of nursing students who are considered to have disabilities. The literature on nursing students living with disabilities was also discovered through viewing related records from articles on nurse recruitment and retention. The literature will therefore be discussed schematically according to the following parameters of published literature considering nurses with disabilities: nurse recruitment and retention, nurses with substance use, and nursing students with disabilities.

The literature review on feeling understood was also primarily conducted through the Web of Science database. Literature on feeling understood was frequently reviewed in related records because many studies considered feeling understood as a complementary aspect of another phenomenon of study. The computer database, Dissertation Abstract International, was also used in searches for theses and dissertations that researched feeling understood. Dissertation Abstract International facilitated access to over 1.5 million references to theses and dissertations written by researchers in over a thousand universities and dated as far back as 1861.

### *Nurse Recruitment and Retention*

Recruitment and retention issues have prompted a heightened recognition of hiring and retaining nurses with disabilities within the human services in the last two decades (Baumann, Blythe, Kolotylo & Underwood, 2004; Canadian Nursing Advisory Committee (CNAC), 2002; Maheady, 2004; Porter, 2004; "Safety to Practice", 2003; Tuttas, 2002; Wallis, 2004). Public awareness of the high rates of illness and injury among nurses has also increased with media exposure to the "nursing shortage crisis" in Canada. For example, findings from the CNAC (2002) report documented that absenteeism associated with injury and illness contributed to overtime costs estimated to be between \$252 and \$430 million. More recently, these same statistics were later reported in the popular magazine *Reader's Digest Canada* (Cornwall, 2003).

The discourses of organizational expenditure related to a viewpoint of health care as a business maintain the hegemony of cost reduction and efficiency (Armstrong et al., 2002; Campbell, 2000; Fuller, 1998; Oke, 2004). One solution considered for this crisis is tapping into the "unused market" of employing nurses with disabilities (Dinsdale, 2000; Winland-Brown & Pohl, 1990). Within the nursing literature, a number of articles addressed employment of nurses with disabilities, labeling this research population as "disabled nurses" rather than "nurses living with health challenges" or "nurses with disabilities" (Agnew, 2000; "Back Injury", 2002; Dinsdale; "Exclusion Zones", 1995; Nemeth, 1995; Restifo, 2001; Sloane, 1998a, 1998b; Smith, 1992; Tammelleo, 1993; Thomas, 2000; Wallis, 2004; Winland-Brown & Pohl). Literature searches under phrases such as "nurses with disabilities" usually produced "no found articles" in the databases.

The term “disabled nurses” is more often used as a key reference in this literature. This penchant towards the use of such labels suggests to this writer that the objectification of people is frequently apparent through diagnostic and labeling processes.

Approximately half of the articles that considered recruitment and retention discussed employment challenges and opportunities for nurses with disabilities. Winland-Brown and Pohl (1990) quantitatively studied administrators’ attitudes towards hiring nurses with disabilities through a questionnaire. The authors found that although attitudes towards employees with disabilities were changing, hiring practices lagged behind. Once a nurse with a disability had found a job or returned to work, assistance and understanding from colleagues could be sought. One entrepreneurial group in Ohio (Nemeth, 1995) founded a support group for nurses with job related disabilities. The goals of the group were to provide support, education, information, and to facilitate change to make their workplace safer for each other, as well as for other nurses with disabilities. Yet, “Exclusion Zones” (1995) reported that nurses with disabilities, despite nursing staff shortages, remain prohibited from practice and creative plans to encourage “good” nurses to stay are not being pursued, possibly because such initiatives would cost money.

Dinsdale (2000) argued conversely with “Exclusion Zones” (1995) that nurses are actually a “neglected resource” (p. 12) and could be of financial benefit to an organization. He provided accounts from nurses who could not find employment due to their disability. One participant poignantly commented: “Nurses are part of a medical caring profession. If one becomes significantly disabled, the medical model of disability kicks in and you are seen as a ‘failed’ patient and thus unemployable” (p. 13). Dinsdale’s article is noteworthy because he was one of the few authors who briefly included nurses’ experiences in his text (also see Agnew, 2000; Nemeth, 1995; Sloane, 1998a, 1998b). However, these nurses’ experiences were ironically portrayed in light of the subversive argument for the betterment of the organization, not for the individual. Hoping to increase nurses’ chances of employability, Restifo (2001) provided strategies for nurses when interviewing, problem-solving, networking, thinking positively, and looking one’s best. When personal attempts to compensate for one’s disability or regain employment were not enough, some nurses found jobs in alternative careers (Agnew, 2000)

The remaining articles addressed areas of legislation that affected recruitment and retention of nurses with disabilities. Smith (1992) and Sloane (1998a, 1998b) both addressed the 1990 Americans with Disability Act. While Sloane (1998a, 1998b) spoke to nurses explaining how the Act provided protection, Smith approached nurse administrators' obligations under the Act. Thomas (2000) further explained that in a certain health region in England, administrators were required to guarantee interviews to applicants with disabilities as a means of helping "employers crack staff shortages" (p. 22). However, at no point did Thomas suggest that administrators were required/encouraged to guarantee employment to applicants with disabilities, therefore reinforcing Winland-Brown and Pohl's (1990) findings that hiring practices lag behind changing attitudes of administrators.

Two court decisions were documented regarding accommodation for nurses with disabilities. According to information retrieved from a legal newsletter in the United States, "manufacturing" a new position for a nurse did not constitute reasonable accommodation in a disability discrimination lawsuit ("Back Injury", 2002). Tammelleo (1993) reported such lack of reasonable accommodation was magnified further when a nurse, who had experienced back surgery, was terminated before her "return to work" period was completed. The enactment of a lengthy lawsuit was required prior to legal compensation for this nurse.

Outside of the discipline of nursing in the arena of human resources and management, employment and accommodation of employees with disabilities was considered both necessary and challenging. While the literature in this area was quite extensive, only two articles will be reviewed and discussed here in relation to nurses with disabilities. Hernandez and Keys (2000) provided an extensive literature review of thirty-seven quantitative studies conducted since 1987. Employer attitudes were highlighted because their review identified that this area remained the main hurdle for employment among individuals with disabilities. Aligning with Winland-Brown and Pohl's (1990) study and echoing Thomas' (2000) article, Hernandez and Keys found that although employers expressed acceptance of workers with disabilities and the intent of the Americans with Disability Act, actual hiring was not evident. Hernandez and Keys also found a persistent disability-hierarchy as employees with physical challenges continued

to be considered more positively than individuals with intellectual or psychiatric disabilities.

Adding to the conversation regarding barriers to employment for nurses with disabilities, Ponak and Morris (1998) reported management perspectives on the logistical problems in accommodating physically “partially disabled nurses” (p. 13) in a hospital in western Canada. Echoing a persistent theme in nursing literature, these authors found consistent conflict over scarce resources, including money, time, seniority, desired and less physically demanding positions, and communication. In the current health care system in Canada, working nurses are also considered scarce and conflict over resources remains a contested issue amidst many human resource crises.

The consistent concern with finances and business endeavours evident throughout this literature could arguably be one of the most significant issues of the recruitment and retention debate within health care organizations. Nurses with disabilities were drawn into this economic issue as human resources that possess possible monetary remuneration (or not) to organizations. The financial issues were accepted as a part of the dominant and unchallenged discourse surrounding the population of nurses with disabilities. Specific details of direct costs to employers (including management, human resources, union et cetera) in relation to recruitment and retention were infrequently explicated (Agnew; Ponak and Morris, 1998; Sloane, 1998b; Smith, 1992; Thomas, 2000). Indeed, the costs and financial challenges to employers or organizations were left implicit and only minimal details were provided. Interestingly, it was never contested as to whether costs and financial challenges was a worthwhile cause (Dinsdale; “Exclusion Zones”, 1995; Hernandez and Keys, 2000; “Occupational Safety”, 2002; Ponak and Morris; Restifo; Thomas; Tuttas, 2002; Winland-Brown & Pohl, 1990).

Considering that the majority of the included articles in this part of the literature review were either written by nurses or published in nursing journals, it is interesting to note that the persistence of money matters was indicative of the economic influence seen to be directing the discipline’s contemplation of the issues of recruitment and retention of nurses with disabilities. However, the following questions must be asked. Is this the direction nursing should be pursuing? Does this financial direction represent nursing’s interests or the interests of others? Do nurses feel they have no option except to address

the economic priorities regarding the management of human resources in health care organizations (Colella et al., 1997)? In what other ways could nursing uniquely address these debates that reflect its phenomenon of concern?

While the financial cost versus benefit debate surrounding nurses with disabilities rose to the fore in the literature, other issues were virtually ignored, dominated by the overwhelming business perspectives. It is understandable that nursing management and human resources must consider the complex economical and legislative responsibilities, the “political correctness”, and the employment concerns involved with nurses with disabilities. However, this economic focus left gaps in the literature that the authors did not address. For example, there were no statistics on the size of the population of nurses with disabilities. While it would be difficult, perhaps even impossible, to count or measure “legitimate” and/or “non-legitimate” disabilities, having some numerical estimate of the size of this population would provide appreciation of the prevalence of disability within the discipline. The literature also rarely detailed the personal costs resulting from disability for the nurses involved (Agnew, 2000; Dinsdale, 2000; Maheady, 2004; Nemeth, 1995; Porter, 2004; Restifo, 2001; Sloane, 1998a, 1998b; Tammelleo, 1993) because costs to employers took precedence. The experience of nurses with disabilities was neither researched nor was there a call within the literature for such inquiry. This study, therefore, addresses some of the identified gaps in the literature and contributes to the body of knowledge by providing information about the experiences of nurses with disabilities regarding feeling understood from their perspective.

#### *Nurses with Substance Use*

The majority of literature on nurses with disabilities focussed on nurses who use substances (inclusive of prescription, non-prescription drugs, and alcohol). Similar to the persistent use of labels such as “disabled nurses” in the literature that addressed recruitment and retention issues, the use of labels to describe nurses who use substances was similarly pervasive. For example, numerous authors referred to the population of nurses who use substances as “impaired nurses”, (Beckstead, 2002; Brewer & Nelms, 1998; Chiu & Wilson, 1996; Champagne et al., 1987; Finke et al., 1996; Green, 1984; Hood & Duphorne, 1995; Penny, 1986; Smardon, 1998; Swenson et al., 1987a,

1987b,1989; “The Indiana State”, 2003; Trinkoff et al., 1991; Wennerstrom & Rooda, 1996; West, 2003; Wheeler, 1992) “chemically dependent nurses”, (Chiu & Wilson; Hutchinson, 1987; Jensen, 1996; Penny; Torkelson et al.,1996) nurses with “substance abuse”, (Chiu & Wilson; Smardon; Trinkoff et al.) or addicts (Chiu & Wilson; Hutchinson; Penny). One additional article sought to gain insight into the experiences of nurses with the challenges of substance usage and referred to these individuals as “nurses with substance misuse problems” (Lillibridge et al., 2002).

The literature on nurses with substance use addressed a range of foci such as prevalence and risk factors, the lived experiences of nurses with “dependence on chemicals”, nurses’ attitudes towards “impaired” colleagues, disciplinary procedures, interventions for administrators working with nurses who use substances, types of withdrawal programs, and re-entry into practice. The prevalence of chemical use by nurses was proclaimed to be on the rise (Chiu & Wilson, 1996; Hutchinson, 1987; Wheeler, 1992). Statistics ranged from 2% to 33% (Green, 1984; Lillibridge et al., 2002; Trinkoff et al., 1991). More recent articles estimated the rate of substance use was similar or slightly below the general population at 20-35% despite nurses’ increased job risks of high stress and access to medications (Beckstead, 2002; Lillibridge et al.; Smardon, 1998). Younger nurses were also considered to be at greater risk for substance use (Smardon). However, as Smardon pointed out in her literature review on the topic, it may be difficult to know the actual prevalence of substance use among nurses due to decreased self-disclosure because of shame and guilt among these women who are caregivers. Interestingly, substance use was frequently regarded as either a moral weakness or a disease (Brewer & Nelms, 1998; Hood & Duphorne, 1995) with each perspective having coinciding preconceptions of individuals who use chemicals.

The recognition of substance use among nurses being labeled as “impairment” began to surface in the literature in the 1980’s. This acknowledgment occurred after the topic surfaced in the late 1970’s as one of public concern (Smardon, 1998). Often addressing issues of legislation and disciplinary actions, the research on nurses with substance use, predominantly from the United States, was also written prior to the Americans with Disability Act. Although state boards of nursing had the right to determine who was “competent” to practice nursing, research revealed that boards

differed in requirements for documentation regarding impairments (Champagne et al., 1987). Disciplinary actions by nursing boards were also found to be targeted towards nurses who used substances more than nurses with mental or physical challenges (Swenson et al., 1987a, 1989). Reinstatement was generally dependent on criteria that the nurse was in treatment and able to complete her job while maintaining patient safety (Swenson et al., 1987b, 1989).

Over the past two decades, disciplinary actions have shifted to focus on rehabilitation. “A successfully rehabilitated substance user is defined by law as a person with a disability, unless proven to have relapsed into active addiction” (“Narcotics Diversion”, 2000, p.5). Yet, if a person continued in the illegal use of drugs, they became exempt from coverage under the Americans with Disability Act and were no longer considered a person with a disability (Smith, 1992). It is unclear if a person is considered to have a disability when they enter into rehab, labeled “non-disabled” if they re-use substances, but then again considered disabled once they stop using. Is a person regarded as having a disability or not if they are in a rehab program and use substances while still in rehab? The literature did not consider the use of labels in scenarios such as these. The labels, stigma, and denial of substance use continues to challenge identification, let alone rehabilitation, within the discipline of nursing.

Amidst the denial and stigma, why is it that the majority of the literature on nurses with disabilities focussed on nurses with substance use? How is it that this population has been recognized in scholarly literature more than other groups such as nurses with spinal injuries/disabilities or nurses with multiple sclerosis? Is it because this topic engaged sensational interest given that it could be illegal (for example, if a nurse reverted back to drug use)? Or is it because of funding for research with “impaired nurses”? Does the focus on nurses with substance use as the highlighted example of nurses with disabilities further stigmatize the population? And does it further imply that nurses are to maintain primary ownership, maintenance, and responsibility for their disability? Brewer & Nelms (1998) were the only authors who critically considered the effects of labeling a nurse as “impaired”. They further suggested in their research that nurses who use substances were in fact stigmatized and labeled by the nursing discipline as “deviant” persons.

With the exception of Brewer & Nelms' (1998) article, the notion of labeling a nurse as "impaired" has been accepted and unchallenged within the literature regarding nurses who use substances. Comparatively, Torkelson et al. (1996) considered the effects of nurse administrators and executives labeling a nurse who uses substances as a "threat" or "non-threat". The authors found that labels of threat and non-threat identified different interpretations and suggested varying actions by nurse administrators who were perceived to act on behalf of the organization. It is interesting to note that these nurse administrators were not acting on behalf of their staff nurses, who in this case, used substances. Would these administrators' actions have been different if they were acting on behalf of the individual nurse with substance use, instead of acting on behalf of the organization? The notion of labeling is further considered in other realms of literature outside of the research area of nurses who use substances (for example, see Deegan, 1993; Olney & Brockelman, 2003).

The word "impair" means unsuitable, unfit, inferior, odd, less valuable, weaker, to grow or become worse, to deteriorate, and to suffer injury or loss (Onions, 1983). Are these definitions what is implied when speaking of nurses who use substances or nurses with disabilities? Is labeling a nurse as "impaired" then a judgement on her/his value as a nurse or as a person? If a nurse who uses substances is also considered to have a moral weakness (Brewer & Nelms, 1998; Hood & Duphorne, 1995) as the cause of the disability, is this nurse in some way considered too morally weak to remain a nurse? The perpetual use of labels such as "impaired nurse" among the nursing literature may also reveal how nurses perceive their colleagues who use substances. Are we as a discipline content with perceptions such as these?

The use of labels among nurses with disabilities may alternatively be required for administrative purposes, therefore requiring the use of disability labels. These labels may represent diagnoses given to individuals by doctors, colleagues, or clinicians. Yet these labels may not represent an individual's experiences or self-perceptions (Olney & Brockelman, 2003). For example, in order to receive adequate supports, nurses with disabilities may need to demonstrate evidence of a disability label (Olney & Brockelman, 2003). Tension is apparent when one considers that the majority of labels used for nurses with disabilities may be imposed on individuals, yet they may also be necessary for

administrative negotiations. Again, with the exception of Brewer & Nelms' (1998) and Torkelson et al.'s (1996) articles, none of the above questions regarding labeling were answered in the literature on nurses who use substances, therefore presenting a gap in the literature.

In the literature, the practice of nursing colleagues assisting and reporting nurse co-workers with substance use was documented, encouraged, and challenged in nursing publications. Peer assistance via relational support and rehabilitation programs was encouraged and supported for the primary rationale of developing prevention strategies through education, expanding program development, and decreasing organizational costs (Finke et al., 1996; Hutchinson, 1987; Jensen, 1996; Penny, 1986; "The Indiana State", 2003; Torkelson et al., 1996; Wennerstrom & Rooda, 1996). However, the questions many nurses faced was whether or not reporting a colleague was supportive or detrimental for the nurse with substance use, for themselves, for the public, or for the organization in which they were working. Hood and Duphorne (1995) found that nurses in general were willing to help or confront colleagues but preferred informal to formal reporting and were not willing to work with them on the hospital unit. Theories of behavioural change explained that a significant antecedent to behaviour adjustment was attitudinal change. Therefore, attitudes regarding substance use were hypothesized to sway nurses' judgments of colleagues' impairments, as well as the likelihood of reporting (Beckstead, 2002). While the use of such behaviourally based interventions, intended to control and predict nurse behaviours or reporting, may offer particular sorts of practice, such practice is devoid of the meaning of this experience for the nurses doing the reporting.

The "costs" associated with having nurses who use substances participate in the workplace was widely considered in the literature. However, attention was directed towards employer/organizational incurred costs due to incidence reports, absenteeism, substandard practice, drug discrepancies, overtime, workers compensation, retention amidst "nursing shortage", resignations, return-to-work programs, lawsuits, and increased monitoring of nurses returning to work (Brewer & Nelms, 1998; Finke et al., 1996; Jensen, 1996; Lillibridge et al., 2002; "Narcotics Diversion", 2000; Penny, 1986; Torkelson et al., 1996; Wennerstrom & Rooda, 1996; Wheeler, 1992). Financial costs

overrode the majority of organizational considerations by nursing unions, state boards, and professional bodies (Champagne et al., 1987; Finke et al.; Hood & Duphorne, 1995; Hutchinson, 1987; Lillibridge et al.; Penny; Swenson et al., 1987a, 1987b, 1989). Costs towards standards of care within the profession (Beckstead, 2002; Hood & Duphorne), as well as care that the public received (Finke et al.; Hood & Duphorne; Torkelson et al.) were also identified as areas that were affected by nurses who use substances.

While the majority of articles focussed on the economic burden of nurses who use substances, there was a small minority of the literature that explored the personal experiences and human costs of substance use among nurses. The following three articles are important in relation to this thesis because they too studied nurses' experiences (Brewer & Nelms, 1998; Hutchinson, 1987; Lillibridge et al., 2002). Review and analysis of what has been discussed among this population in past research will also inform this inquiry. The first phenomenological study was conducted by Brewer and Nelms and they included 14 nurses in recovery for chemical use, all of whom were labeled as "impaired" by the nursing profession. The study identified five themes common to each participant: (1) living with a negative label, (2) denial of employment due to being labeled as "impaired", (3) recovery as a way of life, (4) recovery as a personal identity, and (5) willingness to share one's recovery with professional peers.

The research by Brewer & Nelms (1998) is significant because they were the only authors who questioned the use of labels among nurses who use substances. They also asked their participants about their experiences of being labeled. Of the fourteen participants in this study, one half of the nurses did not see themselves as "impaired" and only one self-viewed as an "impaired nurse". Nine participants "identified themselves as 'recovering' not as nurses, but as persons, separate from their professional roles...and four participants viewed themselves simply as a nurse" (p. 177). All fourteen attached negative meaning to the word "impaired". While the authors problematized the use of the term "impaired nurse", they inconsistently also referred to this population with this same label that they were critiquing.

A second group of researchers (Lillibridge et al., 2002) conducted a phenomenological study in which they interviewed 12 nurses who "misused" substances. The purpose of this two-part research was to achieve insight into nurses' experiences as a

contribution to the development of universal guidelines to assist with prevention, identification, and intervention policies for nurses who have problems with “substance abuse” (p. 1). Phase one included qualitative phenomenological design while phase two used quantitative methodology. Five major themes were derived: (1) nurses’ justifications for using substances, (2) fear surrounding being “discovered”, (3) personal meaning of substance use, (4) professional impact, and (5) the turning points on their roads to recovery. Although the authors discussed their findings related to subsequent implications for the workplace, they did not include recommendations for universal guidelines for prevention, identification, and intervention strategies. However, they were able to articulate the importance of including individuals’ experiences in policy development. I fully agree with these authors when they purport: “It is imperative to listen to these experiences as a basis for developing interventions and guidelines for the workplace that are relevant and responsive to the needs of nurses” (p. 7).

Both Brewer & Nelms’ (1998) and Lillibridge et al.’s (2002) phenomenological studies found that their participants spoke about recovery as a personal experience. Both studies also included recovery as a part of the research findings. Although Lillibridge et al.’s study was conducted in Australia and Brewer & Nelms’ research occurred in the United States, it would be interesting to know if the nurses who participated in these projects knew that recovery and rehabilitation were necessary components for coverage under the Americans with Disabilities Act and to be considered as having a “legal” disability.

A third qualitative study, using a grounded theory methodology, explored the experiences of 20 nurses who use substances (Hutchinson, 1987). Hutchinson identified and presented three progressive stages nurses are said to go through as they become dependent on chemicals, or what the author terms, the self-annihilation trajectory. The three stages include: 1, the experience (including phases of initiating, connecting, and experimenting), 2, the commitment (including dialogue with self, disengaging, and routinizing), and 3, the compulsion (including craving and surrendering). The author’s purpose in describing the three stages was to facilitate nurse executives in acquiring an informed understanding of chemical use so they could better plan and change policies, procedures, and management interventions. Interestingly, unlike the research by Brewer

& Nelms (1998), Hutchinson did not ask her participants about their experiences of being identified with a negative label. Therefore, there is no detail about the experiences of these nurses and their responses to being labeled on a self-annihilation trajectory.

Closer to the topic of this study, the literature briefly addressed the experiences of nurses who use substances. However, there remains a gap based on theoretical perspectives. There was no research that considered nurses' experiences or the issues that were present for nurses who use substances, from a human science perspective. While Brewer & Nelms (1998), Lillibridge et al. (2002), and Hutchinson (1987) did provide some insight into these nurses' experiences, these experiences were all addressed from an objectivist perspective. From such a natural science perspective, human beings are understood by studying parts of their experiences while asserting that they are more than the sum of their parts. Through a human science perspective, human beings' experiences would be considered as greater than and different from the sum of parts and viewed as irreducible wholes (Parse, 2002). The differences between these two perspectives are fundamentally distinct from each other.

A small number of studies explored the interventions used by nurse administrators in the field of substance use and explicated the theoretical basis of their research or practice. Their theoretical perspectives included statistical regression analysis (Torkelson et al., 1996), expectancy theory, path-goal theory (Wheeler, 1992), and ethical theories (Chiu & Wilson, 1996). In a quantitative study including 322 surveys, Torkelson et al., found a relationship between administrators' interpretations of the degree of threat perceived with these nurses and the consequential interventions. The higher the degree of threat perceived by administrators, the higher their tendency to terminate nurses, and the lower their tendency to refer them to treatment, reintegrate them, or hire them. In a guest editorial column, Wheeler briefly identified the expectancy theory, and more specifically, the path-goal theory, as potential guides for administrators' interventions. Path-goal theory suggests that motivation towards attainment of organizational objectives can best be attained by the leader removing obstacles in goal attainment and creating personal rewards for employees dependent on achievement of goals. Ethical theories were also purported in a paper by Chiu and Wilson where the dilemma regarding "best" ethical interventions was considered. They contended, "to make a sound and ethical decision

regarding the choice of intervention, nurse managers not only need to integrate ethical theories and principles but must also clarify their own perceptions and attitudes towards substance abuse” (p. 292).

Although these three articles addressed the practise of nurse administrators with nurses who use substances, the use of nursing theory in these endeavours was non-existent (Chiu & Wilson, 1996; Torkelson et al., 1996; Wheeler, 1992). The theoretically based interventions identified in this section of literature were grounded in knowledge from other disciplines including economics, psychology, and philosophy. Additionally, the pre-eminence of theories that once again were embedded in objective views of reality and reductionistic views of human beings were evident.

These three articles focussed on nurse administrators who acted as representatives of the larger organizations and not as representatives of their nursing staff (Chiu & Wilson, 1996; Torkelson et al., 1996; Wheeler, 1992). It is not surprising, then, that Smardon’s (1998) literature review found that nurses with substance use did not feel supported by nursing management (Shaffer, 1988). It is noteworthy that the three studies that explored interventions used by nurse administrators did not take into account the experiences of nurses. The nurses’ experiences were not considered to inform interventions and policies that were meant to assist them and their recovery from substance use (Lillibridge et al., 2002). The literature also did not address the anticipated absence of studying the experiences of nurses who use substances.

#### *Nursing Students with Disabilities*

The final section addressing nurses with disabilities focussed on nursing students. The majority of this literature was written in the United States with the exception of one article from the United Kingdom (Konur, 2002) and one from Canada (Murphy & Brennan, 1998). The single most apparent theme in the literature considering nursing students with disabilities was the consistent emphasis and acknowledgment of the legalities of disability. Government legislation related to individuals with disabilities was addressed in every article included in this final section (Arndt, 2004; Carroll, 2004; Champagne et al., 1984; Christensen, 1998; Colon, 1997; Helms & Weiler, 1993; Konur; Letizia, 1995; Magilvy & Mitchell, 1995; Maheady, 1999; Marks, 2000; Moore, 2004;

Mueller, 1997; Murphy & Brennan; Persaud & Leedom, 2002; Selekman, 2002; Sowers & Smith, 2002, 2004a, 2004b; Watson, 1995; Weatherby & Moran, 1989; Wood, 1998). This prevalence for examining legal perspective suggests that, for many persons, issues of disability are intertwined with issues of the law. And while the law may be seen by some as protective, just, and fair, for others it may be seen as restrictive, unjust, and prejudiced.

The majority of the literature on nursing students who have disabilities has emerged post-debate on the issues of nurses who use substances and nurses with disabilities. Once nursing began to acknowledge, research, and problematize disability already among practicing and non-practicing registered nurses, the peripheral view extended to consider those who may be coming into nursing with pre-existing disabilities. While it may have been easier in the past to deny acceptance to nursing students with disabilities (Champagne et al., 1987), legislation has now granted access to education.

Two evaluation papers focussed on legislation specifically related to educators in nursing programs (Helms & Weiler, 1993; Konur, 2002). Both articles discussed admission, dismissal, and accommodation for nursing students with disabilities. First, Helms and Weiler identified cases in which statutes have created problems for educators and their interactions with “otherwise qualified disabled students”, further calling for increased education regarding legal requirements for nursing faculty, staff, and administration for the purpose of decreasing risk of liability. Due to changes in legislation, educators have been forced to learn how the law affects their practice. Educators have had to become savvy regarding the law, understanding the extension of legal issues within their own classrooms. For many educators, the issue of disability may then produce a sense of restriction, uncertainty, or fear of liability.

Second, Konur (2002) explicated that it is stakeholders such as nursing administration and academic staff, as well as regulatory nursing bodies, that must educate themselves about the “rules” of the “game” of access by disabled students to nursing education and service provision, thereby shifting the focus of public debate from the “players” to the rules of the game itself. However, Konur’s perspective that calls for a transfer of attention from the individuals to the system may hold inherent dangers. This call further removes from the “bargaining table” those students and educators who are

most affected by the rules of the access-to-education game. Although the effects of shifting public debate and focus may produce a more organized, antiseptic, and highly objective presentation of the issues, it also removes the individuals impacted by these policies. Konur's recommendation implied that the players have already received too much of the focus within public and academic debate. However, the individuals involved have only been considered from an objective perspective. Konur's challenge may further distance individuals' experiences from contributing to and informing the development of policies, guidelines, and future legislation that may be both relevant and responsive to the needs of not only nursing faculty, but also students with disabilities.

Articles addressing an audience of educators in nursing programs discussed issues including: nursing students with disabilities treated less favourably than their peers (Christensen, 1998), an increase of nursing students with learning disabilities (Letizia, 1995; Selekman, 2002), the persistent struggle with the concepts of "essential functions" and "reasonable accommodation" within nursing education and practice (Arndt, 2004; Carroll, 2004; Moore, 2004; Persaud & Leedom, 2002; Sowers & Smith, 2004a, 2004b; Wood, 1998), recruitment and retention of nursing students with disabilities (Carroll; Arndt), and individuals with disabilities who are not just to be "tolerated" but accepted as diverse students (Moore; Selekeman; Sowers & Smith, 2002). Sowers and Smith addressed disability as difference and are the only authors within the literature to consider nurses with disabilities who alluded to understanding. These authors found:

All of the nurses with disabilities whom we interviewed indicated that their patients, with and without disabilities, tended to relate to and trust them because they believed the nurses "understood" what is meant to be a patient of or recipient in the health care system. The nurses with disabilities also believed their disability actually helped humanize them in their patients' eyes – it helped to ameliorate the "myth of perfection" of the health care profession. (p. 332)

Sowers and Smith (2002) were the only authors that included patients' perspectives of being cared for by a nurse with a disability. In Sowers and Smith's study, the patients' perceptions of these health care professionals were very positive. Interestingly, the individuals cared for by nurses with disabilities were not considered at all in the literature among nurses who used substances, or in the literature on recruitment and retention of nurses with disabilities. In these two previous areas of literature review, the public was

only considered in terms of compromised public care or lost public profit. In the previous two areas of literature, the nurse with the disability was inherently considered the “recipient who was in need”. The conversation within the literature rarely considered the actual patients who were being attended to by nurses who were also at times regarded as patients because of their disabilities. Perhaps it is time that nursing considers the preponderance of nurses who are (at times) patients themselves caring for others, traditional patients/clients.

Although legislation has facilitated access to education for individuals with disabilities, schools of nursing continue to address multiple areas of ongoing debate. Students with disabilities continue to be admitted to nursing education in diploma, baccalaureate, and graduate programs, and they are graduating, passing licensing exams, and gaining employment (Magilvy & Mitchell, 1995; Maheady, 1999; Watson, 1995). A persistent area of debate included identification of essential functions (knowledge/skills) for nursing education and practice. This topic was widely considered with regards to nursing students with disabilities (Arndt, 2004; Carroll, 2004; Champagne et al., 1984; Colon, 1997; Magilvy & Mitchell; Maheady; Moore, 2004; Mueller, 1997; Murphy & Brennan, 1998; Watson; Wood, 1998). Admission qualifications ranged from specifically being able to physically perform cardio pulmonary resuscitation (Weatherby & Moran, 1989) to any number of behaviours and work functions, but not physical attributes (Sowers & Smith, 2002).

Traditionally, admission and convocation from a nursing program was linked to licensure requirements (Champagne et al., 1984; Magilvy & Mitchell, 1995; Murphy & Brennan, 1998). However, this notion may be challenged as questions are raised whether there is room in nursing education for those who may never practice in the expected practice area of bedside nursing or do not require registration through a licensing professional body. The question of what exactly nurses “do” may be further debated in the context of nurses who have disabilities (Arndt, 2004; Carroll, 2004; Moore, 2004). Tasks such as changing dressings, using technical monitors, administering narcotics, and performing physically demanding actions do not define “nursing”. Rather, an understanding of discipline-specific knowledge in combination with any number of skills,

tasks, and knowledge from other disciplines may potentially open new opportunities for nurses, including those with disabilities.

Reasonable accommodations of students with disabilities within postsecondary education programs was widely considered (Arndt, 2004; Carroll, 2004; Colon, 1997; Letizia, 1995; Magilvy & Mitchell; Maheady, 1999; Marks, 2000; Mueller, 1997; Murphy & Brennan; Watson, 1995; Weatherby & Moran, 1989; Wood, 1998), predominantly because failure to do so constitutes discrimination. Accommodations ranged from making facilities physically accessible to providing access to technology services. However, reasonable accommodations did not change academic requirements that were essential to the program (Helms & Weiler, 1993).

Two articles stand out among the rest of the literature reviewed thus far in consideration of students with disabilities. First, Maheady's (1999) qualitative multiple case study was the only article that described the experiences of nursing students with disabilities for the purpose of providing research from which nurse educators can make informed decisions about admission, retention, and dismissal. This is significant because individuals' experiences in this research were honoured and described to inform both management and policy. However, Marks (2000) critiqued Maheady's article from a social model perspective and purported that Maheady did not actually honour the participants' experiences. Rather, Marks believed that the use of the medical model in Maheady's study "resulted in a pervasive view of the students with disabilities as lacking in some abilities because of their impairments, which in turn seemed to make them a potential liability to their schools" (p. 205). And second, Colon's (1997) study considered the extent to which nursing programs in North Carolina admit, identify, and graduate nursing students with learning disabilities. Interestingly, this was the only research study framed within nursing theory, that of Leininger's culture care theory. All other literature published in nursing journals that attended to this area of study use theories from other disciplines.

### *Feeling Understood*

Research inquiry with the primary intent of studying the phenomenon of feeling understood is a rare endeavour. Fifteen texts (mainly dissertations) were considered in this literature review and the table below differentiates them according to the theoretical perspectives that guided the inquiry. For the purposes of discussion here, literature is broadly categorized into empiricist and non-empiricist inquiry (Northrup, 2003). The empiricist, natural science perspective of knowledge previously discussed in chapter three considerations *science as product*. The empiricist tradition focuses on objectivity, causality, predictability, and realism (Monti & Tingen, 1999; Northrup; Parse, 1997a). The non-empiricist, human science viewpoint also previously discussed in chapter three considerations *science as process*. The non-empiricist tradition emphasizes multiple realities, living knowledge, perspective, and the uniqueness of human life (Mitchell, 1999; Northrup; Parse, 1997a, 2001; White, 1938). When one considers that all inquiry requires interpretation, the suggestion that empiricist methods are not interpretive seems to be inconsistent (Northrup).

Table 4.

#### *Theoretical Underpinnings of Literature on Feeling Understood.*

Inquiry	Literature on Feeling Understood
Literature related to feeling understood based in empiricist inquiry	<ul style="list-style-type: none"> <li>• Barrett-Lennard, 1962 (dissertation)</li> <li>• Feitel, 1968 (dissertation)</li> <li>• Stolorow, 1982-1983</li> <li>• Lafferty, 1987 (dissertation); Lafferty, Beutler &amp; Crago (1989)</li> <li>• Abrams, 1988 (dissertation)</li> <li>• Bachelor, 1988</li> <li>• Galpert, 1988 (dissertation)</li> <li>• Winfrey, 1988 (dissertation)</li> <li>• Pocock, 1997</li> </ul>

<p>Literature related to feeling understood based in non-empiricist inquiry</p>	<ul style="list-style-type: none"> <li>• Van Kaam, 1958 (dissertation)</li> <li>• Dickson, 1991 (dissertation)</li> <li>• McIntyre, 1994 (dissertation), 1997</li> <li>• Jonas-Simpson, 1998 (dissertation), 2001</li> <li>• Moncrieff, 1999 (thesis)</li> <li>• Sundrin &amp; Jansson, 2003</li> </ul>
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I will begin reviewing the literature related to feeling understood based in empiricist inquiry. Feitel's (1968) philosophy dissertation quantitatively investigated 27 student therapists' behaviours of empathy, warmth, and verbal activity. These behaviours were then compared in relationship with their patients' experiences of feeling understood and liked by their therapist. Therapist verbal activity was measured by the author counting the (1) number of times therapists' spoke, (2) number of words spoken, (3) number of accepting statements, and (4) number of words per utterance (for both accepting and non-accepting statements). Feitel had 35 patients who were considered "moderately disturbed" (p. i) complete a questionnaire after their fifth therapy session in an attempt to measure patients' phenomenological feelings of being understood.

Feitel (1968) found no correlation between feeling understood and therapist verbal activity. Significant correlations were noted between successful therapy outcomes (as noted by therapist supervisors) and patients' ratings of feeling understood and being unconditionally liked. Yet, not surprisingly, patients and judges measuring warmth and understanding did not agree on what composed empathic understanding. These findings support the notion that human experiences may not be generalizable. If more and more research is supporting this notion, then it is interesting to note how slowly both health care and therapy are moving away from generalizable practices.

In a second philosophy dissertation, Abrams (1988) assessed the relationship between satisfaction and feeling understood (using quantitative data) and sought to identify physician behaviours that were related to a patient feeling understood (using

qualitative data). Participants included thirteen physicians along with 102 outpatients who completed a questionnaire that measured feeling understood/misunderstood immediately after their doctors appointment. A qualitative approach applied to the data found which aspects of physician interactions were most important for patients. Abrams observed that patients desired information regarding their illnesses, trust in their relationship, and that their physicians empowered them as patients. The author also found through statistical analysis that feeling understood was positively correlated to the cognitive, affective, and behavioural aspects of satisfaction. She concluded that feeling understood was a predictor of satisfaction.

In the third and last philosophy dissertation on feeling understood, Winfrey (1988) investigated patient perception of early psychotherapeutic process and its relationship to predict therapy durations (length of stay) and outcome. Psychotherapy was defined as “interventions by ‘experts’ with individuals who present[ed] with problems in living” (p. 3). Feeling understood was conceptualized as empathic resonance, a process element from the Generic Model of Psychotherapy. In this quantitative study, 60 adult psychotherapy outpatients rated their third and eighth therapy sessions on a set of variables the author regarded as a predictor for duration and outcome of the intervention. Results found patient perception of early therapy did not predict duration but did predict outcome. Feeling understood and mutual affirmation was found to be prominent in predicting outcome. The change measured between patients’ third and eighth sessions was found to not be related to duration.

In these three dissertations the authors all sought to measure or standardize feeling understood for the purpose of predicting human experiences and actions. It makes sense that causal relationships with feeling understood would be painstakingly researched because such a claim is rooted in a natural science perspective which aims to describe, explain, and predict. The normative process of separating cognitive, affective, and behavioural dimensions (Abrams, 1988) and searching for causal predictors of efficient medical or therapy treatment outcomes (Abrams; Feitel, 1968; Winfrey, 1988) support a system whereby feeling understood remains as an outcome that can be predicted rather than an experience that is explored as part of the process of assessment. It comes as no surprise that within natural science approaches to feeling understood there is a desire to

seek and delineate causal relationships in areas of research, therapy, and nursing practice. Because of the dominance of such thinking, lay people also hold such a view too. This combination permits an “expert” to control or effect outcomes through their predictions (Cody, 1995). These predictions come to be thought of as “true” because of the experts powerful, efficient, and comfortable position as a professional. Thus, the experience of feeling understood is pushed aside because it is an outcome and not central to the process.

Therapy treatment outcomes also considered feeling understood in relation to empathy (Bachelor, 1988; Barrett-Lennard, 1962; Galpert, 1988; Lafferty, 1987; Lafferty, Beutler & Crago, 1989; Stolorow, 1982-1983). Stolorow discussed feeling understood from the perspective of the therapist who interpreted the client’s experience of the phenomenon. Feeling understood was discussed by Stolorow as received empathy, also referred to as empathic understanding. Stolorow found that the “feeling of being deeply understood” (p. 416) enabled the patient to become immersed with the therapist, thereby enabling “early symptomatic improvement” (p. 416). Stolorow’s article, entitled *Feeling Understood*, was informed from a natural science perspective and he acknowledged positive correlations between therapy outcomes and the therapist’s interpretation of the client’s received empathy. At no point in the article did Stolorow discuss the client’s perspective of the experience of feeling understood.

Barrett-Lennard (1962) conducted a study in which he attempted to “connect cause and effect in the therapy process” (p. 30). Unlike Stolorow, Barrett-Lennard looked at the client’s experience of her/his therapist’s response as “the primary locus of therapeutic influence in their relationship” (p. 2). He studied the client’s experiences because he believed that it was what the client experienced that affected him directly. His study led to the development of the now widely recognized Barrett-Lennard Relationship Inventory (BLRI) tool. This tool measured five variables that he believed influenced therapeutic change: (1) level of regard, (2) unconditionality of regard, (3) empathic understanding, (4) congruence in the relationship, and (5) willingness to be known. The sample consisted of 42 clients in the counselling centre of the University of Chicago and their 21 therapists. The BLRI tool was used “after [five] therapy interviews and at predetermined later points” (p. 30). The main hypotheses were supported through the study’s findings that articulated: the tool predicted therapeutic change, the predicted

changes were the greatest when the client's perspective was measured, and the greatest changes occurred with "expert" therapists. Overall, positive correlations were found between successful psychotherapy and a client's perception of empathic understanding.

The therapeutic effect of empathy was also studied by Bachelor (1988) in an attempt to "examine more incisively the structure and phenomenology of clients' perceptions of the helper's empathy as a preliminary basis for a clearer conceptualization of 'received' empathy" (p. 228). The sample consisted of 52 participants, 27 in therapy and 25 who had never been in therapy. Participants were asked to describe in writing a situation in which someone (a therapist or another) had been empathic towards them. Written descriptions were analyzed using a "5-step content-analytic procedure" (p. 229).

From Bachelor's (1988) analysis, four distinct styles of client-perceived empathy were articulated: cognitive empathy (44%), affective empathy (30%), sharing empathy (18%), and nurturant empathy (7%). Cognitive empathy referred to the therapist's ability to accurately recognize "the client's ongoing innermost experience, state, or motivation" (p. 230). The therapist's accurate perception of the client's subjective state resulted in participants feeling understood and reporting this empathy had therapeutic effects on them. Affective empathy was described when the client perceived the therapist was "partaking of the same feeling the client [was] personally experiencing at that moment" (p. 230). Sharing empathy described when the "therapist-client relationship [appeared] to assume the form of an exchange or dialogue, or even a friendship" (p. 230-231). Nurturant empathy denoted the therapist's "supportive, security-providing, or totally attentive, presence" (p. 232).

Bachelor (1988) concluded "empathy has different meaning for different clients" (p. 238). She further purported that just as there are different components within a therapist's empathy, "a global, uniform response of feeling understood should not be assumed in the perception or experience of clients" (p. 238). Although Bachelor wrote of the multidimensionality of empathic understanding, her labels and measurements of the different categories of perceived empathy reflect a normative particularistic approach. Dickson (1991) reviewed Bachelor's research and he concluded that feeling understood was most closely related to the distinct style of cognitive empathy. However, the conceptualization of feeling understood in this study differed from Dickson's view. For

the purposes of this project, feeling understood was regarded as the *person's* perspective of the phenomenon of concern rather than another's "accurate" interpretation of the person's experience.

Lafferty (1987) and Lafferty, Beutler and Crago (1989) studied the select therapist variables that differentiated between more and less effective psychotherapists. Thirty trainee therapists were divided into two groups dependent on their degree of effectiveness with randomly selected clients pre- and post-treatment, as rated on the Global Severity Index. Sixty outpatients from a university psychiatric clinic were assigned to therapists for psychotherapy treatment by an advanced psychiatric resident. One-way analyses of variance (ANOVAS) was conducted to make sure there was no evidence of major differences between patients in the two therapist groups. Eleven therapist variables were measured by patients and therapists. Lafferty reported that "the most discriminating variable was the therapist relationship skill of empathic understanding" (p. ix). It is not surprising that the researchers found clients' perspectives were the best predictors of treatment effectiveness and that clients of more effective therapists felt more understood by their therapists than clients of less effective therapists.

Similar to Lafferty (1987), Lafferty, Beutler and Crago (1989), Bachelor (1988), Barrett-Lennard (1962), and Stolorow (1982-1983), Galpert (1988) also researched empathic understanding in therapy. Galpert conducted a cross-sectional design to study empathic understanding in psychotherapy between therapists and clients and this relationship to therapy outcomes. Therapists practicing in outpatient practice were invited to participate and provide data on five to seven patients. Eighteen therapists participated and 95 patients were included in the study. Galpert used a revised version of the Barrett-Lennard Relationship Inventory (BLRI) tool for correlation analysis (see Barrett-Lennard). Galpert concluded that therapists' attitudes towards their patients, specifically in respect and positive social expectancies, created an interpersonal environment that enhanced patients' feelings of being accepted and understood. Jonas-Simpson (1998) critiqued Galpert's research and identified that several tools used to measure multiple variables in the study were not reported as valid or reliable. Jonas-Simpson responded that while Galpert's findings seemed plausible, "they are suspect due to selection, testing, and instrumentation bias" (p. 28).

Similar to the majority of previously reviewed texts on feeling understood, Pocock (1997) also studied feeling understood in family therapy. He considered aspects of contemporary psychoanalysis and post modernism “to create a theme of understanding as a fully relational activity – making sense together through language of that which lies beyond language” (p. 283). In working with families, Pocock noted that although family members may come to understand each other to a lesser or greater extent, only an individual can express feeling understood. This is an important assertion within the literature because it speaks to the notion of feeling understood as an open or free personal experience, not one that can be enforced on another. Pocock also articulated that feeling understood is a subjective, personal possession that takes time and is cocreated in personal relationships. Pocock further explained:

*Understanding is always personal....* Feeling understood often seems to be a profound relational experience of discovering that one is more acceptable and comprehensible to the other or others than was originally feared. It is a holding base from which some shift in the coherence of the self may be risked. (p. 293)

Pocock (1997) also addressed the notion of discovery amidst fear in relationship to feeling understood (also see Murray et al., 2002). Pocock implied that people primarily fear not feeling understood or being misunderstood. The discovery of feeling understood, then, may involve a process of taking risks in a relationship where feeling understood may or may not occur. However, the benefit of risking oneself, as Jonas-Simpson (2001) articulated, may turn out to be “triumphant bliss” (p. 222) in discovering feeling understood.

Feeling understood was considered a shared personal experience of being appreciated, listened to, and known by others and through them, having a heightened appreciation of oneself (Howell, 1998; Pocock, 1997). Pocock suggested that feeling understood may then be a vehicle through which other people may act as catalysts in enhancing a personal understanding of oneself. One drawback of Pocock’s study is that Pocock did not consider that this phenomenon exists outside inter-personal relationships such as feeling understood by oneself, with a pet, in one’s spiritual life, or in nature. Can an individual feel understood by one’s self or must feeling understood be cocreated? Jonas-Simpson (1998, 2001) and van Kaam (1958) addressed these types of questions.

The previously reviewed body of literature related to feeling understood based in empiricist inquiry (Abrams, 1988; Bachelor, 1988; Barrett-Lennard, 1962; Feitel, 1968; Galpert, 1988; Lafferty, 1987; Lafferty, Beutler & Crago, 1989; Pocock, 1997; Stolorow, 1982-1983; Winfrey, 1988) was predominantly from a positivistic view of science and an objective view of what constituted knowledge. This literature offered an appreciation of the research conducted thus far and displayed the scope of issues considered within a variety of disciplines in relation to feeling understood. These studies purposefully measured, separated, and quantified experiences in order to predict and explain human behaviour. In doing so, this literature considered predominantly objectivist cause-effect experimentation and empirically verifiable results that led to absolute truth (Polifroni & Welch, 1999). Cody and Mitchell (2002) suggest that such reductionistic explanations of human meaning may be used to control peoples' views and actions, further disregarding the practice of honouring human experiences. Such research and practice was deficient regarding the meaning of human experiences from the view of those living the experience. This presents a gap in the literature (Locke, Spirduso & Silverman, 2000).

In comparison to the human science perspective advanced in this study on feeling understood, causal relationships will not be expected, desired, or pursued when human experiences in relationships with others are considered multi-dimensional, acausal, and cocreated. From an alternative human science perspective, individuals' experiences will be supported, not measured or judged by therapists, doctors, nurses or others who are not considered themselves as experts (Cody, 1995; Puig de la Bellacasa, 2004). From this human science viewpoint, the individual/patient is considered the expert on her/his own health (Parse, 1994a).

Turning now to the research related to feeling understood that was based in non-empiricist inquiry, the body of literature included two studies from psychology (Dickson, 1991; van Kaam, 1958) and four studies from nursing (Jonas-Simpson, 1998, 2001; McIntyre, 1994; Moncrieff, 1999; Sundin & Jansson, 2003). One of the earliest and most frequently referenced dissertations on the phenomenon of concern came from van Kaam over 45 years ago. Drawing on then recently published works by Merleau-Ponty, Rogers, and Sartre, the influences of human science notions were apparent in his psychology research, therefore creating his literature as quite alternative for its day. His

phenomenological study sought to investigate the sufficient and necessary components of the experience of “really feeling understood” (p. 139). Participants included 150 female and 95 male high school students along with 60 female and 60 male college students. Students were asked to write for up to one hour complete descriptions of really being understood. Van Kaam found 365 descriptions and then reduced them into constituents and identified the percentage of students that aligned with the findings. He further synthesized the constituents into one description of really feeling understood:

The experience of really feeling understood is a perceptual-emotional Gestalt: A subject perceiving that a person co-experiences what things mean to the subject and accepts him[/her], feels initially relief from loneliness and, gradually, safe experiential communion with that person and with that which he perceives him[/her] to represent. (p. 139-140)

Van Kaam’s (1958) presentation of feeling understood differed from the literature previously reviewed because he directed the purpose of his study to describing the constituents of the experience of really feeling understood versus measuring or predicting this experience. After van Kaam, there seemed to have been a regression from uncovering descriptions back to the pre-established representation of personal experiences as numbers and causal reactions as evidenced by the empiricist literature that followed his work (Abrams, 1988; Bachelor, 1988; Barrett-Lennard, 1962; Feitel, 1968; Galpert, 1988; Lafferty, 1987; Lafferty, Beutler & Crago, 1989; Pocock, 1997; Stolorow, 1982-1983; Winfrey, 1988). This regressive trend remains in the majority of health research, cloaking normative perspectives under newer terminology, such as qualitative and humanistic/holistic human science research, while continuing to perpetuate categorization, separation, measurement, and control of individuals. The identification of this trend is important because there has been a recent rise in a variety of health care discourses that divide human experiences for the purposes of attaining financial efficiency, while marketing their strategy as holistic health care.

Thirty-three years after van Kaam’s (1958) study, a second human science research project considered feeling understood. Dickson (1991) explained his chosen perspective: “In human science research, the phenomena being studied appear in human consciousness, just as is the case in the natural science model. These phenomena have no physical properties, however, and cannot be observed or measured directly” (p. 55).

Therefore, in claiming feeling understood to not be observable behaviour, Dickson purported that it could not be studied meaningfully from a natural science perspective. Dickson's philosophy dissertation was a heuristic, psychology study. His research question was, "What is the experience of feeling understood?" (p. 9). Research data began with his own "self-search" and extended to include ten participants whom he interviewed and referred to as his "co-researchers". His findings were presented as a composite depiction of feeling understood which included "feelings of relief, pleasure, safety, validation, acceptance, freedom, togetherness and a sense of the purity of awareness" (p. 144). Dickson's findings echoed van Kaam's, especially with reference to relief, safety, and acceptance. Dickson further synthesized his findings in a poem entitled, *Feeling understood* (see Appendix F for Dickson's full poem).

A third dissertation on the phenomenon of feeling understood written from a human science perspective was by Jonas-Simpson (1998, 2001). She used Parse's basic nursing theory in her phenomenological hermeneutic study, uniquely conducted through music. The clear purpose of Jonas-Simpson's research was (a) to increase understanding of the universal lived experience of feeling understood, thereby informing nurses and increasing knowledge for future research and guiding practice; (b) to expand Parse's theory of human becoming; and (c) to elaborate the Parse research method through the use of music, specifically the flute, in dialogue.

Jonas-Simpson's (1998, 2001) research question was, "What is the structure of the lived experience of feeling understood?" (2001, p. 223). After interviewing ten women living with enduring health challenges such as fibromyalgia and multiple sclerosis, three core concepts emerged in analysis. She stated that the lived experience of "feeling understood is an unburdening quietude with triumphant bliss arising with the attentive reverence of nurturing engagements, while fortifying integrity emerges amid potential disregard" (2001, p. 222). This statement of findings aligns with Parse's theory in that the three theoretical themes of meaning, rhythmicity, and co-transcendence were all addressed. Her findings were supported by Van Kaam's (1958) and Dickson's (1991) previous studies on the same phenomenon of concern.

Jonas-Simpson (1998, 2001) clearly articulated that her findings, as well as other qualitative research findings, are not directly applied to nursing practice; "rather, they

enhance understanding of the phenomenon under study and change what is known” (2001, p. 229). She further explained that,

the findings in this study provide new knowledge about feeling understood while expanding concepts from the human becoming theory. Nurses are often in situations where persons long to be understood; thus, this new knowledge may create a transformational shift in knowing and provide nurses with insights for new possibilities in being with persons and families in the nurse-person process. (Jonas-Simpson, 2001, p. 229)

Knowledge such as this is very much needed at this point in time for nursing practice, when health care culture moves the patient from the centre to the margins of care (Kimpson, 1995).

Jonas-Simpson’s (1998, 2001) human science research on feeling understood was often used as a guide in this study that also examined feeling understood as a lived experience and was guided by Parse’s theory of human becoming. The population Jonas-Simpson chose were women living with enduring health challenges. These women may also have been regarded as women with disabilities, some of whom may have been administratively considered as “legal” or “legitimate” individuals with disabilities.

Moncrieff (1999) also conducted a study on feeling understood from a human science perspective. Similar to Jonas-Simpson (1998, 2001) and this study, Moncrieff used Parse’s theory of human becoming in her qualitative, descriptive study of the phenomenon of concern. Three participants who were engaged with family services were interviewed in Moncrieff’s research. Analysis included an extraction-synthesis process and heuristic interpretation.

The findings from Moncrieff’s (1999) study were presented as four hypothetical statements. The first hypothetical statement was: “perspectives on the value of self emerge amidst feelings of losing self to others” (p. 75). The second hypothetical statement was: “valuing personal goals and ambitions surface in a desire to communicate with others” (p. 79). Moncrieff merged these two hypothetical statements to form a unified description of the meaning of feeling understood for her participants, thereby addressing the theme of meaning in Parse’s theory of human becoming (Parse, 1981, 1987, 1998). To address the theoretical theme of rhythmicity (Parse, 1981, 1987), Moncrieff developed a third hypothetical statement: “feelings of unburdening surface

amidst shifting patterns of intimate patterns of relating with cherished others” (p. 79). This third statement identified the patterns of relating that participants spoke of in regards to feeling understood (Parse, 1981, 1987). And lastly, she addressed the theoretical theme of transcendence (Parse, 1981, 1987, 1992) in her fourth hypothetical statement: “revitalized feelings of reverence for oneself emerge in the liberated progression of potentiality” (p. 82). Moncrieff’s fourth statement described the possibilities that emerged for her participants when they felt understood.

It is unclear why Moncrieff (1999) described her findings as hypothetical statements. Hypotheses are typically inconsistent with a human science approach to research. Rather, a focal research question is pursued. A traditional study within the natural sciences would seek to disprove a hypothesis. To be clear, Moncrieff did not articulate hypothetical statements at the beginning of her study that she was seeking to confirm or disprove. However, discussion of her findings framed as hypothetical statements is generally considered theoretically inconsistent.

Only two nursing studies were found on understanding that were based in non-empiricist inquiry (McIntyre, 1994, 1997; Sundin & Jansson, 2003). First, McIntyre studied how nurses could better understand patients’ lived experiences of living with terminal or chronic illnesses. Her phenomenological study was based on a hermeneutic interpretive approach. She posed the research question, What does it mean for a patient to be understood by a nurse? Her research participants included five women, ranging from 21 to 65 years old, and each had two to six face to face visits with McIntyre. The five women had all been involved in a serious illness experience, either their own or a family members. In participant conversations, understanding was discussed as a feeling, “as in ‘feeling understood’, as ‘being understood’; and as an unfolding, as in ‘understanding as becoming’ ” (1994, p. 3). McIntyre gathered and analyzed data through the concurrent processes of conversation, narrating (including storying and theming), and journal writing. Seven themes were identified in this inquiry: health in illness, living in dying, strength in difficulty, comfort, acknowledgement, compassionate relationships, and the call to understanding.

McIntyre (1994, 1997) articulated that her theme, a call for understanding “is not a call for instrumental care, but is also a call to be in relationship that takes into account

differences in particular situations” (1994, p. 5). She further explained that instrumental care could be regarded as “doing for care” (1997, p. 25) distinguishing this from relational care, “being with care” (1997, p. 25). McIntyre’s focus was on the exploration of understanding within the nurse-patient process. She studied a person’s understanding of another. McIntyre’s research differs from this study that explored the meaning of feeling understood from the perspective of the person living the experience.

Second, Sundin and Jansson (2003) also considered lived experiences in their phenomenological hermeneutic study on “the meaning of understanding and being understood in the care of patients with aphasia after strokes” (p. 108). Understanding and being understood was studied because the authors believed that in communication these elements are central to care and essential for meeting a patient’s need of care. Researched in Sweden, five care providers (two registered nurses and three “enrolled nurses” (p. 109)) and three patients who had experienced a stroke and ensuing aphasia participated in this study. Aphasia was defined as “linguistic impairment associated with a brain lesion. All modalities of expression and reception [were] affected when stricken with aphasia, i.e. reading, writing, speaking, verbal comprehension, and gesturing” (p. 108). Sundin and Jansson identified that one of the many dilemmas with stroke and aphasia was communication because “they [made] understanding and being understood difficult between communicating parties” (p. 108).

Data collection was conducted through video recording during upper-body care in the morning in a washroom (Sundin & Jansson, 2003). After each video taping, the care provider was asked to narrate her experiences and “give her view of the patient’s experiences” (p. 109). The transcribed texts were interpreted using a phenomenological hermeneutic method. Through structural analysis, the findings consisted of “one main theme, ‘cocreating’, and four sub-themes, ‘silent dialogue’, ‘comprehending and mediating through body actions’, ‘striving for co-operation’, and ‘supporting attitude and permissive atmosphere’ (p. 111).

While Sundin and Jansson (2003) said they valued the unique experiences of the individual, it is interesting to note that they asked the health care providers to comment on their perspective of the patients’ experiences. The authors did not ask the patients of their experiences of being understood. It is possible that the researchers purposefully

asked the health care provider to comment on her view of the patient's experiences because they did not think the person who was living with aphasia after a stroke would be able to express her/himself, although they do not explicitly say so. Their research decision to speak with the health care providers alone reveals their theoretical perspective that a person may correctly, rightly, or accurately interpret what another is saying. Such conceptualization is grounded in an objectivist view of what constitutes knowledge. Sundin's and Jansson's perspective differs from the human science approach used in this study that dissolves the objective-subjective duality into a view of persons as indivisible and focuses on the lived experiences from the perspective of the person living the experience

There is a relatively small body of literature on feeling understood. Jonas-Simpson addressed the problem that "the phenomenon of feeling understood is seldom written about or explicitly explored" (2001, p. 222), a comment echoed by Dickson (1991) and Pocock (1997). Drawing on Parse's theory, lived experiences, such as feeling understood, are considered phenomena for research in nursing that is grounded in the human sciences (Jonas-Simpson, 1998, 2001; Parse, 2001a). There are other research studies and articles written from a human science perspective conducted on related phenomena pertinent to feeling understood. Examples include the experience of hope (Parse, 1990a), joy-sorrow (Parse, 1997b), grieving a personal loss (Cody, 1991), bearing witness (Cody, 2001a, 2001b), quality of life for individuals living with Alzheimer's disease (Parse, 1996a, 2001b), restriction-freedom (Mitchell, 1999), suffering (Daly, 1999), quality of life (Bournes, 1997; Parse, 1994b), being exposed to chemicals while working (Weiner, 1985), and laughing and health (Parse, 1994a). While these studies all sought understanding about human experiences, they also heralded a shift in nursing research inquiry. All of these studies used Parse's basic nursing theory as a guide in theory-based research. These studies also provided innovative findings about human health articulated by those living the experiences. It is studies such as these that identify alternative forms of inquiry in researching health and challenge the traditional modes of rational, objective research.

*Feeling understood as a complementary aspect.*

The majority of the literature considered feeling understood as a complementary aspect of another phenomenon of study (Allen & Thompson, 1984; Antonucci, Fuhrer, & Dartigues, 1997; Baker & Daigle, 2000; Black, 1991; Burgoon, Bonito, Bengtsson, Cederberg, Lundeberg & Allspach, 2000; Carlson et al., 2001; Carroll et al., 2000; D'Avanzo, 1992; de Groot & Rodin, 1998; Gray et al., 1997, 1999; Howell, 1998; Jan & Smith, 1998; Murray et al., 2002; Peltz, 1992; Reis & Shaver, 1988; Reis, Sheldon, Gable, Roscoe & Ryan, 2000; Rowe, 1992; Stallard et al., 2001; Sullins, 1992; van der Kolk, 2002; Van Hook, 1996). Feeling understood was often included in one of the questions asked in an interview / questionnaire or it surfaced as a theme in the research findings. All of these articles that considered feeling understood as a complementary aspect, with the exception of two (Baker & Daigle; Jan & Smith), were based in empiricist inquiry.

Feeling understood or being understood was frequently regarded as a subjective, personal sense or experience in the literature that researched feeling understood as the focus of study or as a complementary aspect of another phenomenon (Abrams, 1988; Allen & Thompson, 1984; Antonucci et al., 1997; Bachelor, 1988; Baker & Daigle, 2000; Barrett-Lennard, 1962; Black, 1991; Carlson et al., 2001; Carroll et al., 2000; D'Avanzo, 1992; de Groot & Rodin, 1998; Dickson, 1991; Feitel, 1968; Galpert, 1988; Gray et al., 1997, 1999; Howell, 1998; Jan & Smith, 1998; Jonas-Simpson, 1998, 2001; Lafferty, 1987; Lafferty, Beutler & Crago, 1989; McIntyre, 1994, 1997; Moncrieff, 1999; Murray et al., 2002; Peltz, 1992; Pocock, 1997; Reis & Shaver, 1988; Reis et al., 2000; Rowe, 1992; Stallard et al., 2001; Stolorow, 1982-1983; Sullins, 1992; Sundin & Jansson, 2003; van der Kolk, 2002; Van Hook, 1996; van Kaam, 1958). The experience of being/feeling misunderstood (Abrams; Allen & Thompson; Baker & Daigle; Feitel; Pocock; Reis & Shaver; Sullins) or less understood (Murray et al.) was articulated as the opposite or absence of feeling understood within the literature. From Parse's theory of human becoming, the notion of living paradox is advanced as residing inherently within humans (Parse, 1999a). Paradoxes are not regarded as opposites but as one phenomenon with two dimensions (Parse, 1998). Although the opposite or absence of this phenomenon was frequently discussed as feeling misunderstood, Jonas-Simpson discussed "not feeling

understood” (2001, p. 228). Grey et al. (1997) and van Kaam also found their participants spoke of “not feeling understood” (p. 281). Although not discussed in the literature, there may be a difference between these two concepts. Feeling misunderstood may imply that one feels as though another hears or understands them incorrectly or in a way other than what she/he was trying to express. However, not feeling understood may mean that another has not tried, taken the time, or attempted to listen or understand.

Feeling understood was predominantly regarded from an empiricist viewpoint in the literature that considered feeling understood as a complementary aspect of another phenomenon of study. While the majority of the authors quantitatively measured this phenomenon as a statistic through questionnaires or scales (Allen & Thompson, 1984; Antonucci et al., 1997; Black, 1991; Carlson et al., 2001; Carroll et al., 2000; D’Avanzo, 1992; Grey et al., 1999; Murray et al., 2002; Reis et al., 2000; Stallard et al., 2001; Sullins, 1992; Van Hook, 1996), a minority of the studies only used qualitative methods, such as interventions or inquiry into experiences, from a natural science perspective that categorized and differentiated between individuals’ perspectives (Baker & Daigle, 2000; Gray et al., 1997; Peltz, 1992; van der Kolk, 2002). From the same paradigm, positive correlations were also acknowledged or predicted between therapy conclusions and the phenomenon of feeling understood (de Groot & Rodin, 1998; Peltz; Rowe, 1992; Stallard et al.; van der Kolk, 2002).

Two articles studied feeling understood as a complementary aspect of the research area of the DSM-IV diagnosis, post-traumatic stress disorder (PTSD). The first article on PTSD was by Stallard et al. (2001) and they investigated factors associated with persistent PTSD in children following road traffic accidents. Through a quantitative exploratory study, the authors found that talking about the accident and feeling understood was associated with recovery from PTSD. Children who talked with others and felt their experiences were understood were “significantly less likely” (p. 39) to present with PTSD at an assessment time of eight months post accident.

The second article on PTSD was by van der Kolk (2002). He considered PTSD in the age of neuroscience from psychological and psychiatric perspectives. This author only partially agreed with Stallard et al. (2001) that for an individual with PTSD, talking, putting an event in context, and making meaning may “provide a means of feeling

understood, rejoining the human race, and gaining perspective on the experience, but it may do little to reorganize the person to feel safe and focus on fulfilling the demands of the present” (p. 381). Rather, the author suggested that treatment should include effective therapy and physical response to stimuli that initiated the PTSD.

Another diagnostic area that considered feeling understood as a complementary aspect was in research with individuals who had cancer. From a bio-medical perspective, self-help groups were researched exploring family physicians’ attitudes (Gray et al., 1999), changing physicians’ attitudes after educational intervention (Carroll et al., 2000), and studying the experiences of women in four community breast cancer self-help groups (Gray et al., 1997). All research groups (Carroll et al.; Gray et al., 1997, 1999) explained that they were positively inclined towards self-help groups because they fostered not only feeling understood, but also the sharing of experiences and information, overcoming isolation, and connecting with survivors. The women with breast cancer who participated in Gray et al.’s (1997) study provided rich descriptions of the similarities, expressed through a sense of being understood, that they shared with others in the group. While shared experiences were recorded, individuals also had unique responses in how they felt understood. For example, individuals with advanced stages of cancer more frequently spoke about being understood only by certain women or about “not being understood” (Gary et al., 1997, p. 281). Once again, feeling understood was discussed in consideration of inter-personal relationships, in these cases, within self-help groups.

Feeling understood was also considered as a complementary aspect within research from a psychological stance that examined spouses’ understanding of patients’ experiences with breast and prostate cancer (Carlson et al., 2001). This quantitative, exploratory study found that female partners had a more accurate understanding of their husbands’ experiences with prostate cancer than the men had of their wives’ experiences with breast cancer. Overall, the individuals with cancer expressed feeling understood by their partners, often linking this experience with support, especially emotional encouragement. The authors questioned if this correlation was related to the patients’ high rates of “positive adjustment” to cancer. In relation to the previous research with self-help groups (Carroll et al., 2000; Gray et al., 1997, 1999), Carlson et al. reported that

only 25% of participants with breast cancer attended support groups, while none of the men with prostate cancer nor any partners were involved with such support systems.

Relationships between two people were studied in four areas of literature and all elected to quantitatively measure feelings of understanding (Allen & Thompson, 1984; Black, 1991; Murray et al., 2002; Sullins, 1992). First, Allen and Thompson considered feeling understood, along with agreement, understanding, and realization, as predictors of communication satisfaction in marriage relationships. They measured high levels of feeling understood, along with the other predictors, and found no significant differences between wives and husbands. Overall, agreement and feeling understanding were found to be the most important determinants of satisfaction within marital communication. Second, in the discipline of social work, Black similarly addressed couples' patterns of communication and support after loss of a wanted pregnancy. Although the women in this study reported feeling understood and supported by their partners, many women also saw their responses to loss as different from their partners' responses. This noteworthy finding speaks to the notion of each individual's uniqueness.

Third, in psychology, Murray et al. (2002) researched the correlation of egocentrism in romantic relationships. Egocentrism was considered a construction of one's partner as a mirror of the self, even if similarities were not explicit. Feeling understood, defined as one's partner seeing her/him according to her/his self perception, was said to mediate between egocentrism and marital satisfaction. Interpersonal relationships were found to experience intimacy if the disclosing individual perceived her/himself feeling understood, validated, and cared for by another, regardless of the accuracy of this perception (Reis & Shaver, 1988). "Thus, people may not actually need to possess a partner who actually understands them to feel understood. Instead, feeling understood may partly be a construction that comes from seeing a romantic partner as a kindred spirit" (Murray et al., 2001, p. 3). Murray et al. suggested that when a spouse perceived her/his partner to be a kindred spirit – whose values, daily feelings, and traits reflected their own – she/he felt understood and therefore, reported greater satisfaction in the marriage (see also Allen & Thompson, 1984).

Fourth, also in psychology, Sullins (1992) examined interpersonal perceptions between same sex friends. Feeling understood in this study was considered the extent to

which an individual believed her/his friend knew her/his own views. As predicted with the author's hypothesis, women's friendship displayed "higher quality" (p. 409) interpersonal perception. Yet, the author further found that interpersonal perceptions were highest when congruence existed between subject gender and gender-typing of the trait being measured (ie. male perceivers judging masculine traits or female perceivers judging feminine traits). The study's results were considered in light of individual experiences and role-congruent traits derived from expectations of social roles.

The previous four studies all quantitatively measured individuals' felt understanding within relationships (Allen & Thompson, 1984; Black, 1991; Murray et al., 2002; Sullins, 1992). Causal relationships related to feeling understood were solely considered in the research area of interpersonal relationships. While this body of literature based in empiricist inquiry provided initial knowledge development, it ignored lived experiences that could not be wholly represented through a number value. Such reductionistic explanations of human meaning have the potential to be used to control peoples' views and actions, further disregarding the practice of honouring human experiences (Cody & Mitchell, 2002). The human science perspective advanced in this study is unconcerned with prediction of human behaviour. Rather, research focuses on explicating truths about language and the human world (Cody & Mitchell, 2002). The human science belief system supports and values an understanding of "life as it is humanly lived" (Cody & Mitchell, 1992, p. 54), human freedom, dignity, multidimensionality, and illumination (Cody & Mitchell, 1992, 2002).

Feeling understood was also considered as a complementary aspect within the literature that examined cross-cultural experiences by Vietnamese refugees, Mi'kmaq, and Pakistani immigrants with regards to health. The first study set out to quantitatively determine the dynamics of why Vietnamese refugees have not or may not optimally use existing health services in the United States (D'Avanzo, 1992). Four barriers were identified and measured, and the author found the following four concerns: 1) not having a translator, 2) not having a primary provider, 3) feeling understood by health care providers, and, 4) being able to understand written and verbal instructions. The research identified a gradual increase in confidence in relationship with feeling understood by

providers, with the newest Vietnamese refugee arrivals having the highest lack of confidence.

The second cultural study by Baker and Daigle (2000) addressed cross-cultural hospital experiences of Mi'kmaq patients from the Big Cove reserve in New Brunswick, when hospitalized in non-aboriginal settings. The authors qualitatively sought to understand cultural sensitivity from the patients' perspective. This applied nursing research found themes revolving around understanding. The authors further explained:

Participants often felt misunderstood by caregivers in a way that made them feel lessened as persons.... Each, however, had experienced valued encounters with at least one caregiver when they felt understood. They felt these caregivers had been kind to them, accepted the Mi'kmaq custom of family visiting, and treated them as social equals. Compassion and a non-discriminatory attitude were more important than cultural knowledge in this context in which the caregivers' culture rather than the care recipients' culture predominated. (p. 8)

This postmodern exploratory study is important because it addressed the connection between a person's experience of feeling understood or misunderstood and the potential effects on an individual's feelings about them self.

The third study by Jan and Smith (1998) researched the meaning of staying healthy as experienced by immigrant Pakistani families living in the United States. One of the four relational themes from their study was feeling understood. Feeling understood was found to encourage participants in believing that health was possible. This research is significant in this literature review because Jan and Smith provided the only secondary study considering feeling understood that held a human science perspective. This non-empiricist phenomenological research concluded that, "viewing health and illness as unitary and planning care once the meaning people assign to health and illness is clearly understood is important for clinical practice" (p. 157).

It is interesting to note that a number of articles that conducted research with "cultural minority groups" also discussed the phenomenon of feeling understood. It is worth mentioning that other minority groups, other than nurses with disabilities, have considered this phenomenon of concern (Baker & Daigle, 2000; Carroll, 2004; D'Avanzo, 1992; Jan & Smith, 1998; Marks, 2000). While all individuals may long to feel understood, it is significant within the literature that it has been those who are

quickly labeled by society as a “minority” who have identified the phenomenon of feeling understood as an important aspect of their experiences.

The last article considered in this literature review that addressed feeling understood as a complementary aspect was within Peltz’s (1992) psychoanalytic study on the wish to be soothed as resistance. The author explained that when an analyst accurately interpreted resistance in the beginning stage of an analysis with a patient, the individual began to feel understood, possibly for the first time. As a result, her/his anxiety decreased and she/he began to perceive the analyst as a soother. The patient may have found a calming effect from the experience of feeling understood. The first exchanges – the patient feeling understood and the analyst’s accurate interpretation – set the foundation for positive transference within therapy. However, the author concluded that due to past traumas in childhood, some patients became resistant to the analysis of the desire to be soothed and avoided the analysis of conflict. The writer provided explicitly detailed clinical accounts that confirmed these contentions.

Peltz’s (1992) article initially piqued my curiosity because when I initially considered a phenomenon of inquiry for this thesis, I began researching the phenomenon of resistance among persons with health challenges. However, as my studies deepened, feeling understood surfaced as a more intricate experience. It was significant for me to see another author connecting resistance and feeling understood.

In a review of the literature, this study is unique in both its phenomenon of concern, feeling understood, and its population of inquiry, nurses with disabilities. Although there are no other studies that examine this combined inquiry, there are theoretical and research writings that addressed recruitment and retention within nursing, nurses who use substances, nursing students with disabilities, and feeling understood, all of which inform this study based in a human science perspective.

Within this review, a minority of the literature, which was extremely limited by comparison, emanated from a human science perspective and offered an alternative understanding of human experience, knowledge, and science (Dickson, 1991; Jan & Smith, 1998; Jonas-Simpson, 1998, 2001; Moncrieff, 1999; van Kaam, 1958). Human science is a belief system situated in human meaning, interested in uncovering truths about the universe. This perspective is available to researchers, practitioners, educators,

and scholars who seek knowledge regarding life as it is lived (Cody & Mitchell, 2002). Such a proposition is frequently dismissed because it diverges from the entrenched patterns of biomedical, technical nursing. Moving beyond the objective-subjective duality, human science dissolves each into a view of humans as indivisible. From a perspective of indivisibility, human science provides the needed lens to focus inquiry towards humanly lived experiences (Cody & Mitchell, 2002).

Lived experiences of health, such as friendship, bearing witness, feeling understood, et cetera, are precisely the phenomena in need of rigorous study within the human sciences. This claim is in direct opposition “to the scientific realist belief that these phenomena, if they exist at all, exist on a plane of reality that is truly less real than that which is objectively verifiable” (Cody & Mitchell, 2002, p. 9). Although opposition remains, scientific study of lived phenomena from a human science perspective offers to fill the gap that is present in science and scholarly literature and complement the natural sciences (Mitchell & Cody, 1999). The human sciences are accessible to individuals seeking to understand the meaning of life and what being human represents, for the benefit of humankind (Cody & Mitchell, 2002; Parse, 1998). This study on feeling understood with nurses living with disabilities is composed from a human science perspective. This perspective was chosen because human science research examines the meaning and essences of experience and is therefore consistent with inquiry of the phenomenon of feeling understood.

#### *Policy on Duty to Accommodate*

My literature review on policy was initially pursued to consider policies and/or public documents within Vancouver Island Health Authority (VIHA) that are used to direct interactions by management, administrators, and employers with nurses who have disabilities. However, investigation with human resources, client relations, and occupational health has identified that VIHA does not have a formal policy that specifies or guides employer directions/ procedures with this population. In its absence, administration is guided by broad legislation under *The BC Human Rights Code* (BC Human Rights Commission, 1998; Revised Statutes of British Columbia, 1996). This legislation directs employers in their actions with their employees. An example is an

employers' legal duty to accommodate a nurse who is injured or living with a disability. In this instance, the employer has a legislated obligation to the employee. This piece of legislation will be examined as a starting point for a review of policy.

Although there is government policy that addresses duty to accommodate, I spoke with several administrators who referred to the "actual practice" with employees who are injured or living with a disability. The informal and unwritten practice directs the employer to ask the employee to have a physician document their injuries and work restrictions. Then the employee attends a meeting with representatives of the union and employer, and with their manager to "explore options" and consider available positions. The goal is retention, to find alternative areas of work for the employee suitable to their prescribed level of functioning. Each situation is considered unique and handled case by case. The administrators acknowledge that such negotiations are easier for large employers, such as VIHA, and more difficult for smaller employers. Retention is the priority for the employer and long-term benefits are regarded as a last resort. This word-of-mouth practice aligns at times with what is discussed in the legislation. In certain domains, however, the practice of employers seems to diverge from prescribed policies.

Two specific articles addressed the duty to accommodate and both were found on the B.C. government's human rights web site (B.C. Human Rights Commission, 2000; Joanis, 2001). Whereas the first writing was from a government policy and procedure manual (B.C. Human Rights Commission, 2000), the other was a memo addressing the historical aspects of this law and directing how duty to accommodate may be applied in the context of services and employment (Joaanis). Unfortunately, the government of B.C. introduced legislation that began elimination of the B.C. Human Rights Commission in November, 2002. Although the B.C. Human Rights Tribunal has been maintained, allowing the public to file discrimination complaints, the B.C. Human Rights Commission, which intervened in cases before the tribunal, investigated and mediated complaints, and undertook education and advocacy work has been abandoned. Web sites containing policy under the B.C. Human Rights Commission were removed in spring, 2003 (see The B.C. Human Rights Coalition, 2003 for archives). It remains unclear if any replacement will be issued for the province's independent human rights commission ("B.C. Government to Disband", 2002). B.C. is now the only province or territory in

Canada without a human rights commission (B.C. Government & Service Employers' Union, 2002; Human Rights Research & Education Centre, 2004). Policy on duty to accommodate is considered in a review of the literature because this legislation guided the practice of accommodation (when applicable) for the five nurses with disabilities that were interviewed in this thesis research.

Duty to accommodate is initiated from application of *The BC Human Rights Code* (BC Human Rights Commission, 1998; Revised Statutes of British Columbia, 1996) and applies to all prohibited areas of discrimination to ensure services and workplaces operate in an inclusive fashion (B.C. Human Rights Commission, 2000; Joanis, 2001). The law announced in *The BC Human Rights Code* (BC Human Rights Commission, 1998; Revised Statutes of British Columbia) is legislation and has precedence over all conflicting legal provisions including collective agreements (B.C. Human Rights Commission, 2000; Joanis). While this human rights statute has a high profile and much symbolic value, never the less, the provincial government has removed this legislation.

Both of the articles (B.C. Human Rights Commission, 2000; Joanis, 2001) that addressed the duty to accommodate were complex (although Joanis claimed to be less so), used legal jargon, as well as unexplained abbreviations, and explained/rationalized the law. They both touched on similar issues including definitions, responsibilities of parties involved, case studies, additional legislation, and discrimination. Both texts purported that duty to accommodate is enacted by reasonably accommodating the requests or needs of individuals short of causing undue hardship. The qualifier in the accommodation standard was the phrase, "short of undue hardship", but the articles only addressed hardship or costs for the employer (B.C. Human Rights Commission, 2000; Joanis). Duty to accommodate is included in *The BC Human Rights Code* (BC Human Rights Commission, 1998) as a defence to claims of discrimination with relation to employment. Examples were provided of accommodation addressing issues of disability, religion, family stress, and pregnancy (B.C. Human Rights Commission, 2000; Joanis).

The policy and procedure manual (B.C. Human Rights Commission, 2000) and Joanis' (2001) memo both specifically addressed the responsibilities of parties involved. The manual directed advice towards parties seeking to reach settlements, as well as to resolve complaints. The employer, also referred to as the respondent or the

accommodation provider, had to initiate the search for accommodation. A union could have been, at times, included with an employer as an accommodation provider. The employer was to first consider accommodating the person in their existing job, and then elsewhere. Echoing considerations in the literature on nurses with disabilities, the accommodation provider was not required to create a new job for the employee but could initiate a temporary reassignment. The employer was also entitled to specifically consider the costs, as well as the safety and interference with the operation of a business, in determining whether or not undue hardship could be incurred. The employer was at no point directed to consider or discuss with the employee her/his own costs or interference in contemplation of undue hardship from the employee's perspective.

The employee, also referred to as the complainant or the accommodation seeker, was required to notify the employer of a disability or a need for accommodation, and to "positively contribute" to the search for an accommodation while being "reasonable and cooperative" (Human Rights Commission, 2000; Joanis, 2001). Interestingly, there were no personal attributes required of representatives of the employer. There was also no mention of restraints, hardship, or costs in consideration to the individual employee. Both the manual and the memo highlighted that assessment of reasonable accommodation was "fact based" and accommodations would vary case by case. This stipulation could have provided room for each individual's case to be considered as unique, as long as responsibilities by parties involved were adhered to. The manual (B.C. Human Rights Commission, 2000) further explained that the examples discussed in the article were restricting because they only suggested possible factors that could have or not have been included in any account.

While the policy and procedure manual (B.C. Human Rights Commission, 2000) and the memo (Joaanis, 2001) both established the theoretical basis, or the "why", related to the law of duty to accommodate, the practices of administrators demonstrated the "how" or the interventions that enacted the law thus moving "policies from the printed page into everyday practice" (McLeod & Spée, 2003, p. 115). The "actual practice" aligned with the policy with regards to the parties involved, their responsibilities, and the consideration of each case as unique. However, the avoidance of long-term benefits and pursuit of retention pursued in practice was not specifically directed by the written policy,

although it may have been implied or encouraged through other types of government education or discipline.

Many questions remain regarding how this over-arching policy directed administrators as they interacted with nurses living with disabilities or injuries (Human Rights Commission, 2000; Joanis, 2001). What was said, implied or done at times in practice differed greatly from what was either written or intended by the policy. For example, the policy on duty to accommodate implied that both parties were to benefit from negotiations surrounding duty to accommodate. However, outside of the employers' costs, the question of "who pays" was not explicit. Further, in many intersections of policy and practice, policies and associated political decisions (Cheek & Gibson, 1997) frequently have unanticipated and unexpected results in practice and in people's lives.

The policy on duty to accommodate (Human Rights Commission, 2000; Joanis, 2001) considered quantitative measurement but did not take into account the impact on the employees affected by the policy and their life experiences. The costs to individuals with disabilities may be easily ignored. If such individuals are to rise above exclusion or remain in employment, then their experiences should be recognized in policy agenda (Morris, 2000). The focus within duty to accommodate policy on measurement and facts reveals the values, beliefs, and assumptions upon which the policy was made (Cheek & Gibson, 1997; McLeod & Spée, 2003; Mitchell, 2001). In other words, the development of policy within the B.C. Human Rights Commission (2000; Joanis, 2001) is founded on values and beliefs consonant with an objectivist, mechanistic view of human beings and the world. Thus, an interventionist, normative perspective flowing from this foundation has given rise to policy considered generalizable. Although the policy said each employee's situation was to be treated as unique, the directive statements that were to be based on "facts" did not provide room for practice to complement what the employee envisioned for them self. Thus, a gap is apparent within the policy on duty to accommodate. Policy that is directed by an interventionist approach will not focus on honouring an employee's desires and her/his experiences of restraints, hardship, and costs within duty to accommodate because of differing values, beliefs and assumptions. An alternate development of policy that is based on different values, beliefs, and assumptions that honour quality of life for the individuals affected by the policy may advance policy

that guides practice. With new understanding, policies that honour and reflect the experiences of nurses with disabilities may be developed.

### *Summary of the Literature Review*

Currently, organizations across B.C. and Canada are struggling with recruitment and retention of nurses in health care (Baumann et al., 2004; Canadian Nursing Advisory Committee, 2002; Cornwall, 2003; Maheady, 2004; Porter, 2004; “Safety to Practice”, 2003; Tuttas, 2002; Wallis, 2004). The literature suggests that issues of recruitment and retention have created a renewed interest in nurses with disabilities as they represent an untapped market for the financial benefit of businesses (Armstrong et al., 2002; Arndt, 2004; Campbell, 2000; Carroll, 2004; Dinsdale, 2000; Fuller, 1998; Oke, 2004; Winland-Brown & Pohl, 1990). This business perspective was apparent within the literature that addressed recruitment and retention, nurses with substance use, and accommodations towards nursing students with disabilities and employees with injuries or disabilities. The dominant search for organizational efficiency, commonly situated in positivist science, was reflected in the literature relevant to nurses with disabilities. However, within this literature there was little recognition of the human experiences of nurses living with disabilities.

In consideration of the literature on feeling understood, the focus of the majority of medical, psychological, and social science research was not on this phenomenon of concern. Rather, these texts revealed feeling understood as a complementary aspect of another phenomenon of study. The frequency of the appearance of feeling understood within empiricist inquiry suggests to this researcher, that further non-empiricist exploration of this experience is indeed warranted. Therefore, this human science research study was framed within an alternative perspective that aimed to uncover the meaning of feeling understood for nurses with disabilities.

Government policy provided very broad direction for representatives of employers and unions as they worked alongside nurses with injuries or disabilities. Written from a natural science paradigm, personal experiences were not acknowledged in these policies. However, policies directly impact peoples’ lives. Policy has the capacity to be responsive to individuals’ experiences when it is developed upon alternate values,

assumptions, and beliefs that honour non-interventionist approaches in practice (Cheek & Gibson, 1997; Cody et al., 2001; McLeod & Spée, 2003; Mitchell, 2001). Further, policies may be created, developed, and altered with involvement from service users and practitioners (Cheek & Gibson; Lillibridge et al., 2002; Marks, 2000; Mathiesen, 1974; Moore, 2004; Morris, 2000; Office of Nursing Policy, Health Canada, 2003).

In the following chapter, the five nurses with disabilities that volunteered to be interviewed will be introduced along with their descriptions of feeling understood. The three research themes in this study are presented in the language used by the nurse participants. The three themes are considered to be the study's findings and together they answer the research question, "What is the meaning of the experience of feeling understood for nurses with disabilities?"

## *Chapter 5 - Presentation of Findings*

In this chapter, themes that surfaced from my analysis of participant data will be presented as findings. First, the participants will be introduced. The nurses will be referred to via pseudonyms which I chose because they reminded me of people I have known in my life. Their personal stories of their disabilities will be described as a means of both introducing them as unique individuals and explaining how they qualified as participants in this research project. Each participant's description of her experience of feeling understood will also be summarized. Both the introduction of participants and the summary of their descriptions of the phenomenon will be presented using the words and phrases they shared in their interviews. There were many instances of different participants repeatedly using similar words and phrases including "get / got it", vulnerability, fake, phoney, justifying, pulling my weight, letting go, judgement, isolate, relief, expectations, et cetera. These direct quotes of words and phrases will be repeatedly seen throughout the analysis of findings.

Second, three themes are identified in the language of the participants. I will explain how these themes emerged through the process of analysis-synthesis. Descriptive quotes from each individual will be presented in relation to each of the three themes. The three thematic findings address each of the three research objectives, specifically:

Objective 1: To describe the meaning of feeling understood for nurses with disabilities through dialogue.

Objective 2: To describe patterns of relating within the experience of feeling understood for nurses with disabilities.

Objective 3: To describe personal hopes, concerns, possibilities, and visions of what might be in relation to feeling understood for nurses with disabilities.

Together, the findings answer the research question, "What is the meaning of the experience of feeling understood for nurses with disabilities?"

### *Introductions*

Before introducing each of the five participants I interviewed, I would like to acknowledge that each of them answered my questions with forthrightness and thoughtfulness. I did not initially recognize that the interview questions I asked them were, in fact, quite difficult questions to answer. And sometimes their answers were startling and challenging to hear. Their stories were deeply personal and I became aware of the fact that I was often more uncomfortable than I thought I would be listening to their candid reflections. As a nurse, one is taught within the discipline that to be privy to a new acquaintance's reflections on meanings in her/his life, relationships, hopes and dreams is something that is central to our practice. However, my discomfort with the candour of several participants challenged my acceptance of this often cited and articulated premise. Although my goal was to practice "true presence" with each participant during the interview, I found that I had undertaken what was, in fact, a tremendously difficult task. "True presence is a special way of 'being with' in which the nurse bears witness to the person's or family's own living of value priorities" (Parse, 1992, p. 40).

If bearing witness is central to nursing practice, why did I encounter true presence as a difficulty? Although the skilful art of true presence is what nursing practice *should* be focussed upon, other prevailing values have taken precedence and directed practice in other pursuits (Northrup & Tschanz, 2004). For example, in the majority of practice settings efficient care is valued and directed according to what the nurse determines is the "correct" or "best" care for individuals. The nurse assumes responsibility in making decisions for people with regards to their health care. This practice directs the focus of nursing away from a belief that people have the ability to make their own choices regarding their health care based on the premise that they know what is best for themselves (Northrup & Tschanz). From such a normative perspective, persons are objectified and health goals are determined for them, instead of with them (Northrup & Tschanz). There is no value placed on practicing true presence because individuals' choices are neither sought nor honoured, despite the fact that persons' choices are based upon their own values, beliefs, preferences, and hopes. Bearing witness to individuals'

pain or reflections upon their health may not be considered a valued or efficient practice and is therefore, not supported.

Although I personally valued true presence, I still encountered challenges. I was surprised at my personal difficulty in attempting to practice true presence. In my own experience of living with a disability, I have often longed for those closest to me to bear witness to my own pain, hopes, reflections et cetera. Yet, when I was the one in the position to bear witness to another, I found it uncomfortable to listen to a person's hurt and not try to give advice or change the subject. I began to understand why it had been difficult for those nearest to me to bear witness to my experiences. Further, it is understandable that nurses, including myself, find it hard to practice true presence considering that it is both personally challenging and frequently not supported as a central component of nursing. True presence is indeed an art form that takes both time and mentorship to learn how to practice and dedication to the beliefs and values upon which it is based, especially within settings where such practice is not honoured (Northrup & Tschanz, 2004).

In the pursuit of practicing true presence, I found I needed to "unlearn" responding with leading questions or paraphrasing ("skills" students are often taught in nursing school) and relearn the art of deeply listening to what another is sharing. All interviews were conducted within 15 days and were over more quickly than I wanted them to be. At the end of the interviews I felt I was only just beginning to learn what it meant to be with another in true presence.

*Christine – participant 1.*

Christine was the first person to contact me about participating in an interview after hearing about my study in her long-term disability (LTD) group. Christine was a part of this group because eight years ago, at the age of 31, she was diagnosed with lupus nephritis. At the time of her diagnosis, she was working in northern outpost nursing. Due to her disability, Christine had to give up her job, leave her home, move to an urban setting for medical treatment, and take LTD. Two years later, she attempted to return to work part-time in an accommodated position but continued to struggle with her health. After 11 months, she decided to leave work permanently. After her choice to leave work,

she felt liberated. Due to Christine's passion for nursing, she has continued to maintain her RNABC registration since her disability. At the time of the interview, for the first time, after many years of struggling with this consideration, she had decided not to renew her registration. This was a difficult decision for Christine. She spoke of experiencing intense sadness and grieving the loss of nursing since her diagnosis eight years prior. Christine explained that she had come to a place of feeling fine with her decision and believed it was "a good place to be".

In the interview, Christine was soft-spoken and often paused for thought before she spoke. She talked about seeing her relationships change after she became ill and being gradually excluded from old friends and traditions. She also spoke of how she struggled to explain to people why she could not have children due to her disability and spoke of many memories, some pleasant but for the most part, difficult.

She had recently turned to pursue her creative interests, taking art classes, and reading autobiographies of individuals (similar to herself) who had unique lives yet impacted our society. She hoped to find both joy in looking at the "simple things" and meaning in her life. She came to the first interview with hand written notes, her reflections on feeling understood. A second interview was conducted to follow-up and clarify information from the first interview. Christine asked to have her interviews at the University of Victoria because she was there on a regular basis for art classes.

*Christine's description of feeling understood.*

Christine explained that she felt understood when, after she told someone something about her own situation, the other person would seek clarification through their own descriptive examples of what she may have meant. She called this "perception checking" and this communicated to her that she/he "got it". Christine believed others got it when they understood why she could not work and what was "wrong" with her. Feeling understood included that a person accepted and believed that what she was telling them was the truth. To facilitate feeling understood Christine repeatedly tried to explain herself to make others believe her. She said she longed to feel understood. Yet, she had also experienced times of feeling that it was not important to explain herself, times it was not necessary to feel understood, usually with people with whom she did not have a deeply

valued relationship. Christine described her experience of feeling understood as a relief. She also experienced joy in feeling understood by others and contentment surfaced as she saw herself come through difficult times. Once she felt understood by someone, she could stop worrying about explaining herself and their relationship could “go into more depth”.

Christine said that feeling understood had affected all her relationships and her feelings about herself. For example, not feeling understood left her feeling vulnerable and caused her self confidence to lessen, often leading to repeated patterns of lonely retreat. And while she felt “okay” in those times of isolation, she also “hated it”. “It’s like I do *isolate myself because it just takes so much energy to explain what’s going on with me* (said quietly). And then to not be understood, to almost maybe be a bit rejected, not included in things with people ... I don’t know why”. Christine also spoke of not feeling understood by friends and neighbours because of her different lifestyle and the fact that she did not work. Her expectations of feeling understood by others were scarcely being met and over the past five years, she has been gradually “letting go” of these expectations. Further, Christine found “comfort” and “freedom” in reading auto/biographies of individuals that were of value to society but did not fit the cultural norm. She strove to “celebrate” her “unique life” and explore untapped abilities in music and art. As Christine explored these interests, she stopped worrying about what others were thinking of her, and confidence in herself began to rise.

*Rose – participant 2.*

Rose had been called by a friend who had seen one of my research advertisements and told Rose she would be an excellent potential participant. Rose agreed and e-mailed me in response. *Rose began nursing 30 years ago and had worked in a wide variety of practice areas. Then, eight years ago, she had three, significant, work-related injuries all within one year. Two years later she was diagnosed with fibromyalgia (FM), a highly contested illness (Moss & Dyck, 2002; Moss & Prince, 2004) that many of Rose’s health care colleagues and friends did not believe to be “real”. FM is sometimes linked to Myalgic Encephalomyelitis (ME); except FM focuses more on pain and ME, on fatigue (P. Moss, personal communication, March 3, 2004).* Rose described how her very own

sisters, also nurses, did not believe that her disability was real. Rose's doctor insisted she be treated with antidepressants, but the medications significantly impaired her work and her eyesight for driving and she was forced to go on LTD. At the time she contacted me, she had been off work for five years and was pursuing her nursing degree with the hopes of going on into graduate school.

Rose and I met for our interview in a coffee shop. While we talked, espresso machines and operatic music filled the background. Rose was very articulate when she shared her experience of feeling understood. For over two hours she graphically described her joys and struggles in a personal way. The majority of her experiences were of not feeling understood. Rose openly talked about her desperation for those around her to believe her disability was real. At one point she felt so alone in her pain she contemplated suicide and had a suicidal plan. She felt she could not go on. Rose longed for a family member to reach out to her but no one did. She did have one girlfriend who was there for her. This was her only relationship in which she spoke of feeling understood. She described her friend as the "backbone" of her support system who provided her with strength. Rose's friend invited her to talk and if her friend thought she was "off base", she would tell Rose and help her "get back on track".

Rose spoke passionately about her spirituality, her view of health, her connection with nature, and her horseback rides. Rose explained that one must experience pain to understand joy. Joy was evident in her life, specifically in her horseback riding and spiritual beliefs. Through meditation, called "presencing" by Rose, she refocused on herself and her spirituality, resulting in enjoying being present in the moment, recognizing her physical limitations, and paying attention when her "pain would go away and [her] emotions would find peace". Acceptance of herself was her definition of health, and it moved her beyond her pain and sense of immobility.

*Rose's description of feeling understood.*

Rose's experience of feeling understood began when she first learned of her disability. She explained that she did not feel understood by others and did not know what she needed to ask for from others to feel understood. She repeatedly spoke of feeling understood as "understanding". She believed one could not empathize or

understand another if she/he had not gone through a similar process her/himself. Yet, she struggled with still expecting understanding from others. Rose recounted, “(I) hit the real low in the depressive process where I was suicidal . . . . It comes to the point you feel that nobody understands your pain. And living in this pain is too hurtful to go on.” Rose wanted to feel understood. Her support came from a girlfriend who listened and invited her to talk.

Rose said she was not sure she understood herself because she did not understand fibromyalgia, her disability. Rose believed the answers to her questions about understanding were within herself, therefore she spent a lot of time introspectively. She began re-exploring her spirituality and found this gave her life. Although Rose did not feel she understood herself, she repeatedly said, “I want to understand”. Yet she resolved, “It’s okay to have questions and not answers. It’s even okay if I don’t understand”. Rose spoke of her discovery that she needed to learn the lesson of “letting go”. She needed to let go of her expectations of understanding from other people, as well as her expectations of herself to perform. This included being a “super mom”, taking care of her house and kids, working, feeding the animals on the farm, and many other tasks she felt she had to do. Depression and a sense of immobility came from having an expectation to perform, or as she said, “to do”, but not being able to, because of her disability. Some days she couldn’t get out of bed due to pain, yet staying in bed was also a painful experience. Since Rose on occasion experienced that she couldn’t stand up, couldn’t lie down, and everything was painful, she called fibromyalgia the “catch 22 disease”.

One of the most validating experiences for herself and her husband came from a piece of research they found that “quantified”, through medical science, the existence of fibromyalgia. Using MRI’s, scientists found a very high pain response in individuals with the illness. Rose spoke of feeling “relief” that there was empirical evidence to her subjective experiences. She felt she no longer had to keep defending herself.

*Crystal – participant 3.*

Crystal volunteered to participate in this study early on in its conception when she had heard of my need for volunteers through word of mouth. When it came time for our predetermined date for an interview, she reluctantly had to re-schedule due to a

resurgence of her disability. Crystal was diagnosed four and a half years ago with post-traumatic stress disorder after a patient physically attacked her. She returned to work for the following three days after the incident, later believing she had still been in shock. After the realization of the magnitude of the situation culminated, she was then off work for nine months on a Workers' Compensation Board (WCB) claim. She has worked full-time since.

Her first reoccurrence with her disability took place only a few days before we were to meet. We rescheduled for the following week and met at my house, at her request, directly after one of her doctor's appointments. Crystal was filled with a longing for loving acceptance and a deep sadness as she spoke of her lived experience of feeling understood. She believed she was in a "depression" and didn't feel "normal". She felt like everything in life at that moment was an "effort", whether it was brushing her teeth, calling her grandchildren on the phone, or talking with patients at work. She considered herself a failure at life. Crystal spoke about how her house was messy and even that was a representation of her life. Another illustration she gave of herself was of a deflated balloon: "Well it's like a balloon's function is to be nice and round and up there for everyone to look at. Like I feel that the shape of the balloon is there but there's no air in it.... I guess I just want to feel good about myself ... and that other people say, '...She looks like she's got it all together,' because right now I don't. I don't have it together". As Crystal shared her experiences and stories, she drew on her 31 years of nursing experience, her relationships with family, friends, and colleagues, and her perception of herself.

*Crystal's description of feeling understood.*

According to Crystal, feeling understood involved being accepted and loved for who she was amidst the changes in herself due to her disability. She found comfort in this and a reassurance that it was okay if she was not always perfect, not always efficient at work, or not always a good friend. When Crystal felt understood, she relaxed, let go of her tension, accepted herself in spite of her "limitations or fallibilities", and believed she was doing the best with what she had. To her this was "a form of success for that day or for that hour".

Crystal's experience of not feeling understood involved encountering people who thought: "I should just be able to snap my fingers and snap out of it and be the person I was before". With great sadness, she shared times she felt judged by others and herself. She felt judged as being a phoney person and a phoney nurse and in response thought she had to somehow fake something to restore her credibility. During these times she believed she was not good enough, to the point of feeling like a failure. She frequently used the metaphor of treading water, an image of moving and being still all at once. While Crystal wished at times that her challenges would vanish, she knew it was "not reality". In the midst of her pain, she felt directionless. Yet feeling understood surfaced as a catalyst of direction for Crystal.

Crystal wanted people to like her. In compensation for feeling judgement and a desire to be accepted, Crystal felt she justified herself to others and even to herself. She also believed she was expected to be "a strong person" despite the fact that she thought she had "nothing left to give" her friends, patients, or even herself. Crystal found herself lying to others when asked, "How are you?" She said, "Things are great", because she believed that people didn't really want to hear what the answer was. She knew she could not judge someone for not really wanting to know how she was doing, realizing she has responded similarly to others.

When Crystal did not feel judged, she felt understood. In feeling understood, she found relief discovering she no longer had to justify or prove herself to anyone but herself. This relief brought her feelings of comfort, relaxation, and a freedom to let go of the tensions of trying to be believed. She believed she could show other people she was still the same person as before her disability. In feeling understood Crystal experienced hope that she would be able to function as she once had with self-assurance at work, because others trusted her ability to perform her job well. Amidst the overwhelming pain in her life, when Crystal felt understood she felt all was okay in the world.

*Jan – participant 4.*

Jan participated after hearing about my study through word of mouth. Jan qualified as a participant because she had taken a short-term leave from work due to a disability before she returned to work full-time 18 months later. After contracting a

serious viral infection at her place of work seven years ago, she developed further chronic neurological complications that affected one of her arms. Jan had a very difficult time when she first became ill because her doctors could not diagnose her illness and she experienced a tremendous amount of pain to the extent that it would affect her sleep. She would wake up sobbing in pain. Yet she could find no one to help her. Eventually she “had a gift at work” when she met a doctor who was able to diagnose her condition and refer her to a specialist. While she initially received beneficial steroid injections, over time they were less helpful. Her shoulder and arm remain affected to this day. Despite her disability, she continues to work full-time in nursing and is pursuing graduate studies.

Jan came to a university office where our interview occurred and shared her experience of feeling understood primarily in relation to her nursing career of 21 years. She spoke passionately about her vision of nursing, her collegial work relationships, her disappointments, and her rare moments of professional recognition. As Jan rapidly talked, she frequently laughed. She did not refer to her disability as such, but rather as a “physical challenge”. Jan believed that while she was totally committed to the discipline of nursing, she was a “workaholic” and she spoke of feeling understood with much soul searching. In anguish she asked why she had this insatiable drive to work. She did not know where it came from but she did recognize that her disability had been devastating because it had taken her away from the work she loved.

*Jan’s description of feeling understood.*

Jan believed that every person wanted to feel understood and heard. In her work environment, sheer acknowledgement of what she was feeling, saying, or even struggling to articulate was a rare and wonderful experience. Whether or not Jan felt completely understood, the acknowledgement allowed her to “let it go”. There were times however, when she was recognized by her colleagues for her work and she did not know how to handle it so she minimized or downgraded it, something she said was an “abusive” thing to do. When Jan could receive acknowledgment, she explained that it was “liberating” to know someone heard her and “got it”. She knew they got it because they would respond with a nod, a reiteration, or an encouraging pat on the back. She also said she didn’t always know what it looked like when another got it, but she could feel it. Describing the

feeling as fantastic and awesome, she felt that afterwards she could let it go and move forward in any direction.

One working relationship that Jan spoke of in which she felt understood was with her manager. While this colleague was abrupt and at times even derogatory, Jan knew she was willing to listen to her, valued what she had to say, valued not only who she was, but also what she could contribute to the team. It was a new experience for Jan to have someone in a leadership position care enough to listen. A second relationship where Jan felt understood was with the medical specialist she was referred to after she had to leave work. He “got it” because he listened to her about her experiences and what they meant to her. He cared about how the chronic pain was affecting her. She was initially shocked at this doctor’s response but said it was proof that feeling understood could happen.

The key incident in which Jan experienced not feeling understood was when she came back to work part-time and had to justify to her boss how her job was a full-time position. This began a season where she felt dissatisfied at work, an issue continuing to this day. “I didn’t feel valued. And I felt like nobody really cared about whether I was there or not, or that the work I did was meaningful”. She also felt she did not fit in with her colleagues. Jan could not articulate what nursing’s role was in her place of work and was frustrated that she was not being heard. She felt alone, isolated, and disconnected from her colleagues in wanting to explore nursing’s role in the health team.

Jan chose to focus on “connecting with others” at work both in creating new relationships and re-establishing old relationships. She said that it was painful at times because some relationships she did not want but needed because of her work. At these times she felt fake and had a hard time with the “façade”. In her words, “It eats me up,” always needing to justify herself. Jan connected such feelings with becoming “overwhelmed”, “driven”, and a “workaholic”. Lately she started to realize she didn’t have to “take it all on” at work; however she admitted not being totally convinced of this. Jan desired to balance her driven workload. She dreamt of pure space where she could clear her frustrations and calm down. When Jan felt understood, she felt she could let go of work frustrations. In keeping with her focus of connecting with others, she has asked a colleague to share her office with her so she could have a partner and would feel less

isolated. The patterns of relating associated with feeling understood were considered a priority by Jan, something she valued and was committed to pursuing.

*Gladie – participant 5.*

Gladie called me to participate after she saw a poster of my research advertisement at her place of work. She asked to meet at a coffee shop. Over the background noises of babies crying and Placido Domingo, she explained that two years ago she suffered a steep fall and shattered her leg in 30 places. As she talked she frequently rubbed her leg where it had been broken. Gladie was off work for one year before she returned part-time and slowly increased her work load. At the time of our interview she was working in education full-time, although she planned to decrease her workload because she could no longer physically stand for more than two hours at a time. Gladie had been a nurse for 27 years and had worked in many different areas of nursing. While she loved her job and career, she acknowledged she may not have much time before having to lighten her work hours or give up her job due to her disability. She found it difficult to admit this and instead took courses related to her current job and her career aspirations with a hope to remain within the discipline. In her job, Gladie appreciated not only the flexibility of her work hours, but also being able to decide her own limitations. Through these adaptations she felt empowered and able to function. Gladie spoke about feeling understood specifically in relation to her career as a nurse educator.

She told the story of her accident and shared how her disability had far reaching effects in her life. While in hospital, Gladie had felt understood by some nurses and not by others in the care she received in the E.R., O.R., and in a treatment room (because there were not enough beds on the ward). The nurses who were concerned with their tasks and did not listen to Gladie were those with whom she did not feel understood. She spoke of the excruciating pain after her fall. While in the hospital for one week she was not able to sleep through a single night because her pain kept her awake. In those moments of pain, she recalled her longing to have a nurse reach out to her in compassion and empathy. However, she also felt understood by other RN's in the hospital when they reached out to her in empathy at a time when she felt exhausted, stressed, and vulnerable.

Once released from the hospital she struggled with being dependent on others for assistance. She initially could not ascend the front steps to her home, clean her house that was on the market to be sold, or drive her car. She used a walker for seven months and found a new appreciation for those who have permanent physical disabilities and are totally dependent on others for their day to day living. Gladie also spoke of her financial stress while off work. Because she was receiving \$1000 less each month after her accident, she had to sell her country home, her truck, trailer, and her horse. These losses were even more significant because of the effects on her daughter. Her disability impacted her hobbies, her children's hobbies, her career, home, finances, work, and her hopes and dreams for a future relationship. Gladie feared she would be less attractive to a man and worried about finding a partner with whom she would feel understood. At the same time, she hoped for a future relationship.

*Gladie's description of feeling understood.*

According to Gladie, feeling understood meant having relationships with colleagues/friends, her doctor, and family who provided her with a "support system". Having support meant she had to "be up front and honest with people". Supportive individuals spent time with her, were caring, wrote letters on her behalf, and welcomed her to choose regarding work responsibilities. Gladie believed she couldn't survive without emotional supports. Gladie said there were also times she had been a support for others. She spoke of times in which some supportive individuals were also not supportive towards her. Gladie had particularly felt disappointed and hurt when her children were not supportive at the time of her injury. Whereas Gladie had previously been the main support for her kids, when she could not give them support, friends and family stepped in offering support to her children, and in turn, to Gladie. Overall, she actively pursued building supportive relationships.

Gladie gave examples of taking great pains to explain and show both colleagues and students what happened to her so they would "buy into" her physical disability and support her. By doing this she hoped to receive less judgement from others. She also found that telling others about her injury helped her deal with her illness and helped her

to function and work more effectively. Choosing to communicate facilitated feeling understood, lessened the judgement and devaluing she felt from others.

While it was very important to Gladie to be up front with people so they could support her, she also said she didn't know how she'd cope if she didn't have "such a good denial system". Denying meant she could "pretend" things were fine and that she didn't have to acknowledge that there were things she could not do or things she may have to give up, such as her job. She implied that her denial was mostly about how she perceived herself, as opposed to denying things to other people, although this was not explicitly stated. She said that denial worked 80 percent of the time. The other 20 percent were times when she had to face her disability, although she didn't like to do that a lot.

It was very important to Gladie to not feel judged. Gladie pushed herself to try and show her colleagues that she was pulling her weight. In turn she found her administrators did not give her a hard time, which Gladie believed was because they were nurses and knew about her injury. Gladie said that she could move beyond those who judged her, protecting herself with the aid of "good self-esteem". Post-injury, Gladie chose to only be affiliated with hospital units with whom she already had established credibility because, having to initiate it could be both exhausting and difficult when staff were not receptive. Having credibility and others "buying into" her disability was very important to Gladie.

One issue Gladie had begun to acknowledge was grieving the loss of her independence. This had been difficult because being dependent, especially as a single mom, had left her feeling vulnerable. Due to a past relationship, she explained, "I *know* what it feels [like] to be vulnerable and it feels *awful*. It feels like you've totally been betrayed and, like that part of you *dies* in the worst sense of the word...". A sense of vulnerability also meant she had been judged by others. Not wanting to be betrayed again, she chose not to associate with people who she could not trust or those who judged her because she was left feeling fragile, vulnerable, and challenged with regards to her abilities. Rather, when vulnerable, Gladie surrounded herself with trustworthy and supportive people with whom she felt understood.

The following table describes the five participants interviewed for this project. The table provides specific information regarding their ages, years of nursing practice

before their disabilities, the natures of their disabilities, how they met the disability criteria to qualify as participants in this study, and their employment status at the time of their interviews.

Table 5.

*Profile of Participants*

Participant	Age	Years of nursing practice before disability	Nature of Disability	Length of time on leave from work due to disability. Return to work?	Employment status (at time of interview)
Christine-Participant #1	39	10	Lupus nephritis	2 years on LTD*. Returned to work in accommodated part-time position for 11 months. Then left nursing permanently on LTD*.	Unemployed on LTD*. Taking university arts and sciences classes.
Rose-Participant #2	51	24	Fibromyalgia (FM)	Worked part-time after diagnosis of FM. One year later left work permanently on LTD*.	Unemployed on LTD*. Taking Bachelor of Science in Nursing.
Crystal-Participant #3	52	27	Post-traumatic stress disorder	Off work for 9 months on WCB* claim. Returned to work full-time.	Employed full-time.
Jan-Participant #4	43	14	Viral infection with neurological complications permanently affecting arm	Off work for 9 months on STD*. Returned to work for 9.5 months part-time. Full-time since then.	Employed full-time. Grad. student in Masters of Nursing.
Gladie-Participant #5	49	25	Shattered leg	Off work for 1 year on STD*. Returned to work part-time, progressing to full-time.	Employed full-time. Taking critical care course.

\* LTD – long term disability

\* STD – short term disability

\* WCB – Workers' Compensation Board

*My Process of Analysis-Synthesis*

Analysis–synthesis was the heuristic tool used in the data analysis for this project (Parse, 2001a; Parse et al., 1985). The goal of utilizing analysis–synthesis is to construct separate themes that align with the research objectives. After examination, these themes are compared and combined to create synthesized descriptions of the phenomenon of concern arising from the research participants' accounts of living this phenomenon. For my study, the phenomenon of concern was feeling understood and the findings for this project were the themes found in the participants' descriptions of their experiences of feeling understood.

There is no singular prescribed or set way to engage in qualitative analysis while using the process of analysis–synthesis. Therefore, as a student engaged in my first full attempt at qualitative analysis, I found that the analytic path often seemed hidden, hazy at best. I began my process by listening to the audio recordings of the interviews while reading the transcripts. I frequently made changes or corrections to the transcripts, adding pauses, um's, ah's, and other non-verbal cues that I either heard or remembered from the interview. I then took large pages of art paper and colorfully mapped each participant's stories of feeling understood. This visual mapping helped me to make sense of the participants' lives and stories. It was also helpful to synthesize up to 60 pages of transcript onto a few art pages. During this time I began to journal similarities I noticed between participants.

Before delving into similarities between participants, I looked at each participant separately, searching for the themes of her interview. Each transcript was formatted with the participant's words only on one half of the paper, leaving the other side blank. In this empty column, I copied significant words and phrases from the transcript that addressed my research objectives. I looked at each transcript one sentence at a time. I recorded in a journal each significant word/phrase with a page number and grouped them when similarities appeared. I photocopied these pages, cut up the words/phrases with scissors and manually arranged them in themes according to my three objectives. This process was completed for each participant separately and took me approximately three months.

I then explored similarities among participant descriptions looking for common themes. Throughout this process, I discovered that I needed to look for conceptual

similarities, as opposed to word similitude. I was initially inclined to explore word similarities, but to maintain the analysis-synthesis process, I realized that I needed to shift from word comparison to conceptual resemblance as a means of maintaining methodological integrity. For example, all of the participants spoke of “listening” and I initially identified this word similarity. Yet when I compared the participants excerpts regarding listening, the participants used the word to describe diverse conceptual ideas, often not related to feeling understood. If I had stopped at word similitude, listening could have been included within a theme because it was recurrent. However, the participants did not describe listening in a fashion that was conceptually similar, specifically in relation to my research objectives, so it was not incorporated within my theme development. In the process of searching for common themes, I repeatedly returned to the transcripts looking for descriptions from each participant that shed light on a potential theme. I likened a theme to a recurrent melody within participant stories. As themes emerged, I created a computer document in which I grouped statements from one participant at a time that supported each theme. I then wrote a paragraph synthesizing the descriptions from each individual within a theme. This document filled 82 pages, single-spaced.

Throughout my process of analysis-synthesis, I created a table that could inform and remind me of what various participants had said of their experiences. This table provided a visual representation of the analysis-synthesis process. Yet, I also struggled with maintaining both sides of analysis-synthesis. My intention to uphold the integrity of the analysis-synthesis process fought against my tendency to just use analysis. This struggle was apparent in my resistance to putting participants’ words in “boxes”, deciding where their experiences would or would not be categorized in the table. I acknowledged that the boxes were not guiding me and peoples’ lived experiences were not that straight forward. The table was simply a heuristic tool that again helped me include synthesis within the simultaneous analysis-synthesis process. I saw the lines of the table as permeable borders, recognizing that when I placed a word or phrase under one objective or theme, it was interconnected with all other themes and objectives.

The participants’ statements, along with my notes, were then used in the articulation of each theme in the language of the participants. Once completed, the

themes were re-constructed in the language of the researcher. This latter aspect of the analysis-synthesis process took approximately another three months, totalling six months.

A significant challenge in the analysis-synthesis process was the notion that feeling understood surfaced in patterns of relating. Although patterns of relating are identified in study objective two, an inability to isolate such patterns surfaced while attending to the other study objectives. Such difficulty sheds further light on the wholeness or irreducibility of human experience. My first objective addressed meaning, what feeling understood meant to participants. My third objective considered how feeling understood was related to the participants' hopes and dreams. More often than not, descriptions of meaning (objective one), as well as hopes and dreams (objective three), were integral to participants' patterns of relating (objective two) with other persons as well as important projects. Yet, in keeping with the process of the chosen methodology, these intertwined ideas were organized around discrete study objectives. The challenge I confronted was that I was trying to attend to participant descriptions within three study objectives while proposing to maintain the whole of irreducible life experiences. What I encountered was a confrontation between differing paradigm perspectives. The action of separating study objectives within participant statements functioned in contrast with my intention of maintaining the whole of inseparable human experiences.

For purposes of clarification, my methodological decisions and actions surface the difficulty related to maintaining the integrity of the wholeness of human experience while challenging the convention of reducing human experiences for the purposes of research analysis. Such difficulty is echoed in the multiple challenges of practicing true presence amid a nursing culture where individuals are regarded as a series of parts that are compared with expected outcomes and are viewed as separate from the universe/environment (Northrup & Tschanz, 2004). In reflection, my process was not as straightforward as it may have been presented here, but rather, it was often repetitive and experimental. My process of analysis-synthesis often felt like I was repeatedly un-entangling a ball of string, and then entangling it up again. With each un-entangling the themes took greater shape and with each re-entangling, differing emphasis emerged.

Through analysis-synthesis, the findings of this study provide the answer to my research question that emerged through the discovery of themes organized by my three

objectives. Each theme will be presented in the language of the participants. Direct quotes from each participant will be presented to provide the reader with substantive data depicting how the themes are a synthesis of the major statements from each participant's interview. Each theme will then be interpreted in the language of the researcher and discussed in greater detail in the following chapter.

### *Description of Findings in Three Research Themes*

Consistent with inquiry that is posited as theory-guided research, the research conducted for this thesis was explicitly theoretically driven. In using Parse's theory of human becoming, the three themes of meaning, rhythmicity, and co-transcendence (Parse, 1981, 1987) informed the identification of this study's three research objectives. The following three research themes were extricated from the interviews.

#### *Theme One in Participants' Language*

My first objective was derived from the theoretical theme of meaning in Parse's theory:

- Objective 1: To describe the meaning of feeling understood for nurses with disabilities through dialogue.

Research theme one was synthesized from all participants' descriptions of their experiences of feeling understood. Theme one, in the language of the participants, was:

- Theme 1: *An acceptance–non acceptance of changing abilities amid expectations engenders joyful relief and aching hurt.*

Theme one, in the language of the researcher, was:

- Theme 1: *Acquiescence-non acquiescence of shifting capabilities with prospects give rise to serenity-anguish.*

(Theme one in the language of the researcher will be further discussed in the following chapter.)

The following quotations were taken directly from participant interviews to portray the significant concepts that were shared by all interviewees, together constructing theme one. Italics have been added to represent emphasis when the participant spoke.

*Participant #1 - Christine's description that expressed theme one.*

Well I think for me, feeling understood is when I may be...telling someone something about myself, and if the other person seems to be able to give a parallel example or say something that tells me they were really listening... then I think, "oh yeah, they're really getting it"...And they're also maybe accepting that what I'm telling them is the truth....Ah, well it's a huge relief at times that they get it....

At first when I was off work, I wanted everybody to get it. I wanted everyone to understand, like why I couldn't work, or what was wrong with me even, because it's not visible always. And then often, not being understood, was just *so powerful* and made me *so sad*, that I just thought, what's the point of trying to have people understand me, because often they'd make comments that really didn't let me know they got it and it was so hurtful or sad, yeah, that I just thought, I shouldn't even tell people....I remember this friend who lived just down the road. She saw me on the sidewalk as I was walking, and I remember her saying: "Oh. It's like I forget you're even here! That you've moved here – I forget!" And I was going through the most *devastating* thing in my life and here she was forgetting I even kind of existed? Just broke my heart! (whispers)

Some of my friends...to have to sort of make them-*make them-* (whispers-Ahh!) *expect*, I haven't talked about that, expect that they will understand. Or anyone really, even my husband has trouble. You know, [to] expect that people will understand what it's like to live in my body, I don't know if it's as important anymore....And it took me *years* to let go of wanting something from people, as far as concern or caring, that *equaled* the amount of pain and fear that I was feeling....

So, I've given up on some of those *expectations*....And so there's freedom with that.... It feels like there *are* things to get on with, to experience, and I'm just a lot happier. Happy? I'm just a lot more content, I think.

*Participant #2 - Rose's description that expressed theme one.*

My experience of feeling understood is at the beginning of my disability when I was just learning about it, I didn't feel understood at all. Because I didn't understand it and I didn't know what I needed to ask *for*, to get understanding ....It was very *painful*....Well at first, I probably hit the real low in the depressive process where I was suicidal at one point. I did get to that and I even knew exactly how I was going to do it....It comes to the point you feel that nobody understands your pain, and living in this pain is too hurtful to go on....

So, it comes to the question I asked myself, was my expectations of what [my friends] could do for me,...were they too high?....You can't put any expectations on anyone. You really can't....The lesson for me is learning to let go...and not expect that understanding from other people.

One of the most validating things was to find out that they've done MRIs on people with Fibromyalgia and they've found the pain response is really high....I want something that says, "yes, this does exist"...I can remember that was a big relief.

[Now], I'm starting to re-enjoy life so it's like okay, what joy can I get out of the next moment? And that's even with recognizing there are going to be moments that you don't live in constant joy. You don't understand what joy is unless you experience pain, sadness, any of that.

*Participant #3 - Crystal's description that expressed theme one.*

I have a really hard time telling myself its *okay* to be sick....When [I'm] at work I know how I feel about the patients. There's this division: they're the patient, you're the nurse. And now I feel that that line is not there anymore. I feel like I'm just as much as *them* as *they* are....Like I just sort of want someone to look after me for a change. You know? Rather than be this strong person that everyone expects of me, because I always have been a strong person....

I think being understood is the *big* thing and just being accepted for someone who still is the person that she was, but she's just away for awhile right now. And still being loved for that...Instead of people that kind of give the [advice], "oh, (snaps her fingers) just snap out of it. You should just be able to, it should just go away"....When I felt like someone didn't like me or if someone was judging me I would go overboard in trying to *make them*, [but] I don't have to prove *anything* to *anybody* other than to myself. And if I feel like I'm being accepted for myself, I'm accepting myself for *who* I am, with my own limitations or fallibilities...I really do *feel* that *that* in itself is a form of (pause) success for that day or for that hour.

*Participant #4 - Jan's description that expressed theme one.*

When I came back to work, I could only come back part-time. I didn't feel valued. And I felt, like nobody really *cared* about whether I was there or not or that the work that I did was meaningful....It was just so *traumatic*, so consuming....

I want to see the new leaders that are in place [in VIHA] fulfill my expectations, quite frankly(laughs)...I must have really high expectations because they're not meeting them....I'll give them a chance. And I don't feel [responsibility] has to sit on my shoulders anymore...Well it's not entirely liberating....I still have a lot of responsibilities that I continue to take on when I shouldn't.

I just think everybody wants to feel like they're understood or heard...And it really doesn't matter whether the change or the idea that someone has...happens, or somebody does something with it. It's just the *shear acknowledgement* that what you're feeling, what you're saying, what

you're trying to say, [that someone] would get it. I don't do that really well *either*, for people. But I *try*.

Kara: What is that like for you when someone acknowledges your idea?

Jan: Awesome – [I] let it go...For me, it's just *liberating* because it's like somebody's *heard* you. Somebody's *got* what you said or what you *felt*, and now you can go forward. In any direction!...

Kara: How do you know that they got what you said?

Jan: I'm not really sure about that, whether it's just a pat on the back, or a nod, or a reiteration....I don't really know what it looks like but I *feel* it.

*Participant #5 - Gladie's description that expressed theme one.*

Well, my experience when I got to emergency was *horrendous*....I said to the nurse that was caring for me, what I really wanted her to do was just *touch me* and say, "I know this is hard for you." Like if she would have done that, that would have made *all* the difference in the world. But instead I said to her, "You don't understand because this is so very, very painful." She was just *so* flippant, she just said, "Oh, I've broken bones many, many times." And there was absolutely *no* compassion, *no* empathy, *no* nothing (pounds fists on the table)...They were just very technical....And then I was finally transferred into a four bed ward...Then I had an excellent nurse who was very empathic and gave me really excellent care....

I guess I felt very vulnerable when I [broke] my leg, for about seven months until I started getting my mobility back...I *only* allow myself to be vulnerable with certain people, really close friends. Cause otherwise I put up a bit of a wall. So I think it's self-protective. And I don't *allow* myself to be vulnerable very much....And it's not necessarily a great place to be, so I *try* not to put myself in that position and I *try* to surround myself with people that I can trust.

*Discussion of Theme One in Participants' Language*

Research theme one sought to answer the question regarding what feeling understood meant to the five participants. From a theoretical perspective, theme one synthesized the nurses' descriptions of the meaning of their interpretations of feeling understood (Parse, 1981, 1987, 1998). Three common concepts arose for each participant: joyful relief/aching hurt, acceptance-non acceptance, and changing expectations of feeling understood. Together these three central concepts created research theme one.

One of my first observations was that all the participants contextualized the meaning of their experiences of feeling understood in relation to their physical and/or mental-emotional pain due to their disability. As Christine (participant #1) explained:

You know, you've got *PAIN!* *Pain* is such an energy sapper. And people could say the simplest thing that on one day you wouldn't even think twice about *but* if you're feeling in that vulnerable state, it's just *so* hard. And with being understood *too*, I mean if you're really ill or you've got a lot of pain, whatever happens between people with relationships is going to be intensified. I think for me, I'm at times more sensitive. I'm at times more vulnerable. People can *hurt me a lot easier* when I am kind of holding on with my fingertips.

Although all the participants were individuals with disabilities and they were asked to describe their experiences of feeling understood, they were not directed to discuss their experiences of the phenomenon specifically *in relation to* their disability. However, all did so. Because this study was not researching causal relationships, the observation that all these participants discussed their physical and/or mental-emotional pain from their disability in relation to feeling understood is not purported to suggest that this relationship is generalizable to other individuals' experiences of feeling understood, even if they are also nurses with disabilities.

The participants were acquainted with physical pain, changing abilities, and changing work situations due to their disabilities. From these contexts, all participants spoke of feeling understood and of not feeling understood. I did not specifically ask about the latter, or about an opposite, absence, or paradox of feeling understood. Two of the five nurses, Rose (participant #2) and Crystal (participant #3), spent the majority of their interviews describing their experiences of not feeling understood. Interestingly, at no point did any participants discuss feeling "misunderstood", a phenomenon distinct from not feeling understood. I do not consider the phenomenon of "not feeling understood" as contrary to feeling understood. From a theoretical perspective that acknowledges and supports experiences in paradoxical rhythms, shared experiences of not feeling understood provide further insight into the complexity of the phenomenon of concern.

The joy of feeling understood and the hurtfulness of not feeling understood were also discussed by all the nurses, creating the first main concept in theme one. Accounts of feeling understood were portrayed by the participants as feeling contentment, joy, relief, empathy, freedom, liberated, cared for, wonderful,

empowered, extraordinary, and comforted. Further, three of the five nurses in this study referred to feeling understood as being understood. Part of the joyful relief of feeling understood for these five participants included being accepted, also described as being acknowledged, loved, and recognized. Meaning was created in these individuals lives as they shared stories that reflected feeling understood. Examples included being empathically cared for by a nurse, being listened to by a manager, and being empowered by an administrator to decide work hours.

Experiences of not feeling understood were described by the participants as feeling painful, sad, vulnerable, fearful, hurt, and traumatic. A consistent similarity of the aching hurt of not feeling understood for the five interviewees included being rejected, not being accepted, further explained as neither being acknowledged nor recognized. For example, non-acceptance was described by the nurses in relation to feeling rejected by friends, family, or co-workers, not being recognized as having a “real” disability by health care professionals, not acknowledged as being a creative member of their work team, as so forth. Many of their narratives related varying accounts of not feeling understood such as: feeling forgotten by friends, feeling suicidal, and feeling that men would no longer be interested in a relationship due to one’s disability.

The second concept in theme one related to all five participants when they spoke of the meaning of expectations in relation to feeling understood. They shared their expectations of others and themselves in different contexts including their friends, families, colleagues, patients they cared for, or nurses who cared for them. All participants at one point used a similar terminology of pulling their weight or their share of the load in relation to friendships or work. Two of the five participants, Christine (participant #1) and Rose (participant #2), additionally shared about a shift in their expectations, towards “letting go” of their expectations of others and themselves. This perception of letting go was not expressed by the other three nurses. However, the remaining three nurses also discussed times in which they did not have expectations of themselves or others. Therefore, all participants discussed, in one way or another, changing expectations. The finding of expectations provided awareness on the meaning of feeling understood for these

five nurses with disabilities. Combining the three concepts of joyful relief/aching hurt, acceptance-non acceptance, and changing expectations of self or others offered insight into the meaning of feeling understood for the research participants.

*Theme Two in Participants' Language*

My second objective was derived from the theoretical theme of rhythmicity in Parse's theory:

- Objective 2: To describe patterns of relating within the experience of feeling understood for nurses with disabilities.

Research theme two was synthesized from all participants' descriptions of their experiences of feeling understood. Theme two, in the combined language of the participants, was:

- Theme 2: *Being believed—not being believed by others resides along with honesty-dishonesty manifesting wavering support.*

Theme two, in the language of the researcher, was:

- Theme 2: *Bonds of security-insecurity surface with candour-concealment amid tentative assistance.*

(Theme two in the language of the researcher will be further discussed in the following chapter.)

The following quotations were taken directly from participant interviews to portray the significant concepts that were shared by all interviewees, together constructing theme two.

*Participant #1 - Christine's description that expressed theme two.*

Part of being understood for me is that I'm being believed...It takes a lot of energy to have to convince people that...what I'm saying is the truth!...And it can be quite stressful if you think that someone has a lot more power over you in a situation to get them to - believe me...Somehow I feel like if people don't always understand they might not (pause) believe me, I guess!...I tried...[to] get people to understand. And it just didn't work! And so I ended up feeling like I might as well just isolate myself...because it just takes *so* much energy to explain what's going on with me. And then to not be understood, to almost maybe be a bit rejected, not included in things with people - *I* don't know why...If you just can't get support....then you're

scrambling to have people to understand you and then when they *don't*, there is tons of self doubt and I just retreated...well, the other day someone accused me of disappearing (laughs)...So I don't pick up the phone that much or I don't socialize....Like, nobody understands how serious this is for me. And it's just easier for me to stay at home....Yeah, [it's] lonely....For a long time I *pretended*...I just carried on to the point of, like exhausting myself to make it look like my life *was* normal. Except *inside*, it wasn't at all....Well, okay [but then] I decided to just not prove to anyone that I could carry on the façade of being busy and what everyone else seems to be....My hopes are that I can continue to try to be honest with myself about situations – so that I can be more honest with people, which means speaking *the truth*.

*Participant #2 - Rose's description that expressed theme two.*

It was just the simple fact that when colleagues...don't believe that [FM] exists that I can say to them, "There [is MRI] research [that] has shown...this does exist."...I can actually take this and show somebody that says it doesn't exist. Excuse me!...Yeah - I don't have to keep...defending myself. So, I could take this to family members because I have sisters who just kind of poo poo it....It's that medical science, empirical domain that says *you* have to show me something on the piece of paper, you have to give me data that says this does exist, [rather] than your subjective experience....I went through a period of time when I tried to *ignore* [my well being]. Like the old adage - if you ignore it, it will go away. Well it didn't. It kept....I was living in a lot of pain, a lot of denial....

I felt like I didn't have any support and certainly I didn't get any support at work....I didn't realize I was hurting myself (sighs) by keeping my distance from certain relationships and not seeking support...because I was afraid of people. I was very aware that I was getting to the point where I didn't want to even be around people....I have [one] really good friend...she was probably the backbone of my support system. She just allowed me to talk. And she would just let me say what I needed to say and if she felt that I was way off base, she would tell me. She would help me get back on track....

*Participant #3 - Crystal's description that expressed theme two.*

I think that I'm a person that needs to justify myself a lot. And in doing that, I get a little verbose at times and do overkill in explaining myself....And I've probably made...people shun away from me at times and then I get really quiet inside....I guess the unknown made me feel like I was a phoney, like I had to fake something. It's very hard to explain. That is sometimes even how I feel [as] a nurse. Sometimes I feel phoney....And I feel like I'm judging myself as well as other people judging me. I feel like a bit of a failure I guess....I just want to be able to *feel* like I'm a functioning member of my society...and not to be a phoney....[When I feel understood] it's like I don't

feel like I have to prove myself any more and it's a comforting thing....I just feel like I don't have to *justify*....

I don't want to be around people....I can think of at least five people right now that I need to phone that have phoned me that have been in trouble...and I feel like I have nothing to give them....What I really *should* do...is I need to phone them and tell them that I'm going through a tough time right now and it's not that I don't care about them it's just that I don't have anything left to give myself right now....I think that is something that's really suffered is relationships I've had with other people. Because I used to do things a lot of things with people....Like, you just don't want people to see how bad things are....(laughs) And it's almost like you're *lying* in order to not have to deal with peoples' reactions....it's almost like, "How you're doing?" "Not too good." "Oh, that's great." Cause it's a pat reaction to a question. In other words, those people don't *really want* to hear what the answer is. Instead of feeling bad about that I try to turn it around and say, "you are there yourself sometimes"...I've found myself being that way too. So I can't judge when someone else is doing it, you know? In a crazy way, it's good because it shows that they're just as human as you are. That we're not always perfect. That we're not always going to have the right reactions to things. We're not always going to be on top of things. We're not always going to be efficient. We're not always going to be a good friend, you know?

*Participant #4 - Jan's description that expressed theme two.*

One of my focus areas [at work] was connecting with others....It's *painful*. Because some of [my professional relationships] I *don't* want, (laughs) but I have to have them because they're part of the job....[Then I feel] like I'm a big *fake* bull shitter. And I'm *not* a fake person. What you see is what you get, always. I'm very honest, very, very loyal, and very trustworthy and I have a really hard time putting on that façade....I always feel like [I have to justify myself], it's probably why I'm so driven....why I feel like I have to work 400 hours in a day or produce what I produce. I don't know (quietly). That's what I'm trying to figure out. It's a bitch of a question!....

Like I created this...standard space orientation program....My colleagues at work didn't appreciate it....I was just wanting a pat on the back from them....I work with them. Why wouldn't they do that?....That's so not supportive....I don't really give a shit if they didn't want to use it but just the *recognition* or *acknowledgement* that somebody did something really creative, really sort of pioneering, something different. That to me is amazing! Cause it doesn't happen very often....[I've felt] very isolated. Disconnected. Like I don't have...collegial relationships....It's frustrating to feel like you're never getting heard. I keep asking the question, "So what is nursing's role, what does nursing look like then? We're all talking about a business model, a medical model, *we're not* talking about nursing.... When I tried to do something really innovative, it was like, "Oh that's great. (laughs) But we're not doing that here because that's too *nursing*." They didn't say

*that* but that was the feeling that I got. And then I would sit around the table with my colleagues and it was like, they don't understand what I *do*. They're not interested in where I come from and I'm not articulating it well, to help them understand....Then I feel like an idiot - alone...I just disconnected....

I just think everybody wants to feel like they're understood or heard....It's just the *shear acknowledgement* of what you're feeling, what you're saying, or what you're trying to say....I'm working with a manager right now who....cares enough to at least *hear* me. Well maybe she values what I have to say or *who* I am or what I *contribute* to the team. Maybe she doesn't totally but...but ultimately, she really thinks that I contribute. So that's cool.

*Participant #5 - Gladie's description that expressed theme two.*

I don't know what I would do...if I didn't have such a good denial system. Well sometimes, by denying that I have got an injury....it's almost like I don't have to *admit it* if I pretend that it didn't really happen....By denying I feel like I can say there's nothing wrong with me (laughs). And it *works*, about 80 percent of the time....So there are [also] times I *can't* deny it...I *have to face it* and *have to deal with it*. But I don't go there on a regular basis....

And so what I do is....I have a little x-ray and I show [my class] how many screws [and plates] I had in my leg. So when they can physically see how badly my leg was injured, besides just seeing my scars, then they kind of *buy into it*. I don't *look* physically disabled....And so I find then that the students on the whole have been very supportive as well....I find that people who...are really up front and *work* to get people to *buy into* what has happened [can deal with their chronic illnesses] - so that others can support you and you can do your job more effectively....In terms of work, I have felt understood. I found that my [employer] has been very, very supportive....

It's *really important* for me not to be judged....What's worked is just to be really *up front* and really *honest* with people. And that has made a difference, in terms of building in support to allow me to function....Like I'd rather people be honest and it be hurtful but I know that they're honest, than for people to be dishonest and I feel very betrayed....I'm very, very *cautious* because my ex was very dishonest and I found out about it...I *know* what it feels to be vulnerable and it feel *awful*....

Well I felt my biggest support [when I broke my leg] was my colleagues from work, most of them who are also my friends. They were *hugely* supportive because when I came home I couldn't weight bear for like seven months, so I was totally dependent....friends would make food for me and they would come and visit me.... At the time, I found that my teenagers...were not supportive or not understanding *at all*....I had always been the *main* support system for my children and all of a sudden I couldn't give them as much support. But then, friends and family sort of stepped in to give them more support, and me support....Like I've built a really good support system and I've *been* a good support system for other people.

### *Discussion of Theme Two in Participants' Language*

The second research theme sought to address how feeling understood surfaced within relationships for these five participants. From a theoretical perspective, theme two synthesized the participants' descriptions of feeling understood in rhythmical patterns of relating to others, themselves, and their universe (Parse, 1981, 1987). Rhythmical patterns of relating refers to an inseparable connectedness in relationship with self, others, communities, literature, events et cetera (Parse, 1987). Three common concepts arose for each participant: being believed-not being believed, honesty-dishonesty, and wavering support. Viewed together, these three central concepts created research theme two.

The first concept that all participants discussed was the topic of being believed-not being believed. All the participants talked of either why it was important for them to be believed or what they did to facilitate being believed by others. Examples included: desiring to be believed as speaking the truth honestly, finding validation when research supported the physical existence/manifestation of a disability, and being perceived as a contributing member at work. Similar to theme one, expectations also surfaced within being believed-not being believed. Paradoxically, all the participants described instances in which they were not being believed. Stories were told about friends and family not believing that a disability was "real", experiencing judgement from others, judging oneself as a failure, and having concern about one's disability not being physically apparent. All the nurses spoke of explaining, justifying, or convincing others. Two of the five, Christine (participant #1) and Crystal (participant #3), further explained a shifting in their beliefs, that it was no longer important to explain or justify themselves.

Intimately linked to being believed-not being believed was the second concept of honesty-dishonesty, which all interviewees also talked about in relation to feeling understood. Each nurse shared descriptions of honest and dishonest accounts of her disability. The theme of honesty-dishonesty surfaced in participants' stories when they spoke of either honestly engaging or dishonestly engaging with others. The participants openly engaged in relationship with others by articulating their thoughts, feelings, and concerns. Such articulation often included an account of their disabilities and at times included showing their physical limitations. Participants told colleagues/students about

themselves and the challenges of their disabilities. One nurse participant felt she knew what needed to be said to friends, family, or patients but would not always say it. A different participant struggled with trying to articulate nursing's role at her place of work. Another was concerned about showing physical scars. Whereas one participant felt it was important to honestly share what was truth to her, another felt she needed to defend herself and her disability. Yet another nurse built credibility with colleagues by being upfront and honest so others would buy into her disability.

Paradoxically, all five participants also described instances in which they dishonestly engaged with others, withdrew, or did not want to share their reflections or accounts of their disabilities. Participants expressed honesty-dishonesty through the use of words such as pretending, not telling the truth, faking, isolating, denying, and lying (associated with betrayal), vulnerability, protecting oneself, and retreating from others. Demonstration of their choices to protect themselves was evident in stories about their disabilities, such as: not wanting to talk about the challenges related to a disability, having an invisible disability, and coping by not acknowledging that a disability may limit what one can do at work or in play. Examples of not wanting to honestly engage included ignoring, lying, and saying, "things are fine" because of not wanting people to see how bad things were. Honesty-dishonesty was also displayed in how the participants were honest and dishonest with themselves. The participants shared narratives portraying issues such as: denial, contemplating or ignoring living with a disability, and feeling like they were a fake/phoney or honest and loyal. The participants' multiple patterns of honesty-dishonesty provided insight into how these five nurses experienced feeling understood within relationships.

The third concept that all the participants addressed as a relational component of feeling understood was the idea of wavering support. The nurses gave examples of varying degrees of support they received in relationships with others. Accounts of support included relationships with other nurses with disabilities who had a heightened capacity to care, a professional counsellor, or a close girlfriend. The participants felt supported when they received praise from colleagues or received support at a time of being physically dependent on others for mobility. While all five recounted times in

which they received support, only Jan (participant #4) and Gladie (participant #5) spoke of personally providing support for others.

Stories of diminishing support were often described in the context of much hurt. Illustrations revealed tales of wanting support from friends, family, and colleagues but not receiving it. Examples were identified such as: experiencing disappointment when teenage children were not supportive, sensing a boss trivialized one nurse's work, having trouble engaging in relationships, and being told to "snap out of it". Each participant also described periods in which she withdrew from others and into times of seclusion, thus not receiving support. Some explained these actions as isolating, retreating, shunning away, and disconnecting. Such times of isolation were primarily seen as a challenge when the nurses were separated relationally from others due to shifting circumstances. Synthesizing these three concepts of being believed–not being believed, honesty–dishonesty, and wavering support shed light on how feeling understood emerged within relationships for these five participants.

### *Theme Three in Participants' Language*

My third objective was derived from the theoretical theme of co-transcendence in Parse's theory. Co-transcendence refers to moving beyond to where a person's hopes and dreams may transform from possibilities into actualities.

- Objective 3: To describe personal hopes, concerns, possibilities, and visions of what might be in relation to feeling understood for nurses with disabilities.

Research theme three was synthesized from all participants' descriptions of their experiences of feeling understood. Theme three, in the language of the participants, was:

- Theme 3: *Self-confidence fluctuates with the enthusiasm and fear of wanting to make plans.*

Theme three, in the language of the researcher, was:

- Theme 3: *Buoyant conviction wavers amid fervour with fright.*

(Theme three in the language of the researcher will be further discussed in the following chapter.)

The following quotations were taken directly from participant interviews to portray the significant concepts that were shared by all interviewees, together constructing theme three.

*Participant #1 - Christine's description that expressed theme three.*

I think when you're not understood...your self-confidence...can go down.... Then there is tons of self-doubt....I went into....three years of these cycles of...self-doubt, low self-esteem because...my opinion then was if I can't work, well then what's the point of me existing?...Like, it was a big adjustment to *not work*. And our society just puts so much value on that and *I did too*....

So I [had]...stopped making plans....Someone said to us, "Well... what's your five year plan?"...And I'm like, I don't know what we're doing next week. Because we were *so scared*, *so* stuck in worry of my illness....And you know, medical wise and health wise and there was a lot of *fear* about my life. (pause) I mean I would actually would even say fear of death at times, because I was so ill....So to have any plans? That just seemed so frivolous. (laughs)...I'm just getting through today!...We didn't have much hope....Well I just desperately wanted to stay well for awhile....And then a couple of years ago we said, "Okay we're going to go on a trip when we turn 40", so that's coming up next year....So, you know, we're *trying* to make some plans....The hopes and dreams...are starting to happen again because I've kind of stabilized with my health. Um, but for a while, there was *nothing*. There was just surviving!...

Yeah, I have noticed in the last couple of years, just feeling a lot stronger, a lot more self-confident. You know, sort of setting things up in my life the way I want them.... So, now it just feels so liberating....[that] I've just built [up my] self-esteem....I've just been really trying to...*celebrate* those things that I feel fortunate about in my life instead of *continuing* to look at what I don't have....I mean being understood, it really does affect...my feelings about myself....I know myself a lot better.

*Participant #2 - Rose's description that expressed theme three.*

[I was] thinking, "Well okay, I'm in this pain. I'm not quite sure what is going on. So, what do I need to do?" And there was no sense of direction....It was like, I didn't have the strength at that time to think for myself....I was living in a lot of pain, a lot of denial, a lot of beating-up-of-self....You're immobilized. You're waiting for whatever is going to happen, to fall. It's like you know you can't save yourself. (pause) But you don't know what you have to save yourself from. I say that Fibromyalgia is the catch 22 disease (laughs). Because at times you feel you can't go back, you can't go forward but staying where you are isn't healthy either....So you have to go [on] in your searching for answers, to find out well, can I deal with this?...

The only one that you can ask these questions to and get the answers that you really need are within yourself. ....That means a lot of internal work. It means that I have to be comfortable with where I am at, within myself and not project my needs out onto other people. ....It's just having a confidence in myself that had been lacking for a good long time. ....Health for me would mean acceptance of myself at whatever stage I'm at. And. .... meditation does a lot for me. ....It's like refocus on something else. ....[And then I have] a sense of peace that everything's going to be okay. That nothing in this moment is too overwhelming. That I can go on to the next step. ....It's okay to have questions and not answers. It's even okay if I don't understand.

*Participant #3 – Crystal's description that expressed theme three.*

I mean [nursing] is an intense job and there are times that we have to really listen but sometimes when it gets too intense...like I hate it when there's confrontation between people. ....And I know that it's affected my feelings of, I guess my self-worth. Just feeling down on myself. Just thinking that I've done something *wrong*. ....*Change* has always been a tough thing for me. Like, I'd rather have a horrible situation to live in, than the unknown. ....Anything new that [arises has been] a *real* fearful thing for me. ....Um, I guess self assurance is the big thing. I feel that there was a period of time in my life where I had felt self assured and that I felt confident. And I feel that it's a number of incidences that have happened to me at work, that's made me fearful. That's taken away my sense of security. Has kind of *augmented* that feeling of *not* being self assured? The difference is that I don't feel like I'm effective as a nurse or as a person when I'm feeling that way. ....I'm not giving everything of myself. ....I'm only giving a part of [myself] and I'm just treading water. It feels really *bad*. Because in some ways you kind of feel empty, ...directionless. ....I've lost my focus. ....

[I hope] just to feel a spark again and to feel like I have the energy to *function*. ....I try to pick on one thing that I can do to kind of make me feel like I've accomplished something. ....So it's almost like it's *too* much to try to do at once. .... Like it's so overwhelming, where do I start?...[When I feel understood], I feel maybe like there's hope...that this is going to go away and that I'm going to be able to function again like I did before.

*Participant #4 – Jan's description that expressed theme three.*

I just *never* seemed to recover from [having to return to work part-time]...Cause it was like nothing I could do could affect anything, because I was only there two days a week now. ....The work that I did as a *leader*...[didn't seem] to matter. ....I became this person who just kept hitting her head against a brick wall trying to create [communication about what nurses do, but] no one else wanted [it]. ....To be that person with that bleeding hematoma, ...it just constantly makes me feel like an idiot. Like I'm *so* unrealistic that...my goals, my dreams are not appropriate. ....Because, here I am, frustrated, overwhelmed, feeling alone, feeling

isolated, hitting my head against a brick wall because what I'm saying or doing is not being understood....If I don't feel like I fit in, then why am I there? But I always felt like I'm not finished....But I'm not feeling *even* that anymore....

But I would like eventually to just kind of slow...this life, this drive...down a little bit....It overwhelms me....I dream about a Starbucks' life. Where I can get up and just go work at Starbucks and come home. I dream about that but I don't really want it. But I do. What I like about it is the simplicity....I'm very self reflective, but it's always in the car. Or it's like a taking a second out of a boring meeting. It's never really pure. I think [time to veg out]...would help me clear frustrations more readily and not hang onto them....Like I said, [feeling understood] makes me feel like I can move forward and I can let it go. (cries quietly)

Like I envision, um, never retiring. I just couldn't, from nursing? No. My husband and I in a motor home...and we're on the road and I have a lap top. And I'm connected to...sessional teaching. Because I don't know about a PhD. So I don't know if I'd ever get on faculty, but...I *love* lecturing and writing - in nursing. That's my topic of interest, but you know...so it's not anything, sort of, unattainable. I know it can happen. And see, that way, I'm moving. I'm doing and I'm influencing. And still, you know, being with my family.

*Participant #5 – Gladie's description that expressed theme three.*

I still have the ability and a good enough self-esteem to move beyond those people [who judge me]....If you're judged, it makes you feel more *fragile*, more vulnerable in terms of people questioning your abilities and *who* you are and what you're doing....And it feels *awful*. It feels like...part of you *dies* in the worst sense of the word....But I guess [it] is sort of a *worry* that...I will be less attractive *now* as a result of this disability....I would like to have a relationship with somebody in my life, like a male, and I don't know if because now I'm disabled whether I'd be *less* attractive to somebody? So I guess that's a worry or fear. Would I be able to attract somebody who I'm also attracted to now that...I *do* have a disability....If you sort of educate...people around you, then...people understand what has affected you [and] there's less *judgement* and *disvaluing* you as a person....

[I have decreased my load at work and] it allows me to...get to the point to where I [can] function....So, there are times that I can't deny [nothing's wrong with me] but *most* of the time, I just carry on with life...And it works....Sometimes I don't know if it works well or not....So I keep hoping that something will happen and [my leg] will get better. I just went to a rehab specialist...but he said, more or less, what I have is what I'm stuck with....[He also said] that I'm going to have to have job retraining. That I'm probably only going to be able to do this job for a little while because of the amount of standing that I have to do on my leg. And that's *really, really hard for me* because I *love* my job...So I haven't kind a really gone there yet....Well, I guess...I'm lucky in that I am very independent and very self reliant but what I find with the grief [of my losses] is that I have to *admit* that

there are times that I can't deal with everything that life...sort of throws my way, completely on my own.

### *Discussion of Theme Three in Participants' Language*

Research theme three considered feeling understood in relation to these participants' concerns, hopes, and dreams. From a theoretical perspective, theme three synthesized the participants' descriptions of cotranscending or transcending beyond with intentional hopes and dreams (Parse, 1981, 1987, 1992) with consideration of feeling understood. Two common concepts arose for each participant: self-confidence and the enthusiasm and fear of wanting to make plans. Together these two central concepts created research theme three.

In the participants' descriptions of their experiences, all commented on feeling understood affecting their feelings of self-confidence. While some discussed the effects of not feeling understood in relation to their diminishing self-worth, others told of finding security by maintaining self-worth. The language of this concept varied among the participants. Examples included self-confidence, self-worth, acceptance of self, taking care of self, and self-esteem. Seeking self-confidence kept each participant going on despite her challenges. Tension arose for each nurse when her self-confidence was challenged in connection with feeling understood. Yet each sought to either attain or maintain a strong self-worth.

All told of the enthusiasm and the fear of wanting to make plans. Despite physical illness, changes in employment, and emotional challenges of living with a disability, the participants were determined to press on and persevere. Some hoped to find meaning in life, searching for answers about their disabilities, and moving forward to make a difference. For others enthusiasm surfaced in planning holidays and pursuing hobbies such as art and choir. Others identified that they carried on in life by not acknowledging anything was wrong with their bodies, or choosing only one accomplishment to pursue at a time. Yet, while all moved onward, they all admitted times in which they felt stuck and fearful of wanting to make plans. The nurses described times of not being able to move onward as feeling immobilized, directionless, stuck in their bodies, and having nothing in common with people. All five participants explained the fear they experienced in their desires to make plans. While some described this fear as worry or feeling scared, others

feared change or not being able to save themselves. Experiencing fear was uniquely expressed in each participant's life, but in varying circumstances. Some stopped making plans for their lives, while others felt like they could not be effective. These paradoxical rhythms co-existed in the participants' concerns, hopes, and dreams.

Distinct from feeling fearful of wanting to make plans, all the individuals also articulated a wish that things were like they were before their disabilities. The participants described this as wanting to go back to the way they were, wishing it would all go away, wanting to forget their disabilities, and denying anything was wrong. In expressing such views, all acknowledged that they did not believe this would happen, and some even said that their lives were not necessarily better before their disabilities. Yet all had moments they wished to be freed from having to engage in the challenges of their disabilities. The synthesis of these two concepts of self-confidence and the enthusiasm and fear of wanting to make plans provided insight into how feeling understood emerged within these five participants concerns, hopes, and dreams.

### *Summary*

The five participants interviewed for this study were introduced and their descriptions of feeling understood were summarized. Themes that surfaced from the data (transcribed interviews) through the process of analysis-synthesis were presented as the findings of this study and answered the research question, What is the meaning of the experience of feeling understood for nurses with disabilities? Statements from each interviewee were presented as a method that provided substantive data that depicted how the themes were a synthesis of the major descriptions from each participant's interview. Research themes were presented first in the participants' language, and second in the researcher's language. The themes have been summarized in the following table.

In the following chapter the three research themes will be discussed in the language of the researcher and theoretically interpreted. Further discussion of the research themes will be in consideration of the relevant literature.

Table 6.

*Research Themes in the Participants' Language and the Researcher's Language*

Research Themes in the Participants' Language	Research Themes in the Researcher's Language
An acceptance–non acceptance of changing abilities amid expectations engenders joyful relief and aching hurt.	Acquiescence-non acquiescence of shifting capabilities with prospects give rise to serenity-anguish.
Being believed–not being believed by others resides along with honesty-dishonesty manifesting wavering support.	Bonds of security-insecurity surface with candour-concealment amid tentative assistance.
Self-confidence fluctuates with the enthusiasm and fear of wanting to make plans.	Buoyant conviction wavers amid fervour with fright.

## Chapter 6 - Discussion of Findings

The purpose of this chapter is twofold. First, the research findings (research themes) will be interpreted using the theoretical lens of Parse's theory of human becoming. Findings will be discussed in light of the three research objectives that were derived from the three theoretical themes of meaning, rhythmicity, and co-transcendence (Parse, 1981, 1987). Second, the research findings will be discussed and analyzed in relationship to relevant literature.

### *Theoretical Interpretation of Findings*

The interpretations of the research findings are explicitly theoretical, corresponding with the pursuit of theory-guided research. Theoretical interpretation will be guided by a nursing theory, that of Parse's theory of human becoming. Application of Parse's theory does not provide a "given" or generalizable theoretical interpretation of findings; similarly, the research findings of this thesis are also not generalizable. Rather, Parse's theory offers a new language of words, concepts, and relationships between these words through which the researcher may engage in theoretical explanation, commentary, and a construction of reality through language. However, theoretical interpretation is just that; it is one of myriad possible interpretations. In this vein, Martel (2001) comments in his best-selling novel, *Life of Pi*:

Isn't telling about something—using words, English or Japanese—already something of an intervention? Isn't just looking upon this world already something of an intervention?...The world isn't just the way it is. It is how we understand it, no? And in understanding something, we bring something to it, no? Doesn't that make life a story? (p. 335)

Individual interpretation is also a notion supported by the theory of human becoming because it attends to the unique reality of the person living the experience. My interpretations of the findings through the lens of Parse's theory are further informed by my own experiences and personal understandings of the theory. Therefore, my theoretical analysis may differ from another Parse scholar's interpretation of the research findings. This is an important distinction because theory is not presumed to exist in a non-biased

bubble (Parse, 1996b). Rather, when a researcher looks through a theoretical lens, her/his perspective is informed by her/his own life experiences.

A majority of the research findings in this inquiry arose within paradoxes. For example, the participants all spoke of the joyful relief and aching hurt of feeling understood, interpreted as the paradox of serenity-anguish in the language of the researcher. Parse's theoretical perspective posits that all experience is paradoxical. The expression of my research findings in paradox indicates to me that theory informed how I engaged with the data. It is very clear to me that theory gives language to perspective and perspective informs the choice of language. Parse's theory definitely informed my interpretation of the data.

Living paradox is a fundamental concept within the theory of human becoming (Parse, 1994b). Paradoxes, such as serenity-anguish, are one phenomenon with two dimensions (Parse, 1998). A simple way to consider paradox is to compare it to a coin. The two sides of a coin cannot be separated. With a toss of a coin, one side faces up while the other faces down. In living paradox, one side of the paradoxical rhythm is in the foreground, while the other side is in the background (Parse, 1998). One side of a coin is not opposite to the other side. Similarly, paradoxes are not opposites but are rather united, with two sides of the same rhythm simultaneously present (Parse, 1992, 1998). The character of paradox is indivisible, therefore one aspect of a paradox cannot be discussed separately from the other side. This characteristic also creates a challenge in writing of paradoxical experiences in a manner that does not establish dualism or divisibility within a rhythm. The research themes in this study are frequently framed within paradox and discussion of these paradoxes must include perception of both aspects. For example, serenity may not be considered separately from anguish. Consideration of the multiple paradoxes found with the participants' experiences of feeling understood must be discussed as indivisible dimensions. In the following theoretical interpretation, the research findings will be reconceptualized through theoretical language and perception.

*Research theme one.*

Research theme one in the language of the participants is: *an acceptance-non acceptance of changing abilities amid expectations engenders joyful relief and aching*

*hurt*. Theme one, reconceptualized in the language of the researcher, is: *acquiescence-non acquiescence of shifting capabilities with prospects give rise to serenity-anguish*. Research theme one addresses the theoretical theme of meaning, as well as the first research objective: To describe the meaning of feeling understood for nurses with disabilities through dialogue. Research theme one attends to the first principle of human becoming which states: “Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging” (Parse, 1981, p. 42). Principle one addresses how participants constructed meaning in their lived experiences in multiple realms all-at-once, thereby cocreating their realities with others and the universe (Parse, 1992; Pilkington & Millar, 1999). In freely choosing personal meaning, participants selected meaning in the moment as they spoke of feeling understood. The meanings they chose to share were shaped by previous experiences, choices, and values. Theoretical interpretation of research theme one incorporates the theoretical concepts of imaging and valuing.

Parse (1992) states that imaging “refers to knowing; knowing exists at the explicit and tacit realms....Explicit and tacit knowing evolve simultaneously and mutually in the meaning moments of day-to-day living” (p. 37). The research participants described the meanings of their experiences of feeling understood in explicit and tacit ways of their day-to-day living of reality. Participants frequently languaged their meanings of feeling understood through metaphor. Imaging may also be described as picturing or symbolizing (Parse, 1981, 1992), of which metaphors are examples. All participants described their experiences of the phenomenon of concern using metaphorical images. The serenity-anguish of feeling understood was imaged by the nurses as: contentment and relief along with painful sadness, a house built on a good foundation but at times blown over, liberating freedom amid traumatic judgement, and comfort with hurtfulness. Through imaging, the participants pictured, symbolized, or realized the meanings of their experiences of feeling understood.

The participants created patterns of acquiescence-non acquiescence of shifting capabilities with prospects as they imaged a path of constructing meaning regarding feeling understood, thus co-creating reality. The participants spoke of shifting prospects as changing expectations in relation to feeling understood. In the shifting, they pictured

what a situation might be like for themselves (Parse, 1990b) to feel understood. One nurse said, "I'll tell these women I have fibromyalgia...[but] I'm still expecting negative responses." Another person explained, "I really thought [my daughter] would have been there for me....Now, two years later, I think she could." Yet another poignantly described her shifting prospects: "Even though I wanted the understanding [from my husband], I recognized that I couldn't expect him to. But I did." Within imaging, the participants structured the meanings of their multidimensional experiences that were being lived all-at-once (Parse, 1981, 1998). Interpretation of the participants' experiences as imaging is specific to the theoretical perspective. From a particularistic perspective, explicit knowing located in facts, norms, or cause and effect relationships would have been explored. Rather, from the human becoming perspective, languaging as explicit and tacit knowing is considered from the perspective that such knowing evolves simultaneously as individuals describe the meanings of their experiences.

Shifting prospects included picturing what could be while simultaneously contending with not having or letting go of expectations. At the same time, participants faced the challenges of shifting abilities while living with disabilities. Imaging as picturing or "creative imagining" (Parse, 1990b, p. 138) is portrayed in light of the participants' experiences regarding shifting expectations of feeling understood. All participants described their experiences as changing expectations in various ways. For example, one nurse explained, "You can't put expectations on anyone....The lesson for me is letting go...and not expect[ing] that understanding from people." Another participant remarked, "I can't expect people that aren't going through the same process to have understanding", yet she repeatedly found herself expecting others to understand her situation. Shifting prospects facilitated participants to create images of what could be while living amidst what was, what is, and what is not yet, all-at-once. The nurses experienced change as they pondered their expectations of what might be while they evolved with the imagined possibles (Parse, 1998). Imaging was apparent as participants described their changing expectations in light of their present engagement with altering abilities. The nurses' personal knowledge, constructed through explicit and tacit knowing, continuously evolved as new experiences reshaped knowledge of their shifting capabilities with prospects.

Imaging also includes aspects of personal questioning and searching for answers in life (Parse, 1981). Personal questioning and searching for answers was apparent in how participants described what feeling understood meant to them. As Rose said, "It's okay to have questions and not answers. It's even okay if I don't understand." Their descriptive answers were full of paradox rather than conclusive responses. For example, all of the participants described both acquiescence and non acquiescence of their evolving capabilities while living with disabilities. For these nurses, no aspect of the paradox existed alone. Rather the indivisibility of the paradox was apparent as participants questioned various aspects of their disabilities, as seen in the following statements: "There's a part of me that has a hard time understanding [my disability]. I don't totally understand it...[But] my job...is to accept myself at whatever stage I'm at." "I'm in this pain. I'm not sure what's going on. What do I need to do?" "Did I do this to myself?...Did I get sick because I wasn't looking at the right thing? I don't know."

Prospects were constantly shifting as participants spoke of questioning their expectations. In this questioning, personal expectations of feeling understood were reshaped. The shifting of individual meaning was portrayed in the following statements: "Now, whether they understand or not, I'm not sure if I care as much...I don't know if it's as important anymore." "I've given up some of my expectations." "Maybe my expectations were too great or something." "I've lessened my expectations...and that's okay". As such, participant imaging through engagement with personal questioning and searching for answers engendered the simultaneous reshaping of personal meanings and the meaning in their lives.

Participants were at times uncomfortable with their descriptions, questioning the co-existence of paradoxical ideas. They frequently asked: "Does that make any sense?" "Isn't that funny?" "Am I being true to myself?" They repeatedly commented, "I don't know", and "I don't know if that makes any sense." In their languaged questioning, they were puzzled by the presence of paradoxical experiences within feeling understood. Two of the nurses, Christine and Rose, voiced acceptance of their paradoxical experiences stating, "It's okay", "I've changed", and "It's okay if I don't understand." Meanwhile, none of the participants referred to their experiences as paradoxical, but simply said it was "the way life is" or "that's kind of an oxymoron [but] that's who you are".

Interpreting human experience as paradoxical is particular to the theoretical perspective guiding this study. In the normative paradigm, paradoxes are frequently regarded as ambivalent problems needing to be solved or eliminated (Cody & Mitchell, 2002). The mysterious element of paradox is often uncomfortable because of the ambiguity that people tend to interpret within that notion. There appears to be a societal expectation for us to live in an “orderly” fashion, experiencing only one side or the other of a paradox according to a circumstance. For example, many would regard it as inappropriate to experience joy at a funeral. Rather, the paradox of sorrow would be expected. Yet, for the individual in the situation experiencing both sides of the paradox, they may feel sorrow at losing a friend but simultaneously may experience joy that their friend’s suffering has ceased. For this individual, two sides of the rhythm coexisted simultaneously. It is often the element of the unknown or surprise within the notion of paradoxical experience that makes us question its presence.

According to Parse, imaging is a theoretical concept within the first principle of the theory that identifies the way humans continuously structure the meaning of multidimensional experiences that are lived all-at-once (Parse, 1981, 1992). Within principle one, imaging is intricately linked with speaking-being silent related to the concept languaging, and confirming-not confirming related to the concept valuing. Valuing refers to a person’s process of confirming cherished beliefs or priorities that reflect a personal worldview (Parse, 1981, 1992, 1998). Valuing is giving meaning to multidimensional experiences as a way in which a person creates reality (Parse, 1992).

From the human becoming perspective, research participants are understood to have cocreated their realities with others, the researcher, literature, events, and so forth (Parse, 1987) through describing what feeling understood meant to them. The participants’ descriptions are interpreted in the language of the researcher as: acquiescence-non acquiescence of shifting capabilities with prospects give rise to serenity-anguish. Valuing signifies meaning and this was disclosed as participants described experiences, feelings, relationships, and situations that were important for them within the serenity-anguish of feeling understood. Feeling understood was something participants longed for and described in a variety of ways: “important”, “awesome”, “valuable”, and made “all the difference in the world”. The serenity-anguish that came

from feeling understood was the acceptance-non acceptance and joyful relief-aching hurt that the participants spoke of in various ways. Christine spoke of content relief and painful sadness, as well as freedom amid disappointment and loss. Rose shared her significant experiences of wonderful relief and pain, as well as joy amid sadness and hurt. Crystal said that what was most important to her was feeling acceptance and love, although she also experienced judgement. Jan explained that feeling heard and acknowledged were a priority for her and something she valued although she also felt there were times no one heard her. Jan also valued feeling recognized but at times when this did not occur, she described it as traumatic and tough. Gladie explained that what was most important to her in feeling understood was to experience care, empathy, and empowerment although she also experienced feeling vulnerable, disappointed, fragile, and not being heard. The paradoxical experience of serenity-anguish was apparent in the participant descriptions of cherished values related to feeling understood.

The process of valuing involves choosing, prizing, or acting to confirm a cherished priority (Parse, 1981, 1992, 1998). Participants lived the serenity-anguish of feeling understood which was confirmed-not confirmed all-at-once. Parse (1994b) described the confirming-not confirming aspect of valuing as “the persistent living of what is treasured and not treasured simultaneously” (p. 18). The participants’ descriptions of joyful relief and aching hurt was an expression of their experience of the confirming-not confirming of serenity-anguish while living that which was treasured and not treasured all-at-once (Jonas-Simpson, 1998). The nurses openly described a treasuring-not treasuring associated with the serenity-anguish of feeling understood. Feeling understood was something they expectantly hoped for, “wanted”, “valued”, “desired”, and thought was “important”. For example, Jan portrayed her cherished relationship with her specialist: “He paid attention to [me] as a human being, a pretty extraordinary experience.” Gladie also told of how she chose to establish relationships with those she trusted and with whom she felt understood. When she was around individuals with whom she felt judged, she acted by choosing to “[move] beyond” those relationships. The participants’ processes of valuing were seen in their choices to pursue the treasured experiences of feeling understood amid shifting capabilities with prospects.

“Valuing is the process of living cherished beliefs while assimilating the new into a personal worldview” (Parse, 1992, p. 37). Assimilating the new was constantly unfolding for these participants amidst shifting capabilities with prospects. Some described living the unknown with regard to their health, being constantly challenged by progressive disabilities. Others identified that what had once been important to them had become unimportant in their journey. Yet others explained that it was difficult to pursue what they valued as they created their own way to persevere in the midst of enormous adversity. Feeling understood was lived as a value priority even in the midst of changing abilities amid expectations that at times challenged the viability of feeling understood. Therefore, it is highly significant that this phenomenon of concern is studied in depth with persons challenged in living with disabilities.

While imaging and valuing were the predominant theoretical concepts related to the participants’ statements of meaning within research theme one, the concept of languaging was also apparent. Languaging refers to the way an individual constructs and represents her/his own structure of reality (Parse, 1992). Parse (1992, 1994b, 1998) explains that the paradoxical rhythms of languaging are speaking-being silent and moving-being still. Thus, languaging is an expression of valuing and imaging. Through languaging, participants expressed valued images through their words, stories, metaphors, voice, emotions, gestures, and stillness. The nurses spoke of the importance of conversing, sharing openly with others, telling of their experiences, and being silent. Through their descriptions participants languaged their meanings of feeling understood.

The meaning of feeling understood was structured multidimensionally by the participants in this study who cocreated their realities through the languaging of valuing and imaging (Jonas-Simpson, 1998). The research findings predominantly addressed the meaning of imaging and valuing in the experience of feeling understood for these five nurses with disabilities. The findings further enhanced the human becoming theory through further description of the concept of languaging.

The nurses spoke of acquiescence-non acquiescence of shifting capabilities with prospects that gave rise to serenity-anguish in light of their relationships. The relationships that they primarily discussed were with their families, friends, colleagues,

and their health care professionals. Discussion of their experiences of the meaning of feeling understood in light of their relationships reflects the second research theme.

*Research theme two.*

Research theme two in the language of the participants is: *being believed-not being believed by others resides along with honesty-dishonesty manifesting wavering support*. Theme two, reconceptualized in the language of the researcher, is: *bonds of security-insecurity surface with candour-concealment amid tentative assistance*.

Research theme two addresses the theoretical theme of rhythmicity, as well as the second research objective: To describe patterns of relating within the experience of feeling understood for nurses with disabilities. Research theme two attends to the second principle of human becoming which states: "Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating" (Parse, 1981, p. 50). Theoretical interpretation of research theme two incorporates the concepts connecting-separating and revealing-concealing.

Connecting-separating represents a rhythmical process of moving together and moving apart (Parse, 1992). As with all paradoxes, both elements are simultaneously present. Connecting-separating encompasses multidimensional choices for an individual to engage-disengage with others, ideas, objects, and situations in the past, present, and future all-at-once (Bunkers, 1999b; Parse, 1981, 1992, 1998). Within the research findings, tentative assistance and bonds of security-insecurity were patterns by which the participants connected-separated with others all-at-once in feeling understood.

Bonds of security-insecurity refer to the participants' *perceptions* of others believing them and not believing them. This finding expresses both the closeness and the distancing associated with being believed-not being believed (Parse, 1992). For the participants in this study, feeling understood was experienced through connecting-separating with others with whom they felt they were being believed-not being believed. Within cocreated patterns of relating, bonds of security-insecurity were established. In the following quote by Christine, she described being believed-not being believed as a pattern of relating through which she was connecting-separating with another.

Part of being understood for me is that I'm being believed, I think in the most sort-of serious situations of when I really want to be understood....Because then I feel like I don't have to keep going on to try and explain....They've got it. And they're relating to me....When they can say something that lets me know they're believing me and they're wanting to know more and, sort of relating maybe to even their own experience, even if they don't have a disability, that they can see how I'm feeling or what I've been going through or what I have, can be true or is real.

Crystal also described connecting-separating related to being believed-not being believed in the following way.

[When I felt understood] it's like I don't feel like I have to prove myself anymore and it's a comforting thing....I just feel like I don't have to justify myself...I'm tired of justifying myself, even to myself....I can let that tension go. I kind of get the feeling like they understand and then it's okay, you know?

Each of the participants similarly described her experiences of being believed-not being believed. Aligning with Crystal, the others repeatedly shared that in being believed they no longer had to prove, explain, or justify themselves as they had when they were not being believed. Gladie spoke of being believed-not being believed by work administrators because she was "not given a hard time" but feared they would not purposefully hire a nurse with a disability. Jan also described experiencing bonds of security-insecurity in her work place as either receiving or not receiving "recognition and acknowledgement". The rhythmical concept of connecting-separating is further perceptible in the following quote from Jan: "One of my focus areas [at work] was connecting with others....It's *painful*. Because some of [my professional relationships] I *don't* want (laughs) but I have to have them because they're part of my job." While Jan pursued connecting with others, she also spoke about wanting to distance herself from others. Like Jan, all the participants lived both connecting-separating in developing bonds of security-insecurity. In doing so, they reveal that they valued being believed more than not being believed. They described various ways they pursued being believed while battling not being believed by explaining and justifying, convincing others, making others believe, and building credibility. Gladie gave the example of showing her x-rays and scars to colleagues and students so they could "buy into" her disability. In reference to working with her colleagues, she also said, "I *push* myself more than what I need to do, to try and *show* that ya, I'm pulling my weight".

For all the participants, feeling understood was experienced with connection and separation from others with whom they felt they were being believed-not being believed. In connecting-separating, bonds of security-insecurity were experienced. While Christine spoke of others who “got it”, she also said, “I tried...[to] get people to understand. And it just didn’t work!...Sometimes I feel like if people don’t always understand, they might not believe me, I guess”. Similar to theme one, Christine’s and the other participants’ expectations of others surfaced within the connecting-separating that encompassed being believed-not being believed. Jan also pursued “connecting with others”; yet, she experienced separation when she felt her colleagues were not believing or hearing her. “What I was trying to do was explain to them...[but] they *never heard* it!” Rose found herself in a similar situation with her colleagues: “It was just the simple fact that when colleagues...don’t believe that [FM] exists that I can say to them ‘There [is MRI] research [that] has shown...this does exist.’” Some of the nurses also described their experiences of feeling judgement in being believed-not being believed. Gladie illustrated this in the following:

It’s *really important* for me not to be judged. Cause you know, I still see myself as a very capable, competent person and so I guess for *me*, if someone judged me, then I wouldn’t want to be associated with them.

Gladie described that if she felt judged, she would choose to separate and move away from that person. Crystal too explained her experiences of judgement. “I feel like I’m judging myself as well as other people judging me. I feel like I’m a bit of a failure I guess”. As participants experienced bonds of security-insecurity in feeling understood, they selected both relationships and actions that were important to them and moved away from some relationships and towards others.

Parse (1981) states that when two or more people are in an intersubjective relationship, “they are truly present to each other, simultaneously unifying and separating as their togetherness evolves. While these individuals are participating with each other, they all at once are separating from others” (p. 54). The nurses in this study described their connecting-separating with others as wavering support with those with whom they were in relationships.

Wavering support was identified by all participants as an integral component of simultaneously unifying with and separating from others in their feeling understood. Participants told stories of how feeling understood was connected with experiencing support from others who cared for them without judgement while separating from others who were not supportive. Jan described receiving wavering support from her colleagues:

Like I created this...standard space orientation program....My colleagues at work didn't appreciate it....I was just wanting a pat on the back from them....I work with them. Why wouldn't they do that?....That's so not supportive. So I got squat!...[I've felt] very isolated. Disconnected. Like I don't have...collegial relationships....

I just think everybody wants to feel like they're understood or heard....I'm working with a manager right now who....cares enough to at least *hear* me. Well maybe she values what I have to say or *who* I am or what I *contribute* to the team. Maybe she doesn't totally but...but ultimately, she really thinks that I contribute. So that's cool.

In their descriptions of connecting-separating amid wavering support, participants described withdrawing from others and entering times of isolation and retreat in which they experienced loneliness and disconnection. They spoke of spending less time socializing, not picking up the phone as often, withdrawing from crowds, and remaining at home. Christine explained such a period in her life:

I tried...[to] get people to understand. And it just didn't work! And so I ended up feeling like I might as well just isolate myself....because it just takes *so* much energy to explain what's going on with me. And then to not be understood, to almost maybe be a bit rejected, not included in things with people – I don't know why....If you just can't get support....then you're scrambling to have people to understand you...

These periods of connection-separation for the participants shed a light on the rhythmical processes of moving apart and together. All spoke of times in which connecting with others replaced separation in their experiences of feeling understood. Gladie retold accounts of her experiences of wavering support.

Well I felt my biggest support [when I broke my leg] was my colleagues from work....I couldn't weight bear for like seven months, so I was totally dependent....friends would make food for me and they would come and visit me.... At the time, I found that my teenagers...were not supportive or not understanding *at all*....I had always been the *main* support system for my children and all of a sudden I couldn't give them as much support. But then, friends and family sort of stepped in to give them more support, and me support....Like I've

built a really good support system and I've *been* a good support system for other people.

Gladie perceived wavering support from colleagues, friends, and family. She also acknowledged the wavering support she could give to those with whom she was in relationship. During times of being physically dependent on crutches, separated from others, and often being unable to leave her house, Gladie described connecting with and separating from others in diverse patterns of wavering support. In research theme two, patterns were identified in which tentative assistance was intricately linked with bonds of security-insecurity as participants spoke of being connected with and separated from others in feeling understood.

Revealing-concealing is another paradoxical, rhythmical pattern of relating (Parse, 1992). When participants disclosed or revealed aspects of themselves to others, they also concealed or hid other aspects. "Revealing-concealing is disclosing-not disclosing all-at-once" (Parse, 1998, p. 43). Within research theme two, revealing-concealing was apparent within candour-concealment, stated by the participants as honesty and dishonesty. All participants described how candour-concealment with others disclosed and did not disclose who they were while they desired to enhance their opportunities to feel understood, even when they did not understand themselves. Crystal explained, "[When I feel understood] it's like I don't feel like I have to prove myself anymore....What I really *should* do...is phone [my friends] and tell them I'm going through a tough time." The participants chose to reveal-conceal aspects of themselves in relationships with candour-concealment. They spoke of honestly-dishonestly revealing and concealing their thoughts, feelings, concerns, and experiences of living with their disabilities. At times, Gladie also revealed-concealed her bodily scars. Gladie accounted,

What's worked is just to be really *up front* and really *honest* with people....Like I'd rather people be honest and it be hurtful but I know that they're honest, than for people to be dishonest and I feel very betrayed...

The participants also spoke of honestly-dishonestly telling colleagues, friends, and family about the rigorous aspects of living with disabilities. Jan explained, "I'm *not* a fake person. What you see is what you get. I'm very honest." The participants described that revealing-concealing aspects of themselves also came with challenges. Christine said, "It

takes a lot of energy to have to convince people that...what I'm saying is the truth!" Yet Rose found comfort in the candour-concealment, stating, "I don't have to keep defending myself. It's a big relief. You just take a big sigh. Ahhhhh..."

Participants explained that they revealed themselves with what they described as more honesty to those with whom they felt understood while tending to conceal that honesty from others with whom they did not feel understood. All of the nurses described times they chose to reveal-conceal their experiences while living with a disability. Christine identified, "For a long time I *pretended*...to make it look like my life was normal." Crystal also explained, "Like, you just don't want people to see how bad things are...(laughs) And it's almost like you're *lying* in order to not have to deal with peoples' reactions." Living amidst persistent and often unforeseen shifting capabilities evoked the participants' responses to reveal-conceal aspects of themselves. As Crystal illustrated, "I guess the unknown made me feel like I was a phoney, like I had to fake something."

Revealing-concealing was also apparent in participants' expressions of wanting to deny and wanting to accept the implications of their disabilities. Many did not wish to acknowledge to themselves, as well as to others, that their disabilities could potentially limit their opportunities at work or in leisurely pursuits. Rose recounted, "I went through a period of time when I tried to *ignore*. Like the old adage – if you ignore it, it will go away. Well it didn't." Gladie also said:

Well sometimes, by denying that I have got an injury....it's almost like I don't have to *admit it* if I pretend that it didn't really happen....[but] there are times I *can't* deny it....I *have to face it* and *have* to deal with it. But I don't go there on a regular basis.

Similar to the participants' descriptions of their openness and honesty with others, participants spoke of an honesty-dishonesty with themselves evidenced in such words such as pretending, ignoring, denying, and not admitting.

Although revealing-concealing and connecting-separating were the predominant theoretical concepts incorporated within research theme two, enabling-limiting was also visible within the text. The rhythmical concept of enabling-limiting refers to the infinite opportunities and limitations/restrictions that are inherent within choosing one direction over another (Parse, 1992, 1994b, 1998). Participants told stories of opportunities that were enabling, simultaneously limiting other options. Movement in one direction limited

movement in another (Parse, 1992). Participants were both enabled and limited with each choice they made or did not make as they spoke of feeling understood while living with disabilities. Rose told a story that illustrated the concept of enabling-limiting. After her diagnosis of fibromyalgia (FM) she chose to continue working in the hospital, despite feeling guilty and fearful that she “wasn’t doing a good job”. Her doctor asked her to try antidepressants as a pharmaceutical treatment for FM but she was too sedated to work and discontinued usage. Rose tried working full and part-time over the next three to four months, but found that, even with decreased work, her disability progressed and she got “worse and worse”. She then chose to leave work, re-start antidepressants, and try long-term disability (LTD). When Rose initially continued to work, she was enabled to continue to provide financially for her family, stay within her work place, and retain contact with colleagues. She was also restricted in her treatment because medications interfered with her ability to work. Eventually her choice to go on LTD renewed financial support and commencement of pharmaceutical treatment, but restricted her desire to work. Rose was enabled-limited by all choices (Parse, 1992). According to Parse, “the human continuously makes choices; every event in the universe is an opportunity to choose” (1998, p. 44).

Paradoxical rhythms were lived by the participants in their experiences of feeling understood. The research findings identified that the participants in this study cocreated rhythmical patterns of relating in feeling understood specifically through connecting-separating and revealing-concealing. The findings also shed light on the theory of human becoming through further description of the concept enabling-limiting.

*Research theme three.*

Research theme three in the language of the participants is: *self-confidence fluctuates with the enthusiasm and fear of wanting to make plans*. Theme three, reconceptualized in the language of the researcher, is: *buoyant conviction wavers amid fervour with fright*. Research theme three addresses the theoretical theme of co-transcendence, as well as the third research objective: To describe personal hopes, concerns, possibilities, and visions of what might be in relation to feeling understood for nurses with disabilities. Research theme three attends to the third principle of human

becoming which states: “Cotranscending with the possibles is powering unique ways of originating in the process of transforming” (Parse, 1981, p. 55). Theoretical interpretation of research theme three incorporates the concept of powering.

In research theme three, the words chosen to express the language of the researcher incorporate the theoretical concept of powering. The word, buoyant, was chosen to reflect the resilience of participants in feeling understood. The notion of buoyancy or resilience attends to what Parse (1992) describes as “the back and forth experienced by humans in all life situations, an energizing force which sparks moving beyond the moment” (p. 38). Parse (1992) coined the word powering in her theory to depict the pushing-resisting rhythm in mutual human-universe processes.

Buoyant conviction refer to the participants’ desires to make plans in light of their fluctuating self-confidence. Further, participants spoke of their enthusiasm and fear associated with wanting to make plans. The researcher’s desire to capture the indivisibility of this aspect of feeling understood for the participants in this study surfaces in the researcher’s choice of words. Consistent with the researcher’s language related to participant experiences is the theoretical notion of powering within human becoming theory. Therefore, the researcher’s language abstracts the participant’s language of the theme and further theorizes that language in terms of the concept of powering. The participant’s explained that they experienced fluctuating self-confidence in feeling understood yielding the enthusiasm of wanting to make plans which moved them beyond the moments of fear or fright.

Parse (1992) explains that powering is “the pushing-resisting rhythm in all human-human and human-universe interrelationships” (p. 38). Further, Parse (1998) explains “powering is a human-universe process recognized in a continuous affirming-not affirming of being in the presence of the possibility of [non-being]” (p. 47). Being non-being is further described:

Being is continuously confronted with non-being. Non-being shows itself in everyday life as [humans risk] losing self in [human]-other interrelationships. The risk of losing self here refers not only to dying but to the risk of losing one’s self through being rejected, threatened, or not recognized in a manner consistent with expectations. (Parse, 1981, p. 57)

For this study's participants, buoyant conviction wavers amid fervour with fright was the pushing-resisting of being non-being in light of feeling understood. The risk of losing self, which Parse speaks of in the above quotation, was evident with the participants' descriptions of feeling understood. They spoke of the risks involved with feeling understood, fluctuating self-confidence, and making plans. The potential risks of losing these valuable experiences identified the non-being in the not-yet known for these nurses (Parse, 1998). Participants repeatedly spoke of how they risked losing themselves through feeling rejected, not acknowledged or recognized, threatened, or judged. They further risked losing themselves within interrelationships to which expectations were connected. Yet these nurses found buoyant conviction wavers amid fervour with fright in feeling understood amid their hopes and dreams

Buoyant conviction, when described by the participants as times when their self-confidence fluctuated, was explained to be interconnected with feeling understood. Amid fluctuating self-confidence and the risk of losing one's self, each nurse described buoyant conviction as an energizing force that facilitated her to move beyond the moment.

Christine clearly explained:

I think when you're not understood...your self-confidence...can go down.... My opinion then was if I can't work, well then what's the point of me existing?... Yeah, I have noticed in the last couple of years, just feeling a lot stronger, a lot more self-confident.... So, now it just feels so liberating.... [that] I've just built [up my] self-esteem.... I mean being understood, it really does affect...my feelings about myself.... I know myself a lot better.

Rose also described:

I was living in a lot of pain, a lot of denial, a lot of beating-up-of-self.... So you have to go [on] in your searching for answers, to find out well, can I deal with this?... The only one that you can ask these questions to and get the answers that you really need are within yourself.... It's just having a confidence in myself that had been lacking for a good long time.... Health for me would mean acceptance of myself at whatever stage I'm at.... [And then I have] a sense of peace that everything's going to be okay. That nothing in this moment is too overwhelming. That I can go on to the next step....

Crystal shared her experiences of fluctuating self-confidence. "I hate it when there's confrontation between people.... And I know that it's affected my feelings of, I guess my self-worth. Just feeling down on myself. Just thinking that I've done something

*wrong...*” The pushing-resisting rhythm of being non-being was revealed within Crystal’s description of the risk of losing her “sense of security”. Amid non-being, being arose with buoyant conviction.

[I hope] just to feel a spark again and to feel like I have the energy to *function*....[When I feel understood], I feel maybe like there’s hope...that this is going to go away and that I’m going to be able to function again like I did before.

Jan spoke about the risk of losing herself by not being recognized or acknowledged at work. Through her tears and quiet sobs, she said: “nothing I could do could affect anything....The work that I did as a *leader*...[didn’t seem] to matter....Like I said, [feeling understood] makes me feel like I can move forward and I can let it go.” Gladie shared how her self-esteem helped her to move beyond the risk of losing herself through being judged. “I still have the ability and a good enough self-esteem to move beyond...those people [who judge me]....If you’re judged, it makes you feel more *fragile*, more vulnerable in terms of people questioning your abilities and *who* you are...”

Parse (1981) claims, “powering is a continuous rhythmical process incarnating one’s intentions and actions in moving toward possibilities” (p. 57). For the participants, powering was evident in the rhythmical interplay of enthusiasm and fear related to wanting to make plans. Their cherished hopes, plans, and dreams encompassed reaching beyond the moments, amid their fervour with fright, towards buoyant conviction.

Christine described the story of her fear and enthusiasm of wanting to make plans.

So I [had]...stopped making plans....Because we were *so scared*, *so* stuck in worry of my illness....There was a lot of *fear* about my life. (pause) I mean I would actually would even say fear of death at times, because I was so ill....And then a couple of years ago we said, “Okay we’re going to go on a trip when we turn 40”, so that’s coming up next year....So, you know, we’re *trying* to make some plans....The hopes and dreams...are starting to happen again because I’ve kind of stabilized with my health. Um, but for a while, there was *nothing*.

For Rose, the fear of making plans left her feeling “immobilized”, with “no sense of direction”, and unsure if she could “save [her]self”. Describing FM as the “catch 22 disease”, Rose stated, “You feel you can’t go back, you can’t go forward but staying where you are isn’t healthy either.” Amidst this tension, Rose found meditation helped her “refocus” and move toward possibilities. Accordingly, she explained, “so you have to

go [on] in your searching for answers....Meditation does a lot for me....It's like refocus on something else....[so] that I can go on to the next step.”

Similar to Rose, Crystal spoke of change within making plans. She asserted, “*change* has always been a tough thing for me. Like, I'd rather have a horrible situation to live in, than the unknown....Anything new that [arises] in [life], [has been] a *real* fearful thing for me.” Crystal frequently described such times in her life as though she were “treading water”. The pushing-resisting of powering was apparent in her actions as she described moving toward and away from possibilities. She said, “I try to pick on one thing that I can do to kind of make me feel like I've accomplished something.”

Jan shared how she was pursuing cherished plans within her job. However, she did not feel understood by her colleagues and felt alone in her pursuits.

I became this person...trying to create [communication about what nurses do, but] no one else wanted [it]....It just constantly makes me feel like an idiot. Like I'm *so* unrealistic that...my goals, my dreams are not appropriate....Because, here I am, frustrated, overwhelmed, feeling alone, feeling isolated, hitting my head against a brick wall because what I'm saying or doing is not being understood.... It overwhelms me....I think [time to veg out]...would help me clear frustrations more readily and not hang onto them....Like I said, [feeling understood] makes me feel like I can move forward and I can let it go.

Gladie also shared her desires amid fears of her many hopes and plans. For example, she longed to be in a relationship but feared she was undesirable. She hoped her leg would “get better” but her doctor said, “What I have is what I'm stuck with”. She dreamed of continuing her education in critical care but knew she would eventually have to plan to decrease her work as a nurse. For Gladie, the pushing-resisting rhythm of powering was apparent as she explained, “So, there are times I can't deny [nothing's wrong with me] but *most* of the time, I just carry on with life...And it works.” In this study, the powering of feeling understood was clearly apparent within the participants' hopes, concerns, possibilities, and visions of what might be.

While powering was the predominant theoretical concept of co-transcendence within research theme three, the concepts of originating and transforming were also apparent. Originating “means creating anew, generating unique ways of living which surface through interconnections with people and projects” (Parse, 1992, p. 38). The participants revealed their unique selves through individual expression, as well as through

the ways they lived their interconnections. The nurses shared unique expressions of themselves when they felt understood. Some said that being open, honest, real, and risking communication facilitated their experiences of feeling understood. All the participants also spoke of the importance of taking care of themselves. They did this in varying and unique ways, such as taking care of their bodies, taking art or university classes, singing in a choir, walking, horseback riding, meditating, going to counselling, and continuing education. The participants repeatedly spoke of being “the same person” or saying “I’m still me” as they sought the experience of feeling understood while living with a disability. It was very important to the nurses that others knew that although they had changed and had found creative ways to live amid their disabilities, they were still the same persons they were before encountering disabilities. Christine explained, “You realize your whole life is kind of changing and then everyone starts looking at you differently and all those other things that go along with disability”. Many spoke of their experiences of their aversions toward being labeled as disabled or being forgotten or disregarded while explaining that they remained as unique as they were before having a disability. In these ways, the participants uniquely distinguished themselves from others.

Transforming, the third and last concept of co-transcendence, is “the shifting of views of the familiar as different light is shed on what is known” (Parse, 1992, p. 38). Within the experience of feeling understood, participant’s shared how their views of the familiar were shifted. All the nurses in this study spoke of living with a disability and accepting and engaging with the challenges of their disabilities. While all wished that things could be “like they were” before they had disabilities, many explained that their lives were not necessarily better before their disabilities. Some said they wished their disabilities would “go away”, or that they could “forget” about them. Another participant chose at times to deny anything was wrong. Although living with disabilities was now considered familiar, what Christine called “normal”, in many ways it was also unknown and unforeseen. As the participants shifted their gaze to an unfamiliar future and their familiar past, their descriptions spoke to an everchanging now. In this shifting, the participants did not believe things would ever be “like they were”. Transforming is considered the changing of change (Parse, 1998) and this was seen as the participants in this study shifted their gaze from the familiar to the unfamiliar, and from the unfamiliar

to the familiar, all-at-once. Priorities changed for these nurses living with disabilities in their experiences of feeling understood as they chose to move beyond.

The research findings identified that the experience of feeling understood was lived by the nurses through the pushing-resisting of powering. The findings also enhance the human becoming theory through further description of the concepts of originating and transforming. When the theoretical interpretation of the three research themes are combined, feeling understood is conceptualized as powering of imaging valuing amid connecting-separating with revealing-concealing.

### *The Research Findings in Relation to Relevant Literature*

In the following section, the research findings from this study are discussed in light of relevant research literature. Such literature includes text in the forms of books, articles, theses, and dissertations that primarily address either the population for this study, that is, nurses with disabilities, or the phenomenon of concern, that is, feeling understood. Literature that attends to both the phenomenon of concern in combination with the study population could not be found. A search of various databases including ISI Web of Science (Thompson ISI, n.d.), CINAHL (Cumulative Index of Nursing and Allied Health Literature), MEDLINE (database for medicine and related areas), and Dissertation Abstracts International yielded approximately one hundred sources of literature considered relevant to the findings of this study. In addition, several pertinent articles were received through collegial support.

The three research themes identified in this thesis represent participant descriptions of their experiences in relation to meaning, rhythmicity, and co-transcendence (Parse, 1981, 1987). The descriptions that address each of the theoretical dimensions are in themselves a synthesis of various concepts. Accordingly, each thematic finding of this study is an indivisible whole. Needless to say, literature related to this indivisibility is nonexistent. Therefore, aspects of each theme are considered in light of the relevant literature.

To begin, research themes are considered in light of research literature that studied the phenomenon of feeling understood based in empiricist or non-empiricist inquiry. Additionally, literature that attended to or addressed the experience of feeling

understood as a complimentary aspect of a study is included here. Further, literature that included issues or aspects of relevance to one's experience of feeling understood, such as nurse recruitment and retention, nurses with substance use, and nurses or nursing students with disabilities, is examined in light of study findings.

#### *Research Theme One and Related Literature*

Research theme one in the language of the participants is: *an acceptance–non acceptance of changing abilities amid expectations engenders joyful relief and aching hurt*. Theme one, reconceptualized from the findings in the participants' language into the language of the researcher, is: *acquiescence–non acquiescence of shifting capabilities with prospects give rise to serenity–anguish*. Research theme one is discussed in relation to relevant literature.

#### *Acceptance–non acceptance: Non-empiricist inquiry.*

A number of research studies grounded within non-empiricist inquiries had themes or participant descriptions that were consistent with the finding of acceptance–non acceptance in research theme one (Baker & Daigle, 2000; Dickson, 1991; Jonas-Simpson, 1998, 2001; McIntyre, 1994, 1997; van Kaam, 1958). Starting with the research on feeling understood based within non-empiricist methods (Dickson; Jonas-Simpson; McIntyre; Moncrieff, 1999; Sundin & Jansson, 2003; van Kaam), four inquiries by Dickson, Jonas-Simpson, McIntyre, and van Kaam were found to be similar. One noteworthy comparison among the four studies is that they all specifically identified acceptance as a facet of feeling understood. Similarly, the nurses in this study all spoke of acceptance–non acceptance within their descriptions of the meaning of feeling understood.

Specifically, acceptance–non acceptance arose within Dickson's (1991) findings in his dissertation on feeling understood. Through the use of Moustakas' heuristic method, he sought to answer the research question, "What is the experience of feeling understood?" Dickson interviewed ten people that he referred to as co-researchers. Interestingly, he did not require that the participants meet the criteria for a discrete population. His findings were creatively synthesized into a poem (see Appendix F for

Dickson's full poem). The following is an excerpt from Dickson's poem that appears to convey consistencies with acceptance-non acceptance in theme one.

Different, alienated, alone,  
Struggling for understanding....

Feeling the understanding acceptance,...  
I am recognized, validated, honoured. (p. 141)

In these particular verses, Dickson identified being recognized, validated and honoured amid feeling different, alienated, and alone. Although Dickson did not articulate these experiences as paradoxical, from a human becoming perspective, they could be interpreted as such. Similar to Dickson's participants, participants in this study also spoke about acceptance-non acceptance as being accepted, recognized, loved, and acknowledged amid being rejected, acknowledged or recognized. Although this paradox of feeling understood is specific to this study, it is apparent in light of Dickson's findings that others have previously found and written of similar features of this phenomenon of concern.

Consonance with acceptance-non acceptance within theme one was found within participant descriptions from Jonas-Simpson's (1998, 2001) phenomenological inquiry of feeling understood. Jonas-Simpson explained that some of the women with enduring health problems in her study spoke of experiencing acceptance and belonging in feeling understood. While Jonas-Simpson identified acceptance, she did not speak to the paradoxical experience of acceptance-non acceptance identified in this study.

In a similar vein, acceptance-non acceptance was identified within research by van Kaam (1958) on "really feeling understood" (p. 139), although he did not refer to the experience as paradoxical. In van Kaam's phenomenological study, acceptance-non acceptance was found to be consistent within the participants' descriptions in his study. Much like the nurses in this study, participants in van Kaam's research spoke of feeling accepted, loved, wanted, and cared for amid fears of being ridiculed, not taken seriously, or laughed at. Dissimilar to this study's findings, van Kaam's data from participant statements were not discussed as paradoxical. Rather, he regarded the descriptions as positive and negative aspects or "seemingly contradictory statements" (p. 90). Van Kaam explained that the participants in his study mentioned the dissatisfying states of feelings,

such as fear, and that these states disappeared when replaced by expressions of more satisfying states, such as acceptance and love. Van Kaam articulated a co-mingling of what he considered polar states. Van Kaam's perspective differed from the theoretical interpretation advanced here in that he did not support the coexistence of paradoxical experiences; instead suggesting a persistent shifting from negative to positive experiences.

One qualitative nursing study on understanding (McIntyre, 1994, 1997) was consistent with acceptance-non acceptance within theme one. McIntyre's research on constituting understanding was based in interpretive methods through the use of a hermeneutic interpretive approach. Through her research question, "What does it mean for a patient to be understood by a nurse?", McIntyre studied how nurses could better understand patients' lived experiences of living with terminal or chronic illnesses. Similarities between this study and McIntyre's study revolved around participant statements related to being acknowledged and not being acknowledged, and comfort and suffering. The overarching difference between these two studies was that McIntyre's intent in her study was to explore the constitution of understanding within nurse-patient interrelationship. Dissimilarly, this study did not focus on a person's understanding of another. From the human becoming perspective that guided this study, there is not a given assumption that a person will understand another's experiences. Rather the focus of this study was on exploring the meaning of feeling understood for the person living the experience.

While the preceding literature represents an exploration of feeling understood as the primary focus of research, a number of studies revealed feeling understood as a complementary aspect of another phenomenon of study (Allen & Thompson, 1984; Antonucci et al., 1997; Baker & Daigle, 2000; Black, 1991; Burgoon et al., 2000; Carlson et al., 2001; Carroll et al., 2000; D'Avanzo, 1992; de Groot & Rodin, 1998; Gray et al., 1997, 1999; Howell, 1998; Jan & Smith, 1998; Murray et al., 2002; Peltz, 1992; Reis & Shaver, 1988; Reis et al., 2000; Rowe, 1992; Stallard et al., 2001; Sullins, 1992; van der Kolk, 2002; Van Hook, 1996). Within this body of literature, only one research article by Baker and Daigle (2000) addressed the theme of acceptance-non acceptance. Baker and Daigle qualitatively studied cross-cultural hospital care as experienced by Mi'kmaq

patients from the Big Cove reserve in New Brunswick when hospitalized in non-aboriginal settings. The themes from the authors' findings "revolved around issues of misunderstanding, being misunderstood, and feeling understood" (p. 15).

Nurse participants in this study spoke about feeling understood including the experience of acceptance-non acceptance which they explained as being accepted, acknowledged, loved, and recognized amid being rejected, not being accepted, recognized or acknowledged. Acceptance-non acceptance similarly arose within participant statements in Baker and Daigle's (2000) study when Mi'kmaq patients described that they felt understood by caregivers who accepted their customs of family visiting and treated them as social equals; yet, the clients also experienced a sense of being strangers in the "white man's" (p. 8) world. The authors interpreted these participant statements as understanding and misunderstanding respectively. However, they did not distinguish between understanding, misunderstanding, being misunderstood, and feeling understood. One of the main differences between these two studies was the theoretical interpretation of data. Baker and Daigle explicated that they used a qualitative postmodern methodology of interpretive interactionism developed by Norman Denzin. Their inquiry sought "to investigate the relationship between personal troubles and the public institutions created to address these troubles....Its aim [was] to provide authentic understanding of the problem being investigated"(p. 10). Baker and Daigle's intent to pursue the causal relationships between problems needing to be solved through an accurate/correct explanation differs from this study because, from a human becoming perspective, one would not pursue causal relationships with intent to explain or predict.

*Changing expectations: Empiricist inquiry.*

The nurse participants in this study spoke of the meaning of expectations in relation to feeling understood. They all shared their expectations of others and themselves in relationship with their friends, families, colleagues, patients they cared for, or nurses who cared for them. The participants also discussed, in one way or another, how their expectations changed. Similarly, the notion of changing expectations was found to be present in two studies (Flaherty, 1998; Galpert, 1988) that researched feeling understood based within empiricist inquiry.

For example, Galpert's (1988) research on empathic understanding in psychotherapy between therapists and outpatients was consonant with changing expectations in research theme one. From a focus on prediction of therapy outcomes, Galpert found that therapists' attitude of positive social expectancies towards their patients, or considering their patients to be "socially adept" (p. 79), created an interpersonal environment that enhanced patients' feelings of being accepted and understood. In his research, expectations were therefore discussed in relation to the therapists' expectations of their patients as socially adept. Conversely, in this thesis the participants spoke of their own expectations of others and themselves in relation to feeling understood. At no point did any nurse speak of experiencing expectations from others, their therapists (if applicable) or otherwise, as a catalyst toward feeling understood. However, such expectations fuelled a feeling of not being understood which, when framed in an understanding of human experience as paradoxical, *is* an expression of feeling understood. Rather than circular, changing expectations is being posited as a manifestation of feeling understood.

The finding of changing expectations was further considered within a second text by Flaherty (1998) who studied expectations in relationship to feeling understood in her communication studies dissertation entitled, *Communication expectations, feeling understood, and relationship development*. Flaherty used a repeated measures design to examine communication, feeling understood, and five "various stages of relationship development and decline" (p. 11). Expectancy violation, the theoretical framework used to guide Flaherty's research, purports that "negative expectancy violations lead to negative evaluations of others, whereas positive violations of communications expectancies lead to positive evaluations of others" (p. 22). Flaherty defined communication expectations as "norms of expected behaviour that exist on continua within relationship development decline" (p. 61). She suggested that people assess their partners' communicative behaviours as either meeting or violating expectations, thereby determining the level of feeling understood in the relationship.

Feeling understood was considered by Flaherty (1998) to be "the interpretive vehicle that propels relationship development and decline" (p. 11). Feeling understood was also regarded as a subjective, individual "assessment of communicative messages in

relationship interactions” (p. 43). Flaherty conceptualized feeling understood as a measure of met expectations that became more important as relationships developed. Feeling understood was therefore used to distinguish between the five stages of relationship development and decline.

Flaherty (1998) argued that relationship development depended upon levels of feeling understood regarding communication expectations. One hundred and ninety eight participants completed questionnaires on communication expectation, feeling understood, and relationship stages a total of five times (one for each relationship stage). The participants were individuals who had been romantically involved in the past year. Multiple statistical analyses were conducted on the questionnaires. The results of Flaherty’s study provided “some support for communication expectancies, which are important for understanding the various stages of relationship development and decline” (p. 110). She also found that feeling understood was positively correlated with communication expectations throughout all stages of relationships.

Similar to the expression of changing expectations within feeling understood for the five nurses with disabilities in this study, Flaherty (1998) found a positive correlation between communication expectations, feeling understood, and relationship development. However, this is where the similarities between Flaherty’s study and this study end. Flaherty’s research supported sequential stages of human experiences within relationship development and a linear correlation with feeling understood. However, sequential or linear notions are not theoretically consistent with a human becoming perspective purporting that individuals are engaged in an everchanging process of becoming (Parse, 2004). Although Flaherty’s research discussed feeling understood and expectations, her conclusions were inconsistent with this study’s findings.

*Joyful relief and aching hurt: Non-empiricist inquiry.*

Within the research on feeling understood based within non-empiricist methods, two inquiries by McIntyre (1994, 1997) and Moncrieff (1999) were found to be similar with the finding of joyful relief and aching hurt. One similarity between the two texts is the inclusion of *relief* as an expression of feeling understood. While the notion of relief was identified in the research literature, neither study identified a paradoxical experience

that included relief, such as the findings illuminated in this study of joyful relief and aching hurt.

Studies by Moncrieff (1999) and McIntyre (1994, 1997) related participant descriptions that were consistent with joyful relief and aching hurt, although neither author interpreted their descriptions as paradoxical. First, Moncrieff studied the experience of feeling understood for persons engaging with family services. Similar to Jonas-Simpson's (1998, 2001) research and this study, Moncrieff used Parse's theory of human becoming in her qualitative, descriptive study. Moncrieff's participants spoke of feeling understood as feeling positively good, relieved, happy, and, mutually respected as well as feeling negative, frustrated, angry, afraid, intimidated, and discomforted. The participants' descriptions were consonant with the nurses in this study who described joyful relief and aching hurt as: contentment and relief along with painful sadness, liberating freedom amid traumatic judgement, and comfort with hurtfulness. It is interesting to note that both Moncrieff's study and this thesis used the same theoretical perspective, methodology, and both found similar descriptions of the meaning of feeling understood for their research participants. Yet the research populations were different with Moncrieff speaking with persons engaged with family services and this study interviewing nurses with disabilities. Such similarities probe the inquiry of feeling understood potentially as a universal phenomenon in which anyone, regardless of population, may be able to speak of the phenomenon.

Second, the finding of joyful relief and aching hurt was consonant with McIntyre's (1994, 1997) research, particularly within her participants' descriptions. Many of the participants spoke of feeling understood as relief or comfort along with experiences of pain, the unknown, devastation, and horror. The situations in which joyful relief and aching hurt were discussed between McIntyre's participants the nurse participants in this study were very different. However, from a human becoming perspective, context as a discrete entity of experience is not the focus of inquiry. Rather, focus is on the person's perspective of joyful relief and aching hurt. Participants from both studies spoke of their relief and pain in relation to feeling understood, discussed as understanding in McIntyre's study.

Both Moncrieff (1999) and McIntyre (1994, 1997) presented participant descriptions that were resonant with the finding of joyful relief and aching hurt. Yet again, neither researcher identified these descriptions as paradoxical. At this juncture I am reminded that the expression of research findings as paradoxical is indicative of theory informing how one engages with, and interprets data. Interpretation of data using a different theoretical perspective, such as with McIntyre's research, or even with the same theoretical perspective, as with Moncrieff, can create myriad possible interpretations. Interpretations of findings through theoretical lenses are further informed by our own experiences and personal understandings of theories. In a similar vein, when I consider other literature in light of the findings, I am also reminded that my theoretical perspective further informs how I engage with other research.

#### *Research Theme Two and Related Literature*

Research theme two in the language of the participants is: *being believed—not being believed by others resides along with honesty-dishonesty manifesting wavering support*. Theme two, reconceptualized from the findings in the participants' language into the language of the researcher, is: *bonds of security-insecurity surface with candour-concealment amid tentative assistance*. Research theme two is discussed in relation to relevant literature.

#### *Being believed-not being believed: Non-empiricist inquiry.*

Beginning with consideration of being believed-not being believed within theme two, three research studies on feeling understood that used non-empiricist methods identified similarities (Jonas-Simpson, 1998, 2001; McIntyre, 1994, 1997; Moncrieff, 1999). For the nurse participants in this study, feeling understood was lived in connection with and separation from others with whom they felt they were being believed-not being believed. The participants described various ways they pursued being believed while attending to not being believed by trying to make people believe them. They described spending enormous effort on building credibility through explaining, justifying, and convincing. Some of the participants also described feeling judged when being believed-not being believed. Gladie illustrated this in the following statement:

It's *really important* for me not to be judged. Cause you know, I still see myself as a very capable, competent person and so I guess for *me*, if someone judged me, then I wouldn't want to be associated with them....I would try to move beyond those people.

The articulation of judgement within the experience of feeling understood was echoed in a number of non-empiricist studies (Jonas-Simpson, 1998, 2001; McIntyre, 1994, 1997; Moncrieff, 1999). Moncrieff's nursing theory-guided study described the experience of feeling understood for persons engaged with family services. All participants in Moncrieff's study "explained that they felt misunderstood in situations when they felt that other people were judging them" (p. 54). Moncrieff related participants' descriptions of situations when they felt judgement from others or from themselves, as well as times they did not feel judged. Similarly, nurse participants in this study also spoke of being believed-not being believed in terms of feeling judged and/or not judged. Similarly, in Jonas-Simpson's phenomenological research on feeling understood, the women with enduring health problems in her study spoke of the experience of feeling understood as connecting with others who listened without judgement. McIntyre also found that the participants in her hermeneutic study with persons who were living with terminal or chronic illnesses spoke of people who accepted them and others who judged them.

The identification of the experience of judgment among these three studies (Jonas-Simpson 1998, 2001; McIntyre, 1994, 1997; Moncrieff, 1999) and the findings of this study provides an interesting comparison within research on feeling understood. Yet in this study, judgement comprised only an expression of some participants' experiences of being believed-not being believed by others. All participants either spoke of why it was important for them to be believed or what they did to facilitate being believed by others. Paradoxically, all the participants described instances in which they were not being believed. The finding of the paradox being believed-not being believed was specific to this study when compared with the literature related to feeling understood based in non-empiricist methods by Moncrieff, Jonas-Simpson, and McIntyre.

*Honesty-dishonesty: Non-empiricist inquiry.*

In consideration of honesty-dishonesty within research theme two, a number of studies surfaced similar findings (Brewer & Nelms, 1998; Jonas-Simpson, 1998, 2001; Lillibridge et al., 2002; McIntyre, 1994, 1997; Porter, 2004; Restifo, 2001; van Kaam, 1958; Winland-Brown & Pohl, 1990). One prevalent finding among all reviewed studies on feeling understood (Jonas-Simpson; McIntyre; van Kaam) was the notion of honestly sharing about oneself as an experience of feeling understood. In a similar fashion, the nurse participants in this study all spoke of portraying honest and dishonest accounts of their disabilities.

All participants in this study described how honesty-dishonesty with others enhanced their opportunities to feel understood, even when they did not understand themselves. Their descriptions of honesty-dishonesty were expressed through the use of words such as pretending, not telling the truth, faking, isolating, denying, and lying (associated with betrayal), vulnerability, protecting oneself, and retreating from others. Participants in van Kaam's (1958) research on "really feeling understood" (p. 139) also spoke of honestly revealing themselves while not having to fake or pretend. Jonas-Simpson (1998, 2001) similarly addressed honesty in her research findings on feeling understood under her second core concept, "attentive reverence of nurturing engagements" (1998, p. 100). She explained that some of her participants described how being honest and sharing enhanced their experiences of feeling understood. While Jonas-Simpson and van Kaam identified honesty, neither author spoke of the paradoxical experience of honesty-dishonesty identified in this study.

Honesty-dishonesty was discussed in a number of articles by Porter (2004), Restifo (2001), and Winland-Brown & Pohl (1990) within the relevant literature addressing nurse recruitment and retention. However, not one of these authors considered feeling understood in their discussions of honesty-dishonesty. Rather, they all identified honesty-dishonesty in relation to disclosure of disability (Porter; Restifo; Winland-Brown & Pohl).

For example, Porter (2004), a nurse with a disability, shared her story of having to leave her job due to a catastrophic illness and subsequently losing her job. Two years later, she re-certified in nursing and applied for a new job. Situated in a legal perspective

she explained that, in a job interview, an employer may not ask a job candidate if she/he has a disability until the job has been offered. Porter also identified that employers can not require an applicant to take a medical examination that differs from what is required of all applicants. Porter required the use of hearing aids due to 70% hearing loss from her illness and she did not have to disclose her disability in her interview. The Americans with Disabilities Act provided safety for her and other individuals, not requiring them to disclose disabilities. In Canada, duty to accommodate employees with disabilities is required by the Canada Human Rights Act. Employers are required to accommodate employees to the point of undue hardship under the direction of antidiscrimination legislation from the Supreme Court of Canada (B.C. Human Rights Commission, 2000; Joanis, 2001; Ponak & Morris, 1998).

Winland-Brown & Pohl (1990) also addressed disclosure of disabilities in an interview setting. The authors conducted a phenomenological study that involved nurses with disabilities. Participants shared with the authors that few work positions were available to them and therefore, “they would be inclined to be deceptive about their health” (p. 26) status when interviewing for a new position. Restifo (2001) supported these participants’ perspectives in her article on career tips. Restifo further advised nurses with disabilities that they should not mention their limitations, inconveniences, substance problems, or challenges in their cover letters, resumes/CVs, interviews, or job applications. She suggested that nurses should state what they may need only when they are asked if they can provide the duties required of the position with or without reasonable accommodation. Otherwise, nurses were advised to focus on abilities versus inabilities, a comment often repeated in the literature addressing nurse recruitment and retention (Sloane, 1998a, 1998b; Porter, 2004). While nurses are enabled and protected by the law to not be required to disclose their disabilities, this choice may also limit accommodations available to them due to not identifying themselves as nurses with disabilities. These arguments presented by authors who addressed disclosure of disabilities in the literature on recruitment and retention (Porter; Restifo; Winland-Brown & Pohl) were juxtaposed, highlighting the tension surrounding disclosure to the nurse participants in this study.

*Wavering support: Empiricist inquiry.*

The nurse participants in this study described how wavering support included receiving support from others who cared for them while distancing themselves from others who were not supportive. Within wavering support participants described entering times of isolation, withdrawing from others, and experiencing loneliness and/or disconnection. They spoke of spending less time socializing, not picking up the phone as often, withdrawing from crowds, or remaining at home. Similarly, the notion of wavering support identified in theme two was found to be present in a number of studies using empiricist inquiry (Black, 1991; Carlson et al., 2001; Carroll et al., 2000; Gray et al., 1999) within the literature that considered feeling understood as a complementary aspect of another phenomenon of study.

For example, Carroll et al. (2000) and Gray et al. (1999) discussed wavering support in relation to isolation and cancer support groups. Gray et al. (1999) studied self-help groups and explored family physicians' attitudes towards such self-help groups. They found that physicians gave especially high ratings of groups' "helpfulness to sharing common experiences, overcoming isolation, feeling understood, and sharing information" (p. 10). Carroll et al. conducted a follow-up study that researched changing physicians' attitudes after educational interventions. Among the findings, physicians' attitudes were more positive about the potential for self-help groups to provide individuals with the opportunities for feeling understood and overcoming isolation. While these two research studies were framed within a bio-medical perspective to consider cancer self-help groups, the authors did not include individuals who were members of these self-help groups within their research sample. These study findings are useful in circumstances related to physicians' recommendations for cancer support groups, but clearly this does not contribute to or offer further understanding related to the lived experience of feeling understood. As an additional note, none of the nurse participants in this study spoke of being involved in a self-help or support group.

A third study on cancer by Carlson et al. (2001) discussed wavering support in relation to spouses' understanding of patients' experiences with breast and prostate cancer. In Carlson et al.'s research, patients with cancer spoke of feeling understood by their spouses. Carlson et al. suggested that patients linked feeling understood with

support from their spouses, especially emotional congruence. These findings were suggested from an assessment of congruence between patient's reports and partner perceptions not only of the experience of living with cancer, but also of receiving social support. The correlative, linear recommendations in Carlson et al.'s study are considered generalizable findings that are applicable to other samples (Ryan & Bernard, 2000).

Another research study by Black (1991) discussed correlations among wavering support, feeling understood, and couples' patterns of communication after the loss of a wanted pregnancy (Black, 1991). Through the use of semi-structured telephone interviews and questionnaires (Profile of Mood Status (POMS) and Dyadic Adjustment Scale), the researcher found that the women felt that they shared much in common with their husbands and generally felt understood and supported. Unfortunately, the women also reported a significant decline in perception of support from their husbands over time. These women's reports echoed the nurse participants in this study who spoke of experiencing support at times and not at other times from their spouses, families, friends, and colleagues.

### *Research Theme Three and Related Literature*

Research theme three in the language of the participants is: *self-confidence fluctuates with the enthusiasm and fear of wanting to make plans*. Theme three, reconceptualized from the findings in the participants' language into the language of the research, is: *buoyant conviction wavers amid fervour with fright*. Research theme three is discussed in relation to relevant literature.

#### *Self-confidence: Non-empiricist inquiry.*

Research theme three considers feeling understood in relation to the nurse participants' concerns, hopes, and dreams. In the participants' descriptions of their experiences, all commented on feeling understood affecting their self-confidence. Each of the nurse participants in this study referred to their enthusiasm and fear associated with wanting to make plans in light of their fluctuating self-confidence. A number of articles that used non-empiricist inquiry addressed the theme of self-confidence (Agnew, 2000;

D'Avanzo, 1992; Dickson, 1991; Dinsdale, 2000; Jonas-Simpson, 1998, 2001; Maheady, 1999; Moncrieff, 1999; Olney & Brockelman, 2003; van Kaam, 1958).

Beginning with the literature related to feeling understood based in non-empiricist methods (Dickson, 1991; Jonas-Simpson, 1998, 2001; McIntyre, 1994, 1997; Moncrieff, 1999; Sundin & Jansson, 2003; van Kaam, 1958), four studies by Dickson, Moncrieff, Jonas-Simpson, and van Kaam were found to be similar to the finding of self-confidence. One noteworthy comparison among the four studies and this study is that they all identified perceptions of self as a quality of feeling understood. In Dickson's heuristic inquiry on feeling understood, he creatively expressed his findings in a synthesized poem entitled, *Feeling understood* (see Appendix F for his full poem). The following is an excerpt from his poem that appears to convey consistencies with theme three:

...Poised and confident,  
New strength races through me.  
Fuelled and empowered  
I move forth assuredly.  
I fluidly dance to internal rhythms....

Defences dissipate, anxiety lowers,  
Awareness broadens.  
Subtle nuances of shifting sensations register within me, and  
Ignited feelings swarm into open channels of consciousness.

I feel understood.  
My life is transformed:  
I am connected, calm, relieved, authentic. (p. 142)

In these verses, Dickson analytically expressed his experiences and those of the participants in his study regarding moving forward while feeling confident and empowered amid dissipating defences and anxiety. Unlike the nurse participants in this study, Dickson, in his poem, alluded to a shifting from the more negative aspects of defences and anxiety to the more positive perspective of awareness and authenticity.

Much like the participants in Dickson's (1991) study who spoke of moving forth, the nurse participants in this study explained that seeking self-confidence kept each one going on in spite of challenges. While some of the participants discussed the effects of not feeling understood in relation to their diminishing self-worth, others spoke of finding security by maintaining self-worth. The language used in relation to this concept varied

among the participants. Examples included acceptance of self, self-esteem, self-confidence, self-worth, and taking care of self. Similarly, the language used to discuss perceptions of self varied within the literature related to feeling understood based in non-empiricist methods (Dickson; Jonas-Simpson, 1998, 2001; Moncrieff, 1999; van Kaam, 1958).

For example, the participants in Moncrieff's (1999) human science study on the experience of feeling understood for persons engaged with family services identified self-confidence as painfully losing parts of self, feeling rejected, and not caring for self amid times of feeling stronger. In Jonas-Simpson's (1998, 2001) phenomenological research on feeling understood she related participants' descriptions under the theme "fortifying integrity amid potential disregard" (p. 101). She explained that participants experienced their sense of worth when feeling understood through fortifying integrity that moved them beyond the moment of potential disregard. And in van Kaam's (1958) research on "really feeling understood" (p. 139) the participants spoke of shifting or growing self-confidence "because of the feeling that one is understood and that one is able to make oneself understood" (p. 108). Similar to the participants in Dickson's, Moncrieff's, Jonas-Simpson's, and van Kaam's studies, the nurse participants in this study articulated their fluctuating self-confidence as feeling more worthwhile, feeling empowered, and being themselves. While the identification of fluctuating self-confidence within feeling understood for these five nurse participants is specific to this study, it is apparent in light of these four studies that others have previously found and written of similar features in relation to this phenomenon of concern.

Self-confidence was further discussed in two articles by Dinsdale (2000) and Agnew (2000) within the relevant literature that addressed nurse recruitment and retention. While neither of these authors considered feeling understood in their discussion of self-confidence, they discussed self-esteem and self-worth in relation to nurses with disabilities. For example, Dinsdale interviewed a nurse with a disability who spoke of the loss of self-esteem. The nurse's name was Rachel and she used a wheelchair. Rachel explained:

A typical reaction of other nurses is: What would the patient think, being cared for by a person that medicine can't cure? Nurses with [disabilities] feel this loss of self-esteem more acutely. They are carers by nature and are being forced to accept

receipt of care and are no longer allowed to participate in the giving of care. (p. 13)

Rachel's comments identified concerns of what other nurses and patients thought of her because she could not be "cured". Her perspective identifies an inherent biomedical value that medicine/health care should be able to "fix" a person by altering parts of her/his body. Crystal, a nurse participant in this study, also commented on the expectation that nurses must be physically well to give care but not receive it:

I have a really hard time telling myself its *okay* to be sick...When [I'm] at work I know how I feel about the patients. There's this division: they're the patient, you're the nurse. And now I feel that that line is not there anymore. I feel like I'm just as much as *them* as *they* are...

In another article on nurse recruitment and retention, Agnew (2000) interviewed a nurse named Linda who had multiple sclerosis and used a wheelchair. Linda described that when she was diagnosed, she had thought her nursing career was over. But when she had the opportunity to pursue an alternate career for nurses with disabilities through a health district in England, she experienced "a wonderful sense of being *valued*. You feel worthwhile, that you have something to offer" (p. 9). Christine in this study also spoke of the value placed on working. She explained:

Like, it was a big adjustment to *not work*. And our society just puts so much value on that and *I did too*. Cause I'd done the three year nursing in training, and then I decided to go back and get my degree and you know, you're really proud of it and you think, gosh I had all those different jobs and I'd really built a good resume and everything and then to give it up! I think that's another thing that employers and people don't kind of get.

Similar to Christine, tensions arose for each of the nurse participants when their self-confidence was challenged in connection with feeling understood. Yet each sought to either attain or maintain a strong self-worth. Christine further explained, "So, now it just feels so liberating...[that] I've just built [up my] self-esteem...I mean being understood, it really does affect...my feelings about myself...I know myself a lot better." In comparison with this study, it is interesting to note Dinsdale's (2000) and Agnew's articles on nurses with disabilities also expressed fluctuating self-confidence in considerations other than feeling understood.

*Enthusiasm and fear of wanting to make plans – Non-empiricist inquiry.*

Research theme three referred to the participants' in this study who spoke of the enthusiasm and fear of wanting to make plans in light of their fluctuating self-confidence. For some nurses, enthusiasm surfaced in pursuing hobbies, such as art and choir, or planning holidays. Others identified that they carried on in life by not acknowledging anything was wrong with their bodies, or choosing only one accomplishment to pursue at a time. And while they moved onward, they all described times they felt stuck and/or fearful of making plans. The nurses spoke of not being able to move onward as feeling immobilized, directionless, and having nothing in common with others. All five participants explained the fear they experienced in their desires to make plans. While some described this fear as worry or feeling scared, others feared change or not being able to save themselves. Experiencing fear was uniquely expressed in each participant's life in varying circumstances. Some stopped making plans for their lives, while others felt like they could not be effective. Distinct from feeling fearful of wanting to make plans, all the participants also articulated a wish to be freed from having to engage in the challenges of their disabilities.

The enthusiasm and fear of wanting to make plans is discussed in two studies (McIntyre, 1994, 1997; Moncrieff, 1999) within the literature related to feeling understood that used a non-empiricist inquiry (Dickson, 1991; Jonas-Simpson, 1998, 2001; McIntyre; Moncrieff; Sundin & Jansson, 2003; van Kaam, 1958). In Moncrieff's nursing theory-guided study on feeling understood with persons who used family services, the participants described being able to work on goals, trying new things, being adventurous, and not missing out on opportunities, games, or adventures. Similarly, the participants in McIntyre's hermeneutic study on understanding spoke of the hesitancy amid anticipation and hope they experienced in making plans. The participants in McIntyre's study spoke of this finding in relation to planning their own or their family members' health care. Plans were also discussed regarding trips or leaving town. The participants in McIntyre's study echoed the participants in this study who described a comingling of enthusiasm and fear within wanting to make plans in light of feeling understood.

*Summary*

In this chapter, the research themes were interpreted using the theoretical lens of Parse's theory of human becoming. Each of the themes was discussed in light of the three research objectives that were derived from the theoretical themes of meaning, rhythmicity, and co-transcendence (Parse, 1981, 1987). These interpretations were explicitly theoretical and thus, corresponded with the pursuit of theory-guided research. This discussion of theoretical interpretation using Parse's theory is only one of myriad possible interpretations. When the themes were interpreted in the language of the theory, feeling understood was conceptualized as powering of imaging valuing amid connecting-separating with revealing-concealing.

The process of writing this section on theoretical interpretation was very intriguing. My consideration of the theoretical themes and concepts beyond abstract conceptualizations was greatly challenged. As I identified theoretical concepts within quotations from participant interviews, my understanding of the theoretical principles deepened when I considered them in light of the nurses' lived experiences of feeling understood. This section was one of the most enjoyable and difficult to write. I developed a new appreciation of theory when I saw the tenets of human becoming transcend from books and research objectives to the experiences of nurses living with disabilities.

Additional discussion of the findings was provided in relationship to the relevant research literature. This dialogue returned to the literature reviewed in chapter four and also considered new texts in light of this study's findings. The purpose of this section was to engage in discussion of this study's research themes in relation to the relevant literature that addressed either the population of this study, the phenomenon of concern, or an aspect of a research theme. In the following and final chapter, suggestions for nursing practice, education, research, and policy will be discussed.

### *Chapter 7 - Suggestions and Reflections*

The purpose of this study was to answer the research question, What is the experience of feeling understood for nurses with disabilities? Framed within a human science nursing theory, that of Parse's theory of human becoming, a descriptive exploratory methodology was utilized to study the phenomenon of feeling understood for five nurses with disabilities. Beyond self-identifying as having a disability, each of the nurse participants was considered to be living with a disability by her employer/union as evidenced in the participant's receipt of disability benefits specific to each study participant. Face to face interviews were tape recorded, transcribed, and used as data in this qualitative project. A process of analysis-synthesis was undertaken to create a synthesized description of the meaning of feeling understood for these five nurses.

First, participants' descriptions addressing the meaning of feeling understood, consonant with objective one, was: An acceptance–non acceptance of changing abilities amid expectations engenders joyful relief and aching hurt. Interpreted in the language of the researcher, this theme was: Acquiescence-non acquiescence of shifting capabilities with prospects give rise to serenity-anguish. Second, the nurses' descriptions of rhythmical patterns of relating, associated with objective two, was: Being believed–not being believed by others resides along with honesty-dishonesty manifesting wavering support. Interpreted in the language of the researcher, this theme was: Bonds of security-insecurity surface with candour-concealment amid tentative assistance. Third, participants' descriptions of co-transcendence, related to objective three, was: Self-confidence fluctuates with the enthusiasm and fear of wanting to make plans. Interpreted in the language of the researcher, this theme was: Buoyant conviction wavers amid fervour with fright. When the research themes were interpreted in the language of the theory, feeling understood was conceptualized as powering of imaging valuing amid connecting-separating with revealing-concealing. Research findings were also discussed in light of the relevant literature. Knowledge generated from this research has contributed to nursing science, expanding knowledge related to the phenomenon of feeling understood.

The purpose of this chapter is to make suggestions based on the research findings from this study in relation to practice, education, research, and policy. Reflections on this research will follow. I have purposefully not entitled this chapter “Recommendations” or “Implications.” Instead, I offer these suggestions from this study toward nursing practice, education, research, and policy.

In my studies within the Masters of Nursing, Policy and Practice program, one of the considerations I have begun to reflect upon relates to implementation of policy (Cheek & Gibson, 1997). The implementation or practice of a policy is often seen to differ from what is written in the policy or intended by the policy developers. Indeed, implementation involves interpretation of general policy and regulation. As such, interpretation of this research may be taken up and lived out in many different ways than what I may have anticipated. One response to various enactments of research is that each individual will interpret policies, research, and life differently from another. Therefore, I offer suggestions instead of recommendations for consideration from the findings of this research.

Also, the knowledge generated in this thesis cannot in and of itself activate change. Indeed, it is the people who take up the information who will be the ones who may create change. When I initially considered a phenomenon of inquiry for this study, I began exploring the experience of resistance. However, as my studies deepened, feeling understood surfaced as a more pervasive experience. From my previous exploration of the phenomenon of resistance among persons with health challenges, I began to consider that social change begins when it is lived by one person at a time (Aptheker, 1989; Brodie, 1999; Morris, 2000; Scott, 1985; VanderPlaat, 1997; Wendell, 1996; Wharf & McKenzie, 1998; White, 1993, 1999). In the three years that I have pursued this project, I have come to recognize that the person most likely to be changed by this thesis is myself.

### *Suggestions for Nursing Practice*

The findings from this thesis offer insight into what feeling understood meant for five nurses with disabilities. While the research findings cannot be generalized to the experiences of feeling understood for all nurses or individuals with disabilities, they may

inform nursing practice with individuals/nurses with disabilities, and in practice alongside colleagues with disabilities. Qualitative research findings are not directly applied to nursing practice; rather, they provide greater comprehension and shift what is known of the phenomenon of concern (Jonas-Simpson, 1998, 2001). Theory, rather than research findings, guides practice. The findings from this research provide new knowledge of the experience of feeling understood. Such knowledge may provide nurses with new possibilities of being with individuals in practice. Nurses' choices about how they practice may be reconsidered based on the new knowledge from this study.

When nurses in practice gain insight into the experience of feeling understood for these five nurses with disabilities, they may be alerted to the meaning of this experience for persons with whom they interact. Such insight may shift nurses' understandings of this experience, thus fostering different choices about how they practice. Also, nurses who practice in the area of Human Resources may approach the traditional economic priorities of managing nurse recruitment and retention (Colella et al., 1997) in different ways when they are informed by the experiences of feeling understood for nurses living with disabilities. Approaching Human Resource issues and decisions within the view of persons' experiences of feeling understood may in fact shift priorities in practice from concerns with finances and business endeavours towards honouring the experiences of nurses with disabilities. The pre-eminence of financial implications to employers may indeed be challenged when one considers the personal costs of disability and the lived experiences for the nurses involved (Agnew, 2000; Brewer & Nelms, 1998; Dinsdale, 2000; Hutchinson, 1997; Lillibridge et al., 1997; Maheady, 1999, 2004; Nemeth, 1995; Porter, 2004; Restifo, 2001; Sloane, 1998a, 1998b; Tammelleo, 1993). Honouring individuals does not mean that economic issues of human resources are ignored. Rather, finances may be attended to in practice in such a way that allows space for nurses with disabilities to also be honoured and potentially, to feel understood.

Knowledge generated from this theory-guided research offer nurses an alternate nursing theory base from which they may practice. Nursing practice that is guided by Parse's theory of human becoming provides nurses with an option to draw upon a foundation of nursing science. This thesis supports that while theory guides research, it also guides practice. The goal of nursing practice from the human becoming perspective

is quality of life as defined by the person living the life (Parse, 1987, 1994b). A perspective that considers individuals as indivisible, unpredictable, and everchanging (Parse, 2004) offers an alternative to the prevailing bio-medical perception of persons as totals of separate parts that can be measured, reduced, manipulated, isolated, objectified, and controlled.

One of the suggestions from this thesis is for nurses in practice to consider the notion that each individual's experiences are uniquely her/his. A nurse, or another person, may never fully understand one's unique experiences. As McIntyre suggests, "only those who live an experience can ever hope to understand it. That is, only the ill person can hope to have more than a partial understanding of the illness experience" (1994, p. 6). McIntyre's suggestion counters the clichéd response of many nurses towards others, which is, "I understand". This study suggests that we may not fully understand another's experiences. One of the participants in the study, Rose, believed that one could not empathize or understand another if she/he had not gone through a similar process her/himself. I would add that even if a nurse has gone through a similar experience, each will still own her/his unique experiences.

Participants in this study shared situations when they felt understood by health care professionals. I would like to share their comments for consideration in relationship with nursing practice. When Gladie was first admitted to the hospital after her fall, she said that the nurses who were concerned with their tasks and did not listen to Gladie were those with whom she did not feel understood. Gladie recalled that, in her pain, she longed to have a nurse reach out to her in compassion and empathy. She also said that amid the times she felt exhausted, stressed, and vulnerable she felt understood when nurses reached out to her in empathy. Gladie's descriptions suggest that when nurses do not focus on their tasks, but instead, focus on the person and listen or respond with compassion, these practices may create space for an individual to feel understood. Rose also described an experience of feeling understood with a nurse who was also a friend. Rose said that she felt understood and supported by this nurse because she listened, welcomed her to talk, and let her say what she needed to say. Jan also told of a rare moment when she felt understood by a doctor. She said it was an extraordinary, fascinating, and amazing experience because he listened and paid attention to her as a

human being. He also asked her what her pain meant to her and how it had affected her life.

Gladie's, Rose's, and Jan's descriptions suggest that in practice, listening, welcoming someone to talk, and taking an interest in what is most important to her/him provides not only esteem, but also space in which she/he may feel understood. While the participants' suggestions may seem simplistic, they are fundamentally distinct from a nursing practice that focuses on completing tasks and efficiency. A practice that focuses on a person, instead of the tasks that may need to be performed for that person, provides a practice that honours the experiences of individuals.

### *Suggestions for Nursing Education*

The discussions within this research offer suggestions for education for nurses. Education that may enhance nurses' appreciation of the unique experiences of others is needed. Baccalaureate and post diploma education that shifts the emphasis from nursing-focussed care to patient-focussed care may be considered when alternative theory-based practice is discussed and studied. Nursing education that presents options of nursing theory from which students and nurses may develop their practice is essential if schools are to fulfill their positions of granting degrees that are called Bachelor of *Science* in Nursing. Education that focuses on nursing's disciplinary knowledge expands its own knowledge base and not that of other disciplines (Cody, 1994). While the discipline of nursing is greater than its science (Cody, 1997; Northrup et al., 2004), nursing knowledge, generated within the totality and simultaneity perspectives, will broaden when nurses are rooted in nursing theory for the maturation of its science (Huch, 2001). Nursing science has the opportunity to expand when nurses are educated within their own specialized body of knowledge, providing further direction for graduate students and scholars to advance the discipline.

Inquiry within this thesis also suggests that schools of nursing should consider students with disabilities who are interested in nursing education. There is growing recognition within the literature that students with disabilities are being admitted to nursing education in diploma, baccalaureate, and graduate programs, and they are graduating, passing licensing exams, and gaining employment (Magilvy & Mitchell,

1995; Maheady, 1999; Watson, 1995). One suggestion offered here is that nurse educators reconsider what disciplinary knowledge base and essential functions are required of students, keeping in mind those who may never practice in traditional bedside care (Arndt, 2004; Carroll, 2004; Champagne et al., 1984; Colon, 1997; Magilvy & Mitchell; Maheady; Moore, 2004; Mueller, 1997; Murphy & Brennan, 1998; Sowers & Smith, 2002; Watson; Weatherby & Moran, 1989; Wood, 1998).

### *Suggestions for Nursing Research*

Only a few other nursing inquiries explored the phenomenon of feeling understood. More research is needed to expand understanding of this phenomenon. This thesis was conducted with five nurses with disabilities. I chose to study feeling understood within the population of nurses with disabilities because of my own disability. Further researchers considering future study of feeling understood might contemplate speaking with various individuals who do not live with disabilities. Speaking with individuals about this phenomenon of concern without placing limiting parameters on the population would expand exploration of this lived experience.

As my study of feeling understood progressed, one reflection I often dwelt upon was what we mean when we respond to others with the statement, "I understand." What do we imply when we say this? If an individual's experiences are unique, how is it that we still say we understand? Can anyone ever really know another's experiences? What do we mean when we say we understand another's experience? Further suggestions for nursing research may consider studying understanding, specifically from a human becoming perspective. Theoretical study of the conceptualization, as well as research of the lived experience of understanding would be a significant contribution to nursing's discipline-specific knowledge.

Suggestions for future research also include further study of the findings within the three themes from this thesis. For example, the first research theme was: an acceptance–non acceptance of changing abilities amid expectations engenders joyful relief and aching hurt. This first theme may direct future inquiries to study the lived experiences of expectations, relief, or joy. The second research theme was: being believed–not being believed by others resides along with honesty-dishonesty manifesting

wavering support. The second theme offers suggestions of further research of the lived experiences of support and being believed. The third research theme was: self-confidence fluctuates with the enthusiasm and fear of wanting to make plans. The third theme suggests that one may conduct further research that includes study of the lived experiences of self-confidence or making plans.

### *Suggestions for Policy*

When every individual's experiences are considered unique, how may generalizable policy be responsive? A question such as this sheds light on the tension between honouring unique experiences of persons who must be served within the constraints or limitations of a "one size fits all" policy.

Specifically in regards to this study on feeling understood, the findings are not considered generalizable. However, they alert people who read or hear of this study that the experience of feeling understood may be significant for individuals whom they encounter in practice, policy, education, or other avenues. Such acknowledgment prepares people for the possibility that feeling understood may be important for others and such awareness may be taken into account for consideration. Each individual's experience of this phenomenon of concern will also be unique.

This thesis has shown that the experience of feeling understood was a very important aspect of living with a disability for the five nurses who participated in this study. In turn, this research alerts readers to the potential importance of this phenomenon for nurses with disabilities who interact with policies that supposedly enable them in their lives. This thesis does not suggest that all policy must be changed. Nor does it suggest that policy must be non-generalizable. Rather, the suggestion proposed is this study is that there must be space within policy (Mathiesen, 1974) that is attended to within practice for people to feel understood. The enactment, implementation, or practice of policy involves interpretation. Thus, interpretation offers space for policy to be taken up and lived out in many different ways.

A suggestion offered from this study is the practice of honouring individuals' unique experiences while being aware of policy. For example, if a nurse with a disability were to speak with an administrator about not feeling understood in the process of

navigating through a duty to accommodate policy and procedure, an administrator who honours individuals' experiences may welcome the nurse to say more about her/his experience. This nurse's experience would not direct the administrator to change the policy but the administrator may invite the nurse to speak, be listened to, and included in the process of enacting the policy. For example, in a duty to accommodate procedure nurses may be asked to offer suggestions about how this could unfold for them. Or they could be asked, what would or would not be helpful?

Previously reviewed literature in the area of nurses with substance use addressed the issue of interventions by nurse administrators who acted as representatives of the larger organizations and not as representatives of their nursing staff (Chiu & Wilson, 1996; Torkelson et al., 1996; Wheeler, 1992). In the literature, nurses' experiences were not considered to inform interventions and policies that were meant to assist them and their recovery from substance use (Lillibridge et al., 2002). Not surprisingly, Smardon's (1998) literature review found that nurses with substance use did not feel supported by nursing management (Shaffer, 1988). As well, these same authors did not anticipate the absence of research that considered the experiences of nurses who use substances. The suggestion of honouring nurses' experiences presented here, offers an alternative view of policy in an area where individuals may not feel understood or supported.

While the research findings from this study are neither directly applied to policy nor considered generalizable, they may inform and provide a standpoint from which suggestions can be offered with regard to varying policy areas (Office of Nursing Policy, Health Canada, 2003). Areas of policy that may consider these suggestions include: policy related to nurses with disabilities, other nursing policies, health care policy, and policy related to persons with disabilities.

In the area of policy related to nurses with disabilities, appreciation of participants' experiences of feeling understood in this study may provide further insight for a diverse range of persons whose practice and work interactions with this population take place or are lived within the shadow of numerous policies. Attending to policy related to nurses with disabilities may also take place in new ways when informed by the findings of this study. Indeed, awareness of the experience of feeling understood and

what contributes to or influences this experience in the work place may have far reaching effects in nursing practice, administration, and policy development.

For many individuals, the experience of feeling understood brings a sense of intimacy, support, and acceptance (Allen & Thompson, 1984; Antonucci et al., 1997; Baker & Daigle, 2000; Black, 1991; Carlson et al., 2001; Carroll et al., 2000; Dickson, 1991; Galpert, 1988; Gray et al., 1997, 1999; Jan & Smith, 1998; Jonas-Simpson, 1998, 2001; McIntyre, 1994, 1997; Moncrieff, 1999; Murray et al., 2002; Pocock, 1997; Reis & Shaver, 1988; Sowers & Smith, 2002; Sullins, 1992; Sundin & Jansson, 2003; Tuttas, 2002; van Kaam, 1958; Wallis, 2004). For nurses with disabilities, consideration of their experiences in choices for employment may significantly reflect how they choose to participate in their work lives. Incorporation of nurses with disabilities in revisions of nursing policy may further develop analysis of what changes are needed in consideration of future endeavours of policy creation (Cheek & Gibson, 1997; Lillibridge et al., 2002; Marks, 2000; Mathiesen, 1974; Moore, 2004; Morris, 2000; Office of Nursing Policy, Health Canada, 2003).

Similar suggestions of involvement from those whose lives are affected by policy can be considered in relation to areas of health care policy and policy related to persons with disabilities. While the experiences of individuals with disabilities were rarely explored in the literature, Lillesto (1997) and Morris (1995) found that persons who were receiving assistance reported that health professionals focussed on the aspect of them that was disabled, neglecting to address them as whole individuals. Participants in these two studies (Lillesto; Morris) reported feelings of humiliation, lack of control, violation, and feeling misunderstood. Findings such as these surface the necessity for education of health care professionals that attends to the development and use of policy in practice that incorporates lived experience.

In their attention to creating an inclusive paradigm in policy-making, Wharf and McKenzie (1998) assert:

In a very real way, only service users and practitioners know how policies are being implemented and understand the real effects of these policies. Unless that knowledge is included as an integral and ongoing part of the policy process, the outcomes from policy-making will inevitably fail to respond adequately to the needs of service users. (p. 134)

Wharf and McKenzies' suggestion of a partnership between service users and practitioners in continuing policy process would be a responsive approach to Lillesto's (1997) and Morris' (1995) call for a shift in involvement of individuals who are affected by policy and practitioners who must attend to policy.

The theoretical basis of this research on feeling understood for nurses with disabilities acknowledges each individual as the expert of her/his own health (Parse, 1994a). From this perspective, academic and/or practice professionals are not considered to be experts who can recommend what others do or how they live (Cody et al., 2001; Puig de la Bellacasa, 2004). Mathiesen's (1974) work on social change lends support to this view. He discussed concepts in categories such as competing, contradictory and unfinished. Regarding Mathiesen's work, Reitsma-Street & Brown (2002) explained that "contradictory ideas help to abolish the certainty of current practices and open up spaces for community members to imagine other possibilities. Thinking about competing, but not finished, alternatives support the opportunities for people to go beyond reaction and into creation, to take control of their own destiny" (p. 79). In light of Mathiesen's (1974) and Wharf and McKenzies' (1998) suggestions, strategies of social change occur when practitioners who develop or implement policies along with service users are a part of analyzing what change is needed.

Given the notion of expert held within this research, what would the creation and/or use of policy look like if it were informed, at least in part, on a set of nursing theoretical beliefs that place value on individuals' experiences (Cheek & Gibson, 1997; Cody et al., 2001; McLeod & Spée, 2003; Milton, 2001; Mitchell, 2001)? Policies and procedures that may influence interactions with nurses with disabilities are meant to facilitate the best or right decisions when engaging in particular situations. Policies with legal underpinnings are generally standardized across varying work settings (Cheek & Gibson; Mitchell, 2001). Thus, when policies conflict with nurses' beliefs about reality and their values within practice, many practitioners experience moral dilemmas (McLeod & Spée; Milton; Mitchell, 2001). Policy has the capacity to restrict or enhance practice (Cheek & Gibson) despite the fact that theory, not policy, guides nursing practice. Nurses may experience conflict or feel restricted by policy that is intended to facilitate the best

decision for the individual but the policy-driven initiative is contradictory to what the person wants for her/himself (Mitchell, 2001). Nursing knowledge grounded in the theory of human becoming may provide an alternate lens through which policy may be created and attended to (Cody et al.; McLeod & Spée).

Policy that is imbedded in values and beliefs located within nursing knowledge that recognizes the pre-eminence of lived experience offers an alternate view of the place of policy in professional practice. If theory guides practice, nursing knowledge must have a place within policy and practice (Cheek & Gibson, 1997; Cody et al., 2001; McLeod & Spée, 2003; Office of Nursing Policy, Health Canada, 2003). McLeod and Spée further purport that such policy development must occur “if nurses are to practice in a humane, ethical, and moral fashion” (p. 116) that is consonant with a human science view of nursing (Cody & Mitchell, 2002). These author’s comments were in response to moral dilemmas that arose when nurses were in conflict with their intentions to practice from a nursing theory-guided perspective. McLeod and Spée, as well as Mitchell (2001), further articulated that nurses should refrain from taking actions that individuals, and possibly their families, do not consider helpful.

Envisioning the possibilities (Mathiesen, 1974) of the creation of policy that is informed and guided by nursing knowledge may provide a shift in consideration of policy that reflects the values of persons served by policy. McLeod and Spée (2003) further explain that

when there is an attitude of openness among health professionals and an intention to be helpful according to what persons find helpful, organizations become capable of transforming policy from a traditional basis to a patient-focussed one....When policy is challenged from a nursing theoretical perspective,... new policies respectful of human rights and dignity of persons can be crafted. (p. 119)

Consideration of policy from such an alternate perspective may provide the potential for a diverse range of persons who practice with nurses with disabilities to honour their experiences. Further, such persons may provide a work environment that these nurses imagine as possible (Mathiesen, 1974) for those who may have the choice to remain in or return to nursing.

### *Reflections*

As I reflect over the past three years during which I have conducted this research, I am reminded of the many blessings and challenges I encountered along the way. When I started this study, one of the first challenges I met was from my colleagues (both faculty and students) who questioned my decision to use Parse's theory in my thesis. I was frequently asked how I would make my research decisions while being "confined" by theory. I had to admit that theory-guided research presented limitations. Some of the challenges I encountered included language / semantic restrictions, a relatively small literature base of theses guided by Parse's theory that offered exemplars, my neophyte understanding of the theory of human becoming, and the perpetual undermining of my decision to conduct research within this perspective by well meaning colleagues. Amid restrictions, I also encountered many opportunities in using Parse's theory. The theory provided new insight and language that reflected many of my own values and beliefs. I had an opportunity to consider unchallenged assumptions and engage in learning of new ways to see myself, others, and nursing.

Once engaged in this project, one of the most significant opportunities I encountered was to be able to practice true presence (Parse, 1992) with the nurses I had the privilege to interview. Research conducted with the theory of human becoming directs the researcher to practice true presence and invite participants to further describe their experiences in greater depth. However, I found this practice was very challenging. Although my goal was to practice true presence with each participant during the interview, I found that I had undertaken a tremendously difficult task. One of the limitations I faced was my lack of experience in practicing true presence in research interviews. Listening to my tapes after my interviews with my supervisor, I realized that the art of true presence requires study, practice, and mentorship. When the interviews were completed, I felt I had just begun to learn this art.

Over the course of this project, and in the midst of multiple challenges and opportunities, the meaning of feeling understood for five nurses with disabilities was explored. While the purpose of this study was met, I learnt much more than was represented in this thesis. This scholastic endeavour provided me with the opportunity to

advance nursing science by engaging in theory-guided research and thus, offer new knowledge about the experience of feeling understood.

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*Appendix A - Recruitment Advertisement*

ATTENTION-NURSES WITH DISABILITIES: Would you like to participate in a research project? I am a graduate student at the University of Victoria and I am interested in interviewing nurses with disabilities about your experiences of “feeling understood”. Whether you are practicing or non-practicing, this invitation is open to you if you are over 19 years old, able to speak English, have completed an accredited nursing education program to become a RN, and you have a disability that is recognized by your employer/union. If you are interested in participating or would like further details, please call me at: (250) 385-3397.

*Appendix B – Revised Recruitment Advertisement*

**ATTENTION - NURSES WITH DISABILITIES:**

Would you like to participate in a research project? I am a graduate student at the University of Victoria and I am interested in interviewing nurses with disabilities about your experiences of “feeling understood”. Whether you are practicing or non-practicing, this invitation is open to you if you are over 19 years old, able to speak English, have completed an accredited nursing education program to become a RN, and you have a disability that is recognized by your employer/union.

If you are interested in participating or would like further details, please contact Kara at:

**(250) 385-3397 or [karimasm@uvic.ca](mailto:karimasm@uvic.ca)**

For the purpose of this research, the disabilities accounted for will include long-term or recurring physical, mental, psychiatric, sensory, or learning disabilities, disfigurement, and past or present drug or alcohol dependence. Criteria for qualifying as a nurse with a disability in this research stipulate that both the nurse and the employer/union must agree that the nurse qualifies as disabled in employment by reason of disability. These criteria may include:

- 1) nurses who have taken a short-term leave from practice before returning to work,
- 2) nurses whose functional limitations due to disability have been accommodated in their current workplace or job, and
- 3) nurses who have left nursing practice due to disability.

*Appendix C – Ethics Certificates of Approval*



University  
of Victoria

**University of Victoria - Human Research Ethics Committee**

***Certificate of Approval***

<u>Principal Investigator</u> Kara L. Makaroff Graduate Student	<u>Department/School</u> NURS	<u>Supervisor</u> Dr. Deborah Thoun Northrup Dr. Michael Prince	
<u>Co-Investigator(s):</u>			
<u>Title:</u> The Experience of Feeling Understood for Nurses with Disabilities			
<u>Project No.</u> 254-03	<u>Approval Date</u> 11-Jul-03	<u>Start Date</u> 11-Jul-03	<u>End Date</u> 10-Jul-04

**Certification**

This is to certify that the University of Victoria Ethics Review Committee on Research and other Activities Involving Human Subjects has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

J. Howard Brunt  
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions/minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

Office of Vice-President, Research - UVic  
Room 424, BEC- P.O. Box 1700  
Victoria, BC V8W 2Y2

Tel: (250) 472-4362  
Fax: (250) 721-8960  
E-mail: ovprrc@uvic.ca

254-03  
Makaroff, Kara L.



University  
of Victoria

Human Research Ethics Committee  
Office of the Vice-President, Research  
University of Victoria  
Room 425 Business and Economics Building  
Tel (250) 472-4545 Fax (250) 721-8960  
Email ovprhe@uvic.ca Web www.research.uvic.ca

## Human Research Ethics Committee Certificate of Approval

<u>Principal Investigator</u>	<u>Department/School</u>	<u>Supervisor</u>	
Kara L. Schick Makaroff Graduate Student	NURS	Dr. Deborah Thoun Northrup	
<u>Co-Investigator(s):</u>			
<u>Project Title:</u> The Experience of Felloing Understood for Nurses with Disabilities			
<u>Protocol No.</u>	<u>Approval Date</u>	<u>Start Date</u>	<u>End Date</u>
245-04	21-Jul-04	11-Jul-03	20-Jul-05

### Certification

This certifies that the UVic Human Research Ethics Committee has examined this research protocol and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

Dr. Martin Taylor  
Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions or minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

245-04 Schick Makaroff, Kara L.

*Appendix D - Letter of Informed Consent*

You are being invited to participate in a study entitled *The Experience of Feeling Understood for Nurses with Disabilities* that is being conducted by Kara L. Schick Makaroff. Kara Schick Makaroff is a graduate student in the department Human and Social Development at the University of Victoria and you may contact her if you have further questions by phone: (250) 385-3397 or e-mail: [karimasm@uvic.ca](mailto:karimasm@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, Policy and Practice program. You may contact my committee as follows:

Dr. Deborah Thoun Northrup (supervisor), (250) 472-4609 or e-mail: [dnorthru@uvic.ca](mailto:dnorthru@uvic.ca) ;

Dr. Michael Prince (committee member), (250) 721-8051 or e-mail: [mprince@uvic.ca](mailto:mprince@uvic.ca) ;

Dr. Mary Ellen Purkis (committee member), (250) 721-7953 or e-mail:

[mepurkis@uvic.ca](mailto:mepurkis@uvic.ca) .

In addition to being able to contact the researcher and the committee at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250) 472-4362.

The purpose of this research project is to provide a description of the experience of feeling understood for nurses with disabilities that is framed within the human becoming theory. The three objectives of the proposed research are: 1) to describe the meaning of feeling understood for nurses with disabilities through dialogue, 2) to describe patterns of relating within the experience of feeling understood for nurses with disabilities, and 3) to describe personal hopes, concerns, possibilities, and visions of what might be in relation to feeling understood for nurses with disabilities.

Research of this type is important and relevant as health care organizations across Canada are currently struggling with the compounding issues of recruitment, retention, financial strain, and efficiency. No research has been conducted with this phenomenon of feeling understood in relation to nurses with disabilities despite the fact that the Canadian Nursing Advisory Committee (2002) has reported that nursing has an eighty percent higher incidence of absenteeism because of injury and illness in comparison to the

average statistic in Canada's full-time labour force. Findings from this inquiry will contribute to nursing knowledge of this experience that can inform clinical practice and nurse administrators in the development of health care policy.

You are being asked to participate in this study because you demonstrated an interest in this research and you volunteered to do so. Your response to my advertisement to participate in the study on feeling understood for nurses with disabilities is very much appreciated. You will be one of 5–8 individuals who volunteer to participate in this study.

If you agree to voluntarily participate in this research, your participation will include one to two interviews. Each interview will be 30-60 minutes long; however, if you wish, interviews may be greater or less in duration. You will be interviewed individually by myself, the researcher. Interviews will be face-to-face and audio taped. Open-ended questions related to the research objectives will be asked.

Participation in this study may cause some inconvenience to you including the time commitment required with participation in one to two 30-60 minute interview(s). To facilitate minimal disruption of your schedule, I am flexible to the timing and location of interview(s). I am hopeful that the benefits of sharing your personal experiences will counter the inconvenience associated with participation.

There are some potential risks to you by participating in this research and they include physical and/or emotional responses possible when discussing personal experiences. Potential risks are related to the possibility of becoming upset, feeling fatigued, and/or having pain when engaged in the interview. To prevent or deal with these risks the following steps will be taken:

- if you experience any fatigue, pain, or unease during or after the interview, you may end the interview, reschedule at your convenience, or call me at the phone number provided;
- if requested or thought to be appropriate, you will also be provided with names and phone numbers of support services available to you.

The potential benefits of your participation in this research include the opportunity to explore and discuss your own experiences of feeling understood while living with a disability, as both meaningful and beneficial to you. Society will also benefit from understandings arising from this research when nursing and other health care professionals have a greater knowledge base that guides their support towards colleagues

who have disabilities, and their care for individuals with disabilities. Quality of care for those individuals receiving care will also be enhanced. The state of knowledge in health care about nurses with disabilities will be informed, expanded, and promoted.

Your participation in this study must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequence or any explanation. Although you may benefit from discussing your experience of feeling understood, you are under no obligation to do so. Your decision to participate or not participate will not affect your relationship with any individual, agency, or the care you may receive. If you choose to withdraw from the study, your data shared to the point of withdrawing will not be used in the research. However, if you wish for your data to be included in the research, your signature will be required below at the point in time that you wish to withdraw from the study.

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	Signature	Date
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In order to assure myself that you are continuing to give your consent to participate in this research, I will repeat the information from this letter of informed consent, if an occasion arises to have a second interview.

In terms of protecting your anonymity, it will be completely maintained. I will not reveal your identity to anyone. Audiotapes will be numerically coded and kept in a locked filing cabinet available only to myself and my primary supervisor for the purpose of maintaining anonymity. Tapes will be transcribed and tracked through number codes. Tapes will be erased after data analysis is completed. In published reports and presentations, participants' names will be replaced with pseudonyms. One list of participants' names, addresses, phone numbers, e-mail addresses (if applicable), and codes will be kept by the researcher for the purposes of communication with participants. This list will be kept in a separate location from the transcribed data and will be destroyed at the end of the study.

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). All data will be kept in a locked filing cabinet. Interviews will be transcribed by a paid transcriptionist who will also uphold ethics of confidentiality and sign a contract. Confidentiality will be upheld if research findings are shared in any publications or presentations.

Other planned uses of these data include being of benefit to me personally in my studies and contributing to scientific knowledge. After my interviews are completed, I will analyze the data while adhering to qualitative methods. Results of data analysis will be fully discussed in the thesis.

Data from this study will be disposed of by erasing audio tapes after data analysis is completed. The only copy of the participant list will be destroyed at the end of the study. Transcribed data will be kept for the possibility of secondary analysis because this research is the first of a series of studies with the phenomenon of feeling understood and with nurses who have disabilities.

It is anticipated that the results of this study will be shared with others in the following ways. 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 also be published in scientific journals/books or publicly presented while adhering to ethics of anonymity and confidentiality.

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 researcher.

-----	-----	-----
Name of Participant	Signature	Date
-----	-----	-----
Name of Researcher	Signature	Date

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

*Appendix E – Contract for Transcription of Interview Tapes*

You have agreed to be a transcriptionist in a study entitled *The Experience of Feeling Understood for Nurses with Disabilities* that is being conducted by Kara L. Schick Makaroff. Kara Schick Makaroff is a graduate student in the department Human and Social Development at the University of Victoria and you may contact her if you have further questions by phone: (250) 385-3397 or e-mail: [karimasm@uvic.ca](mailto:karimasm@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, Policy and Practice program. You may contact my committee as follows:

Dr. Deborah Thoun Northrup (supervisor), (250) 472-4609 or e-mail: [dnorthru@uvic.ca](mailto:dnorthru@uvic.ca) ;

Dr. Michael Prince (committee member), (250) 721-8051 or e-mail: [mprince@uvic.ca](mailto:mprince@uvic.ca) ;

Dr. Mary Ellen Purkis (committee member), (250) 721-7953 or e-mail: [mepurkis@uvic.ca](mailto:mepurkis@uvic.ca) .

In addition to being able to contact the researcher and the committee at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250) 472-4362.

This contract for transcription of interview tapes constitutes an agreement between Kara L. Schick Makaroff, 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.
- The audiotapes, disks, and hardcopies of the data, when not being actively used by me for transcription, will be kept in a locked filing cabinet or a locked box supplied to me by the principle investigator.

- Once tapes and transcriptions (disks and hardcopies) are returned to the principle investigator, I will erase any and all computer files pertaining to this research.
- Payment will be made upon completion of transcripts at a rate of \$20.00 per hour of work. It is expected that each one hour 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 the opportunity to have your questions answered by the researcher.

---

Name, address, phone number of Transcriptionist

---

Signature

Date

---

Name and address of Principal Investigator

---

Signature

Date

---

Name of Witness

Signature

Date

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

*Appendix F – Dickson’s Poem on Feeling Understood*

Dickson (1991) wrote the following poem as a synthesis of his dissertation findings on feeling understood.

Feeling Understood

Different, alienated, alone,  
 Struggling for understanding.  
 I move from person to person,  
 Unsure of what is wrong,  
 Desperately trying to express my pain.  
 I am trapped,  
 Frantically, I strike think, frozen walls  
 Without making a dent.

Feeling understood is a change of season,  
 A Spring thaw.  
 Relief that melts tension,  
 Lightens desperation, eases anxiety.  
 Confusion quiets, struggle subsides.  
 Frenzy is replaced with timeless calm.

Isolation dissolves into cozy communion  
 And intimate emotional bonding.  
 Boundaries soften.  
 I and thou are warmly united.

Feeling the understanding acceptance,  
 Soaking in supportive attention,  
 I am recognized, validated, honoured.  
 A snug blanket of caring heals my hurt,  
 Cleanses my spirit and protects me from chills.  
 My previously cramped, closed-in body stretches tall,  
 Face to the sun.

Poised and confident,  
 New strength races through me.  
 Fuelled and empowered,  
 I move forth assuredly.  
 I fluidly dance to internal rhythms.  
 Spontaneous movements flow uninhibited.  
 Unrestricted, unedited, I cut loose,  
 Authentically expressing my being.

Defences dissipate, anxiety lowers,  
Awareness broadens.  
Subtle nuances of shifting sensations register within me, and  
Ignited feelings swarm into open channels of consciousness.

I feel understood.

My life is transformed:

I am connected, calm, relieved, authentic. (p. 141-142)