PORTRAITS OF NURSING KNOWLEDGE: CONTEMPLATING NURSES' LIVES

by

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ABSTRACT

How do nurses know? Review of extant nursing literature suggests that nurses are informed by

multiple sources of knowledge, including knowledge arising in clinical practice experiences. What

is not clearly and sufficiently described, however, is how knowledge arising in nurses' life

experiences outside the clinical realm informs their nursing knowledge. Through exploration of

one nurse's life, I reveal that nursing knowledge is life-informed and contextual. Nurses interact

with other human beings in times of joy and sorrow, in harmony and stress, and during

experiences of crisis and recovery. They have encountered these experiences of life, experiences

that inform how they know, in similar and dissimilar ways in their own lives. It has, however, been

suggested that nurses can separate personal and professional experiences of life, somehow holding

their lives outside the clinical practice setting at arm's length. I demonstrate that this cannot be the

case, that we must begin to consider life-informed knowledge that nurses bring to their nursing

care. Life history method is used to reveal the life and practice of Patty, a nurse on a palliative

care unit in a large urban center. The use of life history method reveals the richness of Patty's life

and knowledge embedded therein, while enabling consideration of how that knowledge is

expressed in the particular practice context in which she nurses. Over a period of nine months,

Patty shared with me, stories of her life. Rich points, those elements repeatedly brought forth with

great emotion, formed the basis of understanding the life-informed nature of Patty's nursing knowledge. Observational experiences provided the opportunity to understand how that knowledge is delimited by the context of practice. Ultimately, what is revealed is a rich, thick description of Patty's life, the knowledge embedded within, and through juxtaposition with her clinical practice, insight into life-informed knowledge as an aspect of nursing knowledge. A framework for nursing education, reflexive practice, is proposed to bring forth this aspect of knowledge in a mindful and deliberate manner.

DEDICATION

Dedicated to the memory of my first and dearest teacher

my grandfather

Wasyl John Sarchuk

March 15, 1901 - September 2, 1968

ACKNOWLEDGMENTS

me under their wings during my sabbatical year. My sisters, Nancy and Leslie, have contributed support, advice, and guidance through the writing process.

Ultimately, this work is for Patty. Her willingness to open her life and practice to me, in support of my educational endeavor, is illustrative of her own lifelong commitment to learning and teaching. I am honored to know her, and to share her life with all who read this portrait of nursing knowledge.

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CHAPTER ONE

Contemplating Life Experience

I have but one lamp by which my feet are guided,

and that is the lamp of experience. I know no way of

judging the future but by the past.

Patrick Henry (1775)

1968

When I was fourteen, my paternal grandfather died. I was staying with my grandparents

while my parents were away. On Monday of the Labour Day weekend, feeling unwell, my

grandfather washed, shaved, dressed in a suit as he had every day of his adult life, and drove

himself to the doctor's office. He was immediately admitted to hospital, having suffered a major

heart attack. Four days later, he put down the book he was reading and died alone in the intensive

care unit. I clearly remember my grandmother and aunt leaving for the hospital and then, my

father's breaking voice on the telephone, telling me they were on their way home.

Later I learned that my grandfather was moved to the morgue before my grandmother and

aunt arrived at the hospital. They learned of his death by finding his bed empty when they entered

the room. I remember, in the midst of grief, being amazed at the callousness of this act. How

could the nurses and doctors have let this happen? Why didn't someone stop them, take them

aside, tell them?

1975

Immediately after graduation, I went to work on a terminal care unit. Today, these wards are palliative care units, but in 1975, our predominate focus was revealed in the name; terminal care. I worked there for fifteen months, being present for many patients' deaths. Only the first remains clearly etched in memory; his name, diagnosis, and the room he was in, 209. He was about 75 and had cancer of the bone. Surgeons had excised his cheekbone, the orbital fossa, his right eye, and his upper mandible. The result was a huge crater which became an awful, foul-smelling wound. Changing the dressing was a nightmare, because of the smell and the fact that it took about forty-five minutes to complete. No one wanted to be assigned to this patient.

For some reason, I took to him. I would traipse down to his room, set up my tray, and we would chat about a whole variety of topics, forgotten now. I did the dressing changes for several months and became quite attached to him. Eventually, he was dying. I wanted to sit with him but was told by the Head Nurse to attend to my other responsibilities as the chaplain was with him. Despite my status as a "novice" nurse, I argued with her, believing it my responsibility to be with him. Arguing with the Head Nurse was an exercise in frustration. I was not present when he died. I was, however, assigned to attend to post-mortem care with a young, new orderly. I think he was more scared than I, but not much. Part of that job was packing up belongings. In the man's bedside table I found a bus pass with his picture on it, a picture of him before cancer and surgery had changed him into something almost unrecognizable. I showed it to the orderly and started to cry, overwhelmed by what this man had experienced and where he was at the end of his life, alone with two strangers putting his things into bags.

<u>2000</u>

At the time of the second story I was a very new nurse with only a few months of clinical experience. The story, in fact, describes my first "professional" experience of death. I had taken no courses in my nursing program about death or palliation. I do not remember a discussion about the end of life in four years of nursing education. My knowledge of dying did not arise in my nursing education or clinical experiences. My only experience of death was my grandfather's, six years earlier.

This thesis is an exploration of nursing knowledge. Its genesis lies in reflection on my life experiences and what historic, and contemporary, significance they have for how I create meaning of particular events. I offer the story of my grandfather's death as an illustration. As a child, I knew this experience as the loss of a beloved grandparent. As an adult, I recognize that it profoundly affects the way in which I understand the death of a family member, of how I **know** that phenomenon. And, as a nurse, I believe knowledge arising in this life experience informs my nursing practice, as evidenced by the second story. The second story also reveals, however, that the context of practice, in this case the structure and norms of a particular nursing unit, organizes nursing knowledge in a consequential way.

In the nursing profession, the life-informed and contextual nature of knowledge has not yet been sufficiently examined, and so, in this thesis, I endeavor to illuminate these aspects of nursing knowledge. The inquiry is important because nurses engage with other human beings at profoundly intimate times, providing care and support in circumstances they may have personally experienced. These life experiences produce a unique and subjective way of knowing a particular

event, a way of knowing further defined by the context within which the event has been, and is

being, lived. Family life and tensions; social, cultural, educational and religious influences; and

vastly different practice settings, are examples of nurses' divergent contextual frames. In the

remainder of this chapter, I detail, by exposing my immediate and particular context, as well as

elements of the broader context of the nursing profession, how I understand my knowledge to be

informed as I begin this inquiry.

Denzin and Lincoln (1998) state that there is no "clear window into the life of an

individual. Any gaze is always filtered through the lenses of language, gender, social class, race,

and ethnicity" (p. 24). I am mindful that my age, 47, gender, family background, experiences as a

nurse, and now, experiences as academic and researcher, afford me a particular perspective. I am

informed by 26 years of nursing experience. I have nursed in hospitals and community settings, in

palliative and long term care. I have held general duty and administrative positions. I have been a

Director of Nursing, in a personal care home specializing in psycho-geriatric care. For the last 12

years I have been a teacher of nurses, first in a hospital-based diploma program, now in a

university-based, post-diploma, baccalaureate program. A common thread in many of these

experiences, is that the people I have cared for have almost always been elderly, and life-

threateningly or chronically ill. I have developed, over years and patients, a philosophy of living

until the moment of death, and am committed to honoring this sentiment in all aspects of my

practice.

I am also informed by my biography. My grandfather's death is but one of the lenses

through which I apprehend the world. I have been married for 27 years, to a man who shares my

passion for travel, dogs, and birding. I am the eldest child of well-educated parents, a lawyer and

an occupational therapist. I have three siblings, all of whom hold a Master's degree, and four

nieces and nephews, for whom I hope similar academic opportunities. I am informed by culture. I

grew up in a Ukrainian household, my abiding commitment to that culture nurtured by my

grandparents with whom, as a child, I spent considerable time.

I am a lifelong resident of Manitoba, and so am informed by infinite sky, summer days

with 16 hours of daylight, and -40 degree temperatures in winter. I lived most of my life in the

province's largest urban center, but for the last 13 years have lived on an acreage in the southwest

part of the province. I now know the experience of residing in an agriculturally-based community

where seasonal change and weather often dictate how our lives are lived. It was not until I entered

this community that I became aware of the demands of seeding and harvest. More than once,

female students have shared stories of their fall days; full-time employment as a nurse, a class after

work, family care, and then, several hours on a combine.

As an academic, I am further informed by my experiences with students and colleagues.

The courses I teach reflect my clinical expertise in palliative and long-term care, and my efforts to

understand how nursing knowledge is created and revealed. To that end, I am immersed in

literature that contributes to my learning, teaching, and research initiatives. It is to this literature,

and to the nursing context within which it is embedded, that I now turn.

Knowledge Development in Nursing

On reflection, it seems that I have been moving toward this thesis inquiry since my adolescence. I had originally intended to become a physician. I was, however, an uninspired high school student and my grades were only mediocre. Discouraged by my father, I changed my application from pre-med to nursing, a month before I began the first year of my program. University life and nursing education were not what I envisioned. I did not fit faculty members' ideas of a "good" student, and was told as much. They did not fit my ideas of "good" teachers, and were not told as much. It seemed we were at an impasse for four years. I, certainly, was not prepared to be as self-directed as expected, but self-direction and support are not mutually inclusive. Perhaps I harbored some resentment about my choice to undertake the nursing program, perhaps I believed I had settled for "second-best". I cannot, at this point in my life, understand that decision in the same way I did then. I do recognize, however, that much of my discontent in the nursing profession is certainly informed by these, and other, experiences.

My first work as a nurse was on a palliative care unit that was part of a three-hospital, city-owned complex. Established shortly after the beginning of the 20th century, the facility once housed a tuberculosis sanatorium. In 1975, it was home to chronically ill, primarily elderly, persons requiring lengthy periods of rehabilitation. It was also home to two (male and female) palliative care units, and a small population of persons who had remained in hospital since the polio epidemic 20 years earlier. There were wonderful aspects of the institution. Many staff had worked there for years and there was definitely a sense of family. Special occasions, both patients' and staff members', were routinely honored. But, there were also limitations. It was a tightly hierarchical environment in which house physicians were subordinate to attending

physicians, and nurses were subordinate not only to the physicians, but to an equally tightly ordered nursing hierarchy. Frequently frustrated and angry in the early days of my career, I was especially dismayed at the treatment I received as a new graduate.

I felt ostracized, an outsider, particularly, with respect to my nursing education. In 1975, I was an anomaly, a graduate of one of the first classes of a baccalaureate program. Nursing education in Manitoba had exclusively been the province of hospital-based training schools, and university-based education was very new to the scene. Those of us who chose that educational path were perceived, by and large, to not have necessary and sufficient skills. My recollections of those first 15 months of practice include frequent comments and references to my educational background, and the gaps therein. I was also the first, and only, baccalaureate-prepared nurse in that particular institution, a state of affairs that made me even more vulnerable to criticism. As a new graduate and the only one of my ilk in the facility, it certainly never occurred to me to challenge the pre/misconceptions of my peers.

Practice consultants of the Manitoba Association of Registered Nurses recently challenged experienced nurses to support new graduates (Crawford & Maté, 1999), new graduates who since 1998, have all been educated in a baccalaureate program. The challenge is motivated by an assumption that hostile work environments pose barriers to recruitment and retention, and ultimately, contribute to the nursing shortage. For me, continuing hostility toward new graduates, in particular baccalaureate graduates, is one of many unsettling contradictions of the nursing profession I have become aware of in 30 years of education and practice.

I have, over the course of my career, tried in different ways to counter the parts of my

nursing practice I believed were contributing to my discontent. I moved from an institution to a

community setting, in the hope that community-based practice would offer greater independence

and autonomy. Baccalaureate preparation was the minimum position requirement. I would be with

like-minded nurses. Four years later, however, I returned to the institution in which I had spent

those first 15 months, now in a managerial position, hoping that management offered

opportunities for decision-making and change. I completed a Master of Business Administration

degree, in a similar hope, that a more senior administrative position would provide greater

opportunity. Unfortunately, none of these shifts in my career trajectory had the intended effect.

In my search for resolution, I turned to academia and research. I naively expected a

environment of mutual inquiry and support, and encountered one of the most competitive

atmospheres in which I have ever worked. The Department of Nursing and Health Studies was

located within the Faculty of Science, and I, and my colleagues, underwent several years of

adversity prior to becoming a separate academic unit. My experiences, as a woman and a nurse,

attempting to articulate my position, and that of the nursing profession's, to male scientists who

clearly did not share my ontological and epistemological position, led me to explore feminist

theory. This exploration, while illuminating in a particular way, my understanding of my

experiences, still did not provide what I was searching for.

In 1997, I entered the doctoral program in adult education. I chose an education degree

because I believed, and still do, that many nurse educators achieve their appointments by virtue of

clinical excellence, and, that excellence in clinical practice does not necessarily assure excellence

as a teacher of nurses. Bevis (1989) also expresses this concern. "There is a whole movement in

nursing education *away from education* [italics in original] as a choice of functional specialty.

Nursing, once again, wishes to follow in the footsteps of other academic fields that assume that if

you know your specialty area, you can teach it" (p. 172). Throughout the doctoral program, I

have not only been supported in my efforts to embed my learning in the context of the nursing

profession, but have been expected to do so, and to do so in a deliberate and thoughtful manner. I

have, nevertheless, already been confronted by colleagues who suggest that I cannot further

nursing knowledge development without a doctorate **in nursing**.

So, even as I reach this penultimate point in my doctoral studies, I am still disturbed by

others' perceptions that there is a "right" path, that I have not yet found. I understand these

perceptions, my own and others, to be informed, in part, by the socio-historical context of the

nursing profession: a female-dominated profession, developed in the shadow of the medical

profession.

Socio-historical Context

Although a self-professed caring profession, nurses are often identified as perpetrating

horizontal violence. "Witness the conflict over education for entry to practice, and the lack of

cooperation in the workplace" (Rather, 1994, p. 264). We are depicted as "physicians'

handmaidens" (Perry, 1993; Reverby, 1987); as an "oppressed" group (Roberts, 2000; 1983).

whose members engage in intra-professional disputes grounded in perceptions of inter-

professional powerlessness; as "victims" (Bowman, 1993); and, as semi- (Etzioni, 1969).

working-class (O'Neill, 1992), and under-professionals (Perry, 1993). Our leaders have been

viewed as an elite and marginal group, rewarded for maintaining the status quo (Roberts, 2000),

and our media images range from "angels of mercy", to subjects of prurient interest (Kalisch &

Kalisch, 1986). At the same time, we are exhorted to claim our unique place within the health care

system, and to articulate caring as the core of nursing (Newman, Sime, & Corcoran-Perry, 1991).

These contradictory messages cannot help but contribute to the manner in which nursing is

understood, and represented, by nurses and others.

The characterizations of nurses are embedded in a long history of physician/hospital/

administrator control of nursing practice and education, and implicit and explicit expectations of

nurses' compliance with physicians as leaders of the health care team (Jolley, 1993; Perry, 1993;

Reverby, 1987; Rafferty, 1996). Jolley (1993) details the transfer of patriarchy from home to

hospital settings, in which the family hierarchy of husband-wife-child, became the health hierarchy

of doctor-nurse-patient (p. 15). She states that

> by the first decade of the twentieth-century nursing as an occupation ... was
>
> emerging as a socially heterogeneous, predominately female grouping, subjected to
>
> strict discipline, operating within a hierarchical bureaucratic framework, poorly
>
> remunerated, and experiencing a continued relationship of dominance by, and
>
> subservience to the medical profession. (p. 17)

Reaction to this legacy, and its disparaging images of nurses, was a concerted effort to secure

professional status.

Professional-status Seeking

There is substantial account in nursing literature of the occupation's history of professional-status seeking (Melosh, 1989). Turkoski's (1992) review of 80 years of articles in the American Journal of Nursing, the journal of the American Nurses' Association, is particularly revealing. The review identifies two primary assumptions still in existence (a) professions hold a superior position to non-professions, and (b) being recognized as a profession is desirable for nursing. On the basis of these assumptions, the better part of half a century has been spent in attempting to achieve professional status. To do so, members of the occupation have accepted the premises of a trait-based model of professionalism (Carter, 1994; Larson, 1977; O'Neill, 1992; Rafferty, 1996; Witz, 1992). These premises include the notion that occupations to which society ascribes professional status feature essential traits, and that when other occupations achieve the traits, they will necessarily achieve professional status (Witz, 1992). As medicine has realized virtually unparalleled success as a profession (Larson, 1977; Witz, 1992), it is medicine's unique attributes that nursing has actively sought.

Following the example of the medical profession, nurses have created professional associations, negotiated legislation to represent the scope of practice, and shifted entry-to-practice requirements from diploma preparation to baccalaureate preparation. Examination of these undertakings as a response to subordination reveals, however, simultaneous privilege, enjoyed by only some of the profession's members. Das Gupta (1996) clearly enumerates nursing's historic use of racist exclusionary strategies in professional practice. She identifies white-only policies, admission quotas, admission requirements different from those for white nurses, additional training requirements for nurses of colour, and failure to recognize previous certification, as some

of the strategies used against black nurses in hospitals and nursing schools. Das Gupta also draws

attention to patterns of systemic harassment, which are more insidious, and result in

marginalization of minority group members, including: (a) management denial of racism, including

in part, the use of victim-blaming strategies; (b) bias in work allocation; (c) underemployment and

denial of promotion; and (d) "tokenism" in management.

These patterns are also evident in Hardill's (1993) account, and Glenn's (1992) scathing

indictment of racial division of labour in nursing. Given current widespread intolerance for racism,

strategies have become more sophisticated and less blatant. Vaguely stated and informal policies,

open to different interpretations, and differences in hiring, promotion, and termination,

rationalized in the context of workload or patient assignment, are examples of the strategies

experienced by the nurses in Hardill's study. Exclusion based on the collective attribute of race is

not the only evidence of exclusionary strategies in nursing. Poliafico (1998) and Holyoake (2000)

analyze the historic, and current, experiences of male nurses. Gray et al (1996) and Randall

(1989) describe heterosexism and lesbian phobia in nursing education, revealing ignorance and

uncritical acceptance of a dominant paradigm of heterosexuality.

Hardill's (1993) analysis reveals yet another hierarchy in nursing, particularly relevant to

this thesis, that of preferred areas of work. Division is evident in the assignment of nurses of

colour and nursing attendants (frequently one in the same), to "less desirable" or "less

prestigious" patient groups, those in long-term care areas, psychiatry, or those with heavier care

needs. This hierarchy results in patients differentially receiving care on the basis of specific causes

of hospitalization, rather than consideration of individual needs, a phenomenon which also occurs in medicine (Larson, 1977).

Baccalaureate education as the entry-to-practice requirement, has been the most contested of the professional-status initiatives taken on by nursing. Turkoski (1992) states baccalaureate entry is "an effort to establish hierarchies of nursing labour, and to disenfranchise large groups of nurses as "less than professional" " (p. 150). The shift to baccalaureate entry results in closure and amalgamation of education and training programs. The impact is camouflaged by cost-savings rhetoric, but is, nevertheless, control by one privileged part of nursing's membership, university-educated nurses, over access to the profession. When program delivery is collapsed into one site, generally in large urban centers, as it has been in medicine, potential candidates in remote and rural areas are disenfranchised. Turkoski's statements, although predating the Manitoba experience by several years, describe it with almost prescient insight. Of seven Schools of Nursing in Manitoba that prepared nurses for entry to the work force, one remains, the on-campus, baccalaureate program, located in the province's largest urban center. Satellite campuses, of which there are two, provide some access for rural and remote students, but access to different philosophical or pedagogical practices does not exist. The program, in which I teach, was somewhat unscathed in the centralization of nursing education, because it does not prepare students for entry-to-practice. It is a post-diploma program.

Baccalaureate entry reinforces a divisive "educational attainment" hierarchy that ranks baccalaureate-prepared registered nurses over those with diploma-preparation, and registered nurses generally, over licensed practical nurses, nursing attendants, and health care aides. Rather

(1994) found that returning registered nurses (RRNs) were wary of "education as the credential

for professionalism" (p. 266) and experienced oppression as a common theme in their experience:

Through the ideology of professionalism and its trappings (nursing models,

theories, and diagnosis), attempts were made to "deskill" the RRN by redefining

the work of the nurse on the basis of the teacher's control over the specialized

knowledge needed to carry it out. (p. 269)

Turkoski (1992) and Carter (1994) view advanced certification as further deepening

divisions between nurses, by creating an additional layer in the educational attainment hierarchy.

Taylor (1997) suggests nursing is also split along lines of generalist and specialist. For the

generalist, consideration of working conditions; wages, hours of work, and control over

education, are of key importance (O'Neill, 1992). For the specialist or private practitioner,

separate legislation requires the key focus be consideration of professional accountability and

authority (O'Neill, 1992). The result is further fragmentation of nursing on the basis of differences

between the goals and values of the groups.

Divisiveness arising from the subordination implicit in hierarchies, lends itself beautifully to

use, by dominant groups, of "divide and conquer" strategies. The failure of the 1991 nurses' strike

in Manitoba is an example. A government tactic of demanding that registered nurses and licensed

practical nurses negotiate separately, led to deep schisms in the membership. Many registered

nurses understood the strategy as a quicker route to the end of a 25 day strike, and supported

separate negotiation. They were then threatened by union leaders, that if they "gave up" on

practical nurses, in the future, it would be them against baccalaureate-prepared registered nurses. The strike collapsed soon afterward.

Professional-status seeking activities, inspired, in part, by gender-motivated subordination to members of the medical profession, have had a significant impact on the development of the nursing profession. In some cases, response to negative images has resulted in the intra-professional violence of which we are often accused. One aspect of professional-status seeking is, however, most relevant to this thesis and merits exploration in greater depth. In the next section, I focus specifically on the most sought after of medicine's attributes, a unique body of knowledge available only to the members of the group (Carter, 1994; Larson, 1977; Moloney, 1992; O'Neill, 1992; Rafferty, 1996; Schön, 1983; Taylor, 1997; Turkoski, 1992; Witz, 1992). I detail trends in nursing knowledge development and summarize the prevailing state of affairs. I show that the profession's current conceptualization of nursing knowledge is limited and does not serve nurses well, given the rapid pace of change in the health care system. Nursing academe has concentrated first on the development of an empiric knowledge base, and latterly, on knowledge embedded in clinical practice, with little evidence of consideration of who nurses are; of their lives, aspirations, and achievements. The life-informed and contextual nature of their knowledge is frequently alluded to, but is a poorly understood phenomenon. This inquiry contributes significantly to understanding of these aspects of nursing knowledge by critically examining one nurse's life history, from the perspective of another's, to reveal knowledge embedded therein.

Theoretical Context

My position in this inquiry is grounded in several assumptions. First, there is an explicit connection between nursing knowledge and nursing practice. As such, understanding nursing knowledge is an avenue to understanding the dilemmas and contradictions of nursing practice. Second, many nurses do not, in a deliberate and systematic way, reflect on their nursing knowledge. Third, failure to do so, originates in, and perpetuates, a positivist bias which claims as knowledge only that which is objective and verifiable. And fourth, this positivist bias is neither unexpected, nor particularly surprising. It is, after all, the medical model of knowledge development that nursing's academicians and researchers chose to emulate (Kidd & Morrison, 1988; O'Brien & Pearson, 1993), a model grounded in the empirico-deductive or positivist paradigm, emphasizing reductionism and empirical validation.

The positivist view of knowledge construction underestimates and underutilizes the knowledge-creating capacities of practitioners (Eraut, 1985; Pearson, 1992). Maeve (1994) suggests failure to recognize the contribution of practitioners has caused nursing to be divided into two worlds, "the intelligentsia and the working class of nurses", with one reason for the division being that "the knowledge base posited as the core of nursing does not meet the reality of practice" (p. 11). Maeve's concerns are echoed by those who argue the existence of a "theory-practice gap" (Fealy, 1997; Pearson, 1992; Rafferty, Allcock, & Lathlean, 1996; Reed, 1996; Rolfe, 1996). This discourse challenges two fundamental positivist assumptions: (a) the ontological position that knowledge is comprised of discrete "bits", that can be objectified and communicated through formal education to practitioners; and (b) the epistemological position that academics and researchers are the generators of knowledge, while practitioners are its

appliers (Eraut, 1985; Rolfe, 1996). Detractors of the "gap" call for an epistemological shift to consideration of knowledge created and held by practitioners, knowledge which is both research-based and grounded in the everyday experience of nurses (Reed & Proctor, 1993).

As early as the late 1970s, nurses examining knowledge embedded in clinical practice (Benner, 1984; Benner & Tanner, 1987); intuitive knowing (Agan, 1987); aesthetic, personal and ethical knowing (Carper, 1978); and nursing epistemology in general (Kidd & Morrison, 1988; Schultz & Meleis, 1988) began to challenge the positivist status quo, calling for attention to multiple sources of knowledge. Schultz and Meleis invited agreement that "there are different ways of knowing, different unknowns to be known, different propensities of knowers for knowing and different aspects to be known about the same phenomenon" (p. 220). Perhaps these nurses believe, as I do, that as human experiences are reduced to theory, "the subject has become the object, the person has become the statistic, the creative has become constrained, the human being has become the abstraction" (Plummer, 1983, p. 77).

Interest in multiple ways of knowing in nursing has since intensified. As such, there is evidence of a thirty year shift away from a scientific medical model, towards a more holistic model. But, as Newman (1992) says, "we seem to be hedging. Are we afraid to give up the certainty in knowing that the positivist view offers" (p. 13)? Bradley (1996) shares this concern:

> A reliance upon traditional values and routine has restrained the development of
>
> new ideas and the active construction of knowledge for nursing. Whilst much
>
> knowledge may spring from practice, the culture and assumptions of the profession
>
> may limit the extent to which it is described and explored. (p. 723)

Bradley's (1996) fears may be justified. There is a growing body of work promoting the role of the practitioner in the construction of nursing knowledge (Meleis, 1987; Pearson, 1992; Reed & Procter, 1993; Vaughan, 1992; White, 1995), but few authors (Drew, 1997; Jenks, 1993; Williams, 1996) explore <u>with</u> nurses, their reflections about how and what they know. Despite rhetoric to the contrary, the literature is essentially silent on nurses' contributions to the creation and development of nursing knowledge. As Chinn (1992) contends, "we have not yet called forth the voices within ourselves and taken what we find within to be matters of serious consideration as the "knowledge" of the discipline of nursing" (p. 7).

The Voices Within

"Nursing contexts are replete with encounters in which ... knowledge can be gained through imagining or *experiencing* [italics added] events such as surgery, the death of a loved one, or even being a hospital patient" (Moch, 1990, p. 157). In this statement, Moch refers to what I conceptualize as life-informed knowledge. Through her life experiences, a nurse comes to know an event in a certain way. This way of knowing is subsequently manifested in her nursing care, which in and of itself, has informed, and will continue to inform, life experience. I have noted throughout my career, however, that nurses are reluctant to reflect on how their nursing knowledge might be informed by experiences outside the realms of theory and clinical practice. In fact, they frequently strive to separate experiences they identify as personal, from those of their professional lives.

The pursuit of separateness is revealed in the words of a nurse caring for a patient with the same diagnosis as a family member. "Because my own mother had [breast cancer] ... personal

feelings can get into it. You have to really ignore that, leave your feelings at home" (Will & Fast

Braun, 1997, p. 12). And, although Pinar (1981) states "our life histories are not liabilities to be

exorcized, but are the very precondition for knowing" (p. 184), this nurse appears to see her

experience of her mother's illness as the former, a liability better left at home. Dunlop (1986)

attributes this in part to the contradictory messages of nursing education. "Nursing sought to

teach me to maintain both separation and linkage in my practice-separation [hyphen in orig.], 'you

must remember that the other is a stranger' and linkage, 'you must think and act as if he [sic]

were not' "(p. 663). It is not surprising that many nurses attempt to maintain separation between

their personal and professional lives. It is a position consistent with the highly polarized "theory-

practice" debate.

Munhall (1993) advances "unknowing" as a way of knowing for nursing. Analysis of her

position again reveals contradictory messages communicated to nurses. According to Munhall,

knowing "leads to a form of confidence that has inherent in it a state of closure" (p. 125).

Unknowing, a process of de-centering from one's own organizing principles, precludes closure.

Munhall believes unknowing opens the nurse to authentic engagement with others, and through

engagement, to new understanding.

In her discussion Munhall (1993) states, "placing aside a cogent argument that might

speak to just how well nurses know themselves, there can be little doubt that they do not know

the patient" (p. 126). I understand, and fully support, Munhall's intent to focus nurses on patients'

perspectives. My concern is that an inevitable outcome is the separation of the nurse from

knowledge arising in understanding of self. Munhall does not share my concern. She sees the

nurse's de-centering as only a *"temporary* [italics mine] suspending of self as the nurse allows the patient's subjective structure of reality to become known" (p. 126). I remain skeptical. In a profession, evidently still dominated by a positivist stance, it seems unlikely that nurses will seamlessly shift from centered to de-centered positions every time they encounter a different patient.

Meleis (1987), on the other hand, champions consideration of life experiences. She argues that examination of nursing knowledge must consider nurses' experiences, perceptions and personal meanings, and further, that multiple contexts that inform a nurse's knowledge cannot be ignored. "Personal meanings are understood in the nursing situation within the context of societal and cultural meanings. Meanings attributed to multiple realities create the context for understanding of responses" (p. 13). But again, despite rhetoric, there are few authors who contemplate the contribution to nursing knowledge of nurses' life experiences. Drew (1997) illuminated the meaning of experiences nurses identify as significant in their clinical practice, and nurses in Staden's 1998 study, overtly linked life experience to their professional lives, apparently without recognizing its contribution to nursing knowledge. Their homes were perceived as experimental ground, "where emotional management can be tried out, sometimes unconsciously, before confronting a similar situation at work" (Staden, 1998, p. 151). While Drew's focus was on meaningful caregiving experiences, she acknowledged that "the experiences which they [nurses] found meaningful reflected what they considered important in their non-professional lives" (p. 417). Her words are echoed by Williams's (1996) finding that life experience plays an important role in a nurse's way of being nurse. What that role is, and how it is revealed, has yet to be discovered.

Revealing What is Important

This review of extant literature suggests that members of the discipline of nursing hold

disparate positions on nursing knowledge. There are claims that nursing knowledge arises in

multiple ways of knowing, and suggestions that nurses are acknowledged as knowers, particularly

with respect to their clinical-practice knowledge. Beyond the theoretic discourse, however, there

is evidence of a deep fracture within the profession, of continued divisiveness between

academicians and practitioners with respect to what constitutes nursing knowledge, and how that

knowledge is constructed. Calls for "discovery of self-and-other ... connecting with what is

known" (Moch, 1990, p. 155), and integration "into our legitimate realm of inquiry that which we

know from our own experience" (Chinn, 1992, p. 7), are not matched by supportive practice

environments or curricula that honor who students, and teachers, are, and what they bring to

learning and teaching encounters (Advisory Committee on Health Human Resources, 2000;

Ontario Ministry of Health and Long-Term Care, 2000; Peters, 2000; Rancourt, Guimond-Papai,

& Prud'homme-Brisson, 2000; Rather, 1994).

What we know from our experience, and how it informs nursing knowledge, is not

explicitly articulated or revealed, and the knowledge development discourse continues to be

oppositional, as suggested by Maeve (1994), and inaccessible. Much of the discussion appears in

journals and textbooks intended for an academic audience, and much of that discussion

necessitates a comfort level with the language of ontological and epistemological inquiry that

many nurses do not hold. Our conceptualization of nursing knowledge must become more

inclusive, accessible, and easily understood, if it is to have relevance for all nurses. Each nurse's

life experiences produce a unique and subjective way of knowing a particular event. And because

each nurse's life experiences do inform her knowledge in a unique way, each nurse must be prepared to engage in self-directed activities to reveal the nature and scope of that knowledge. Only when each nurse lays claim to who she is and what she knows, will the nursing profession be able to lay broad claims to a unique niche within the health care domain.

This inquiry, through exploration of critical issues in knowledge development, advances the thesis that knowledge is life-informed and contextual. It makes explicit an aspect of nursing knowledge largely taken for granted, that is, knowledge embedded in the experiences of our lives. It provides insight into life-informed knowledge as a necessary precursor to the empathetic, human engagement now called for by many nurses. And, it demonstrates how a contextualized examination of nursing knowledge, produces a more complete portrait. In the next chapter, I describe how nursing knowledge will be illuminated through a life history exploration of one nurse's life. Life history method is explained in greater detail, as is how Patty and I came to be engaged in this process. The structure of the remainder of the thesis is delineated and some issues of rigour are preliminarily addressed.

CHAPTER TWO

Contemplating Life Experience: Methodological Considerations

In this chapter, I outline the methodological orientation of this research. I begin by locating the study within a qualitative paradigm. I then identify why life history method is a logical means by which to explore nurses' knowledge. I address specific issues related to the research design, particularly, how Patty and I came to participate together in the process. Collection of data, through interviews, observation, and review of documents, is also detailed. How I achieved understanding is discussed in Chapter Six. I undertook numerous strategies to ensure the study was conducted in an authentic and rigorous manner. As issues of rigor and ethical conduct arose throughout the process, they are discussed at the point at which they entered into consideration.

Qualitative Paradigm

My interest in nursing knowledge arises in my life experience of my grandfather's death and subsequent reflection on that experience in the context of my teaching and nursing practice. In telling my story, I both illustrate, and explicitly accept, Peshkin's (1993) statement that "behind the story of any particular life is ... something worth learning" (p. 25). I have already explicated my position that understanding nursing knowledge is an avenue to understanding the dilemmas and contradictions of nursing practice. I now propose that we are able to learn something of the nature and scope of nursing knowledge, by examining the life of a nurse.

I am also acutely aware of continued divisiveness among members of the nursing profession, as to what constitutes nursing knowledge. My choice of research tradition, and of the

method within that tradition, must, therefore, fulfil two objectives. It must be consistent with my twin-pronged assumption that knowledge is life-informed and contextual. And, it must contribute to a broader conceptualization of nursing knowledge than has been previously understood.

This inquiry is, therefore, located in a qualitative paradigm, a fundamental assumption of which is the existence of multiple truths or realities. Acceptance of the concept of multiple realities acknowledges that each nurse has different life experiences, and that each nurse understands differently, how those life experiences inform her nursing knowledge. Each nurse constructs, therefore, a different reality. Lincoln (1992) suggests that these constructions are "socially and experientially based, local and specific in nature, and dependent for their form and content on *the individuals who hold them* and *on the groups to which those individuals belong* [emphasis mine]" (p. 379). Lincoln's words reinforce my position that my chosen method must consider both the nurse, and the context of her life.

In accepting assumptions of the qualitative tradition, I explicitly reject a positivist belief that there is "one right answer" or "truth", identifiable through reductionist strategies and subsequently generalizable to a larger population. A positivist stance suggests there is an observable, verifiable "body" of nursing knowledge, that all nurses hold in the same way, a premise antithetical to my understanding of the life-informed and contextual nature of nursing knowledge. Within the group of research methods originating in the qualitative paradigm, I have, therefore, chosen life history, because of its capacity to illuminate a life-in-context, and thus provide understanding of nursing knowledge not evident to this point. In the next section I discuss life history method, what it is, and why it is appropriate to this study.

Life History Method

Life histories, like snowflakes, are never of the same design

(Borenstein, as cited in Plummer, 1983, p. 7)

Life history method has many definitions and interpretations (Tierney, 2000). I understand it to be grounded in an ontological assumption that human beings make sense of their lives in a manner that is personal and subjective and, that this sense, or meaning-making, is socially constructed. Knowledge is, therefore, created/recreated in human relationship (Kvale, 1999). This is consistent with the assumption that knowledge arises in life experience, and that each nurse's experience, and consequently, life-informed knowledge, is different. Our lives exist, however, in a contextual maelstrom. How we make meaning of and tell the story of who we are is informed, in part, by our biographical stories, familial connections, places of residence and work, and relationships with neighbors and colleagues. All of these, and other contextual features of life, are embedded within socio-historical, economic, political, religious, and cultural perspectives, to name but a few of the factors that have an impact on our lives. Failure to consider these aspects of our lives is to assume life is context-free, that we are in no way touched by events and relationships which transpire around us. Thus, for myself as researcher to understand the meaning the participant, Patty, ascribes to events of her life, it is necessary that I also understand the multiple contexts within which her life is lived.

Life history method, because it explores the intersection of an individual's life and the context within which that life has been and is lived, is methodologically consistent. It is, according to Cole and Knowles (2001),

> about understanding a situation, profession, condition, or institution through
>
> coming to know how individuals walk, talk, live and work within that particular
>
> context. It is about understanding the relationship, the complex interaction,
>
> between life and context, self and place. It is about comprehending the
>
> complexities of a person's day-to-day decision-making and the ultimate
>
> consequences which play out in life.

Specifically, life history method is used in this inquiry to describe how the complex interplay of nursing knowledge and nursing practice is understood within the nursing profession, through interpretation of one nurse's personal, introspective, and contextual story, by another.

Patty's story reveals the rich points of her life. These are "points of profound change and influence" (Cole & Knowles, 1995, p. 141), from which we gain insight into Patty's understanding of the profession of nursing, and of palliative care nursing, in particular. My interpretation of Patty's life history, given that I too bring idiosyncratic knowledge and perspective to our conversations, adds my own understanding. As researcher, it is my further responsibility to bring forth the broader landscape of the nursing profession, by means of additional information; through observation, and through consideration of socio-historical, economic, political, and other perspectives. This provides a contextual frame, and the opportunity to do so, is a unique feature of life history method. This strong contextual orientation, in fact,

distinguishes life history from other personal history methods such as narrative, biography and life story (Cole, 1991; Goodson, 1992).

The nature of the role undertaken by the researcher and the research participant also serves to differentiate life history method from its counterparts. As this is dialogic partnership research (Cole, 1994), in which Patty and I engage in mutual inquiry and interpretation, "synthesis and feedback are central to the process ... 'It is the ongoing dialogue of reflection and feedback that helps to transform personal understandings into ... knowledge' " (p. 191). This is consistent with Kvale's (1999) contention that knowledge arises in human experience, and Peters's (2000) point that "knowledge is a social product, and it develops and evolves via negotiation within discourse communities" (p. 167).

A life history inquiry necessitates, therefore, prolonged engagement between researcher and participant. It is not realistic to expect anyone to reveal the richness of a life in one or two interviews. The first phase of the process is, in fact, negotiation of the relationship (Cole, 1991). Early interviews serve to develop rapport and build trust. Discussion regarding issues of confidentiality and anonymity take place. As well, the researcher may share personal stories, such as, how and why interest in this particular area of inquiry arose. Sharing of personal stories communicates the same openness expected of the participant, and can demonstrate researcher credibility. I shared with Patty the fact that I, too, had been a palliative care nurse, and how that experience followed me in my academic career, informing my teaching and doctoral studies. We spoke generally at first, negotiating the possible number of interviews (five, later renegotiated to seven), and deciding on what days of the week, and time of day, might be most effective. My

willingness to adapt to Patty's schedule demonstrated my commitment to honor her as an active

participant in the process. It also helped to create an environment in which Patty felt safe, able to

begin to share experiences of her life, knowing how they might ultimately be represented.

Life history data are collected in multiple, cumulative, open-ended interviews, that Cole

(1991) refers to as "grounded conversations" (p. 197). The researcher generally begins with a

broad question intended to stimulate recollection of, and reflection on, life experiences.

Subsequent questions arise from participant responses, and researcher responses to the

participant's story. They seek clarification, depth, breadth, insight, and the participant's

perspective of the experiences in the context of externally-gathered data. Patty and I both brought

forward documents (articles, news reports, pamphlets, manuals, institutional policies etc.) that

stimulated our conversations in different ways.

Together, we explored Patty's life on several levels (Goodson, 1992): her life experience

and background; her life style, particularly her fondness for rural life; pivotal experiences at

different stages of her life; and, of course, her career as a nurse. A useful tool was a time-line, or

lifeline, that I sketched after the third interview, plotting the significant events revealed to that

point in time. When I shared it with Patty, she quickly picked up a pencil and starting adding

events and elaborating on others. The time-line proved an effective conversation trigger, adding

nuance and character to her story.

In a life history inquiry, the interview is a relationship in which knowledge is created. To

portray the interactive nature of Patty's and my relationship, my analysis and interpretation of

how Patty's life experiences inform nursing knowledge, is represented as a conversation between

two nurses. The conversation demonstrates how Patty and I construct, hold, and express our

knowledge. It also illuminates many instances in which Patty and I struggled to reconcile our

respective points of view, our respective ways of knowing a particular phenomenon. The

similarities in the way in which we understand events arises, in part, in our similar clinical

backgrounds; the differences, in the vast knowledge each of us holds arising in experience outside

the clinical realm, and in the vastly different contexts, clinical practice and academia, in which our

knowledge is articulated. Knowledge is created, through exploration and conversation, as we

harmonize our positions, as Kvale (1999) suggests "*inter* the *views* of the interviewer and the

interviewee" (p. 101).

There is also a third participant in this inquiry, of whom I am constantly mindful. The

reader encounters and is drawn into the dialogue, and as Charmaz (1999) states "readers come to

our stories with their own knowledge, experience and meanings" (p. 379). Patty's life

experiences, and her understanding of them, are revealed through my interpretation of her

narratives. My interpretation takes into account theoretical and contextual perspectives outside of

Patty's immediate experience. My interpretation, and the contribution of others, is then

considered by readers, who bring their own views and interpretations. Knowledge is thus

constructed in an ever-widening spiral as different readers create meaning of Patty's life history,

or to paraphrase Kvale (1999), knowledge is created *inter* the *views* of the author and the reader.

Through this process, the life of one member of the palliative care community, Patty, offers a

window onto, and insight into, the experiences of the community itself. As Cole and Knowles

(forthcoming, 2001) state "to understand some of the complexities and complications and

confusions within the life of just one member of a community is to gain insights into the collective".

Life History Method in the Health Sciences

Life history method is represented in health sciences literature, however, the majority of work is found in disciplines other than nursing. How the method has been, or could be, used in clinically-based research is summarized by Frank (1996). While Frank broadly defines a narrative genre in which "empirical methods are used to construct and interpret the lives of ordinary persons" (p. 252), she distinguishes life history as a narrative report of a person's life from birth. This narrative unfolds naturalistically, is organized chronologically or topically, and perhaps most importantly, includes the "researcher's reconstruction and interpretation on the basis of the person's life story, interviews, observations, and clinical records and other documents" (p. 253). Frank's discussion is particularly useful in that it compares various narrative methods and provides examples from her own extensive life histories.

Several authors discuss the distinguishing features of life history method (Miller, 1994; Mitchell & Radford, 1996; Saillant, 1990). Saillant focuses our attention on context, particularly the context within which an individual experiences illness. Her poignant life story of a woman dying of cancer depicts an ever-widening gap between the patient's *experience* of illness and death, and the *context* of an oncological discourse of hope and survival. The woman's increasing alienation as she moves beyond the prevailing discourse impresses upon us the need to reveal how her, and others', experiences are shaped and informed by the events of life.

The nature of roles undertaken by researcher and participant, roles that differentiate life history method from its counterparts, are also highlighted (Miller, 1994; Mitchell & Radford, 1996). Miller explores borderline personality disorder from the patient's perspective. In this work, the descriptions of patients' lives are so rich that details not previously shared with therapists are revealed, perhaps because participants perceived that they and the researcher were involved in a more collaborative and egalitarian relationship than in a therapist-client relationship. Miller hypothesizes that information is seen as helpful to others rather than detrimental to self, as may be the case when sharing is linked to treatment decisions.

Mitchell and Radford (1996), like Miller (1994), reveal their experiences of greater participant disclosure in research interviews. They suggest the time-limited nature of research interviews may contribute to participants using the researcher as confidant. There may be "increased personal disclosure due to an increased sense of anonymity and freedom from consequence" (p. 54). The notion of freedom from consequence is echoed by the participants in Miller's study even though her interviews spanned a one year period.

These reports of unanticipated researcher/participant roles, reveal a dilemma sometimes encountered in clinically-based research, that is, the proximity of research and therapeutic interviews. Given the assertion that knowledge is created in human relationship, it is not surprising that there are more similarities than differences, between interviews with theoretically different purposes. Kvale (1999) suggests, in fact, that therapeutic researchers "should pay serious attention to the potentialities of their therapeutic interviews as a research method" (p. 110).

My conversations with Patty cannot be construed as therapeutic. We are two nurses, not

nurse and patient, in conversation. Life history method is explicitly understood as a research

method in this inquiry, as such, extensive discussion of this dilemma is not necessary or

appropriate. It is an important point to raise, however, as further examination of health sciences,

and, particularly, nursing literature, reveals notable differences in the purpose and design of a

study utilizing life history method.

Larson and Fanchiang (1996), for example, link the relational character of life history and

other narrative methods, to an ethic which is a part of the client-therapist relationship. They

propose that the method can serve not only for research purposes, but as a therapeutic

intervention. Life history research is described as a means to assist occupational therapists in

"better understanding the complexity and contexts of the client and his or her experience in the

therapeutic process" (p. 247). The notion of narrative windows of opportunity is advanced as

important in "situating a therapy episode into an ongoing life story" (p. 249), thereby enhancing

the working relationship.

Life History Method in Nursing

In nursing, these and other methodological issues related to life history method are seldom

raised, although Admi (1995) has described what she believes to be the strengths and limitations

of the method, citing particularly a lack of attention currently given to analysis of life histories.

The lack of debate may be because the method seems to be understood differently by different

authors. For instance, Hagemaster (1992) views life history method as a means to "reveal some

shared behavioral and belief patterns across cultures ... [serving] as a common denominator for

comparisons among other ethnic groups" (p. 1127), while Bramwell (1984) defines the method as

a "composite of activities in which older persons engage in an attempt to arrive at some

meaningful, integrated life perspective" (p. 37). Bramwell suggests participants use reminiscence,

selective recall of positive life experiences to buffer present realities, and life review, to "reconcile

old guilts and derive meaning" (p. 38). In this description, particularly given the role a researcher

might undertake to focus reminiscence on selective memories, it is unclear whether life history

method is understood as a research method or a therapeutic intervention.

King's (1989) focus is also elderly persons, in particular the use of a life health-care

history protocol (Leininger, 1985) to document the health history of an eighty-five year old

woman. Leininger describes the protocol as a means by which to "document and identify

longitudinal pattern(s) of an individual's perceived, known, and experienced health, care, and

illness lifeways within particular cultural and environmental contexts" (p. 124). As with

Hagemaster (1992) this view of life history appears to be directed toward culturally-specific

understanding and cross-cultural comparisons. Leininger does view life history method as useful

across the life span, but in keeping with Bramwell (1984) and King (1989), its use with elderly

persons is perceived as particularly beneficial, presumably because their longer lives lend

themselves to historical consideration.

The juxtaposition of biography and context, one of the key features of life history method,

is only discussed by Bramwell (1984) and Leininger (1985). The primary focus in other works is

either life story without attention to its context (Hagemaster, 1992; King, 1989), or the impact of

context alone (Hinds, Chaves, & Cypess, 1992). Hinds et al suggest that "abilities to attach

meaning to and to understand a phenomenon depend on the researcher's and clinician's knowledge of the multiple contexts in which that phenomenon occurs" (p. 62). Context is described as four nested, interactive layers: immediate, specific, general, and meta. These authors believe that consideration of context, not only descriptions of event-specific contexts, but consideration of the nurse's own interaction with the contexts of others, has the potential to reveal aspects of nursing that have been perceived to be invisible.

The health sciences and nursing literature reviewed reveals that life history is clearly understood by some as a research methodology (Admi, 1995; Frank, 1996; Miller, 1994; Mitchell & Radford, 1996; Saillant, 1990). Others seem to understand the method as more limited in scope, with a primary focus on health history (Bramwell, 1984; King, 1989), what Admi refers to as a "thematic life history" (p. 187). Bramwell's definition sounds somewhat like reminiscence therapy. Larson and Fanchiang (1996) see potential in both arenas, where life history research provides insight into patient experiences that are relevant to therapeutic encounters, and opportunities to "switch gears" as it were, during the course of a research interview, into a therapeutic interview.

Significance of Life History Method for Nursing

Nursing knowledge is contentiously debated in nursing literature. Does knowledge arise in theory or in practice? Is the profession of nursing an art or a science? Should members of the profession embrace single or multiple paradigms? The voices of nurses are heard in narratives of clinical practice, but who these nurses are and how they understand their own knowledge of nursing, continues to be invisible. This inquiry begins a long overdue inclusive discourse.

The inquiry also introduces life history method to the repertoire of nurse researchers. As a research method, life history can contribute richer data than communicated in the examples found in nursing literature to date. Through reconstruction of nurses' life histories, and in shared exploration of how those histories are contextualized, we gain insight into how nurses, and nursing practice, are informed by socio-historical, political, and economic influences, such as those evident in systemic changes in health care (Will, forthcoming, 2001). As Cheek and Rudge (1994) state "our understanding of nursing and nursing practice are shaped by texts derived from the wider social context in which nursing and nursing practice are embedded" (p. 15). Any attempt to portray nurses' contemporary situations must, therefore, begin "by recognizing the changing context within which [their] work is undertaken" (Ball & Goodson. 1985. p. 2).

Nurses are tested on a daily basis by varied beliefs about what constitutes nursing care and how it will be accomplished. The institutions in which they are employed. the physicians with whom they work, and the public for whom they care, all have different expectations of what nurses can and will do. What these expectations are and how nurses perceive they define their nursing practice has not been well investigated. Through life history method, the opportunity exists to explore these relationships of individual lives, institutional culture, and social structure.

Politically-mandated health reform and restructuring is an example that illustrates the importance of consideration of context. In health reform, closure of institutions and beds, aimed at reducing health care costs, has resulted in the deletion of thousands of nursing positions. Nurses have been retired, laid off, declared redundant, and "bumped" throughout facilities, out of

specialized practice areas in which they have developed considerable knowledge and expertise. Nurses in hospitals grapple with increasing patient acuity and technological complexity which necessitates both greater time commitments and different knowledge. Nurses in community settings cope with the impact of shorter hospital stays, caring for much sicker people unmatched by resource availability. And diminishing dollars have led to increased numbers of unregulated, minimally-trained staff replacing highly skilled and experienced practitioners, a strategy which increases a nurse's workload by expecting her to be the monitor of service provision.

What is the significance of this context of health reform for nurses' lives and work, for the expression of their nursing knowledge? How do they understand the rapid and dramatic changes which seem to be overtaking their nursing practice? How can their knowledge contribute to the process? Most nurses know that their knowledge is extraordinarily complex, that the knowledge used to nurse is broader than that acquired in nursing programs or through clinical practice experience. And yet, we fail to explicitly consider the life-informed and contextual nature of nursing knowledge, and to reveal it in its richness and depth. Patty's life history, and my interpretation of it, sets understanding on a new course.

Although it is not well represented in nursing, life history method has a time-honoured tradition in other disciplines (Hatch & Wisniewski, 1995), where methodological issues such as relationship and voice, rigour, representation, and ethical considerations have been extensively discussed (Cole, 1991, 1994; Cole & Knowles, 1993, 1995; Finley, Knowles, Cole & Elijah, 1995; Kvale, 1995; Lincoln & Guba, 1990; Measor & Sikes, 1992; Mitchell & Radford, 1996; Sparkes, 1994). The experience of these researchers establishes the efficacy of life history method.

The scope of opportunity to differently understand aspects of nursing knowledge and practice, establishes the importance of including it in the repertoire of nursing research.

Patty

Every nurse's life is a story from which there is much to learn: about life, about nursing, and about nursing knowledge. One other nurse participated with me in this journey of exploration. Patty is a clinical nurse specialist on a palliative care unit located in a teaching hospital in a large urban center. I worked on a different palliative care unit than Patty. My time there predates Patty's by about six years, and is of much shorter duration, about 5 ½ years in total. Patty has been caring for dying people for 20 years.

I first met Patty four years ago, when she acted as a clinical preceptor for a student in a course I was teaching. From this experience, I knew her to be intelligent, articulate, and committed to principles of palliative care, and learning and teaching. Her passion and enthusiasm for palliative care nursing deeply touched me, so I had her in mind from the beginning of the development of the thesis proposal, believing she would contribute to the project in a meaningful way. I invited Patty to join me through a letter describing my interest in nursing knowledge and life experiences outside the realm of clinical practice (Appendix A). Later, when we met for the first time, she revealed that before agreeing to participate (Appendix B) she had shared the letter with her family, particularly with her youngest daughter, a teacher, whose opinion clearly was important. The entire family supported Patty's decision.

In the letter of invitation, I explained my interest in collaborating with a nurse from palliative care, as it was the clinical field in which I had most experience. The palliative connection between Patty and me facilitates development of rapport, but it could, just as easily, limit our conversation, or predetermine and set a tone for acceptable and anticipated content (Mitchell & Radford, 1996). So, while our interest in palliative care is the intersection at which Patty and I meet, I am aware that each of us is an individual. differently informed. and that each of us brings a different perspective to this inquiry. I also wanted to engage with a nurse in this setting, because while palliative care is beginning to come into its own as a recognized specialty, it is still, in our technology-driven, cure-oriented society, less well-funded and perhaps less valued, than other areas of practice. I saw an opportunity to develop insight into the significance of a practice context for the expression of nursing knowledge, particularly given concerns raised earlier, regarding a hierarchical ordering of preferred areas of work (Hardill, 1993).

What follows, in the next three chapters is Patty's story, who she is, what she believes about nursing, and where her nursing practice takes place. It is a rich description of her life as she shared it with me between July 1998 and March 1999. In all, we spoke for almost 30 hours, in seven open-ended interviews, and during three observational experiences. The length of time we spent together was necessary to enable Patty to fully reveal and develop her story. It was also necessary because trust takes time. Patty had to be comfortable that I would honestly and authentically interpret her life.

In response to the question "How did you become a nurse?", Patty began a detailed description of her training. She spoke spontaneously and at length. I found I asked very few

questions except for clarification of the sequence of events. Later interviews added other experiences of her life: family life, educational endeavors, and, of course, her nursing practice on the palliative care unit. Observational experiences provided insight into the varied responsibilities and activities of her position. They also offered the opportunity for further discussion about notable aspects of her practice. Throughout I kept field notes, a diary in which I recorded my impressions of the interviews, my thoughts about how subsequent interviews might proceed, and any details I wanted to apprehend. I also recorded my understanding of practice observations, in conferences for example, I noted who attended, who sat where, and how discussions proceeded. I observed, particularly, for insight into Patty's role and how her contributions were incorporated into the proceedings.

All interviews and field notes were transcribed verbatim. I chose to complete the transcription myself because I believed it would enhance my learning and I found this to be the case. Doing the transcription myself facilitated the process and progress of interviews. As I completed each transcript I identified what stood out for me. This set the tone and directed my opening questions in the subsequent interview. I was also able to identify when I had asked questions that perturbed and strengthened the discussion, and when I provoked closure or inadvertently changed the subject. My ability as an interviewer consequently grew as we proceeded. As I transcribed the interviews I also engaged in a preliminary analysis of the data. Questions and ideas that arose were inserted in italics or in the margins, highlighting aspects which were eventually identified as the rich points.

I used a journal to explore my own feelings and assumptions. I recorded the moments when everything seemed to come together with amazing clarity, when the writing was steady, and my confidence was high. I also recorded my apprehension as the study proceeded: concerns about my research competence, frustrations with my interview style, reservations about the content and process of our conversations, lack of confidence in my writing ability, anything and everything that presented a roadblock, temporary or otherwise. I examined and questioned the assumptions that could potentially limit my capacity to listen to Patty in an authentic way, and engaged in a dialogue with myself to resolve problems.

It took me a long time to decide, for example, how I would represent Patty's words. My first effort was a chronologic, third person narrative, but I had no sense of Patty when I read it. It seemed unnatural. Patty speaks very quietly. When she talks with patients and families she is never impatient or imprecise and she frequently describes experiences with great passion and emotion. As I contemplated how to write the story she shared with me, I had an epiphany. I realized that when I read her words, I could hear her voice. Eventually in the writing I became mindful of hearing her voice. It is the point of connection between the story as told and the story as represented. The most rigorous feature of this work is that I am always able to hear Patty's voice. When I do, I am closest to truly representing **her** life.

How to maintain anonymity was another perplexing detail. In the first meeting Patty stressed that she wanted to remain anonymous. As we proceeded, and particularly as I examined the contextual features of the palliative care unit, I recognized that there were some elements of the story that if shared, would breach Patty's confidence. She and I spoke on three occasions

about this and together resolved how various aspects of her life and practice would be represented. As a result I have deliberately avoided specific reference to her home, to the location of the institution in which she works, and to historical features of the palliative care unit. The community of persons working in palliative care is small. If I were to describe some of these features, even though they might contribute to understanding, I would reveal Patty's identity.

Concluding Thoughts

In the next three chapters, the focus shifts to Patty. Her story is organized in three parts. In the foreground, Chapter Three, Patty's life story is shared in her words, beginning where she began in our first meeting, when she enters nursing training in 1959. Rather than proceeding chronologically, the story moves across her life as she remembered and revealed it. The nursing foreground follows in Chapter Four. Here Patty's description of her nursing practice is complemented by my thoughts, questions, and descriptions of similarities and differences with my own practice experiences. The background, Chapter Five, is the historical, socio-political and local landscape that contextualizes Patty's practice. This is a narrower contextual perspective than that set forth in Chapter One, as it specifically examines the context of palliative care nursing. Here, different voices are heard, other nurses, and those who are involved in the palliative care movement. Their voices situate Patty's experience as a palliative care nurse.

Patty's words are italicized so they can be differentiated from my words when mine come into the text. Pauses are represented by gaps in the text   ...followed by three dots, strong emotion by **bold.** Ellipses ... are used to move the conversation from one segment to another. Most of Patty's story was shared consecutively but we also came back to events in later

interviews. To fully describe these events, I have knit together some passages that were shared at different times.

Patty's life, and the context within which it has been, and is, lived, is presented in considerable depth and breadth. Extensive detail is necessary for the development of insight, and understanding of, aspects of her life that inform nursing knowledge. It is also necessary to fully convey the import of the practice context for the expression of that knowledge. In other words, without a fully rendered portrait of Patty's life, it is impossible "to capture the richness, complexity, and dimensionality of human experience in social and cultural context" (Lawrence-Lightfoot, 1997a, p. 3), and to convey to the reader Patty's perspective of those experiences. And, without a fully rendered portrait that accomplishes these objectives, it is impossible to interpret Patty's actions and perspectives, and through interpretation, to illuminate the life-informed and contextual nature of nursing knowledge, the primary intent of this thesis.

CHAPTER THREE

Contemplating Life Experience: Patty's Story

Becoming a Nurse

I had talked about being a nurse for awhile, writing to different schools in New York, in

Canada, in England. My mother had tried to be a nurse in the 1920s and she always talked

about her experience. She went through, got through as far as the medical, and was rejected

because her pulse rate was quite fast. It was something she wanted to do and couldn't. When did

I know I wanted to be a nurse? Well, back then my Mom always talked about her experience.

Later, when I was in the convent school we used to visit the hospitals and talk to patients. You

would go to the ward and the nurses would tell you who to visit. We didn't get the very sick

people, but I remember seeing someone who had just come back from the operating room and

was bleeding from the mouth. I thought it was awful, but then I was able to keep going back. We

had to go once a week and I did this for about two years and so I got very comfortable going into

hospitals. And then I thought, this looks good, I'd like to do this and I knew that I could take it. I

was comfortable in the hospital.

There were obstacles in getting to another country to do it. They were very strict. Rather

than take foreign students, they would take their own students first. I was going to take nursing

in New York. My grandmother lived there and she and my mother had traveled back and forth,

so it wasn't the culture shock that some people think it is. I could have gotten into any one of

those hospitals because they were specifically for colored people, as opposed to the white

people. So I went to New York, but I didn't like it much. There were too many people, the crowds,

and that was the time of segregation. My grandmother owned apartment blocks, she was a

landlord, and I remember going on the bus with her and as we got on I just sat down, because at

home people on the bus just sat wherever. And she said no. At that time if you were not white you

sat at the back ...and I couldn't take that. I could not. I don't care what they think of me, but if

I'm in a place I should have the same opportunity as other people. So I didn't want to stay there.

My brothers were already in Canada. They had come ahead and started university. My

half-sister had been to visit them and she came to the hospital and talked to them about me and

they admitted me to nursing on the basis of that. There was no problem getting in here. One

other nurse, in the class two years ahead, was also from home. She probably paved the way so

when my sister came, I had that ahead of me. It was difficult leaving home, but then again I had

stayed at home for two years after I finished high school and I thought, I have to move on with

my life. So I came up and I liked it and I stayed.

It was three-year program and nursing training was different than it is now. You lived in

residence, so you ate nursing, drank nursing, lived nursing. Your co-workers and associates were

there, you just lived nursing. Student nurses actually staffed the hospitals. You had your six

month probation time where you went to classes and from then on you were on the wards. You

were on the wards as a junior, with a senior, who'd be a third year, and both of you would be

running the wards. Now students are more sheltered in a sense, they're more protected. They

come onto the units and they have a facilitator and everything they do they're supervised. We

didn't have that.

I finished the probation and in the last six months of my first year I was on a medical ward. There was this patient dying of cancer, lung cancer, and every breath he took he grunted and groaned and was in pain. I kept asking the senior student for something, but we couldn't give him anything. At that time you waited until it was time for the next dose because everyone believed you could get addicted. It was just awful. I just felt terrible. I felt very frustrated and I felt so sorry for him and also sorry for the man who was in the next bed to him, who never slept all night, had his eyes wide open, listening to every grunt and groan of this man. He died about six that morning in severe pain, grunting, groaning, and that really affected me. I didn't realize that nursing would be so painful, painful for the patient, but also painful for me, seeing someone suffer.

That same night we had a woman who, when she delivered, it was discovered she had a brain tumour and here she was. I think she was a week post-partum, diagnosed with a brain tumour, a high fever, and she just died. So we had both those patients on the ward, and for a young nurse, seeing how the patients were suffering and the attitude at that time. That was one thing that I just haven't been able to forget. I couldn't understand it, and you know, thirty years later, I still can't understand, because it's still going on. It's still happening. Yesterday I had a call from the daughter of a woman on our program. She's frustrated because her Mom is obviously starting to progress again and needs more medication, but the doctor won't increase it. I mean this is 1998 and she cannot get the doctor to prescribe more pain medication.

In my second year I was on the neurology ward and we admitted a very young woman, she was in her forties. I still remember this very distinctly. She had an aneurysm and they rushed

*her to the hospital but there was nothing they could do. She had young children, they were in their teens. She died and I was the nurse, the student nurse, looking after her. The supervisor could not go and tell the family that the patient had died, couldn't deal with it. I had to   ...well she practically **made** me do it. She said it was my patient. It was traumatic for me having to deal with that, go and tell a husband and the kids, just like that in the hallway. The supervisor just took off, she couldn't handle it. At that time I didn't know how to talk to people. I didn't come across death very often. Also, you did not deal with families very much. There were strict visiting hours and everything was different, and so here was a husband and the kids screaming and crying. I just felt very terrified of what to do and very angry at the supervisor who was supposed to, really to help me and she couldn't. I just couldn't believe I was going through it.*

In second year, I had a one-month rotation in the intensive care unit, one month of evening shift, looking after four patients at a time. In that month, twelve patients died. I just couldn't believe I was going through this. Those are some of the traumatic things I found happened to me in nursing and there was no support. As a student this was what you went through. In nursing at that time, you were used as staff on the wards.

The third year went quite smoothly but there was an experience that didn't go over too well. We had our infectious disease training. I was there for a month but that hospital was short-staffed on one of the wards. Anyway, the director spoke to our director of nursing, wanting to use us to staff the ward. I complained, and of course that was the worst thing. You're a student and you don't say anything and all I got was a lashing out and to spend an extra three weeks on

the ward. It was not easy to do, because those patients had their set routines and you're putting in new people, especially students, who had no idea what to do. It was an awful experience.

You know, as I look back on my nursing I learned a lot in my three year program. But what is left with me, and I'm not sure if that's why I eventually went into education, was the fact that they just didn't know how to teach. It wasn't a good experience for some things, not theory or the studying and I made friends with girls I'm still friends with, it was more the way you were treated. I found the way we were taught very difficult. It's like you weren't people who were learning, you were   ...students weren't really treated like people, like students should be. Now you value students and you have an important role, a big responsibility, in teaching them. I don't know how I learned. It wasn't easy.

Our class was 120 and about 100 graduated, so we lost some along the way, the majority in the first six months. It's very frightening that first day, you tend to get into a group that you're comfortable with. I guess I would say about five or six of us grouped together and actually two of those have died already. That wasn't easy. One was about twenty years back. She died young and at that point in time our children were young, and yes, I think I put that out of my mind for awhile. I don't even think I was working on palliative care at that time and I couldn't understand it. The other one had more of an impact, I went to her funeral. The irony of it is, her husband had the same disease and he died on this floor, before I got here. I remember being introduced to him at reunions and at that time he had just been diagnosed, and then she developed it about five or six years later. She died about ten years after him and I went to her funeral, it was here in the

city. That was sad. It does hit home, because it's your classmate and we were quite close, you know, in the group.

Our last reunion was our thirty-fifth and that I think most of us found a little bit traumatic. I remember when we graduated and as we sat there and they announced the classes we were thinking, "That's so old, thirty-five years." Now I know what they're thinking and we're thinking, "They're so young, they've got so much to go yet and learn and things are going to change." We come together every five years and it's really interesting to see how your classmates change, what direction they go in, what they've accomplished, what some of them have been through and there's that sort of permanence, that permanence of a link to something.

You know we only see our patients here for two or three weeks of their life. What has gone on for the last sixty or seventy years? We have no idea, yet we're having to deal with them in this phase where they're ending it all, having to help them and their families go through it. You see the end of that life and wonder what has happened from the time they were one day old to this ...it's overwhelming. So part of what I try to get at, as I meet patients and the families especially, is to get a picture of that person. I talk with them and one thing leads to another. I talk, and I come back, you have to keep asking questions. Not that you're being nosy, but it's a continuous asking of questions. You cannot do that in five minutes.

Recollections

I was born in ...you don't have to know exactly when, do you? Anyway, there were eight of us ...no, nine actually. My Dad was married twice and he had a daughter with his first wife.

His wife died when my half-sister was two and right away she went to live with her aunt, her mother's sister. I was quite close to her. She was fifteen years older than I was and I looked up to her. My Mom was busy with all these kids and my sister would spend time with us and take us out. She was a sister and she was more than a sister, sort of a second Mom.

So there were eight of us, four boys and four girls and I am the oldest girl. Two boys and then me, then two younger brothers and three younger sisters. The youngest sister is fifteen years younger than me. She calls me Mom, like my half-sister and I. My two older brothers both had polio. I was just little but I remember how my mother cared for them. We had a little cottage right on the ocean and she'd take them there and they just swam and swam, and she taught them to walk. It put my oldest brother behind in school by two years. Then my next brother was on track and I was two years ahead so we all graduated from high school at the same time. I was just sixteen.

We went to private schools. I went to a convent and the boys to a school run by brothers from Ireland. At home when you finish elementary school, you have to write an exam to get into secondary school. I guess I was about ten or eleven. All the kids on the island write the exam. There were hundreds of kids and the first hundred get scholarships. All the rest of your education is paid for. And I was fifteenth on the island, so I got a scholarship.

My parents never pushed us, but it seems there was an expectation, as you went through school from one level to the next, an expectation that you would pursue further education. When I finished high school there were no universities, there are now because I have nieces and

nephews there and they go, but there were none then. I probably would have stayed if the opportunity had been there. But as I said when I finished high school I was sixteen. I wasn't sure what I wanted to do but I felt I was too young to leave home. I just wanted to get out of school and make some money. So I went and did secretarial, typing and shorthand, because I was interested in that. And I did a sewing course.

I got a job in a library and I worked as, sort of, an assistant for about six months. But I didn't like it and a job came up at Singer and I went to work in the office doing accounting. I was there about two years, though after a while I could not see myself in a job like that for the rest of my life. I needed to learn more, to do more. Maybe that was the environment we grew up in. Learning was important, we weren't pushed, but it was important. My father did several things. First of all he had his own trucking business and then, he died about 5 years ago and he was actually in his nineties, he got out of that and bought taxis and ran his own taxi business. Then he went and managed a quarry. And even after he was retired, when he was in his eighties, he went into real estate, selling houses, so he just never stopped.

My father was a very intelligent man and certainly quite motivated and so was my Mom. There were always books in the house and they were up with the latest things even though he was born in 1898 when the schools only went to a certain point. He went as far as he could and that would have been it. But they saw that we had opportunities. I did piano and my brothers did other things. We were not pushed, but we were exposed to those things and we were continuously learning. If any of my brothers or sisters had problems in the school system my mother and father would hire a private tutor to help them through, so we had exposure to that too. The

interest was there in my parents, and it was up to us to continue. And we did. My oldest brother

is a school principal at home. Two other brothers are teachers and one is a geologist. One of my

sisters is a nurse in England and the two youngest are a chemist and an accountant. We all came

away at some point and did our studies in different universities.

My half sister too was stimulating and energetic. I was quite close to her and sort of,

looked up to her. She was very fashionable and she would help me choose clothes or make

clothes for me or make sure I was dressed well. She came to New York just before I came up to

do nursing, to do dress design. She married an American who lived in Washington. When she

moved to Washington she joined the embassy there and then she developed leukemia and she

died. She died when her daughter was two which is really ironic. She was two when her Mom

died and then she died when her daughter was two....

That was very difficult for me. I knew she had leukemia but she never did tell me how bad

it was. I had decided to visit her, we were up north at the time, in 1967, and I decided to visit her

at Easter because I sensed that something was wrong. Then I got a call just at the end of

February from her husband to tell me that she had died and that was it. There were no phones

where we were, it was radio communication, and I had to pick up and say over and out and so

here is someone saying to you, your sister has died ...over and out. It **really** *...was a shock.*

I didn't feel I could handle that. So right away we made arrangements to come out. My daughter

was two at the time. So we flew out, had to stay in Toronto over night, and we got there right in

time. Her husband came and picked us up and we walked right into the mosque and it was just

time for burial at 12:00 and that was it. So it was the ceremony and we went to the cemetery and

she was buried and that was it. And that was bad... that was.. very difficult to take. Her

daughter and husband, he didn't remarry, have kept contact with me. Her daughter calls me

quite frequently to talk. She and my daughter are six weeks apart.

When I left Washington, my sister had a beautiful home in Washington, I thought I'll

never come back to this place. I'll never go back and I have never been back. It's thirty years and

it seems like yesterday. The shock doesn't go away. My sister's was the only death in the family

that I experienced in years and years. My grandmother died. She lived to be in her nineties so I

was older when she died, but my sister's death was really more traumatic. Grandparents are

supposed to die. Even my Dad's death at age 92. He was healthy, went down to visit his relatives,

had supper, lay down and he died. When we were told Dad was dead, and that was the first we

knew, he was fine before, it was a shock, but what are you going to do? At 92, he'd lived a good

life. Even with my Mom, she'll be 86 this year, it's still, you know, she's lived a long time.

My Mom lives alone, but her memory is starting to go, she's starting to give away

everything, which is not good. What we have done is hired someone to stay with her at night

because you never know what might happen. Someone sees someone alone and they take

advantage of them, but otherwise she's active physically and she does everything. She lives at

home and it is a bother, sort of worrisome, but my brother is there, and we go home. My sister

was just there about two months ago. We take turns going down.

So growing up was easy. It was nice and pleasant, a good family life. We lived in a home

on two acres of land. It was in the city, considered the city, but it was still a fair amount of

property. We had a lot of freedom and there weren't any hardships. My parents were able to hire help, we had someone who came and did the wash and the cleaning and helped with the meals. I didn't really have to look after my younger brothers and sisters but I did. I was 15 when my youngest sister was born. She was premature, about 3 pounds and she was born at home. All deliveries were at home in those days. She wasn't in hospital in an incubator or anything, she was just nursed at home and I remember helping with her and feeding her with a dropper. I was only 15 but that's what I remember doing. We kept her in a drawer because she was so small.

I guess that's why, when my sisters kid around, they call me Mom. But I did help with her, with my two younger sisters in particular, who are 12 and 15 years younger. I started helping out when I was in my mid-teens, I guess with the attitude that, here's someone, you have to help them. I can still remember it. I'm pretty sure they look up to me. Not that what I say goes, but they will usually listen as we have to talk about family matters or make decisions.

My Mother certainly has been quite an influence on me. I saw her with eight children, always cool and calm and she always had control. I went crazy with two, I don't know how she managed with eight. Things were always under control, never kids running all over the house out of control, there was never anything like that. I wouldn't say we were well behaved. I mean, boys will be boys and they got into trouble and difficulty and there were those things, but the way she handled it was always, you talked about it, just calm and cool. This is how we will deal with this. As far as discipline, we always were spoken to, never physically punished. My parents were a good example and that was the type of home I grew up in.

I would say my attitude towards patients and even towards families as patients are sick, started out way back, when I was growing up in my teens and helping out, and it was in a sense a team effort at home. Even though we had people who came in, we still had our chores, we still had responsibilities. It gave you a sort of self-esteem that you were responsible for your room or you were responsible for this and that. I sometimes think maybe being the oldest girl and having that responsibility, I didn't have time to be a teenager. Maybe at that time there was no such thing as teenagers being bad or anything, I don't remember that. It seemed that there was always that family life and you had responsibilities and you kept busy. I don't remember being a teenager like now. I guess things were different. When we went out, to dances and such, my older brothers were always there and so my mother let me go. My mother was not strict, she's very easy going. But she was also business-like, very intelligent and very organized. From her, I learned to be patient and understanding. I'm able to talk to her. I talk to her all the time.

Nursing Up North

Following nursing school, my girlfriend and I thought we'd go up north. We were just fed up with the hospital and with nursing in the city, so we joined Medical Services and went up. We were finished in June, but had to write our registration exams in October so they put us in another hospital belonging to Medical Services first, one closer to the city. It was a small native hospital and the town hospital was right next to it. It was predominately pediatrics and obstetrics patients that we looked after there. It was good, but it was my first exposure to really seeing

...I thought the care could have been better. I got more of that when I went up to the reserve in November and I stayed there for six years.

When we got up to the station, we were the two new nurses and there were about six

who'd been there four or five years and they gave us a difficult time. We were intruding on their

territory and when you work up north in such a small environment, the people you work with are

the people you socialize with ...there's no one else. That nursing station was on an island with

the reserve on the mainland. The hospital was also on the island, which is about five miles long

and two miles wide, as was the RCMP office and the Hudson Bay store and hydro and the

teachers who came in and taught in the Catholic schools. So those were the people you

socialized with, but it was a clique and we could not get in. Fortunately I wasn't by myself, it was

my girlfriend and I, and we could contend with it. We also had to prove that we were nurses, that

we could do what they could do. It was not an easy time, it was not. That really made me a little

bit sensitive to what it was like being a new nurse, and as a teacher, I think it made me sensitive

to what they were going through, and I empathized with them because I remembered that.

Now if I had stayed in the hospital where I trained, I would have just blended in because

I knew the place. I knew the people and I would have just moved from being a graduate nurse to

a registered nurse. It would not have been difficult, but it was very difficult going up north.

Other nurses that came didn't stay. I know there was one nurse stayed one week and left. They do

make it difficult for you, not realizing that they're doing it, but they do anyway. In the six years I

grew as a nurse. I really developed my clinical skills, it was a good place for that, but I cannot

say I developed much anything else. Oh, I met my husband and got married, that's true

[laughing] *but as far as community and things like that, there wasn't anything for that.*

Clinically, it was very valuable experience. I learned a lot, especially how to organize my work. You could be working evenings and the planes would come in with the patients from the rest of the nursing stations and they would bring in about 8 or 10 patients for admission, very sick babies, sick patients. I learned some independence. I learned to practice and I learned physicians weren't perfect because we had physicians there, who, really, any other place they would not have been working because they were negligent and the nurses had to do a lot of covering up for them. That bothered me a lot, the physicians. I remember I worked one night and the physician on call had been drinking. A baby came in that had fallen from the hammock and had brain damage. You know things like that, they weren't attended to properly at that time. I remember another evening. There was a delivery, a breech presentation and the doctor was having his supper. So I went down to the cafeteria and said "She's about ready to deliver, it's a breech and you better come up here, you're the physician". He said he'd just examined her and it wasn't a breech. So it comes and she was a breech. Everything went OK because he did come up though we had to practically drag him up from his supper but it made me feel good that I knew it was a breech. The system has changed considerably and now there are specialists going up there. But at that time, it was an experience that I wish I hadn't seen.

There was good care from nursing, especially as far as community care. I remember we used to do a lot of obstetrics; obstetrics and pediatrics. We had to become midwives in a month because it was a thirty-eight bed hospital and they had 350 deliveries in a year. So I learned how to deliver a baby. The women would come in to deliver and it would be the first time they were coming into hospital, that was their 'pre-natal' visit. Remember at that time there were no roads, so you used boats in the summer and Bombardiers in the winter. We had to run down to

the dock because this woman was coming in on the boat, about to deliver, and you sort of catch

the baby without being able to get gloves and then, find out later that the baby and the mother

had syphilis and things like that. So you learned a lot. The experience really impacted on me and

at that time I didn't really realize how it would impact on me.

My first daughter was born when we were still up north. I came in and stayed for the last

month with my in-laws and I delivered in the city because there wasn't an obstetrician on the

station. Then we went back up north and she lived there the first three years. My daughter was

very precious to me and I couldn't understand how some of the children were so neglected. They

were so neglected. I had been working in the operating room and then when I had my daughter I

stopped work, but they asked me to come back. I said fine, but I won't leave my daughter alone. I

would not leave her with babysitters. So I said I'll come back and work evenings, just evenings,

and I'll just work Monday to Friday and I'll have the weekends off because I have a family. If

you don't want that then that's it. The Director said fine. It didn't go over well with the rest of the

staff, who thought I shouldn't get weekends off, but that's their problem not mine. So I went back

evenings because my husband, who was the administrator in the hospital, could look after our

daughter in the evening time.

The evening was a very difficult time to work. There was a lot of alcohol abuse up there

and violence. We had an outpatient section of the hospital that on evenings and nights became

the emergency department. So as a nurse working evenings in the hospital, you were also

responsible for emergencies. It was very traumatic. I remember some of the things I saw there

were just awful. I really picked up a lot of nursing experience, but it was very traumatic. I

remember this. There was the big lake and then it narrowed down to the river and the hospital was right as it narrowed down. Now the planes as they landed were supposed to land on the lake and just slowly taxi into the river and this one plane just came right in where the river really narrows and landed on the river instead of on the lake and he hit a boat. And oh, it was just awful. Of course they had to bring these people into the emergency. One other evening two boats collided, they had been drinking, so they brought in the people. One, the propeller hit her head and damaged her. Those were some of the incidents that we had to deal with in the emergency. There was fighting and lots of shooting trauma. It was trauma that I found quite violent. I keep thinking to myself how did I live through all that.

After being there for about six years I started to get a little bit frustrated. I don't know if it's burnout, but it's like you teach and teach and teach, for example pre-natal, and they won't do it. You talk about birth control and they won't do it. There were too many children, they couldn't look after them. They would have the children and then go home and you would know within two months they'd be back in pediatrics. There was a high death rate among kids and it was so, so sad. I felt that after six years I couldn't   ...it was a suffering I didn't like. I didn't like to see the kids coming in sick. There was also lots of drinking and violence and you just get so frustrated you feel that you really should get out of there, because you're not able to do your job because you're so angry at them. So I left there after six years and I thought that I really didn't want to go back into nursing. Maybe I was burnt out. I don't know. I just got frustrated with the health care system and trying to deal with people who wouldn't look after themselves or help themselves even though you're trying to teach them. I came from that and I guess I wanted to get out of nursing. I just wanted to get out of it.

Home and Family

We left the reserve in 1968 and moved to another reserve that wasn't fly-in. We stayed there ten years and during that time I didn't work as a nurse. I had two young children, my youngest daughter was born in 1969, and I chose not to work, because I wanted to be at home to look after them. The experiences I saw up north made me think; these are my children, they're my responsibility. I don't want anyone else bringing them up or caring for them. So I stayed home for ten years and I went back to University part-time. At that time they were offering courses because there were a lot of teachers at the Indian schools who needed to upgrade. I took some through correspondence and I had actually completed my first year by the time we moved down. I also got involved with the community, in 4-H, and I taught sewing and cooking. The girls joined figure skating, you tend to do a lot of those things in a small community. So I'd drive them back and forth to figure skating lessons. And then I also taught piano. I taught it privately, but I also went to the schools and taught there to the students. I kept myself busy doing community activities and teaching.

When I stayed away from nursing for those years I spent a great deal of time with my children to give them my time as a mother. My husband was very busy in his work, so I was the main parent at that time. I developed as a mother, as a parent, and devoted my time to that and to the community. I devoted my time to community so that I could help people in the community. I think I grew as a person and then when I came back into nursing, it was a different me. Not only did I have a fair amount of clinical skill that I had developed up north, but I had developed my skills as a person, especially in dealing with other people.

I found that with my children, I had to have an ability to step back. Having children really changed me in the sense that it was no longer just me I was thinking of. I had two other people to think of, little persons that I was responsible for, to make sure that I would give them the skills to go out in the world and survive. I knew I would not be with them for the rest of their lives, that I could only do so much for them, but at the same time I didn't own them and very often I had to step back and let them be their own person and develop their own personality, not my personality, but theirs. I could only guide them. That wasn't easy to do, step back. It's painful to see children grow up because they have to suffer things as they go through life. In a sense, it has helped me quite a bit in developing my own personality. I always say, as my own children grew, I also grew.

It took us about two hours to get into the city from the reserve and we would come in quite frequently because it's where my husband's parents lived. So we would come and stay the weekends very often. In 1978 when my husband was transferred to the regional office, we moved again, to a small community just outside the city. We decided to live on the east side of the city because that's where his parents were. And it's just as well we did because as they got older we were driving back and forth to help them. I didn't want to move right into the city because we were so used to lots of space, living out in the country, and I never did like crowds. I didn't like that about New York, the crowds. That's why I live where I do, almost by myself.

So when my husband transferred and we moved closer to the city I registered full time in University and finished up my Arts degree. I didn't work for two more years and finished my degree in 1980. I thought I'd like to do Social Work, but then I thought I'd go back to nursing

just part-time and work while I went to school. I had to do the refresher course because I'd been away from nursing for ten years and I got assigned to the hospital to do a clinical practicum. While I was there I went to human resources to see what openings they had. I wanted something in social work, but they suggested nursing. I asked for psychiatry because I had just finished my psychology degree and really liked it. There was nothing in psychiatry because they were in the process of moving to a new building, but when the woman looked at my resume and saw that a couple of courses I had taken had to do with death and dying she said "Why don't you work in palliative care? They need a nurse over there and you know about dying, you've taken that. You could do that for a year and then you could move to psychiatry and if you wanted to do social work you still could". That was 1980 and here I am, still in palliative care.

CHAPTER FOUR

Contemplating Life Experience: Patty's Practice

The Palliative Care Unit

Patty works on a palliative care unit; not a few beds, designated as palliative care and stuck at the end of a hall, but on a unit expressly designed for palliative care. The first thing I saw as I came out of the stairwell was the sign on the door ... Palliative Care Unit. I had an instant of apprehension as a picture formed in my mind's eye of what was behind the door. That picture evaporated as my eyes took in the unit. The overall impression was of light and space; my gaze drawn straight ahead, the length of the center hall, to a south-facing wall of windows. I had to back up my visual scan to take in the stretch between me and the windows; the nurses' station, offices and the patients' rooms.

At one time the unit had 28 beds. Fiscal restraint and program changes have decreased the number of beds to 20. Soon there will be beds for only 15 patients. As the number of patients has decreased, offices, storage spaces and lounges have been interspersed throughout, in what were patient rooms. There is a cluttered, crowded feeling. Intravenous poles and wheelchairs are stored in office closets and hallways and Patty is looking forward to the day when she will be able to sit quietly and talk with a family without someone coming into her office after a piece of equipment. The apparent lack of organization of the physical space has, however, achieved an unintended goal. There is no clear physical demarcation between the people who receive care and those who provide it.

The walls are covered with paintings, pictures and wall hangings. Most have been donated by families and bear plaques honouring their family members. There is an abundance of plants, a chapel and family lounge, classical music playing in the background, and coffee twenty-four hours a day, because, as Patty says, there is no day and night on palliative care. And it is quiet. If you know hospitals, the peace and quiet strikes you right away. The unit doesn't sound frenetic, even telephone noise seems somehow muted and distant.

Becoming a Palliative Care Nurse

Patty came to the unit in 1980. Her being there was intended as a one year trial, but

...Patty picks up her story. *I never thought of leaving and then, I really liked doing it. I thought I was able to help people. The way I saw people suffering in my student nursing and up north, and maybe because of my undergraduate courses, it seemed easier for me to talk to people. I wasn't scared or anything coming here. Some of the nurses are really terrified, but it didn't bother me. I was able to walk right in and do it with ease, even though I had been away from nursing for so long. I was not terrified like the time I had to talk to that family in my second year of nursing.*

Coming back to work after being away from nursing for 12 years wasn't difficult to adjust, but it was different. I came back full time and back to shift work. I worked evenings and my children found that difficult because I wasn't home when they came from school. My older daughter once said how hard it was on them when I went back to work, even though she was 16 and my other daughter was 12. It's not that they needed things done for them, I mean, they were

very independent a long time before I went to work. But there's that emotional support, coming home from school and you know, talking about things.

My work was interesting and the first year seemed so easy, I thought I might as well stay here. The head nurse put me in charge after six weeks. My clinical knowledge was good, but the main fact was being able to manage things; to assess, to take control, and to deal easily with the roles that had more responsibility. Within a year I was helping on the team, representing the perspective of the nurse on the ward, doing workshops and giving talks. I started going out public speaking and teaching and I also did some management. All those things give you some self-esteem and a sense of accomplishment. It helped me work better with the nurses on the floor and be, sort of, a leader. I felt I was developing expertise in the things I was doing. It's not just your clinical skills. For instance in palliative care you need to know how to assess and keep people comfortable and what drugs to use, but it's more than that. It's how you deal with patients and families, that's one of the more important parts of it. Because when you keep families comfortable then the patients will be comfortable.

After two years I decided I'd go back to university and do my Master's degree and I went to the day/night shift. I didn't want to go back to nursing. I just wanted to stay away from nursing because I had tried to get into the baccalaureate program when it first started off. I had been up north and came back and they told me I would have to do the whole four years. I said, "Forget it

...there's no way I'm going to do four years and do something over that I've done. I have a lot of nursing experience and I want to do something new and different that I will learn from". *That's partly why I went into the Arts program.*

Patty's frustration with lack of acknowledgment of what she brought to the baccalaureate program is evident in her words. And yet, her experience is representative of fairly common practice in baccalaureate programs at that time. Experienced nurses were expected to undertake virtually the entire four years, with minimal credit for their previous education and practice. When I was in the program from 1971 to 1975, nurses my mother's age, with 15 to 20 years of experience joined us in second year, proceeding through remaining courses and clinical rotations with those of us fresh out of high school. I am unaware how they felt, but I know that I felt intimated by their presence.

Rather (1994) reports that returning registered nurses are often displeased with boring and repetitious curricula, that there is a discrepancy between how they view themselves and how they are viewed by faculty, and that at the same time, there is much theoretic discussion encouraging allocation of credit for previous experience. Today, many baccalaureate programs offer considerably more credit for education and prior learning, or offer post-diploma programs, specially designed for registered nurses. The post-diploma program in which I teach requires registered nurses to complete a minimum of two, and a maximum of four terms, to obtain a Bachelor of Science in Nursing degree. But, even though post-diploma programs are theoretically designed for returning registered nurses, students still relate lack of recognition of knowledge and experience, and redundancy of courses, as prevailing concerns (Hébert & Dumais, 1993). There continues, as well, to be considerable debate among faculty about the necessary scope of post-basic programs.

Patty again picks up her story. *So, I thought of education. I recognized that I was able to do the teaching and I needed more formal knowledge. They had a course called health education at the university at that time and that's what I did. I worked full time, went to school part-time, and in the summer months I took vacation, went full time, and I finished it. I finished in about four years, the pre-masters and the Master of Education, in 1985. Now I look back and I think*

...how did I do that? My husband took on a lot more of the chores around the house and my kids, by that time they were almost on their own. My daughter was driving and she could run herself to dance lessons or things like that. It was just the energy that was missing, the energy to go home and then have studying and assignments to do, but it was good, studying and working at the same time, being able to put the pieces together.

My husband's Mom died the same year I graduated. We were working full time and quite busy as the children were in their teens. It was quite stressful as far as making time. She was only in the hospital about two weeks, her death was pretty quick. But after her death it meant that we were left with his Dad who, emotionally, had difficulty adjusting to living alone and looking after the home. He would have been in his seventies then and he lived until 1996. We had to get more and more involved. He had cancer, diagnosed six years before he died and it got to the point where I would make all the meals for him and just take them over there because he didn't have the energy to do it. While my husband on the one side, was looking after the house and the yard and getting things fixed up, I was looking after the meals and the linen. My daughters would go over and visit him quite frequently and stay with him. In the summer he had a little garden that he liked and so it meant, in order to continue that, we would buy the plants and put them in so he could see his garden. But once we put the plants in we had to go and weed and water it, so it was

like having two homes. That continued quite intensely for about two or three years and it was quite rushed. We would drop by there in the morning, sometimes at 06:30 and drop off some meals, then go to work and then after work, go, check up on him and then go home.

He never really had any home care, he didn't really need that. He ended up in hospital, stayed there about a month and died. It was a sort of a sudden collapse and then he went into hospital. So he never had any nursing or home care or anything. We were the ones who supported him. So when I get phone calls from patients and families saying they can't cope anymore, that it is getting too difficult, I understand what they're going through. I got to that point too. I recognize that there comes a point in time where they have to be admitted to hospital, even though there aren't any pressing symptoms to bring them into hospital, like pain or nausea. Often, they are admitted for things like weakness and inability to cope at home.

That experience in my life really made me understand and be sympathetic, have some empathy, for people who are going through this. I never wondered why am I doing this or begrudged it. It was something that we had to do. I guess our turn's coming and someone will be doing that for us. It was really funny, sometimes my daughter, because my father-in-law could get quite set in his ways, and my daughters would say...if you get like that we're going to put you on an ice flow. But it was also an experience that they had to see and they helped out a lot. When he was first diagnosed with the cancer he was started on some treatment and he was nauseated and vomiting, so he was in hospital for about a month. He ended up with a stroke in hospital and it took about six weeks and he recovered from that. My youngest daughter went and stayed there for about two or three weeks and lived with him until he adjusted. That was difficult for her, she

was about 19, because he was difficult to deal with. But she coped with it and we helped her and now I see family members do the same thing.

The Palliative Care Program

The Palliative Care program consists of Home Care, Outreach, and In-patient Services delivered by an interdisciplinary team. The primary objective is provision of symptomatic, emotional, and spiritual support. Patty is the liaison between the three aspects of the program. She is the first person from the team whom newly referred patients meet. On referral, she makes initial contact, and begins the often slow process of describing the program and explaining what patients can expect.

The clinical nurse specialist position began in January 1988 as a pilot project, and Patty took it on. At first, her primary responsibility was to, in her words, *keep a closer eye on people coming onto the program.* Control of symptoms, which might have been manageable, given support and community-based resources, was a primary reason for patients seeking admission from home. Frequently, patients and their caregivers did not know what to do or who to call. Within the institution, physician referrals were often premature, coming too early in the person's treatment plan. Early referrals seemed to be a function of lack of knowledge about the program, attempts to assure a place for the patient, or to free medical and surgical beds with transfers to the unit. All in all, it seemed that patients were not being adequately assessed for palliative care services.

Eligibility criteria were developed and, rather than admissions coming from different sources, all applications to the program began to come through Patty. She describes how decisions were (and are) made. *We take people diagnosed and treated in this hospital first but we don't hold fast to that rule. They must also be in the terminal phase of a disease. Before they were coming onto the program early just so the physicians could get a bed. Now it is scrutinized. The patients and families are interviewed and the program is explained. In order to be admitted to the unit, they phone me, and first, I try to see what symptoms they're having and if it can be managed at home with home care.*

The program changes reveal a great deal about Patty's and other team members' beliefs about palliative care. *We stopped taking patients who were very early in the illness. Some patients still had to see the medical oncologist, still had to see the radiation oncologist. Why would you register them on a palliative care program when they may live for several years? Those patients were screened out. Our patients now are in the terminal stage of disease. Eighty percent die in their first admission, so they come in, in the terminal phase, and they die. This is what the ward's about. We don't have the money or the facilities to just keep bringing patients in, realizing they shouldn't be here and then letting them go back home...it's not fair to the patient.* Patients still within the treatment phase of their illness are therefore expected to be assessed in emergency when they are in crisis. As Patty explains, *if they fall and break their leg or if they have pneumonia or their diabetes is out of control, they go to a medical floor. If they need symptom control, for pain, nausea and vomiting, or shortness of breath, they come here.* Patients in the later phase, when it is known death is imminent, have direct admission from home to the unit.

Patty's initiatives were extremely successful. Within a few months, the average daily census dropped to 15 or 16, but the same overall number of patients on the program was maintained with no waiting list. *After a year the pilot project showed that we reduced the number of admissions, though we still had the same number of people on the program. We also reduced the length of stay on the ward. Patients stayed a shorter time.* In 1989, the position became permanent and Patty applied. *A couple of people applied and I got it. I was qualified. I had my Master's degree and I was teaching, which is what you need, as well as the experience in palliative care.* She was the successful applicant and retains the position to this day.

In 10 years there have been many changes. How and why these changes came about and what Patty's contribution has been, grounded much of our discussion about Patty's work, palliative care, and health care in general. Again, we hear directly from Patty. *This job has really evolved. It started off with strictly assessing applications by going through them and meeting families. I found assessing applications took 60% of my time. I wasn't getting much information on the application, just the diagnosis and symptoms of the illness, so I had to really do a thorough assessment: talk to the attending, the medical oncologist, go down to the ward, talk to the staff and read their notes, and, then, meet with the patients and families. That's part of the program change. We used to just get people onto the program, register them and that was it, nobody saw them before they were admitted. When the program changed, we changed that, to get a picture ahead of time. It makes it a lot easier for the nurses, but also for the patients. When they come in here they know what we do. They know what palliative care does and doesn't do, what to expect and not to expect, and the staff also knows. They have a picture of that person which really helps the nurses. Occasionally, when patients do just come right up from*

emergency, come up and die, that's difficult for the staff because they're caring for people they

don't know.

I think because of my past experience of managing and working independently, I've been

able to change the job as I've gone along. What it is now is what I've made it. I do a lot of

teaching and keep a lot of statistics. I have a record for each patient with information from all

my contacts so when they call in the evenings or at night, the nurses have some background and

know what has been happening at home. I know someone else doing the job might do it

differently, but for me this is the best thing.

Many things caused this job to be suited to me. I am basically very organized and I think

that goes way back in my life, being the older one with a lot of siblings after me and sort of,

organizing their lives and helping them out. I am business-like and organized in my life. If

something's to be done, I do it. Even taking correspondence courses, I had to organize my time.

When I did the nursing unit management course by correspondence [in 1967], *I had to be*

organized because those assignments had to get in. It made me disciplined. But also, this job

didn't exist before I came into it. I developed it and I developed it in the way that I do things, for

me to remember. If someone else were to come into this they would probably do things

differently. I wrote this job description all the way along. I know what is happening and I know

the people I'm working with, all the different wards, and the nurses, and the VON [Victorian

Order of Nurses] *and I understanding who they are and how to deal with them, but it does take a*

fair amount of skill and organization to keep it on track.

As it is currently construed, the position enables Patty to *do what I feel comfortable in,*

which is teach and assess, and [to be involved in] *clinical assessment and symptom management.*

She is enormously proud of the extent that the position has grown over the past several years.

I've been able to change the job as I've gone along. What it is now is what I've made it... nobody

has written it down for me. I have done it and developed it according to the needs of the patients,

the program and the hospital. The hierarchy established with her words is very natural. When

Patty talks about her practice, the patient is always first. She is not consciously thinking   ...well,

now I have to put the patient first; she just does, with no hesitation as she orders her

responsibilities in her mind. It is a philosophy deeply embedded in the manner in which she

understands nursing.

In the time Patty and I spent together, I had the opportunity to spend several hours

observing how she conducts the day-to-day of her practice. What stood out for me was how

complex her role is and the multiplicity of responsibilities that she carries. As the co-ordinating

link between patient, family, the unit's staff, and frequently, community nurses and home care

providers, she is privy to, and keeps track of an enormous amount of information. She knows

various physicians and what to expect from them with respect to their involvement with the

program. She has developed effective relationships with the nursing staff on many of the

hospital's units and in the community. They are after all, the people best positioned to share

information about patients, their wishes and needs. And she knows the patients on the program

like members of her family. She has to be aware at all times who is out in the community and

might need to come in, and who's in hospital and might need to be moved over, and in general,

what people might need and accept to support their care. Essentially she pulls all the strings

together into a cohesive and coherent package. There is no one else undertaking this degree of co-ordination on behalf of patients, and in fact in some cases, other people constrain her ability to do her job effectively, because there is a lack of clarity about the program or a different agenda at work.

Patty's Day

When the number of beds on the unit was reduced Patty got a small office space. The office is not far removed, however, from its days as a patient room. Intravenous poles are stored in the closet and there is a stretcher at one end covered with books and posters from old presentations. There is a large window; the sill home to flourishing plants, and on the opposite side of the room, Patty's niche: desk, file cabinet, book shelf, and a comfortable chair for visitors with a small table and more plants beside it. A yet to be assembled computer sits in pieces. Patty wants to start using a computer, especially to write her patient notes and manage the statistical record-keeping, but she has roughly a hundred and forty patients and families on her list and an effective strategy already in place. Making time to reorganize her system is not a priority.

The phone seldom stops ringing. Co-ordination of the 140 people on the palliative care list means Patty is in frequent contact with the patients and their family members. As well, if the patient is in hospital, there are various members of the health care team to collaborate with: nurses, physicians, and physio and occupational therapists on at least seven wards. If the person is at home, then the family physicians, visiting nurses and therapists and, occasionally, staff from different hospitals may be in contact.

I walked with Patty through portions of her day on three occasions. When patients are referred to the unit from other areas of the hospital, Patty sees them almost immediately, usually later in the same day, or early the next. Mondays, she reviews everyone's status, looking for changes in their health suggesting transfer to the unit may have to be sooner rather than later. Every Friday, she goes around to all the units again, stopping in to check up on anyone who is waiting for transfer and might need to be moved over the weekend. I was privileged to spend most of one Friday with Patty as she walked her week-end route.

When I arrive Patty is on the phone with a nurse from one of the city's hospices. Their discussion revolves around an individual's prognosis and whether personal care home placement might be more effective than hospice or palliative care. It seems from my end that the nurse with whom Patty is speaking is unclear as to the role of the palliative care unit and the process for referral, because Patty is describing how patients come onto the program. Shortly after, she receives a call from one of the hospitals wards and a similar conversation takes place. Patty is asked to speak with a patient about transfer to palliative care, even though the patient has just had surgery. Patty again explains her role and shares her perception that presenting a palliative care option less than twenty-four hours after surgery is too soon.

I asked her about the repeated clarification of her own and the unit's role in a patient's plan of care. She needs to constantly, it seems, build and rebuild rapport with staff and educate them about her role, and the role of the palliative care program. The biggest challenge seems to be with medical students and residents who are often the ones referring patients. Patty describes how they rotate through various units for three months and don't make time to learn about various

programs and what they might offer to different patients. *It's the physicians,* she explains. *It's*

physicians who think that once they put in an application, we will just take over the care and

their responsibility is eliminated. That's not what we're to do. That patient just had surgery, she's

sick. I'm not going to talk to her. I can keep up on her and when she's ready to be discharged or

if she deteriorates, then that's the time to approach. But I'm not going in there too soon because

it throws patients off.

I am more perturbed by this dilemma than Patty. She understands the physicians to be

abrogating their responsibility for patients, and perceives this to be due, in part, to rapid turnover,

resulting in lack of clarity regarding her role. While I agree, to some extent, with Patty's

assessment of physician practice. I am not convinced that longer rotations and more information

about the palliative care service are necessarily going to change the situation she describes. I

understand her experiences to be a function of more systemic problems within health care,

including; a predominately cure-oriented paradigm that encourages referral to palliative care

services as soon as cure is no longer possible, a historical tendency to isolate and "hide" dying

persons (Byock, 1997), and, particularly, a fundamental disregard by some physicians for others'

knowledge contributions to patient care.

This latter phenomenon, while disturbing, is not surprising. The development of a unique

body of knowledge, available only to members of the profession, has already been shown to be

one of the sought after attributes of the medical profession. Inherent in the concept of a unique

body of knowledge is a positivist assumption that one discipline's knowledge is not only different

from, but superior to another's. As Maeve (1998a) points out, "historically the medical profession

derived its power and authority from the ruling class through legitimization of medical knowledge, which effectively de-legitimized the knowledge of women healers and midwives"
(p. 26). It is beyond the scope and intent of this thesis to further examine physicians' experiences of knowledge development and professional socialization. It is critical, however, to reveal contextual features, beyond those of Patty's immediate and particular practice setting, that I understand may inform her experiences within that setting.

At this point in her day, Patty is anxious to get up to the wards. Before we get away, the medical director comes in to advise her of an unexpected admission. A woman living at home is coming into hospital on the advice of a visiting nurse. This is a concern for Patty. She wonders what has happened since their last conversation, when the woman, and her husband and daughter, were clear that they did not want hospitalization. She tries to contact the daughter at work, is unable to reach her, and then is interrupted by a call from one of the nurses on the unit. They have been advised of the pending admission and need Patty's file and notes of what has been happening at home. Patty spends several minutes filling in the staff on what she knows about this woman and her family.

We return to the office and Patty shares some frustration with this situation. The visiting nurse had called the previous week wanting the unit's medical director to prescribe medications for the woman. When patients are at home, however, their family physicians co-ordinate the plan of care, not the unit's medical director. Unfortunately, as was the case with this woman, some patients do not have family physicians, and there is no one to co-ordinate. The visiting nurse is frustrated because the woman "falls between the cracks" and Patty is frustrated because it

frequently falls to the unit to deal with this breakdown in the health care system. She wonders if the nurse may be trying to circumvent the system by encouraging the woman to seek admission, thereby compensating for lack of access to a physician in the community. Compounding the dilemma is awareness that the woman will occupy the remaining available bed, and a planned admission may have to be canceled.

Patty shares why she thinks the nurse might have chosen this route. *I talked with them* [the family] *and offered her admission. She doesn't want to come in. She says she's comfortable and the daughter, who lives there, says she's comfortable. The nurse wants to send her in because her abdomen's distended. Well, she's got really advanced disease and nothing can be done. If she's comfortable why are we sending her in here? You can be quite sick and still be at home.* Despite her reservations, Patty is aware that something might have changed in the woman's condition, so arrangements are made and we proceed to see patients in the other areas of the hospital.

Our first stop is gynecology. The patient, a 55 year old woman, is very ill and sleeping. Her status has not changed and Patty decides to return later in the day when she knows the family might be in. The next person to see is an elderly man on the medical ward. His wife cannot cope with his care at home and wants him transferred to palliative care, but his needs are not those which can be met on the unit. On a different medical ward, we stop to talk with a woman who has a brain tumour. After a few moments of conversation we both recognize that she is unable to converse and make decisions about her care. Again Patty decides to defer until she can meet with the woman and her daughter. A man on the same unit is wandering about independently, very

confused. His needs, too, will likely be more effectively met in a personal care home setting than on the palliative care unit.

At the desk, Patty, the hospice nurse with whom she was talking earlier, a classmate that I have not seen since graduation, and the unit nurse talk about patients who "fall through the cracks". They have only questions: about the two year wait for personal care home, about the lack of resources to support people at home, about the lack of intermediate care settings, no answers, only questions, and frustration with politics and the health care system. I share their frustration and am amazed at the number of referrals which do not really fit with the palliative care program's objective of end-of-life care. While the people referred do not need to remain on active medical or surgical units, their care needs are often rehabilitative, rather than palliative in nature. As I listen to Patty explain her role, and that of the unit, over and over. I wonder if anyone is listening, or if they just want to move dying and longer stay patients out of their units so badly that any setting will do. Later Patty and I talk about this and I share my perception that the palliative care unit is seen as the place that can solve all problems. *We can fix everything*, says Patty. *They can't seem to think for themselves. I had one application sent because the man can't stay on the ward but he refuses to apply for personal care home. I said, hold on, this is not appropriate. And then, they acknowledged that, but asked me to call the daughter to talk with her about placement and I had to say, you're looking at the application process, you phone the daughter and talk with her.*

We move on to another floor and see the woman who was referred earlier, the one just out of surgery. She has in fact, had a procedure which may change her prognosis. It is too early to

tell, and certainly, too early to talk about transfer. Now, back downstairs to the Home Care office.

People who are admitted to the palliative care program are referred by Patty to Home Care. That

way they can move from hospital, home, to the unit as necessary, and home again if possible, in a

seamless fashion. The appropriate referrals and connections are made before they are discharged

from hospital. Patty and the Home Care co-ordinator touch base, compare notes, and we head

back to the unit.

At the entrance Patty stops to chat with a woman and her son. It is a friendly, how are

you, conversation. The woman sent in by the visiting nurse has arrived and Patty sees her, the

husband, and her daughter next. Her fears are confirmed. The family is distraught. Neither the

woman nor her husband, both of whom speak little English, understand why she has been

admitted. The daughter has been pulled away from work by a distressed call from the father. She

is angry and confused given the previous conversation in which hospitalization was discussed and

rejected. Patty is discouraged and speaks very quietly when we are in private again. *That's not*

fluid (referring to the swelling in the woman's abdomen) *that's tumour...there's nothing we can*

do...it really annoys me, but I'm not sure we can do anything about it.

This situation is an enormous dilemma for Patty. She must rely on the on-site assessment

of the visiting nurse, yet she knows that this particular nurse has a tendency to expect treatment

options which the unit cannot provide. She also has to make arrangements to change an expected

admission, as this unexpected patient will occupy the only remaining bed. And, she is acutely

aware of the disruption in the family's life, the daughter trying to support her anxious parents

while dealing with the constraints of her own workplace, the father possibly not understanding

and panicking, and the patient herself, ill and fatigued, wondering what this new hospital admission might bring.

Unfortunately, this is not an unusual scenario. Patty says, *what we find here is that most of our patients are 65 and over, so often they have children in their forties and fifties and then those children will have their own children and so they will have to deal with that. And we have found very often, two things. First, the children are away from home, so their parents have no help and end up having to get a lot of home care and things like that. Second, if the kids are here, they cannot give help mainly because they probably both work, are trying to establish themselves in a career or have a career and they have to keep on with it. They also have children of their own who they're trying to look after, so it's quite a squeeze. I can understand it because we had the similar experience with my husband's parents.*

For Patty, the primary issue in this situation is not whether or not the patients should be admitted. It is the continuing failure of others to familiarize themselves with the program's parameters, and to follow established processes. A single call to Patty could have simplified the patient's transition from home to hospital, through the establishment of a co-ordinated plan for admission. It means a great deal to her to have the independence and autonomy to structure her work in a meaningful way, and in a way that is respected, and honored, by others. She recognizes, however, that her capacity to counsel individuals and their families depends to a large extent on the practice of the other members of the team.

The pace of Patty's day is rapid and hectic, but I never see her lose her composure. She is calm and straightforward in all her conversations, whether it is with someone with whom she has a close working relationship, or someone to whom she is explaining the objectives of the unit for what seems like the tenth time. I am impressed by knowledge she holds with respect to the program and the workings of the hospital and its myriad staff. She knows a great deal about various diseases, their symptoms, the current treatments, and what combinations of symptoms and treatment plans tell us about a person's prognosis and needs. She has to. She has to know what it might mean for symptom management if a person has a certain type of tumour or what side effects different medications might bring on. She could not respond to the calls from patients and caregivers in a meaningful way if she did not.

The day continues. Patty steps out of the room for a few minutes to photocopy some information I have shared. The phone rings the whole time she is out. We take time to talk about some of the hospital protocols that have an impact on her work and are talking about 'no resuscitation orders' when she is paged. It is yet another discussion about a patient's suitability for the program. This time there is a discrepancy between Patty and the caller with respect to diagnostic information. When she hangs up she says *This is a 92 year old man with cancer of the prostate but he's well. The problem is he lives alone at home and the daughter lives in Toronto where her daughter is expecting a baby. She doesn't want to leave to come and attend to Dad. They want me to call the daughter to talk about personal care home* [because he is not a candidate for the palliative care unit].

The conversations reveal something deeply troubling about the health care system. People, especially elderly people and those diagnosed with cancer, are often referred to palliative care virtually without consideration of other alternatives. This, despite the fact that many have types of cancer which will likely not result in their deaths for some time, if at all. As Patty says, *at 92 there are lots of things you might die from.* Often, they have multiple diagnoses and the predominate one might benefit from more active intervention, such as a program of rehabilitation. My observations of Patty's conversations lead me to think that alternatives are not sought because there really are not any that are viable. Waiting lists for placement in personal care homes are up to two years long, extended stay units are full, and the system is backed up into emergency rooms. Patty and I started this day in fact, talking about a news report on stress experienced by emergency room nurses. Patty expressed her anger at the numbers of nursing positions deleted in the last few years, a downsizing strategy she believes to be responsible for the current state of affairs.

The next call brings out another aspect of Patty's role, one I haven't yet observed. She spends several minutes organizing a home death. She advises the nurse in the home of what needs to take place and shares the names of participating funeral homes and the requirements of the medical examiner's office. One more piece of the vast jigsaw that is Patty's role as clinical nurse specialist. At this point, after about three and a half hours together, things quiet down. Patty and I are able to talk about a variety of topics for about half an hour until the phone interrupts again; someone calling for information about how to get a person onto the program.

Of the three other half days I spent observing Patty's practice, two involved sitting in on the case conferences and death reviews that are integral to the workings of the unit. The third day of observation was similar to this one, with one exception, a more satisfying outcome. On that day, Patty saw a newly referred patient for the first time. This woman understood her recent diagnosis to mean she would die in the next few days. There was no reason for her to move. Patty recognized her fear, but also knew that the care received on gynecological surgery, would be fundamentally different from what the woman would receive on the palliative care unit. She decided not to press and to come back *as often as it takes* to talk with the woman and her family. In a subsequent interview I asked her about that woman.

I finally convinced her to come. It took ...*one visit is not enough. It takes two or three* ...**and she went home**. *We got her symptoms under control and she was comfortable enough to ask to go home. She's been home some time. I think what it was with that lady was she was not comfortable and she thought she might as well be dead. But when she got comfortable, then it was different, then she wanted to go home. We set it up, and met with her and had Home Care and she's been home since August 31* [this day is October 21st]. *When people have symptoms like that, they think they're dying. If you're in a lot of pain...* *but once you get the symptoms under control, they think* ...*hey, maybe I'm not dying and things change.*

The pride in Patty's voice is unmistakable. This is what it is all about for her: managing symptoms, controlling pain, offering options, supporting choices. When patients move through the unit and beyond, whether to their homes or in death, as part of a peaceful journey, then Patty is truly fulfilled.

The Palliative Care Team

To embrace, to grow attached, to lose, to suffer and to transform before the

experience of repeated deaths, consecutive bereavements, multiple losses - such is

the challenge of an interdisciplinary team within a palliative care unit.

(deMontigny, 1993, p. 12)

As the first member of the team to come into contact with patients, Patty often encounters

the brunt of fear and misgivings. Her role, through explanation of the program and its philosophy,

is to ease transition from acute to palliative care, from cure to care, and, frequently, to challenge a

common perspective that the focus also shifts from living to dying. To do so, she describes to

patients a plan of care that focuses on symptom management and return to their homes. She

acknowledges that she would not be able to do this as effectively if she did not believe in the

team's commitment to that objective.

Patty believes working in a team comes easily because *in my family, I guess, we were like*

a team. Seven brothers and sisters helped my ability to get along with people and work together.

If you're only one and you don't have to share with anyone, you might not recognize that you

have to think about people, that you have to take other people's feelings into consideration. It

can be difficult as you get older and go out into the world and have to work in a team. But, my

mother would say   ...you will do this and you will do this. We did work in a team in that sense

...she did that for us. Here when we work in a team, we have to recognize that often

people are different and you have to understand where they're coming from, work with them, and

do the best you can.

The core disciplines of the in-patient team are nursing, medicine, social work, and pastoral care. These members seem to be involved with virtually all patients in one way or another. Other members, like physio and occupational therapists, and the Home Care co-ordinator, move in and out depending on the needs of each patient. This team approach to patient care is integral to the unit, and to palliative care units in general. Patty does not identify a hierarchical division, with physician as leader, so common when I first worked in palliative care in the late 1970s. As she recounts, *the physician is there, yes,* [referring particularly to case conferences] *but listening to what the other members of the team say...recognizing the need to get information from the nurses, from pastoral care, from the social worker, because that makes up the whole person.* Unfortunately, the same cannot be said for referring physicians from other parts of the hospital, or in other institutions.

I envy Patty the team relationships she describes. When I worked in palliative care, nurses were expected to give up their chairs and find something to do when physicians came on the unit. Only the Head Nurse, or in her absence, the Assistant Head Nurse, could make rounds with them. The legacy of that environment remains with me today. I always experience uneasiness around physicians, and I find myself behaving, though much less so as years of practice accumulate, in the deferent, and manipulative, manner that has been described as the "doctor-nurse game" (Stein, 1967; Stein, Watts, & Howell, 1990). Baker and Diekelmann (1994) describe the game in the context of nursing practice. It arises in "dual hierarchies imposed by sexism and by traditional beliefs about professional-occupational accountabilities [and] causes nurses to cloak advice and recommendations to physicians about patient care in indirect and deferential language" (p. 65). I have, over the years, developed some expertise in this "game" and am aware that I, and my

colleagues in the diploma program in which I taught in the late 1980s, facilitated student learning of the same behaviors. I am also aware that I, and my female nursing colleagues, have used the same strategy with male colleagues in the Faculty of Science.

Physical care and symptom management, emotional and spiritual care, bereavement planning and counselling, education and training to perform tasks at home, referral for legal support and advice, and planning for home death are just some of the elements of the care needed and provided by the team. Patty speaks of the team as an entity. *This team has been around a long time. It doesn't just happen. It's a lot of work to keep it going. It has been developed, so that when someone new comes on here, they have to fit into it, as opposed to everyone fitting into them, but that doesn't mean we're not going to listen to what they say. I mean it is a learning process.*

I was privileged to observe two building blocks of the interdisciplinary palliative care team; a case conference and death reviews. The most striking aspect of both was how openly all members of the team shared when a stranger was present. Patty relates their level of comfort to longstanding experience with students and trust that others will honour confidences. The other aspect that stood out for me was how fluid the team is. Each person's area of expertise is clearly defined and understood by the other members, yet there is explicit and implicit acceptance that roles and responsibilities can and will shift with different patients. As Patty says, *it's a matter of doing what is best for the patient and working together and saying, OK   ...if I start the family with home care* [because] *I have more connections and they call me, then I pass it onto* [the

Home Care Co-ordinator] *and vice versa. So it does work. No one person can be everything to the patient.*

Case conferences demonstrate the collaborative nature of planning and organization of care. They are attended by all available members of the team and discussion centers around new patients admitted, their diagnosis and plan of care, as well as review of patients already on the ward and what changes might have occurred in their care plans. Relationships honouring each member's contribution are evident. Consensus about the plan is the norm but differences of opinion do arise. Patty says while differences are raised, aired, and advice is frequently sought from the team member whose particular area of expertise is indicated, the final decision is *strictly what's best for the patient.* Patients' and families' wishes set the stage for decisions regarding treatment and care. Collaboration means collaboration with patient and family, as well as within the team, though interestingly, no patients or family members attended the case conference on the day I did.

While case conferences provide for day-to-day planning and organization of care, death reviews reveal the philosophy of practice on the unit. *What comes out of death reviews is the practice, in a sense, the practice of palliative care on the ward.* Death reviews are exactly what the name suggests, a review of each patient's death, attended by the physician, Patty, the nurses from the floor, the social worker, and the pastor, and, on this occasion, myself. After a patient dies, the nurse who is primarily responsible for the person's care has the option of taping a description of the death. Alternatively she can come to the next death review and talk about the

death with the other members of the team. At the death reviews I sat in on, two of the reviews were taped and two were presented by nurses in attendance.

It appeared that the two nurses who chose to present did so because the particular deaths had a profound impact on them. Their stories had a profound impact on me. The first nurse described the death of a patient who had been on the unit less than twenty-four hours. The patient was a young woman with teenage children. The entire family was devastated by the experience. The nurse spoke of frustration and a sense of helplessness arising from the fact that she did not know, had not had time to come to know, the family. She struggled to make a connection, to support the husband and children, and was not able to do so.

The second nurse presented a very different picture. She spoke with great passion and emotion about the death of a patient who had been on the unit two months, and to whom many of the staff had become quite attached. She talked of how difficult it was for the patient's husband to leave the unit and the people who had been so much a part of his life for so long. She shared how much the staff wanted to spend time with him and how they were restricted by other responsibilities. They too would miss him. She and several others shared "remember when" stories about the patient and her family, and there was much laughter and many tears.

The stories that are so much a part of death reviews afford each participant the opportunity to create meaning of the experience. Some aspects are common to all, aggravation with change-of-shift duties that prevented more time being spent with the grieving husband, or empathy for the nurse who could not connect with the other family in a manner she believed was

meaningful. When the nurses share what happened, and how they felt, others are nodding in support. Their agreement authenticates the narrator's knowledge.

The practice environment deeply contextualizes the construction of knowledge. The death is understood in a particular way, in part, because of the philosophy and practices of the unit. I had an overwhelming sense that if I were to go elsewhere the feeling in the room would, by necessity, given different participants and institutional structures, be different. Perhaps it would be equally effective, but death reviews impressed upon me that it would be different, and, as such, the context of practice has a significant impact.

Other aspects of the experience of death are deeply personal and different for each participant. Patty's story reveals events of her life that inform how she will understand each death, and each death review. Every person in the room has a different story and, as such, creates meaning in a different way. While the nurses did not explicitly make connections to life experience in their narratives, sharing of stories is more likely to enable the expression of knowledge arising in life experience. There is room to manoeuver, to be reminded of other stories of life, and to reflect on how they might illuminate this story.

There are over 400 deaths a year on the unit, sometimes occurring in clusters of as many as five on a weekend. Death could become commonplace, each aggregated with the others. And yet, every person who attended the death reviews that day was touched by each person's story as it was recounted. It was as profound and deeply moving as the next, though, as illustrated, for very different reasons.

CHAPTER FIVE

Contemplating Life Experience: The Landscape Of Palliative Care

Obituary Language

with tremendous sorrow and great regret

the family announces the passing of

died suddenly, in his 71st year

peacefully in her sleep

in hospital ... at home

after a long illness ... a courageous battle

borne with grace and dignity

a service in celebration of will be held

fondly remembered and forever loved

your choice of charity

Hill (1999)

Obituary Language is constructed of deliberately chosen words and phrases appearing in a number of obituaries over a period of several weeks. Obituaries are part of society's *"death system* [ital. in original] ... a multi-faceted, multi-level attempt to mediate our relationship with mortality" (Kastenbaum, 1993, p. 76). Like symbols and motifs on tombstones, they "profile individual lives ... [and] convey information regarding a society's order, values, religious practices, and realities at the time of the individual's death" (Cochenour & Rezabek, 1995, p. 1). The language of obituary reveals much about our perceptions of death and dying. A frequent image, as reflected in the poem, is of a good or peaceful death, often at home, and often in the company of friends and family. An alternate image predominates, death as enemy, the "grim reaper", and dying as battle fought and lost.

Historical Perceptions of Death and Dying

Sitting with the dying used to be something people knew how to do. Tending to

their needs, comforting their body and soul was a part of life, something children

learned growing up. (Sankar, 1991, p. 16)

Death, in the period up to and including the middle ages, was accepted as an integral part

of life. It was "a ritual, organized and presided over by the dying ... a public ceremony shared with

parents, friends, neighbours, and children" (Bacigalupi, 1992, p. 186). Sanctification, prominent

display of bones and relics, and foci of worship suggests that Europeans of the fourteenth century

lived comfortably with the dead. In the sixteenth and seventeenth centuries changes in a scientific

world view initiated changes in attitudes toward death (Krakauer, 1996,

p. 28). Conceptualization of the human body as machine brought about a belief that its parts could

be measured, manipulated and managed. Descartes postulated that "scientific, experimental

medicine [could] not only cure "an infinitude of maladies both of body and mind" but also

possibly even free us from the "infirmities of age" " (as cited in Krakauer, p. 28). Death began to

be seen as enemy to be defeated.

The notion of death as enemy persisted into Victorian times when death was viewed as a

grievous wrenching of life from man [sic] (Bacigalupi, 1992). Stewart (1984) suggests there was

"an escalating fascination with death [beginning] in the novels of Dickens" (p. 8), in which

fictional identity was "founded on death or figured by its extremity" (p. 10). Society began to turn

away from death as a part of life and to seek ways to challenge its inevitability. Advances in

medical care heightened perceptions that death could be contested and as early as the eighteenth

century, "the ability to defer death was attributed to physicians, [giving] them new economic and

social status" (Krakauer, 1996, p. 29). By the end of the nineteenth century, fear of death

necessitated hiding its reality from the dying person. Death was no longer discussed.

An unprecedented rate of medical and technological change in the early twentieth century

further removed death from our lives and increased society's faith in medicine and physicians.

Care of the very sick and dying shifted to hospitals.

> This step was not only intended to give the dying the best care, but to spare the
>
> living, those surrounding the sick, from having to cope with a dying person. This
>
> removal of the dying from the presence of the living further exacerbated the trend
>
> to remove death from life. (Bacigalupi, 1992, p. 188)

This trend is illustrated by my own experience. As a child, I was fascinated by a picture in my

grandmother's possession. It was of a childhood friend, circa 1917. The girl, perhaps twelve or

thirteen years old, had died of tuberculosis and lay in her coffin. Clearly death was a part of my

grandmother's adolescent reality. I, probably seven or eight years old, was alternately horrified

and intrigued by the picture. Death was something completely unknown to me. I had no

experience of it and did not understand it. Unfortunately, when it touched me, I had little

forewarning of the impact.

The mid-twentieth century brought other changes which further alienated us from

experiences of death and dying. From 1914 to 1945, epidemics, war, mass deaths in concentration

camps, and the bombings of Hiroshima and Nagasaki caused death on such a massive scale that it

allowed people, as Kublër-Ross (1969) stated "to conceive of the death of others and not their

own" (p. 10). Victor Frankl's (1959) description of his concentration camp experiences echoes

Kubler-Ross's words. "The sufferers, the dying and the dead, became such commonplace sights

to him [sic] after a few weeks of camp life that they could not move him any more" (p. 20).

Eventually, in the face of overwhelming death, the word itself came to be no longer used.

Kramer (1988) says we have turned our backs on death, a fact made evident by our

frequent use of euphemisms. His list includes sixty-eight words and phrases that have become

part of our lexicon, including: "passed on, kicked the bucket, lost, called home, six feet under, and

called to rest" (p. 14). Kastenbaum (1993), citing Umberson and Henderson's 1992 study of the

social construction of death in the Gulf War, describes how the media have exacerbated this

phenomenon. "Perhaps the most striking finding ... is the absence of direct references to death or

killing and the patterned use of indirect references.... The most common euphemisms for dead and

death include 'casualty and loss'.... "Smash", "bring down", "take out"... were frequent

euphemisms for "kill". The killing of Iraqi civilians was presented as "collateral damage"

(p. 86). Umberson and Henderson concluded that the "psychological consequence is to

dehumanize the human victims of war" (as cited in Kastenbaum, p. 86).

And so we come to the twenty-first century, the time and place of Patty's practice in

palliative care, a society which many suggest is death-denying (Bacigalupi, 1992; Byock, 1997;

Callahan, 1996; Hotson, Macdonald, & Martin, 1999; Krakauer, 1996; Kramer, 1988; Maeve,

1995; Wylie, 1997) and in which prolonged death has become the way we know the experience.

Advances in drugs therapies and technological interventions have depersonalized human

experience, keeping people alive beyond all expectations, including their own.

The Palliative Care Movement

In the mid-1960s, palliative care began to be recognized as an alternative to anonymous death on whatever hospital unit the person happened to be located. It was, in large part, a response to a widening gap between medical advances and the inevitability of death, between cure, and care. This cure/care dichotomy is challenged by a statement in the *Dying Person's Bill of Rights*: I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals (Barbus, 1975).

The first hospices originated in Great Britain, the best known of which is St. Christopher's in London, started in 1967 by Cicely Saunders. With her emphasis on care of patient and family, symptom control, a multi-disciplinary team approach, and a continuum of care from hospital to home, Saunders, trained as a nurse and physician, is widely acknowledged as the founder of the palliative and hospice movement. She had a vision of "patient and family in the foreground and treatment in the background and conviction that listening was an essential art" (Wald, 1996, p. 82). In 1963, she brought the vision to North America, and to Yale University where Wald was Dean of Nursing.

Wald was, at that time, hearing nurses describe experiences of being at cross-purposes with physicians when patients asked questions about their illnesses. Secrecy and denial of impending death was still the norm, but nurses, face-to-face with patients, could not evade the questions. Wald was captivated by Saunders's ideas of how care for the terminally ill could be different. In 1968, she left her position as Dean, to enter into a study of caring for the terminally ill. Her work resulted in the founding of the first American hospice in 1974. Saunders's travels

brought her to Canada around the same time, and the first Canadian palliative care unit was also founded in 1974.

Patty has traveled to England, toured the hospices, and had the great honour of hearing Dame Saunders speak about her vision. *"When I was in England and Dr. Cicely Saunders spoke, she talked to us for a couple of hours at St. Christopher's Hospice, she said she set up the hospices for people because of unnecessary medical interventions and because medicine was prolonging the dying."* Patty echoes this belief. **You allow them to die.** *Why are you doing all these tests, for what, when you can't do anything about it...so why are you doing them? Some patients are really put through too much.*

The Current State of Affairs

It hath been often said, that it is not death,

but dying which is terrible

Henry Fielding (1751)

A lengthy discussion took place in the case conference I observed, about blood transfusions for a woman whose disease process was causing frequent haemorrhage. Knowledge that the blood would be lost as fast as it was poured in was, for one physician, apparently outweighed by a need to "do" something. The other physician, the unit's director, spoke quietly, "You don't want to make her die longer", ending the debate.

Fear of prolonged dying may be a legacy of the twentieth century. "Prolonged dying is what has united us all, not death itself. That is why people sign wills and durable powers of attorney with instructions about the ways in which they want to be kept alive or die. How we die worries us the most" (Spiro, 1996, p. xvii). Chochinov (1998) decries Canadian society's approach to end-of-life care. Fewer than 10% of Canadians have access to home-based palliative care services, despite research data that reveal a majority of people in favour of a home death. Worse still, according to Chochinov, is the abysmal record of medical schools to educate physicians in a meaningful way about care of the dying. "At the time of licensure, Canadian physicians will have had, on average, eight to 10 hours of training in palliative care and symptom management" (p. A15). Krakauer (1996), writing of his experiences as a resident, suggests that medical students and residents are trained to diagnose and treat acute illness. In their zeal to do so, they frequently intervene to postpone death, subjecting patients to "considerable violence and ... significant suffering" (p. 23). Nurses do not fare much better. Some undergraduate programs include a required course in palliative care, but it is generally not viewed as significant enough to warrant extensive preparation. The palliative care course in the program in which I teach is an elective.

Patty agrees and speaks frequently of her frustration with physicians and nurses who are not educated about palliation, particularly about pharmacological control of pain. *It makes you very frustrated and quite angry at times, because the patients are suffering and the families are suffering...how someone dies, they'll remember for the rest of their lives.* She believes physicians are afraid, compromised by their lack of education in palliation and by media representation of high profile trials involving physicians. Whatever the reason, palliative care outside of specially

designed units is a "hit or miss" proposition. As Cole (1998) states, "we know how to extend our lives and increase the quality of time we have. It's the end, the weeks or months spent dying, that we need to dedicate money and efforts to improve. Reluctant to admit its inevitability we are not prepared to accept death as a part of the cycle of life" (p. B4).

Education of other health professionals and the public is a responsibility of the palliative care team members. Patty describes that responsibility and how she came to be involved. *When I first came here, they would go out and give talks and they went as a team. So it wasn't long before I was also on the team. Now, each time it's different depending on the audience we have. If we go out and talk to nursing students about symptom management, I will introduce and emphasize assessment skills and the physician will talk about some of the pathophysiology and the drugs used. We also present at hospice conferences. Palliative care has a national conference every two years. The first one was held here in 1985 and we presented at that, as a team. There's still a picture somewhere of the whole team presenting about death reviews.*

Team members are also actively involved in education and supervision of student physicians, nurses, and social and pastoral care workers. *We do have medical students but there's not much attention being paid to palliative care. In the first year they have a three hour session. The next time we see them is in the second year and they have a two or three hour session on symptom management and that's it for palliative care.* Patty is optimistic, however, as she has seen changes over the course of her career. A rotation to the palliative care unit, once an option, is now mandatory in the Family Practice specialization at the local medical school.

The notion of not wanting to prolong death might suggest that palliative care units do not intervene in any way. Nothing could be further from the truth. To begin, Patty's unit's staff accept the World Health Organization definition of palliative care which is "the *active total care* [italics mine] of patients whose disease is not responsive to curative treatment" (World Health Organization, 1990). There are numerous other definitions of palliative care, but they all have a "common underlying emphasis on holistic care aimed at achieving the best possible quality of life for patients and their families and friends, including support during bereavement" (Bircumshaw, 1993, p. 1665). As Patty says, *the main focus is actually not a place to die, the focus is symptom control and that's what we aim at.*

True to this objective, the average length of stay on the program, from the time people are registered until they die, is four months. Patients come to the program in a terminal phase and their actual stay on the ward is only about two weeks. Death frequently occurs quickly. Patty is proud that most people stay in the community, at home and comfortable, coming into hospital when symptom management cannot be achieved.

What the Future Holds for Palliative Care

The impact on nurses of institutional closure, increasing patient acuity, technological complexity, and fiscal restraint, is widely reported (Erickson, Rodney, & Starzomski, 1995; McWilliam, Burdock, & Wamsley, 1993; Sibbald, 1998). In fact, Sibbald states that nurses are "increasingly finding themselves in an impossible position: they are bound to uphold their professional and ethical responsibilities according to legislation, standards of practice, and policy

statements, but their ability to do so is hindered by budget cuts resulting in RN [registered nurse] lay-offs and delegation of [their] duties to other health care workers" (p. 22).

Patty describes how nurses on her unit have been affected. *They cut back here a lot on nurses. Instead of having three patients, they cut back to where nurses will have six or seven or eight patients. At that point you can't wash a patient and give medications and do treatments, so care is fragmented. You don't have that direct contact with patients, or with the families. You're not in there long enough to really make that contact with a patient and sit down while you give them a medication, because you have to run off to the next patient. And the nurses don't like it. I don't think the patients do. They complain the only time they see a nurse is when they come in to give them something.*

Patty sees the impact extending beyond the nurses, to the orderlies (male and female) hired to replace them. *They cut back on nursing staff and hired these helpers to be with nurses. And the nurses have commented that even if they wanted to do the basic care for patients, they don't have time   ...and they don't like that setup because they don't get to meet the patient and see the patient and talk to the patient. It's a big responsibility for the health care aides. They're directly giving care, they're directly having to listen to what patients say. They have to have that knowledge that they can't brush away little things. They have to have that knowledge that when a patient says it hurts in my chest or whatever, that's a serious thing and they have to pass it on. It is a big responsibility for them. That's why we try as much as possible to include them in the change of shift reports, direct communication with the nurse they're assigned to, the charge nurse and things like that. They are a part of the death reviews. They don't make the tapes but*

they come and listen and give their input as to how that patient and the family was. They have a lot of contact with the families. Participation is not an option for them because they have to know what's going on. And they're part of the team, an important part of the team.

As Patty's unit is located within a large tertiary-care institution, the team expects that systemic changes in health care will have a broad impact. The unit will likely become an "acute" palliative service, focusing on symptom control and management because of the availability of technology. New palliative care beds at other institutions will have a longer term focus. Several times Patty and I talked about my concern that dying persons, similar to what now happens with some patients receiving surgery or treatments, would be transferred back and forth between institutions. Patty doesn't share my concern, believing that the intense focus on patient and family needs will preclude the problems that acute care patients face. *We won't send people elsewhere*

...just get their symptoms under control and [send them] *elsewhere, that's not it.* Patty envisions a much more collaborative structure in which those who are able to, remain home, moving in and out of the unit as necessary, while those unable to be cared for in the home, have access to palliative care beds which can provide for long stays. She does share the belief, however, that education of all staff who will be working in these units is paramount.

Concluding Thoughts

Twenty years. Four hundred deaths a year. Patty has met, supported, counseled, and consoled virtually all of these people and members of their families. Despite tremendous potential to become emotionally overwhelmed, Patty remains committed to the unit, and to palliative care. I asked her what keeps her in palliative care. Laughing, she replied, *the money*, and then *I like the*

type of nursing where you really care for a patient. In training it was functional care. You would

do treatments, or dressings, or medications. It was the same up north. Here it is holistic care

...I like that. I like talking to people and problem-solving, and working things out, and

helping. I look at the little things, not the whole big picture. I look at being able to solve little

things, and little things, and going on that way.

deMontigny (1993) poses an interesting question. "Does a person choose a career in

terminal care because of a personal experience connected with loss or is it the hazards of life that

push one in such a direction" (p. 12)? Patty's and my experiences represent both perspectives of

this question. I am convinced that the experience of my grandfather's death remained with me

over the course of my nursing education. Coupled with positive student experiences in long-term

care facilities it was the impetus for me to seek out employment in a setting with a palliative care

unit. I would have accepted a position anywhere within the institution but once I was on the

"unit" I knew I had found a place in nursing where I could make a difference.

Patty does not recount a single, pivotal experience which brought her to palliative care.

The notion of "hazards of life" may more aptly describe her experience. After years of witnessing

profound suffering in northern nursing stations. she was ready, and perhaps needed, to shift her

practice to an environment in which she could connect with people on a more intimate and

personal level. She too would have gone to a different unit, she was interested in psychiatry, but

once on the "unit" knew she had found a place in nursing where she could make a difference.

I said, okay   ... I'll try that [palliative care]. *And that was 1980 and here I am,*

still in palliative care. I never thought of leaving. I don't know why I settled so

nicely into palliative care, but I did. Maybe it's because in my nursing experience

I'd gone through all that   ... to me I'd seen everything that needed to be

seen...

CHAPTER SIX

Contemplating Life Experience: Lessons From Patty's Life

In the nine months we talked together, Patty told me many stories of her life. Some stories have a beginning and an end; they are concluded. One of these is the story of a child and an adolescent Patty, growing up in a busy household, nurtured by her mother, of whom she speaks with heartfelt love and respect. Another tells of a young woman who leaves home and country, setting out for a new adventure as a nurse, only to realize that nursing is a profoundly painful experience, for her, as well as for the people for whom she cares.

There are also continuing stories, woven through Patty's life. She is a wife and mother. Her experiences of raising two daughters forge for her a deeper understanding of human relationships and impress on her the painful lesson of "letting go", letting them make and live by their own decisions. Another continuing story is of a wise and experienced nurse. Patty has dedicated twenty years to the palliative care unit and to the care of hundreds of persons at the end of life. Her contribution to the development of palliative care nursing has been recognized with a clinical excellence award and the admiration of her peers. Finally, some stories are being lived and others are yet to come. Patty's newest story is of a grandmother. Her first grandchild, a boy, was born a year after we began our conversations.

My representation of Patty's life story is faithful to the manner in which it was told, not chronologically, but moving from point to point on the map of her life, one story reminding her of another and yet another. Patty's voice is predominate, yet my voice is clearly audible, the voice of

the witness (Lawrence-Lightfoot & Davis, 1997); listening, observing, recording, and

representing. Decisions about what aspects of Patty's life to include, which of her words to use,

are mine. Patty and I spoke together for more than thirty hours, of necessity not every word of

our conversations is repeated. Throughout, I was mindful of Davis's (1997) question; "How (to

what extent) does the disposition of my voice inform (give shape to but not distort) the product"

(p. 106)? To be confident that I had authentically represented her life I asked Patty, after she read

her story, if it sounded like her. Her reply was "Who else could it be?"

Patty's voice as storyteller and mine as witness are not the only voices we need to hear.

"Portraitists seek to record *and interpret* [ital. mine] the perspectives and experience of the

people they are studying, documenting their voices and their visions-their authority, knowledge,

and wisdom" (Lawrence-Lightfoot, 1997b, p. xv). As suggested, we must also hear my

interpretive voice. Patty's life is a life lived in context, lived in the ebb and flow of the

community/ties in which she lives and works, as is mine. How does she understand her life within

its contextual frame and how might her, and my, understandings help us to reveal the objective of

our time together, the explication and understanding of Patty's nursing knowledge, its genesis and

expression.

<u>Achieving Understanding</u>

Thirty hours of conversation with Patty and observation of her practice revealed two

predominate themes, suffering and responsibility. I determined these themes through an analytic

process that evolved over the course of several months, and eventually synthesized three

strategies. To begin, I was informed by Wolcott's (1994) notion of three levels of analysis;

description, analysis, and interpretation. Patty's story is the descriptive piece; a rich, thick, depiction of her life that reveals 'what is going on'. I made explicit decisions to include some passages and to exclude others, but throughout I remained consistent to the chronology Patty set in the telling. I was also faithful to her use of language. There is very little editorial revision of Patty's phraseology, except the substitution of ellipses and spaces to reveal where she paused, searched for a word, or for an effective way to describe a particular event.

The second level of analysis, identification of resonant themes, began as I transcribed the audiotapes. From the outset, Patty made repeated reference to certain details of her story, in particular, painful experiences in nursing, her sister's death, her relationship with her mother, and with her daughters. The repetition caught my attention, as it suggested these were pivotal experiences, or rich points (Agar, 1999). The concept of rich points was very helpful in the process of analysis. Rich points were aspects of Patty's story that had an emotional impact, for Patty, and for me. They were apparent contradictions, and repetitive refrains (Lawrence-Lightfoot & Davis, 1997). They were also the seemingly incomprehensible, when I could not understand, from my perspective, how and why, Patty understood events as she did. In all cases, Patty's words were triggers for me. They prompted me to ask questions, and sometimes, to think differently. Occasionally, we agreed to disagree, and different epistemological perspectives were revealed. Incomprehensible points, particularly, became the source of ongoing debate and, more than others, provided insight into the significance of context for the expression of knowledge.

Some passages stood out for me because they were a point of connection with my own experiences or ideas. Others generated questions about the structure and function of the unit, and

about the nature of the relationship between the unit, the institution, and the broader health care

context. The highlighted passages provided direction for following interviews, and formed the

basis of emergent themes. Later in the process, I needed a means to organize these outstanding

passages. In an effort to explore the juxtaposition of Patty's life and practice, I created a grid in

which highlighted rich points were grouped together, and contextual features were identified as

motivating factors, changes Patty was involved in, or institutional supports or barriers (Cole.

personal communication, October, 1997). These clusters of data were eventually integrated and

two overarching themes emerged.

In Patty's story the two themes that stand out for me are suffering and responsibility. They

reveal to me, in a vivid and passionate way, how she knows nursing. I am, however, clearly

informed by my own experience as a palliative care nurse, and as a teacher of nurses. I am familiar

with the language and nuance of nursing care, and have experienced, in similar and dissimilar

ways, some of the events Patty describes. Readers who are not nurses, and nurses whose practice

is grounded in different contexts, bring different perspectives, different contextual frames to

Patty's story. As such, different themes might stand out. I am, therefore, obliged to clearly

articulate my growing awareness and understanding, not only how the overarching themes of

suffering and responsibility illuminate Patty's knowledge, but of how I come to view them as

overarching themes. But, as stated earlier, I am also mindful that readers are active participants in

the process of knowledge construction, and so, I am hopeful that different ways of knowing will

prevail and all readers will find points of resonance within Patty's story and my interpretation of

it.

In the process of articulating how I came to understand suffering and responsibility as overarching themes, I have immersed myself not only in Patty's reflections, but those of other authors. In the next section, I share, in the form of a reflexive conversation, Patty's stories, contributions from others working in palliative care whose thinking informed my own, and my musings and questions as I struggle to understand how life experiences inform nursing knowledge. I also illuminate my attempt to understand more fully how the context of a nurse's practice delimits the explication of her nursing knowledge.

Patty's voice is again the first voice you hear. The conversation opens with a comment Patty made early in our time together that immediately caught my attention and remained with me throughout. As before, her words are *italicized*. My response, intended to reveal how I understand Patty's words, follows in regular font. Later, when it is helpful to include the voices of others, to clarify and extend our discussion, these voices are underlined.

Nurses in Conversation: Revealing Themes

I didn't realize nursing would be so painful. It was painful for the patient, but it was also painful for me, seeing someone suffer.

Patty's comment came not five minutes into our first conversation and it caught me totally off guard. I remember thinking, of course nursing's painful, as if it were self-evident, and then I realized that in twenty-five years I had never really talked with another nurse about how painful nursing is, about how we suffer. In the end, we spoke frequently of suffering. It was a repetitive refrain in our time together, patients' suffering, family members' suffering, staff suffering. No one

is spared. But as I pored over and over Patty's words something else became clear. Experiences of suffering inform, in a fundamental way, how Patty nurses.

Suffering: How We Suffer with Patients

*We had a lady here, with breast cancer and bone metastasis, in agonizing pain. She was admitted here from the oncology unit and we got her comfortable and she went home. Yesterday I got a call from her daughter and she needs more medication but the doctor won't increase it. I think about the patients, about their pain. The doctors don't realize that you have to give a big enough dose. When you don't do that, then you are chasing the pain and the patients are suffering... the patients are suffering and the families are suffering. Our focus is symptom control, that's what we aim at, but it's more than controlling symptoms. It's also dealing with the person and what they want, helping them to work through it. Patients are suffering physically, their breathing is difficult or they are in pain, but they're also suffering emotionally, because they know they are dying. And even when the patients are physically comfortable or unconscious, the family is suffering because that person is dying. They're suffering the grief of separation. And on a lesser plane, the staff is suffering when they go into a room. They can feel it themselves, so they act on it. I guess it's **how we suffer with patients** that makes us act, and that's palliative care.*

How we suffer with patients. How do we suffer with patients? At first, it was not clear to me how this came about, how experiences of suffering were transformed **as knowledge**, into nursing actions, into palliative care. Patty, on the other hand, is quite clear how it comes about,

describing to me situations that revealed how suffering experiences were re/created as nursing knowledge.

Well, it makes me angry and frustrated when patients aren't comfortable, because how someone dies, the family will remember for the rest of their lives. I blame the medical system a lot for patients wanting assisted suicide and euthanasia because I think it is prolonging the dying. As long as we have unnecessary medical interventions and patients' feeling that they have no control, then you'll have those kind of requests. And I'll say...why are you doing all these tests, for what, when you can't do anything about it...so why are you doing them? I questioned one of our physicians on Friday. I wanted to transfer a patient here from observation and the doctor wanted to do this and that. I said, "well, I see this patient as having advanced disease, why is it even being offered to him. And you know, this man went up to an acute medical ward and he died on Saturday."

Patty has seen this happen before. In our time together, she frequently described her frustration with similar decisions; admitting patients for acute intervention rather than palliation, not referring to palliative care, or referring to palliative care and transferring patients between units, and between institutions, at the last minute, when death is imminent. She has also seen decisions of this nature cause patient suffering, primarily as a result of invasive diagnostic tests and procedures that cannot alter an inevitable outcome. And so, she acts on her knowledge that this dying patient will suffer because of admission to an acute service and she questions the physician's plan.

Patty's action, in this situation, is congruent with Benner's (1984) description of expert

practice. Benner says that "expert nurses have "recognitional ability", that is, the ability to

recognize possible consequences, on the basis of their years of experience and intensive study of

patients" (p. 33). My understanding of nursing knowledge has been extensively informed by

Benner's thirty-year examination of clinical knowledge development. I am concerned, however,

that a focus on clinical knowledge alone does not sufficiently describe the knowledge nurses use

to nurse. We are still holding our lives outside the clinical practice arena, at arm's length. The

complex interplay of life and clinical practice revealed in Patty's words: "it's how we suffer with

patients", demands that conceptualization of "recognitional ability" consider knowledge arising in

contexts other than clinical practice. Knowledge also arises in recognition of events of which we

have intimate experience.

When I left my sister's home after the funeral I thought, I'll never come back to this place... you

know, something so painful to you... I'll never go back. I have never been back. It's thirty years

and it feels like yesterday. I think at the beginning I was very sensitive to people who came in

and were dying, because I could feel their pain. Now, maybe subconsciously... no it doesn't come

out at all, because I've done this for so long. It just comes out and I do it now, because I've been

doing this for a long time.

I do not agree that Patty's experience of her sister's death doesn't come out any more,

although I do agree that it is not be expressed in an overt way, in the sense that Patty thinks of her

sister in every engagement with patient and family. My experience of my grandfather's death is

not expressed that way either. And yet, it is expressed. Neither of us can escape the fact that we

have a very powerful remembrance of how someone close to us died. As Cheek and Rudge

(1994) state, "knowledge ... cannot be seen apart from either its historical or social context"

(p. 17). Ira Byock, recently President of the American Academy of Hospice and Palliative

Medicine, has written extensively in this area, describing at length his experience of his father's

death. His words echo my understanding of how experiences of suffering are re/created as

knowledge. When I think about suffering, while I am "informed by the wisdom of cultural and

religious traditions and by scholarly opinion, what knowing I have ... is fundamentally personal. I

know suffering primarily through life experience" (Byock, 1994, p. 8).

Patty's, and my, historical experiences of the deaths of family members, are part of the

fabric of our contemporary nursing knowledge. And, although Patty's words in the previous

passage suggest that she does not consider knowledge arising in the experience of her sister's

death as an aspect of her nursing knowledge, other recollections reveal she is, at least at times,

mindful that how she knows events informs how she nurses. When we spoke of families in which

adult children were caring for parents, for example, she exposed knowledge arising in the

experience of caring for her father-in-law. *He never had any nursing or home care or anything.*

We were the ones who supported him. So when I get phone calls from patients and families

saying they can't cope anymore, that it is getting too difficult, I understand what they're going

through.

"*I understand what they are going through*". Patty's knowledge of this life event is not

expressed as a specific nursing intervention. She does not expect the family members to care for

their parent precisely as she cared for hers. There is no prescriptive outcome of this knowledge.

And yet, how she knows the event is expressed in her care. As she says, *I can understand and be sympathetic, have some empathy, for people who are going through this.*

The knowledge revealed in this example is knowledge about what it means to be human. For Patty, it is to "suffer with" in meaningful ways. It is instrumental to her nursing knowledge, to how she acts as a nurse. I understand suffering as an organizing principle for Patty's practice, and, as a foundational element of her unique ontology, her way of being in the world. Suffering: her own, her children's, patients', their families', other nurses', is an impetus for nursing care.

It's not easy, it's very difficult as a human being, to see the suffering. You try to relieve it, you know, and it's like you're feeling it sometimes. For nurses, the most discomforting thing is when they see patients dying and suffering and they can't do anything about it.

When patients suffer, nurses not only suffer, but sometimes understand that suffering as indicative of less than effective practice. Their greatest dilemma is when patients suffer and "they can't do anything about it". Why? Suffering with the patient is part of this. Maeve (1995) suggests <u>nurses who are part a part of another's suffering, feel that suffering themselves and remember it forever</u>.

With suffering as the impetus for care, Patty could be continually responding in an emotionally-charged manner. In Patty's and my conversation, however, there is one other repetitive refrain that contributes to my understanding. Patty sees herself, and nurses in general, as responsible for patients. Responsibility, to and for patients and families, is, therefore, another

salient feature of the way Patty knows nursing. It connects how she knows suffering to her nursing care.

Responsibility: Responsible Relationships

I think it's because when you are assigned certain patients, you are responsible for them...for their treatments and medications and whatever comes up.

References to responsibility punctuate Patty's accounts of patients and families, stories of her childhood and relationships with her family, and descriptions of the cohesiveness of the palliative care team. Again, as with suffering, the repetition caught my attention and prompted my efforts to understand, how Patty understands, her sense of responsibility.

I have two older brothers. I was the third and the oldest girl, and so for me, that put some responsibility on me. I didn't really have to look after my younger brothers and sisters, but I did. I remember helping with my youngest sister, she was premature, and helping with her and feeding her. I did help with my two younger sisters in particular and I guess that's why all my sisters call me Mom. That sort of nurturing, I guess, started when I was in my mid-teens. I had the attitude that   ... here's someone, you have to help them.

My mother certainly has been quite an influence on me, especially in seeing that even with eight children she was always able to be cool and calm and always had control. It was in a sense a team effort at home. Even though we had a servant that lived in, we had our chores. You were

still responsible for your room, for certain things. So it gave a sort of self-esteem that you were responsible.

And I don't know if maybe it came about in having two children and being responsible for them, because at some point as they became teenagers I could not take on their problems. I mean I could try to help them. I talked a lot and reasoned a lot with them, but I could not solve all their problems. Also, growing up as a family with eight brothers and sisters, I recognized that there are some things [in life] that you have to go through pain. With my daughters I know. But I will not be with them for the rest of their lives. I can only do so much for them. My daughters had to learn that there are some things in life that hurt. You made that decision, it will hurt you. I've told you what's there and I've explained to you, but if you go ahead this is what might happen.

Patty's responsibility narrative was spontaneously shared when she talked of her childhood. To understand, though, why doing for others is so important to her, it is "necessary to consider the cultural and historical context in which [her life] unfolded" (MacRae, 1995, p. 162). Clearly, Patty's understanding, her knowledge of what it means to be responsible is life-informed, and contextualized by experiences of childhood and motherhood. Nurses do not learn responsibility in nursing school. We learn we must be responsible, that we have professional responsibility. How we know responsibility, and consequently demonstrate it in our practice, is not explored. The inherent assumption is that everyone understands and demonstrates the concept in a similar way, but Patty's life story illuminates how responsibility can be differently conceptualized. There is a maternal tone, for example, to Patty's description of responsibility for

patients, that echoes Jolley's (1993) notion of a physician-nurse-patient hierarchy grounded in a

family hierarchy.

Certainly if you're a mother you're responsible for your kids. With my daughters, it wasn't just

me I was thinking of. I was responsible to make sure that I would give them the skills to go out in

the world and survive though it's painful to see them grow up, because they have to suffer all the

things as they go through life. I think also, we are responsible for patients.

This connection, between patients and children, perplexed me at the time of our

conversations, and still does. I find it difficult to reconcile Patty's commitment to patients with a

maternalistic stance that suggests a position and perspective of authority. In the following

passage, Patty reveals how she consistently places patients first.

It's what's best for the patient, a matter of understanding where they're coming from. So often

we see our patients here, they come and we see them for two or three weeks of their life. What

has gone on for the last sixty or seventy years, we have no idea, though we're having to deal with

them in this phase where they're ending it all. Part of what I try to get at as I meet patients, and

families especially, is to get a picture of that person. You have to keep asking questions, not to

be nosy, not in that sense, but it's a continuous asking of questions. You cannot do that in five

minutes. Get that picture.

I watched Patty "get that picture", hours spent going back to patients again and again,

talking with them, telling them about the unit, and letting the idea of transfer percolate in their

minds. The process of "getting the picture" is illustrative of Patty's claim that it is "what's best for

the patient" that is the principle context for her practice. Even her insistence that there is a "time

and place" to talk about palliative care reflects this emphasis. If suffering might be intensified by

conversation, Patty does not initiate one . If suffering might be alleviated by conversation, she

does. She seeks to understand each person's experience, and to present information in a manner

that is meaningful and consistent with that experience. The patient and family are first and

foremost, each unique circumstance at the heart of her nursing care. And yet, in the following

passage Patty's words suggest the maternal viewpoint that perturbs me.

I don't like to see family members make decisions that might hurt them, that's why I go on and

explain and explain. You cannot expect them to make some decisions. They're just standing too

close. And in a sense, the nurses cannot expect, or they should not expect, family members to do

that. They have to watch out that family members don't hurt patients in a loving way.

This description, and other similar statements, appears to be indicative of an hierarchical

relationship between Patty and some patients and families, contradictory to her repeated claims of

"putting the patients first". It is as if she is suggesting that patients come first, but only to a point,

and then her knowledge takes precedence. As I reviewed the transcripts, listened again to her

voice, and pondered this apparent contradiction, I realized that the expression of Patty's

knowledge-in-practice was, again, congruent with her beliefs about suffering and responsibility.

Well, I remember one time we had a lady and her husband was trying to give her fluids and make

her drink. I went through the whole thing   ...she can't swallow, the reflex is gone, she might

choke, it's best not to...   I left the room and ten minutes later he came running out,

screaming, and she died right after that. And I felt badly about that, and I thought how much

more could I have done to help him, because I knew that's what he wanted to do [provide her

with fluids].

But there are some things you can fix, and some you can't. You know, you can feel badly about

it, but at the same time I had to realize that this man was going to do what he had to do. Short of

taking him out of the room and saying you can't do this, that was about it. So, we have a

responsibility to teach, but you can only do so much, you have to realize that family members are

going to do what they have to do.

It becomes clearer, in the example, that rather than assuming a position of authority, Patty

is expressing in her actions, different ways of knowing the experience. She knows the experience

empirically and expresses particular knowledge about the dying process, about patients'

nutritional needs, and about families' needs to provide sustenance. She knows the experience in

profoundly personal ways, in remembrance of how someone dies, and in experiences of suffering,

and so, she expresses life-informed knowledge. Her realization that families are going to "do what

they have to do", mirrors her realization that she could not keep her daughters in a glass case, and

in both examples, she alludes to suffering and responsibility. Responsibility to and for patients, is

the impetus for "protecting" them from suffering inadvertently caused by family members. And,

recognition of the family members' grief, tempers responsibility to patients with awareness that

their loved ones have to undertake certain activities to alleviate their own suffering. Responsibility

to protect her daughters is tempered by awareness that they will suffer in life, as she has, and will

be stronger for it, as she is. For Patty, suffering and responsibility intersect as a way of knowing and being in the world, nurtured over a lifetime.

This is a way of knowing that has been, and is being, constructed within a complex, contextual web. And so, Patty expresses contextual knowledge, from the immediate and particular context of palliative care, and from her unique and personal contexts of gender, race, history, and family. She brings forth, as well, knowledge arising in the many contexts within which the nursing profession is situated, though she may not even be aware of how her knowledge is informed by these, less immediate, contexts. They are, nevertheless, a part of how she knows nursing.

These are contexts of philosophy and pedagogy that frame curricula and learning and teaching. They are contexts of power, organizational structure and culture, and management style that frame nursing units, and the relationships between members of the health care team. They are contexts of multiple stakeholders: government, employers, professional associations, unions, educators, and patients, that inform, and constrain, nursing practice. They are contexts of sexism, paternalism, and parentalism that may, despite inclusive rhetoric that identifies patients and families as integral members of the health care team, enable a socially-sanctioned physician-nurse-patient hierarchy modeled after an historic family hierarchy. They are impossible to enumerate, and their connectivity is difficult to conceptualize. Even though I have made reference to a web in order to facilitate understanding, it is a poor metaphor. Spiders construct webs on a single plane, and the myriad contexts that inform our lives, surely necessitate three-dimensional conceptualization. They are historic, current, and future-oriented. They are immediate and idiosyncratic, and they are global and generalizable. And, in nursing, we have for too long, failed

to explicitly consider how they inform and delimit the construction and expression of nursing

knowledge.

CHAPTER SEVEN

Contemplating Life Experience: In Nursing Knowledge

Fundamental Patterns of Knowing in Nursing

In 1978, Carper advanced the thesis that knowing in nursing is comprised of four

fundamental patterns: empirics. aesthetics, ethics, and personal knowing. Carper's work

stimulated flourishing discussion in nursing literature, about the patterns, and about broader

ontological and epistemological questions (Antrobus, 1997; Bradley, 1996; Chinn, 1992; Chinn &

Kramer, 1999; Schultz & Meleis, 1988; Silva, Sorrell, & Sorrell, 1995). Each pattern has been, to

a greater or lesser extent, elaborated upon (Agan, 1987; Benner, 1984; Benner & Tanner, 1987;

Chinn, 1989; Chinn & Jacobs, 1987; Drew, 1997; Greenwood, 1993; Jenks, 1993; Meerabeau,

1992; Meleis, 1987; Moch, 1990; Rew & Barrow, 1987; Smith, 1992; Sorrell, 1994; Sweeney,

1992; White, 1995), and at least two additional patterns, unknowing and sociopolitical knowing,

have been proposed (Munhall, 1993; White, 1995).

White (1995) and Silva, Sorrell, and Sorrell (1995) note, however, that although Carper's

(1978) work is classic and much cited, it has never been critiqued or examined in light of

ontological shifts in nursing. For me, a significant limitation of the work, and much of that which

follows, is that the patterns of knowing as described and elaborated on, particularly the pattern of

personal knowing, do not explicitly confront knowledge arising in life experience. Further, we

have not examined how nursing knowledge is contextualized, in its construction or its expression.

There is unvoiced acceptance that knowledge is life-informed and contextual, but this

acknowledgment does not appear in the form of direct references to nurses' life histories, only in reference to experiences which cannot possibly be limited to clinical practice.

Reed (1996) states that "building knowledge entails observation of human processes ... and observation of human patterns" (p. 30), and Benner and Tanner (1987) suggest that nurses are able to recognize subtle trends in patients' experiences by incorporating into their expert practice, in-depth knowledge of the human world. In fact, "two experts will not necessarily agree or even have the same possibilities in a particular situation", because of their different ways of being in the clinical world (Benner, Tanner, & Chesla, 1996, p. 27). Silva, Sorrell, and Sorrell (1995) state that there are lived experiences "profoundly felt by its [sic] bearer but often inexplicable, and to those who have never experienced it, unknowable" (p. 10). They argue that in order to create meaning of that which is inexplicable and unknowable, we must shift from epistemological to ontological questions: from consideration of ways of knowing, to ways of being; from how do I know, to how do I find meaning in what I know? With respect to the personal pattern of knowing, the ontological question posed is "Who am I?" (p. 4). In these thought-provoking discussions, Silva, Sorrell and Sorrell, and others are clearly referring to experiences outside the domain of clinical practice and understand knowledge to be life-informed and contextual.

Nowhere in the nursing literature, however, am I able to hear the voices of nurses, am I able to read the stories of nurses' lives. In the last ten years there has been a proliferation of research revealing clinical practice stories and the knowledge embedded in clinical practice (Benner, Tanner, & Chesla, 1996; Maeve, 1994, 1995, 1998b; Moch, 1990; Perry, 1998), yet I

continue to have little sense of who these nurses are. Maeve's (1998b) study, like my own with

nurses who care for dying persons, provides another example of how life-informed knowledge is

implicitly accepted. She states "we often note that maturity gained from life experience translates

into maturity within nursing practice, therefore it is not surprising that nurses incorporate their

professional experiences into their lives as a whole" (p. 1141). It may not be surprising that nurses

incorporate their professional experiences into their lives as a whole, but the first part of the

sentence suggests the reverse is also true, life experience informs practice. So, what of

incorporation of nurses' lives as a whole, into their professional experience? How this comes

about is not revealed.

The ontological question posed by Silva, Sorrell, and Sorrell (1995) is "Who am I"?

Patty's life history hints at the complexities of her life that must be considered in response. She is

a woman, wife, mother, daughter, sister, aunt, nurse, educator, student, and colleague. She is

informed by culture, place of origin, experiences of joy and sadness, birth and loss. She has

encountered prejudice, and she is recognized as expert in her chosen field. She has an intricate

way of being in the world, a personal ontology, and its epistemological expression is the way she

nurses.

Life-informed Knowledge

One of the most significant challenges of this thesis is my awareness that many nurses will

intellectually reject life-informed knowledge as an integral aspect of nursing knowledge. Benner

(1994) echoes my frustration when she says

modern commodified health care highly values what can be made into scientific

and technical procedures, and assumes that what has not yet yielded to means-end

analysis, objectification and procedural accounts is underdeveloped and only

awaits scientific and technical formalization. And until this scientific, procedural

articulation occurs, all other aspects of our knowledge are considered private,

inarticulate, and of lesser epistemic warrant. (p. 138)

Kikuchi's (1992) arguments for philosophical inquiry, as a mode of inquiry for nursing, are a case

in point.

Having differentiated scientific and philosophical questions, Kikuchi (1992) turns to what

kinds of questions constitute philosophical questions. Of particular importance to this inquiry are

epistemological questions. Kikuchi argues that in exploration of questions of this nature an

important distinction has not been made, that is, a distinction between "the knowledge nurses use

in order to nurse", and "the knowledge that comprises the body of nursing knowledge" (p. 33).

She further suggests that the latter is part of the former. Her words concede that the knowledge

nurses use to nurse, is broader than an overt, recognizable "body" of knowledge. This belief is

echoed by Chinn and Kramer's (1999) claim that "as nurses practice, they know more than they

can communicate symbolically or justify as knowledge" (p. 2).

Kikuchi (1992) goes on to suggest that it is only the "body of nursing knowledge" that

members of the profession are responsible for developing. She dismisses what she calls preclinical

knowledge, as taken on assumption and outside the discipline. And she dismisses personal

knowledge as subjective, incommunicable, and publicly unverifiable

[emphasis mine]. Here she parts company with Chinn and Kramer (1999), who do believe that much of what nurses are unable to communicate has potential to become formally expressed. Kikuchi's articulate argument, contesting knowledge arising outside the discipline, is a powerful barrier to attempts to explicitly articulate life-informed knowledge. It is also a paradox.

Kikuchi (1992) argues that because a nurse's ontological and epistemological perspectives are private, subjective, and exclusively her possession, they cannot be shared, and as such, educators are not responsible for them. This is the paradox. Members of the nursing profession are responsible for its body of knowledge, but not for the knowledge used by its practitioners to nurse. Philosophical inquiry, exploring ontological and epistemological questions, is fundamental to creating and understanding the nature of that body of knowledge. Yet, inquiry that explores the very nature, scope, and object of any nurse's nursing knowledge, her own ontological and epistemological perspectives, is not perceived as nursing's responsibility. I assert that it is "impossible to understand [nursing] without understanding [nurses]; ... to understand practice apart from the practitioner; ... to understand knowledge apart from the knower" (Cole & Knowles, 2000, p. 9).

Life-informed knowledge is precisely what Kikuchi (1992) argues against. It is intensely personal, private, and subjective. It is an implicit form of knowledge by Mayeroff's (1971) definition, because it cannot be easily articulated. It is each nurse's way of being in the world, and the manner in which that way of being finds expression in her practice. We cannot disregard it. It is naive to suggest we can. As Mayeroff states "restricting the meaning of knowledge in this way

[to that which can be verbalized] is as arbitrary as assuming that only words can be communicated and restricting the meaning of communication to what can be put into words"

(p. 10).

It is, admittedly, difficult to portray life-informed knowledge. But it is not impossible. Kvale (1999) states "human reality is understood as conversation and action, where knowledge becomes the ability to perform effective actions" (p. 101). Reflection on relationships and examination of actions are ways, therefore, to expose knowledge embedded in life experience. Through Patty's stories of life we gain access to her relationships with others; family, colleagues, and patients, and to her actions, her nursing practice. Through my interpretation of her life history, we see that her relationships are constructed within the context of her organizing principles of suffering and responsibility, and that she is consistent in expressing the knowledge arising in relationships, in her nursing actions. We see, also, how the expression of that knowledge is delimited by the multiple contexts within which her life has been, and is, lived. We would not have this portrait of Patty's life and nursing knowledge had a different research method been used. The opportunity to examine a life-in-context through life history method affords us insight that could not otherwise have been gained.

Patty's life history reveals wisdom, maturity, and acceptance of self. It reveals her understanding of how experiences of life inform her way of being in the world, and it reveals the manner in which this way of being finds expression in her practice. There are a multitude of examples in Patty's life and day that demonstrate her capacity to perform effective actions. I observed the high regard that many on different units have for her. She is repeatedly sought out to

resolve complex problems, even those outside her mandated scope. Recognition of her expertise

extends beyond the unit. She is a frequent speaker at conferences and is a founding, and highly

respected, member of a palliative care nurses' association. She is the recipient of a clinical

excellence award, perhaps the most visible recognition of her expertise, and the regard with which

she is held in the nursing community. Her credibility as a palliative care nurse is clear, and as such,

we are able to look to her actions to illuminate our understanding of her nursing knowledge.

Our conceptualization of nursing knowledge is enriched by Patty's portrait, because it

reveals knowledge and practice in a different way than has previously been available. But, as I

have shown, there is a preoccupation in the nursing profession with knowledge that is verifiable

and publically communicable. This barrier of skepticism, in and of itself, serves to maintain the

status quo, to ensure that life-informed and contextual knowledge are considered of lesser

epistemic warrant. It also perpetuates an exclusive, rather than inclusive, conceptualization of

nursing knowledge, that does not serve nurses well in light of challenges and changes in health,

and nursing, care. Patty's story reveals that she is, to some extent, aware of how her nursing

practice is informed by the immediate contexts of unit and institution. She expresses strong

opinions about how the provincial health care system limits her. She seems, however, to view

broader societal complexities, as less material to her immediate dilemma. I, on the other hand,

continue to hold the opinion that the frustrating aspects of Patty's practice, and those I experience

in my practice, are related more to systemic issues that limit the expression of knowledge, than to

immediate and particular issues of, for example, structure and funding.

Contextual Knowledge

Context, as a mediating condition of practice, is recognized in nursing literature. White (1995), identifying that the predominate ontological position of the time, realism, prevailed in Carper's 1978 work, urged that conceptualization of nursing knowledge needed to include "knowing that seeks not to generalize, but rather through interpretation or description to put before the reader context-embedded stories whose purpose is to enrich understanding" (p. 75). This is consistent with Benner's (1984) premise that expertise is context-specific and not transferable. Benner argues that "any context-stripping approach runs the risk of overlooking or mistaking the quality of caring" (p. 217), or for the purposes of this inquiry, of overlooking and mistaking the nature and scope of nursing knowledge.

White (1995) further argues that the patterns of knowing are missing consideration of the changing context of nursing and health care, hence she advances a fifth pattern, sociopolitical knowing. In White's argument, revealing the context of nursing practice would lift "the gaze of the nurse from the introspective nurse-patient relationship" (p. 83), situating it in the broader context in which nursing takes place and challenging "taken-for-granted assumptions about practice, the profession, and health policies" (p. 83). Consideration of context, White proposes, has to occur on two fronts: that of the persons, nurse and patient, **and** that of the broader context of nursing as a profession.

Patty has had the rare privilege of creating her own immediate practice context, a privilege that has afforded her opportunities for the expression of knowledge grounded in who she is. She is, of her own description, a business-like methodical person, like her mother. And, she has had

the autonomy to create an environment that honors her organizational style and supports her notions of responsible practice. She is able to express her knowledge in a meaningful way as is evident in observation of her daily activities. In the picture of her day, however, there is also evidence of forces that limit the expression of her knowledge.

I envision Patty's practice context as a series of concentric circles, like ripples when the smooth face of a body of water is disturbed. At the source of the water's disturbance, the ripples are well demarcated. The farther away from the source, the greater their distortion. The center of Patty's practice context is the palliative care unit, where there are well demarcated opportunities for the expression of particular kinds of nursing knowledge. Outside the unit, the environment has an increasingly distorting impact on Patty's capacity to purposefully express her knowledge.

Patients don't want to hear about this place. I phone them up and they practically put the phone down on me. It takes a lot of time with patients, talking and explaining. Even the nurses in our own hospital and in the community don't recognize what we do. One nurse was telling a patient that if she came in things would be fixed up. I say, "Well there's some things we can do and some we can't, but we'll see what we can do to make you more comfortable."

Here is the distortion, virtually one step across the threshold of the unit. As Patty says, *even the nurses in our own hospital.* In some ways it is mystifying, this lack of awareness. The program has, after all, been in place for almost thirty years. There is very little turnover of staff, three medical directors in its history, and several of the nurses have been there longer than Patty. There is a tremendous amount of accumulated seniority among staff and yet the unit is still

regarded with suspicion and wariness. Patty has described how she goes back to referred persons

again and again, explaining the unit's mission, focusing on symptom management. Repeated

requests for support: human, material, and fiscal, seem to fall on deaf ears. Many people nearly

hang up on her when she phones. The unit's reputation does not appear to precede it. Patty

describes her perception of why this is the case.

Palliative care is not recognized as a discipline that's worth anything. It's not recognized

because of economics and bureaucracy and that runs   ...the way we do things. They think

anybody can do palliative care because all we do is sit and hold hands. Yesterday I phoned up

[another agency] to tell them about a seminar coming up and I asked if they had nurses who did

palliative care. She said "We all do palliative care" and right away that's sending me signals. If

they're all doing it, it means there's nothing different about it.

It is frustrating for me that you cannot hear Patty's voice. The inflection, nuances of tone,

and expression of emotion add so much to my sense of who she is. In these words her

exasperation is evident. Her dilemma, as she describes it, is that the unit provides high quality,

specialized care to dying persons, and that care is not recognized because few people understand

its complexity. I agree with Patty's assessment, but also understand her dilemma differently. She

has, in 20 years, constructed a specialized body of knowledge, and the structure of the unit

enables and honors its continued construction and expression. It is the knowledge she uses to

nurse, and it includes, not only her knowledge of the care of dying persons, but knowledge arising

from different sources, including from life experiences. As Patty says, on palliative care you use

yourself in a therapeutic way. She speaks frequently of nursing in a manner that is consistent with who she is. *That's who I am, that's me* she says. Beyond the walls of the unit is a another story.

Patty and I discussed this dilemma at length. Patty believes strongly that education and specialist recognition of palliative care is the route to validation, increased funding, and development of enhanced programs and services. I am not convinced that education and specialist status alone would result in the changes she desires. Images that pervade current literature and media suggest that societal and historical perspectives of dying and death have a profound impact on the way we know the experience. "In society the disease cancer appears to have become the metaphor for the deepest fears held about the inevitable disintegration and decay of the body. Cancer is the disease which attacks the body organs about which greatest ambivalences are felt, those of sexuality, reproduction, and excretion. The society "battle" against cancer is then seen as the struggle to resist acceptance of the inevitability in life of death" (Benner & Wrubel, 1989, p. 8). Failure to acknowledge and consider these contextual features limits our capacity to care for persons at the end of life. We are after all, living in an age where, to use Patty's words, prolongation of death is causing people to live far beyond even their own expectations and often not in a comfortable way. How does fear of our own death inform our knowledge and practice?

Patty's experiences, on and off, the palliative care unit, demonstrate the critical importance of context for the expression of knowledge. Based on this understanding of the experiences of one member of the nursing community, I theorize that other specialized areas of care, surgery for example, similarly support the expression of members' knowledge. What happens then, when a palliative care nurse is "floated" to a different area, or for that matter, when a nurse from surgery,

a casual, comes to assist on palliative care? This is an important question, as this workload

management strategy is a daily occurrence in nursing. What does it mean for the expression of

knowledge?

Nursing knowledge, the knowledge nurses use to nurse, is a rich, complex, sometimes

inexpressible, fusion of life, clinical, educational, spiritual, cultural, and other multifaceted layers

of experience. This incredible amalgam of who we are is contextualized by the setting in which it

is constructed and expressed. Palliative and surgical contexts are fundamentally different. The

goals of care and the needs of patients are different, so particular knowledge is consequently, and

necessarily, different. The context is so critical to the expression of knowledge that outside the

specialized environment knowledge is de-contextualized. It is less powerful. Certain aspects of it

may fit, others do not, and the nurse is frequently frustrated by perceived roadblocks and

gatekeepers. Patty's experience with other agencies and institutions reveals how her efforts to

meaningfully express her knowledge can be frustrated.

It is not unlikely that nurses on units other than palliative care feel similar frustration. In

one critical respect, however, palliative care is very different from other units. As Patty says

"*traditionally they're dying all over the place*". People do die everywhere, not just on palliative

care units. They die on medical and surgical units, in labour suites and personal care homes, in

emergency and on paediatric units, in their homes, and on the street. Each dying experience is

differently contextualized, unlike other illness experiences that have clearly identified "homes". It

is no wonder that all service providers involved with dying persons, understand themselves to be

"doing" palliative care.

"We all do palliative care". This is not a perception held about surgical nursing or

nursing in a dialysis unit. No nurse would claim that we all "do" surgical care. It is clear when and

where nursing knowledge about the care of surgical patients is being expressed. It seems it is less

clear about when and where nursing knowledge about the care of dying persons is being

expressed. And so, Patty's dilemma is compounded even though her narratives reveal how

specialized her knowledge of palliative care is.

Discussion about this predicament is one of the most significant points of contradiction in

Patty's and my conversations. Our perspectives reveal how differently two experienced nurses,

albeit with similar practice backgrounds, create meaning of a particular phenomenon. I am of the

opinion that the frustrations that Patty has described exist, and will continue to exist, even if more

substantial resources are allocated to palliative care programs. And, I believe this to be the case,

because, between the unit and society, there exists an epistemic firewall (Walker, 1998).

Story and Counterstory

The epistemic firewall is a "lattice of law, custom, expectation, and the familiarity of what

is pervasive and repeated" (Walker, 1998, p. 173). The firewall works in several ways to

perpetuate practices of exclusion and discrimination by making them appear normal. As Walker

explains, *"privatizing"* confines marginalized groups to private spaces, essentially hiding them

from public view. *"Naturalizing"* suggests an inevitability about certain aspects of experience, and

inevitability precludes consideration of different possibilities. *"Normalizing"* presumes certain

aspects of the practice to be standard, as such, they are taken for granted.

The notion of an epistemic firewall provides a framework for understanding the context of

Patty's practice and its implications for understanding nursing knowledge. For patients, family

members, and staff, the purpose of the palliative care unit is evident. Compassionate care of dying

persons through the management of untenable symptoms is the primary goal. The staff are very

good at what they do. They function as a cohesive team, acknowledging and drawing on one

another's areas of expertise. Their efforts have been recognized in countless obituaries, in

interviews on a CBC radio program about ordinary people doing extraordinary jobs, and in

individual awards to its members. Unfortunately, notwithstanding the obvious expertise of the

staff, there are only fifteen beds and reality is a significant lack of access to the unit's resources.

Beyond the unit, in a catchment area of greater than half a million people, there is one

other small unit and a variety of differently administered community-based services. Each attends

to a unique population with terribly limited resources, relying heavily on volunteers and donations.

Within the unit, a philosophy of compassionate care, of symptom management, of living while

dying. Outside of the unit, many unanswered questions about living and dying, for the hundreds of

persons who have no access to its resources. Socio-historical perceptions of dying and death

comprise part of the firewall, as does the lack of resources that keeps the number of palliative care

beds few and far between. Palliative care units themselves, however, may privatize dying by

confining the experience to a few beds, in a few institutions, effectively protecting the public, and

decision-makers, from exposure to it. It may in fact be argued that the unit is part of the epistemic

firewall.

A colleague's observation (Racher, personal communication, April, 2000), on reading an earlier version of Patty's story and my interpretation of it, supports this contention. In Racher's interpretation, the palliative care unit is a "closed shop". There has been so little turnover in staff over thirty years, that very few people have had the opportunity to experience palliative care, as Patty has, as a context for practice. There are, as well, comparatively few dedicated palliative units across the country, whereas virtually every acute care institution has a medical or a surgical unit. The meager number of beds allocated to palliative care further limits access to it as a specialized context of practice. What makes the unit strong may also be its greatest limitation.

My interpretation of Patty's life history exposes how an epistemic firewall may operate to delimit her nursing knowledge. Within the palliative care community, Patty is clearly recognized as an expert, a leader in the field. Her knowledge is affirmed and honored. Outside of the community she is frequently frustrated. Her expert knowledge is less well recognized because, as she herself has said, there is a perception that anyone can do palliative care since it consists only of "hand-holding". Lack of recognition of Patty's knowledge beyond the context of the palliative care community suggests it is not socially authorized. "For someone's knowledge ... to be recognized as knowledge, the knower must be socially authorized. If one lacks epistemic authority, what one knows about oneself is the very thing one is presumptively disqualified from speaking about" (Nelson, 1999, p. 90).

In my efforts to understand nursing knowledge, I am beginning to see an epistemic firewall that is much larger than that experienced by Patty and by nurses in palliative care. It is revealed in the predicament of nurses. When we attempt to articulate what and how we know, we encounter

a firewall of historical and societal expectations of nurses and of women. As Patty's knowledge of palliative care is less well recognized and accepted outside of the palliative care unit, nurses' knowledge is less well recognized and accepted outside of the specific clinical environments in which they work.

I draw your attention to events in Manitoba unfolding as I write these words. In 1988, members of the profession voted in favour of baccalaureate education as the standard for entry-to-practice. In 1998, the last diploma schools were closed and entry-to-practice education was centralized at one university. In March of 2000, in a unilateral decision that did not include consultation with the professional association or nurse educators, the Minister of Health announced a return to a twenty-three month diploma program, ostensibly to provide a quicker route to entry-to-practice, in order to deal with a perceived shortage of nurses.

In providing this example, I do not intend to further debate the respective merits of baccalaureate or diploma preparation. I have already drawn attention to some of the limiting features of baccalaureate entry as a professional-status seeking initiative. It is the non-consultative process of decision-making on which I wish to focus, as it demonstrates the firewall that continually challenges nurses. The knowledge held by teachers of nurses, about how new members of the profession are to be educated, is disregarded. The knowledge held by members of the professional association, about practices and trends in other parts of the country, is disregarded. The knowledge held by experienced nurses, about what is necessary to know in today's health care environment, is disregarded. The naturalizing function of the firewall claims that if diploma preparation was "good enough" for thousands of practicing nurses, it should

certainly be "good enough" now. The accumulated years of those experienced nurses' knowledge is thus, dishonored, and disregarded. The normalizing function of the firewall presumes a set of skills that can be trained into women in a reduced time frame. I make deliberate reference to women because this is another certainty of the firewall. It is women who are presumed to be willing to accept less education than any other health discipline, because we can all nurse. We are, after all, "innate carers". We need only to be trained in some specific skills and we will be able to undertake the role of a nurse; the care of other human beings at profoundly vulnerable times of their lives, at marginal wage, working under onerous and physically demanding conditions, 24 hours a day, 365 days a year. As Walker (1998) points out, "disabling economic and intellectual conditions" (p. 173) are less subtle elements of the firewall.

The example demonstrates that nursing knowledge, in palliative care or elsewhere, is marginalized and made invisible by a multi-faceted epistemic firewall. And, nurses, unfortunately, have had a role in its construction. We adopted a linear and simplistic line of reasoning; medicine's knowledge is not marginalized, therefore, if we construct ours in a similar fashion, it too will gain the recognition it deserves. This line of reasoning failed, however, to consider the historical and social context of the development of the medical profession, and implications of attempting to reproduce that development process in a different context. Further, many nurse academicians intellectually rejected aspects of nursing knowledge that did not fit assumptions of communicability and verifiability, that could not be understood, explained, or measured within the scientific paradigm. In doing so, we may have rejected precisely what makes nursing, and nursing knowledge, unique; our capacity, and privilege, to consider multiple ways of knowing in engagement with patients. We are not restricted, as physicians are, by diagnostic criteria and

prescribing protocols. We have the very great luxury of being able to authentically engage with patients, a luxury that provides us the capacity to individualize care, by acknowledging each patient as a human being that comes to us with a different understanding of the experience. We have not yet truly capitalized on this marvelous opportunity.

There is hope. Nelson (1999) suggests that counterstories "told by someone whose knowledge is socially authorized, ... may take on sufficient weight to penetrate the prejudices of the biased auditor" (p. 92). This thesis is a counterstory. In the telling and interpretation of Patty's life history, I have revealed aspects of nursing knowledge not previously represented in nursing literature. In revealing the life-informed and contextual nature of Patty's nursing knowledge, I challenge the status quo, and demand that conceptualization of nursing knowledge include consideration of the nurse in nursing, of nurses as knowers. I reach out to other nurses and suggest that each of us has an ontological and epistemological position, that we are all knowers and creators of knowledge, and that we must claim what, and how, we know before we can expect the "biased auditor" to hear our voices.

It may be easier to define nursing knowledge as objective, acontextual, and, therefore, readily transportable and applicable. This definition seems, almost certainly, to be the one applied by Manitoba's Health Minister in the recent decision regarding nursing education. This does not mean that nursing knowledge is, in reality, so narrowly defined. Acceptance of a broader definition, however, one that acknowledges the multidimensional, value and belief-laden, and life-informed nature of nursing knowledge, demands a facilitative practice context, and precludes the notion that "a nurse is a nurse is a nurse". It demands reconsideration of staffing and workload

strategies that move nurses throughout institutions with little or no regard for their specialized knowledge and expertise. It demands reconceptualization of programs of nursing education to acknowledge and honour the lives of students. It demands a fundamental shift in how we understand what it means to be a nurse.

CHAPTER EIGHT

Contemplating Life Experience: In Nursing Education

Current conceptualizations of nursing knowledge, while providing a wealth of information about its character and scope, do not explicitly recognize and affirm the nurse as knower. The contribution of a nurse's way of being in, and creating meaning of, the world, is fundamental to the creation of nursing knowledge, but is, unfortunately, not well represented in current nursing discourse. Failure to do so perpetuates a spurious distinction between nurses' personal and professional lives. It widens the chasm between knowledge that is verifiable and communicable, and the knowledge nurses use to nurse. It sustains a division between an academic elite and thousands of bedside nurses, not encouraged or supported, to "behold themselves as experts" (Maeve, 1994, p. 14). Its implicit acceptance, and explicit absence from our discourse, serves to cloud fuller understanding of what it means to know and how that knowledge is expressed.

How do I know when that patient's going to die and what do I do and things like that? And then, [it develops] into really knowing, and sitting down and relaxing, talking to patients and families and not feeling uncomfortable about it.

What does it mean to **really know**? How has Patty come to "mature and practiced understanding ... almost seamless performance" (Benner, Tanner, & Chesla, 1996, p. 143)? Our conversation reveals Patty's practice to be informed by life, and organized around the principles of suffering and responsibility, principles that are impetus for, and limiter of, action. But life-

informed knowledge is not the sole source of Patty's nursing knowledge. To this knowledge

arising in life experience, she adds her basic nurse's training, her further learning in administration

and education, and the knowledge arising in clinical practice. Patty also makes frequent reference

to her teaching knowledge. It is an aspect of her nursing knowledge which she recognizes

facilitated her career development, and of which she is justifiably proud. *I was qualified. I was*

teaching, which is what you need. Real knowing, then, is the knowledge Patty uses to nurse, and

without consideration of all of these, and other, aspects of her knowledge, understanding is

incomplete.

Critics of a conceptualization of nursing knowledge inclusive of life-informed knowledge,

may argue that its unique and idiosyncratic nature will lead to its being invoked as an

incontestable form of knowledge. This is a potential criticism that merits attention, but it is a

criticism of any way of knowing exercised in the absence of others. Focus on empiric knowing

alone could, for example, ground a preoccupation with cure and technological intervention. By

the same token, focus on knowledge arising in life experience alone could create a situation of a

nurse who believes that her experience, in and of itself, provides nursing knowledge and the

capacity to act. Each could be perceived as an incontestable form of knowledge.

Rubin's (1996) study of impediments to the development of clinical knowledge reveals

this notion of "patterns gone wild" (Chinn & Kramer, 1999), the dilemma of ways of knowing

exercised in isolation of one another. In Rubin's study, a nurse, herself a recovering alcoholic, is

described as leaving assigned responsibilities to care for a patient admitted for treatment of

alcoholism. The nurse sees nothing wrong with what she did, perhaps believing that her life

experiences enable her to contribute something unique and important to the patient's care. Rubin interprets her actions as an indicator of a lack of clinical knowledge. My perspective is somewhat different. I see the nurse's life experience informing her nursing knowledge in a manner that she views as acceptable, and others view as lacking. I also see, in this instance, evidence of "patterns gone wild", wherein the nurse acts on life-informed knowledge in a manner that is not responsible or particularly mindful.

This is not the case with Patty, and with other nurses who might be described as engaging in seamless performance. I have shown in my interpretation of Patty's life history, that she does not heedlessly act on any aspect of her knowledge in the absence of consideration of others. In her descriptions of practice experiences, and there were many more than I was able to relate, she repeatedly comes back to her organizing principles of suffering and responsibility. They are the primary impetus for her nursing care. Further, no one experience of life stands out for her. She does not rationalize a particular nursing intervention on the basis of a particular experience, as the nurse in Rubin's (1996) example seems to do. And yet, on reflection in our conversations, Patty is clear that she is aware of how her experiences contributed to her human journey, to who she is as a person. She repeatedly links who she is, to how she engages with patients, in innumerable phrases and comments:

what is more important [than clinical skills] *is your attitude and your insight and how you behave towards patients:*

I've been through difficult times but I think at this point in my life now I don't

behave as if I can identify with it. I behave because I think it's become a part of

me;

you can't treat people all the same. You deal with them according to who they

are, how they react to things. It's a matter of understanding where they're coming

from;

what it [referring to having seven siblings] *has helped is the ability to get along*

with people and work together.

and ultimately. this. from our fifth conversation. *I know who I am, what I am, and what I'm*

doing.

This is not pride or arrogance. This is not resolute insistence that her way of knowing is

the "right" way. This is a way of being in, and creating meaning of. the world, that arises over a

lifetime, a lifetime that includes clinical, **and** non-clinical, life experiences. It is a well established

and articulated personal ontology, expressed as nursing knowledge. Patty's day demonstrates the

consistency with which this happens. She is frequently observed explaining to others, how and

why she engages with patients as she does. It causes her frustration to have to explain and

reexplain why she does, as she does. It causes frustration to those who perceive her to be stalling

or gate-keeping access to the unit. witness the nurse who circumvents process and jumps directly

to the physician for admission. But Patty perseveres and has for 20 years. It is after all *how we suffer with patients*.

What does affirmation of Patty's way of being, as fundamental to the construction and expression of her nursing knowledge, mean for nursing in general, and for nursing education in particular? What can we learn from this exploration of a nurse's life? When I set out on this endeavor I was determined that my work would have pragmatic validity (Kvale, 1995), that there would be clear evidence of its usefulness for myself, for Patty, for other researchers, and for palliative care nurses. Sparkes (1994) says that life history goes beyond "giving voice", beyond examining experience within existing perceptions, to opportunities for all to think differently about events of life, a concept similar to that which Lather (1986) calls catalytic validity. For Lather, catalytic validity refers to "the degree to which the research process re-orients, focuses [sic], and energizes participants" (p. 67).

A fundamental premise of this thesis is that knowledge arises in human interaction, *inter* the *views* of participant and researcher, and *inter* the *views* of author and reader. The thesis has pragmatic and catalytic validity if, in fact, this does happen; if knowledge that energizes, re-orients, and focuses, is created when someone reads my interpretation of Patty's life history. There are several ways in which this might come about. To begin, readers of the thesis, are exposed to a portrait of nursing knowledge, unlike others currently available in nursing literature. Patty's life history is similar to clinical portraits constructed by Benner (1984); Benner and Tanner (1987); Benner, Tanner, and Chesla (1992, 1996); Maeve (1994, 1995, 1998b); and Perry (1998), in that it reveals how Patty conducts her nursing practice, how she suffers and acts with patients.

Her life history is different, in that it also reveals Patty as a human being, an individual **beyond** the domain of clinical practice and practice experiences. Contemplating Patty's life in this way illustrates that her nursing knowledge is an expression of who she is, an expression that includes an identifiable "body of knowledge", and much more.

Further, the thesis identifies an element missing from clinical portraits. It is a portal into the life of a woman who nurses on a particular palliative care unit, "an entryway, through which the author and reader might understand a culture different from their own" (Tierney, 2000, p. 545), and through which they might differently understand their own culture. The examination of the context of Patty's practice, and how that context supports and constrains her capacity to express her knowledge, is a critical point of this inquiry. Nurses who read Patty's life history may see something of themselves in it because aspects of the story resonate for them: relationships with patients, colleagues, or the health care system. Introspection and reflexivity might follow, a process of critical consideration of "something not thought of before". These same nurses may also think, however, that something is missing: that some critical, contextual feature, relevant to their practice, has not been fully elaborated. This is to be expected. Patty's life history is illustrative. It is not intended to illuminate every possible contextual element that informs the nursing profession. It is intended, through description and analysis of contextual features relevant to Patty's and my experiences in, and out, of nursing, to perturb and provoke: to encourage others to think critically about how their knowledge is life-informed, and about how expression of that knowledge is delimited by the context of practice. Every reader will understand context differently, because every reader brings a different contextual lens. In this way, catalytic validity is

assured. Knowledge is re/created every time the thesis is read, or a conversation about it takes place.

Nursing Knowledge and Nursing Education

Nurses' education provides multiple opportunities for consideration of life-informed and contextual knowledge. Educators must support and encourage students to tell the stories of their lives, and to reveal, and critically reflect upon, the knowledge inherent in those stories. Clinical stories are already well accepted. "Our stories of experience can give others an inside-out view of the fires that have forged our beliefs, our caring, and our practices" (Baker & Diekelmann, 1994, p. 68). Rubin (1996) states, "within the narrative account lies the possibility of understanding in a new way the whole of a nurse's concerns, practical knowledge, forms of engagement, and forms of reasoning in action within the practice" (p. 361). Stories of our lives, and the contribution of who we are to the development of nursing knowledge, can, and should be, equally well accepted. "We are [after all] telling the story of who we are, what are fears are, what our successes and failures are like, what we wish for, how we resolve conflicts, how we care, and how we create practice knowledge" (Maeve, 1994, p. 14).

It is the story of Patty's life that is the window to her nursing knowledge. I would not have been able to reveal the life-informed and contextual nature of her knowledge without constructing her portrait. Boykin and Schoenhofer (1991) argue for storytelling as a link between nursing practice, ontology, and epistemology. For these authors, storytelling is intimacy and distance, "intimacy in that the self as person is involved, and distance in that the method encourages the use of alternating rhythms, moving from a personal view to a broader one of

putting the event into another or new perspective" (p. 246). This is, precisely, what life history method has enabled me to do. In my search to understand Patty's unique and particular ontological and epistemological perspectives, I have come to different understanding of nursing knowledge, of its origins within the knower, and its expression within a web of contexts that both support, and constrain.

Patty's story demonstrates that stories of lives are not merely solipsism. "Unless nurses understand and comprehend their own uniqueness, they cannot admit and respect the uniqueness of each individual. ... This kind of knowledge ... emerges through life and is addressed through inner experience and self awareness" (Rutty, 1998, p. 246). Patty has engaged, on her own, and in conversation with me, in developing inner awareness. Clinical stories alone cannot illuminate this awareness. Patty's clinical stories, as with those of the nurses in Maeve's (1998b) study, are consistently interwoven with stories of her own life. It is, therefore, imperative to reveal stories of life, in order to authentically and honestly represent nursing knowledge.

Stories of lives reveal one aspect of life-informed knowledge, its genesis. To challenge the inevitable critics, however, we must go beyond the sharing of stories to critical analysis of knowledge created in the telling, and of how that knowledge informs practice. Cole and Knowles (2000) refer to this as reflexive inquiry. In my teaching I call it reflexive practice, an ongoing and lifelong commitment to examining how experiences of life contribute to and inform, knowledge and practice. Reflexive practice is distinguished from reflection-in-action or reflective practice, described in nursing literature and arising in the work of Schön (1983), by its broader commitment to examination of the context of life and practice. It is "reflective inquiry situated

within the context of personal histories in order to make connections between personal lives and professional careers, and to understand personal (including early) influences on professional practice" (Cole & Knowles, p. 2). It is interesting to speculate on how different Rubin's (1996) example might have been, had the nurse in question been enabled to reflect on her own experiences of alcoholism. Understanding how these life experiences informed her nursing knowledge in a particular way, might have re-framed how she expressed that knowledge in her nursing practice.

Reflexive Practice

I think that I have been engaged in a reflective process for approximately 10 years. I use the term "reflective" rather than "reflexive" because I do not believe I have undertaken the depth of critical analysis of self and context, implicit in the latter term. Throughout the development of this thesis, however, and in my conversations with those who have supported that journey, and with Patty, I have begun to see how, and why, reflexivity might be incorporated into my teaching. I am now increasingly committed to creating learning spaces in which students reflect on who they are, on how their ontological perspectives inform their nursing knowledge, and, on how the expression of knowledge is delimited by the situation of nursing.

Consideration of self and context is now fundamental to all aspects of my practice and teaching. I can no longer separate who I am and how I nurse, nor do I expect students to do so in the classes I am privileged to teach. The concept, and practice, of reflexivity is, therefore, part of the three undergraduate courses I teach on an annual basis; an introductory methods course, a nursing philosophy course, and principles of palliative care. In the methods course, some

questions that direct our conversations, include: How does who I am, inform how I know nursing, and consequently, how I enter into the conduct of research? How are the questions I ask, and the methods I use, informed by the manner in which I know? Are my methodological choices consistent with my ontological and epistemological frames? Consideration of the centrality of self, in this case, in the conduct of a research inquiry, is facilitated by small group work, and an assignment in which students articulate their partiality for a research tradition, in the context of a topic of interest.

In my own and other baccalaureate programs, the course that explores nursing philosophy and theory has historically focused on "formal" nursing theorists. Students have studied each theorist's understanding of nursing and, usually in a seminar or written form, have been expected to discuss how a given theory might organize their nursing practice. I have revised the course in a way that, as with the research methods course, provides students an opportunity to explore their own ways of being and knowing nursing, and subsequently, to examine how their theoretical perspectives might be informed by other theorists, in nursing, and in other disciplines. The focus is now on concepts of "micro and macro" theory (Cole & Knowles, 2000, p. 10).

Micro theories are personal and contextual. Cole and Knowles (2000) call them particular and idiosyncratic. Macro theories are formal, global theories, the "recognized" theories of the discipline. In the past, students have attempted to "fit" their ways of knowing nursing into those of others. By first focusing on personal conceptualizations of nursing, students are supported to consider the centrality of self. The works of others, then, inform, rather than determine, students' knowledge of nursing and how it is expressed.

Reflexivity is front and center in the palliative care course. This is consistent not only with my ontological and epistemological perspectives, but with current thought regarding palliative care education (Burucoa, 1993; Copp, 1994; Wylie, 1997). "Before health care workers can help others, they need to find answers for themselves. Only then can they walk the journey with fellow humans" (Wylie, p. 47). Repeated calls for understanding of the contribution of self to palliative care practice, in particular, and nursing practice, in general, establish a critical need to adopt a constructivist epistemology in nursing education. As Peters (2000) states "significant knowledge bases from life experience should be tapped, used, and expanded" (p. 171).

My own efforts to understand who I am, and how experiences of my life inform my nursing knowledge and practice, have been initiated late in my nursing career. I recently celebrated the 25th reunion of my graduating class. These efforts have been undertaken, in part, in a search for resolution to my frustration with the nursing profession. I propose, herein, that if a reflexive process were introduced into nursing education, we might see less of the negative professional images described earlier. It is my sincere hope that as students, and practicing nurses in post-diploma programs, learn to claim what and how they know, they too, will write counterstories. It is my hope that those counterstories will challenge the status quo, both in nursing academia, and in the assumptions about nurses and nursing that motivate decisions by "biased auditors". In this final section, I present an outline of how this journey might be undertaken.

Knowledge Creation through Self-directed Professional Development

"Knowledge cannot start from nothing-from a *tabula rasa*-nor yet from observation. The advance of knowledge consists, mainly, in the modification of earlier knowledge" (Popper, 1965, p. 28).

Nursing students, and nurses who are students in post-diploma programs, do not arrive in classrooms without knowledge of what it is to be human, to interact with other human beings in times of joy and sorrow, in harmony and stress, or during experiences of crisis and recovery. They have encountered, in similar and dissimilar ways, a multitude of experiences of life, that inform how they know, and will come to know, nursing. This knowledge, by its very nature, demands that we attend to it, not once, but on an ongoing basis over the course of our nursing careers. What is necessary for this to take place, is assumption of a lifelong commitment to self-directed professional development, responsive to the overarching question,"Who am I as nurse?"

Ongoing attention to knowledge arising in life experience, and how it informs our nursing practice, is supported by reflexive practice: initiatives directed toward understanding self, and understanding self in relation to context. Cole and Knowles (2000), in exploration of teacher development, propose a variety of approaches that can readily be adapted to nurse development. Understanding of self is facilitated through personal history, or autobiographical inquiry, journal writing, and artistic expression. Understanding of self, in relation to context, is facilitated through critical examination of the setting of practice, and of the broader context within which it is located.

Personal histories, "stories of life and experience that have influenced personal-professional understandings" (Cole & Knowles, 2000, p. 27), focus students on consideration of how their lives and practice are interrelated. The histories, along with journals, may take a chronological approach, or be centered on significant events. Either way, the writing is labor intensive, and intensely personal. Heinrich (1992) suggests, and it is my experience, that some students already have a certain level of comfort with the notion of writing about their lives, for example, those who keep diaries. Others may feel overwhelmed, both by the magnitude of the task, and by concerns about sharing intimate details of their lives with a reader.

Student, and faculty, reservations about personal history writing can be acknowledged and honored in several ways. Class time must be set aside for writing. Heinrich (1992) advises students to become "ritualistic", to set aside a time of day and place for writing. I agree, but also believe that students may be less likely to accept any kind of reflexive writing process as fundamental to self-development, if faculty are not prepared to place it front and center in their classes. Students can also be directed, through pertinent questions that reflect course objectives, to focus on particular events of life. The following, adapted from Cole and Knowles (2000), are some of the questions that direct students' autobiographical writing in the nursing philosophy course:

1.   Why did you become a nurse?

2.   What values and attitudes toward health and well-being were expressed in your family? How have these influenced your thinking and practice?

3.   Recall significant experiences or relationships you may have had (inside and outside health

care contexts). What were the contexts? Why do these event stand out for you? How have

these experiences or relationships influenced your thinking and practice?

In response to these, and similar, questions, students have shared powerful and poignant

stories, stories of life-threatening illness; of encounters with nurses that left indelible impressions;

of overwhelming life tragedies; of significant others, especially mothers, who were nurses; and, of

lifelong aspirations to "care". In many cases, they are surprised when they recognize the extent to

which their knowledge is life-informed. As is the case with Patty, students are not overtly

reflecting on life experiences in each and every encounter with patients, yet the process of

critically considering the juxtaposition of life and practice, clearly reveals to them how their lives

and practice are entwined.

Students do not necessarily have to submit their writing in its entirety, or in the same

format in which it is generated. In the nursing philosophy course, class writing time is dedicated to

private journal entries. Journal entries are then summarized into a personal philosophy of nursing.

Quotations from the journals may, or may not, be incorporated, at the student's discretion. I also

encourage students who struggle with the writing process to consider alternate forms of

representation. I await the day when a student will submit a personal theory of nursing articulated

as a poem, or a painting, or in metaphor and story. As Gadow (1990) vividly writes "participation

in vulnerability, one's own and another's, and attempts to alleviate it, are experiences. They are

encountered in only one way, living in the country that is nursing. They are communicated in only

one way, in personal accounts of exploration, in narrative, poem, dreaming, song, – in other

words, story" (p. 14).

Practice contexts, and how they support and constrain the expression of knowledge, are

the other aspect for consideration in ongoing professional development. Observation,

conversations with colleagues, and review of "artifactual data" (Cole & Knowles, 2000, p. 91) are

opportunities for critical reflection on the impact, extant and potential, of contexts of practice. I

have already noted White's (1995) critique of the lack of attention to context in Carper's (1978)

typology. In development of the sociopolitical pattern of knowing, White draws attention to

broad socio-political factors that influence, as seen in Patty's story, a nurse's capacity to express

all aspects of her nursing knowledge in practice. Chopoorian (1986) challenges us to consider

social, political and economic influences on both nurses, and the people for whom they care.

Issues of class, gender, racism, sexism, ageism, and power, among others, which affect health, and

contribute to illness, are absent from theoretical discourse and practical application. And Schuster

(1992), in a treatise on environmental ethics and nursing, states that "nursing theory does not

describe adequately the concept of the environment and that almost all nursing research

conducted in the domain of environment involves only the immediate milieu of the patient, family,

or the nurse" (p. 5).

As with seeking understanding of self, understanding of self in relation to context,

necessitates lifelong commitment. Changes in a nurse's immediate practice environment cannot be

fully understood unless examined in light of broader paradigmatic and societal shifts. Palliative

care, for example, as a specialized context for practice, may always be informed as much by our

beliefs about living and dying, as it is by access and availability of resources. As such, it is

imperative to be as fully aware as possible of these varied beliefs, and how they might delimit

nursing practice in a palliative care setting.

Concluding Thoughts

The women and men who seek to become nurses, and those who are nursing and pursuing

post-basic education, hold vast, unarticulated, reservoirs of knowledge, that inform how they

know nursing, and therefore, how they practice their art. It is no longer acceptable to assume that

who they are can be held to one side, at arm's length, where it will have no impact on their

nursing care. This thesis demonstrates that knowledge arising in nurses' lives can, and does,

inform nursing knowledge. Furthermore, the thesis demonstrates that the expression of nursing

knowledge is delimited by complicated, yet essentially unexamined, contextual forces.

The thesis is a beginning. It draws our attention, through representation of two nurses

lives and practice-in-context, to life-informed and contextual knowledge as aspects of nursing

knowledge. I do not, however, claim to have fully characterized either. Further inquiry is

necessary. I suggest this inquiry be, in part, directed toward two broad areas of exploration:

(a) the infrastructure of nursing knowledge development; and (b) the gendered nature of

relationships within the health care system.

Several points regarding an infrastructure of nursing knowledge development, other than

the historical, professional-status seeking context discussed herein, merit further consideration.

First, nursing knowledge development in Canada has followed, not only a medical model, but also

a predominately American model. American nurses, in part due to their larger population, have had access to graduate education for approximately 20 years longer than Canadian nurses. Many of Canada's nursing pioneers undertook their graduate education in the United States in the 1950s and early 1960s, and, given continued, limited access to doctoral programs, Canadian nurses still seek graduate opportunities there. The impact on knowledge creation, of a differently-oriented health care system, has yet to be explored.

Second, Canadian nurses have, for many years, been subject to differential access to research funding. Again, the bio-medical model predominates, and nursing research designed to examine questions of knowledge development, of human relationship, and of concepts such as suffering and responsibility, have met with resistance. Nursing literature abounds, in fact, with discussion of how research grounded in a qualitative paradigm, might be differently articulated to meet requirements of scientifically-oriented funding agencies. Limited access to research funding seriously undermines the capacity of the discipline's members to explore their own questions, relevant to the development of nursing knowledge.

Third, nurse educators, not unlike educators in other disciplines, are embracing distance education modalities as opportunities to increase access to, and flexibility within, nursing programs. The move toward "virtual universities" demands critical examination of the implications of these alternate learning and teaching strategies for knowledge development. Understanding of, and commitment to, lifelong reflexivity in practice, is difficult enough to conceive of. How might it be represented to students who engage with teachers and classmates, in very different ways than we have previously considered.

The gendered nature of relationships within the health care system is introduced in this thesis. It is discussed, however, from a particular perspective, that of two female nurses, privileged by education, by class, and to some extent, by gender. Nursing is a predominately female profession, and while female nurses may experience oppression within the health care system as a whole, within the nursing profession they are the majority. What is the experience of male nurses? How is it similar to, or different from, the experience of female nurses? Or, can it even be conceptualized in terms of similarities and differences. Perhaps male nurses' experiences need to be examined, in and of themselves, in order to enhance our understanding of life-informed knowledge. Life history method, as a relatively new method of inquiry for nursing, could play a significant role in further developing our understanding.

And so, the portraits of nursing knowledge revealed in this thesis are a portal to the complex, multi-faceted milieu of nursing knowledge. Efforts to explicate just how complex have resulted in members of the profession investing time and energy into articulating the "core" of nursing. In doing so, we have focused on process, on the act of caring. We have failed to consider that it is what we know that is the core of nursing, and we have failed to critically examine how expression of our knowledge is contextually informed and delimited. As such, our current portrait of nursing knowledge is one that does not reveal its richness and depth. The "core" of nursing, is nurses, who we are and what we bring to each and every encounter with other human beings. My challenge, then, to readers of this thesis is that you affirm the centrality of the nurse in nursing, accept the position of nurse as knower, and re/construct learning and practice environments that facilitate the expression of nurses' knowledge in a manner that will, ultimately, only benefit those to whom our lives have been committed.

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APPENDIX A

Since we last met, I have undertaken a doctoral program in adult education at the Ontario Institute for Studies in Education of the University of Toronto. I am now in the thesis phase of my journey and invite you to participate with me in my study. The goal is to enhance understanding of nursing knowledge by illuminating that knowledge which arises in life experiences outside the realm of clinical practice.

I come to this research as a nurse who believes that knowledge arising from cumulative experiences of life is a part of nursing knowledge. When we meet, and to give you a better sense of my interest, I can share with you some of my life experiences that I believe contribute to how I know nursing. I also come to this research having spent the majority of my 23 year career in palliative and long-term care nursing. From our conversations when you acted as preceptor for one of the students in our program, I consider you to be deeply committed to your practice as a palliative nurse clinician. I see our common interest in palliative care as a point of connection from which our discussions can "take off".

Life history method will be used to stimulate discussion about your life and nursing practice. I would like to observe you in your practice and have opportunities to discuss these observations. The observations are intended to illuminate the significance of your practice environment for the expression of nursing knowledge and, as such, are non-evaluative. As well, I hope to explore other materials, such as, photos, journals, or other documents you think might help me to gain insight into who you are as a nurse. I am mindful that while I have specific

objectives related to the research and thesis process, this is your life. I am committed to this journey being shared and collaborative, each of us respecting the other's concerns.

I expect this phase of the research to be lengthy, lasting, perhaps, six to eight months, during which time I will travel to meet with you. I would like to conduct three to five interviews of one, to one and a half hours, duration, and observe your practice as many times as we are able to negotiate, allowing time afterward to talk and share our thoughts. Life history interviews are directed toward developing a picture of meaningful events in your life. I suggest we might begin with a lifeline which you create before the first interview.

If you are interested in further exploring participation and want more information, I would be happy to send you a copy of the proposal for review. I expect we will talk further and I will answer your questions as I am able.

Sincerely

Renee Will

APPENDIX B

I, _____, agree to participate in a research study conducted by Renee Will,

a doctoral student at the Ontario Institute for Studies in Education of the University of Toronto. I

understand that this study comprises Ms. Will's doctoral thesis.

I agree to:

- participate in three to five life history interviews of one, to one and a half hours, in
  duration

- allow the interviews to be audio-taped and transcribed

- allow observations of my clinical practice at times which are mutually agreed upon

- participate in interviews regarding my clinical practice, the number of interviews to
  be determined by the number of observations

- contribute to the development of understanding of my life experiences and nursing
  knowledge by actively participating in review of transcripts and documents

I understand that:

- ongoing discussion about the process and content of the study will take place
  between Ms. Will, her thesis supervisor, Dr. A. L. Cole, and members of her
  committee: Dr. J. G. Knowles, and Dr. H. Maclean.

- participation in this research can benefit me by providing a venue for sharing about
  my nursing practice and through possibilities for learning which arise from this
  experience

- the anticipated completion date of Ms. Will's thesis process is December, 1999,

  and that it may be necessary to continue our contact for the duration of that time

- I reserve the right to withdraw from this study at any time.

_____   _____

Date   Signature