

Daughters Caring for Dying Parents: A Process of Relinquishing

Trudy Read

Western Health

Judith Wuest

University of New Brunswick

Caring for elderly, dying parents is challenging for daughters as they try to balance other obligations and responsibilities. The purpose of this grounded theory study was to explain the domain of daughters' caregiving experiences in Newfoundland and Labrador, Canada. The primary author interviewed 12 women whose parents had died. Three types of turmoil (emotional, relational, and societal) emerged as the central issue for these women. The authors discovered a substantive theory of Relinquishing with interdependent processes of Keeping Vigil, Navigating Systems, Facing Loss, and an end process of Coming to Terms. In moving through the process of Relinquishing, social conditions of personal ideals, family expectations, and societal demands determine strategies employed by any one daughter to manage her turmoil. The findings fill a gap in knowledge related to daughters' caregiving for dying parents by contributing a theoretical framework that will inform women, health care providers, researchers, and health policy makers.

Keywords: *daughters; parent care; grounded theory; relinquishing; vigilance*

Families have traditionally depended on women, particularly spouses, and daughter or daughter-in-law support, for management of health, and acute and chronic illness (Brody, 1990; Parsons, 1997; Wuest, 1995, 1998). In our study, we focus on the experiences of daughters as caregivers to dying elderly parents. Attention to family caregiving has increased with the escalation of situations in which the impaired or chronically ill elderly are taken care of by family members in the community (Brody, 1990; Pepin, 1992). With shorter hospital admissions and the resultant pressure on community-based care, families are expected to assume major responsibility of care of its members at home (Boland & Sims, 1996; Faison, Faria, & Frank, 1999; Jutras & Veilleux, 1991; Pepin, 1992; Rutman, 1996). Although care has moved from institutions to

communities, the rather slippery notion of community care tends to mean unpaid care sustained by families (Aronson, 1991; Jaffe & Blakley, 2000). Most Canadian informal caregivers aged 45 to 64 are looking after their parents (67%) and their spouse's parents (24%) (Stobert & Cranswick, 2004). In Canada, women dominate the field of informal care for seniors, with 55% of women looking after an elderly parent (Frederick & Fast, 1999). Although middle-aged caregivers are just as likely to be men as women, the women spent almost twice as much time per month in their caregiving tasks, at 29.6 hours compared to 16.1 hours for men (Stobert & Cranswick, 2004).

There is a fundamental acceptance in our society that parent care is a woman's role (Brody, 1990; Donorfio & Sheehan, 2001; Gage-Rancoeur & Purden, 2003). Demands on formal and informal health and social services are increasing as the population ages. Thus, people, especially women, caring for elderly relatives, who provide practical help and often invisible emotional work, are a potentially vulnerable population, particularly in rural areas. We need to learn how better to recognize and meet their needs in a way that enhances the well-being of both providers and recipients of care (Aronson, 1991). Despite the prevalence of daughter caregiving, little is known about the impact on the lives of women when a parent is dying. In this article, we provide a grounded theory that illuminates daughters'

Authors' Note: We are appreciative of the daughters who shared their parent caregiving experiences and wisdom. The primary author is grateful for the financial assistance provided by the University of New Brunswick Research Assistantships, and the Association of Registered Nurses of Newfoundland and Labrador for a graduate scholarship. Thanks to Rev. Dr. Tony Newell for your insight and editing of earlier versions of this work. Appreciation is extended to the University of Ottawa 2006 Summer Research Interns and Dr. Nancy Edwards, CHSRF/CIHR Nursing Chair (Multiple Interventions for Community Health Nursing), for valuable feedback and support in shaping this article.

experiences and challenges associated with providing care to a dying parent.

Background to the Study

Economic changes in Newfoundland and Labrador (NL) and the closure of the cod fishery resulted in many adult children working and living many kilometers away from their aging parents. Currently, the province's fertility rate is 1.3 children per childbearing-age woman, the lowest in the country and well below the 2.1 rate required to maintain population in the absence of out-migration. In the near future deaths are expected to outnumber births for the first time in the province's history. As a result of out-migration among young people and the aging population, the island's population has aged much more rapidly than any other Canadian province over the past 30 years (Government of NL, 2005). An older population is inclined to use more health services than a younger one. Thus, shifting demographics will alter the needs of rural areas and present challenges for the public sector and primary health care services.

As people experience the loss of traditional family structures, women who could potentially have cared for ailing parents might live in distant communities, diminishing the supply of informal caregivers available to assist dying parents. It is in this context that the primary author became interested in the challenges experienced by women caring for dying parents while balancing other life roles and demands.

Review of the Literature

Family caregiving has been identified as women's work (Brakman, 1994; Brody, 1990; Rutman, 1996; Zukewich, 2003). In a 1998 General Social Survey, data on time use indicated that women aged 25 to 44 provided nearly 40% of informal care to families in Canada (Zukewich, 2003). Caregiving labor is divided along traditional gender lines, with women adopting housekeeping and helping with personal care and men tending to perform tasks of household maintenance and transportation (Stobert & Cranswick, 2004). Women's work in providing personal care is more likely to consist of bathing, dressing or feeding, and in-home care such as meal preparation and cleaning. Midlife women have been dubbed the "sandwich generation" as they are often caught between the conflicting demands of

raising children and caring for aging parents and other relatives (Williams, 2002). Finally, informal caregiving in 1998 was calculated to be worth \$50.9 billion if parallel services were purchased on the Canadian market, slightly more than the value of labor income generated by the health care and social assistance industry (Zukewich, 2003).

Research has focused on examining women's care of parents during chronic illness but falls short of describing care when a parent is dying (Allan, 1988; Brakman, 1994; Brody, 1990; Gage-Rancoeur & Purden, 2003; Jutras & Veilleux, 1991; Pohl, Boyd, Liang, & Given, 1995; Wuest, 2000). It is widely recognized that adult children, especially daughters and daughters-in-law, are often involved in caring for and tending to the needs of their elderly or infirm parent(s) (Allan, 1988; Brody, 1990; Jutras & Veilleux, 1991; Pohl et al., 1995; Raveis & Pretter, 2005). Society, culture, and religious traditions enforce the predominance of adult daughters and daughters-in-law as caregivers (Brakman, 1994; Ward-Griffin, 2004). Research of concepts of dutiful daughters and filial expectations and responsibilities in the context of societal expectations for women has shown that women often stretch themselves to the breaking point to provide care (Aronson, 1991; Brody, 1990; Donorfio & Sheehan, 2001; Lewis & Meredith, 1988). The willingness of daughters to care for their parents has been influenced by a feeling of responsibility and moral duty as a core motivation, and for a sense of reward in providing care or to reduce guilt for not "caring." Intrinsic rewards have been identified as a feeling of closeness to the care recipient and as a repayment of some other aspect of care they have received from others and from life, such as repaying mothers for past sacrifices on their behalf or simply for having raised them as children (Geister, 2005; Lewis & Meredith, 1988; Stobert & Cranswick, 2004).

Research on daughters providing care to their dying parents is scarce and often subsumed in broader studies of women's caregiving. For example, studies of family caregiving have provided some insight about caring for relatives with dementia and Alzheimer's disease (Bedard, Koivuranta, & Stuckey, 2004; de la Cuesta, 2005; Parsons, 1997; Wuest, Ericson, & Stern, 2001) and outcomes for families of patients with cancer (Gaugler et al., 2005; McMillan, 2005; Stetz & Brown, 1997). Other research has resulted in explanations of women's broader caregiving experience. Wuest (1995, 1998, 2000) delineated proactive strategies that women used to manage competing and changing family caregiving demands.

Others have investigated balancing parent care with other roles (Stephens, Townsend, Martire, & Druley, 2001), nurses as double-duty caregivers of elderly relatives who negotiated personal and professional boundaries in their paid and unpaid work (Ward-Griffin, 2004), the existential plight of daughters following their mother's breast cancer diagnosis (Raveis & Pretter, 2005), and the process of caregiving as a daughter of a cardiac patient during hospital admission and postdischarge (Gage-Rancoeur & Purden, 2003). Others have focused on employment decisions of daughters and daughters-in-law during parent care (Pohl, Collins, & Given, 1998). Despite this accumulating body of knowledge about women's caregiving, and specifically caregiving by daughters, little is known about daughters' caregiving for dying parents.

There is evidence that rural caregivers, compared to urban caregivers, might experience a heavier workload and have special needs in maintaining their own health. Rural caregivers, who have fewer accessible formal supports, limited social resources, and geographic dispersion from neighbors, might experience feelings of isolation (Bedard et al., 2004; Jaffe & Blakley, 2000). The resulting greater reliance on informal supports provides further impetus to examine the needs of daughter caregivers in rural Newfoundland and Labrador.

The driving force for this study, then, was the paucity of literature available to policy makers and clinicians about the experience and process of daughters' caregiving for dying parents. Our goal in embarking on this study was to develop an explanatory theory that would inform policy and practice related to women facing the challenges of caregiving for a dying parent, with particular relevance for those situated in rural or remote communities.

Method

We used grounded theory to understand the complex array of phenomena that influence daughter caregiving experiences and the meaning of those experiences for the women. The goal of grounded theory, a method developed by Glaser and Strauss (1967), is the discovery of dominant social and structural processes that account for most of the variation in behavior in a particular situation. In grounded theory research, the goal is to generate a theory that explains how the central problem in the study domain is resolved, solved, or processed (Glaser, 1978). The design is emergent; that is, initial data are coded and compared for themes and

concepts that, in turn, guide future data collection. Through constant comparison and theoretical coding an explanatory framework is developed.

In grounded theory, the process of data collection is guided by the emerging theory, and "the analyst jointly collects, codes, and analyzes data and decides what data to collect next and where to find them" (Glaser & Strauss, 1967, p. 45). Recruitment took place through distribution of letters and a poster about the study to informal bereavement support groups, church groups, nurses, clergy, and women involved in palliative care public awareness in a mainly rural region in Newfoundland and Labrador, Canada. Some participants were recruited through word of mouth as women who were caregivers became aware of the study. The first author interviewed 12 women for this study who ranged in age from 34 to 66 years at the time of their parents' deaths. Daughters and their parents lived in communities with populations ranging from 35 in a fishing outport to 20,000 in an urban area. The average age of the daughters was 50 years at the time of the study, and each had cared for a dying parent prior to the interviews. Although all who were interviewed cared for a parent, the women also shared experiences of caring for other loved ones who died, including a grandmother, husband, friend, and aunt. Half of the daughters had lost both parents. The ages of the parents and other relatives ranged from 57 to 99 years (average age of 80). In total, deceased caregiving recipients involved nine mothers, seven fathers, one grandmother, one aunt, two husbands, and one friend. More than 20 caregiving experiences were relayed to the researcher. The medically diagnosed conditions of the dependents included diabetes, cancer, heart disease and stroke, arthritis, and chronic renal failure.

At the time of caregiving, 9 daughters were employed outside the home. Two were full-time unpaid caregivers at home, 1 caring for a disabled adult child and 1 for a chronically ill elderly parent other than the dying parent. Two participants worked part-time, and 7 were employed full-time; 1 was retired. Types of work varied and included secretarial, nursing, administration, entrepreneurial, custodial/janitorial, fisherperson, and receptionist. Participants had children ranging in age from infancy to the 40s at the time their parent was dying; some had no children. All of the women were English-speaking Whites.

We coded data and used a constant comparative method of data analysis to identify similarities and differences across participant data. We continuously asked, "What is going on here?" Data were moved to

a conceptual level to construct developing theory using theoretical sampling and theoretical coding (Glaser, 1978). Theoretical sampling was achieved by going back to previously collected data, through second interviews with participants, and seeking out participants with varying duration and types of caregiving experiences, such as caring for relatives other than parents. Selective sampling of relevant literature was used to support emerging theory (Stern & Pyles, 1985). The researcher was acknowledged as an interacting participant who was not viewed as a detached observer as in quantitative research (Clark, 1997). Ethical approval was granted from the University of New Brunswick, Faculty of Nursing Ethics Committee, and the local health care organization.

Confidentiality, anonymity, and the rights of participants were protected, and the women were not knowingly exposed to health risks during the study. The primary author explained that participation in our study might not benefit the participants, and they were advised they could withdraw from the study at any time; none did. All of the women were eager to help advance the “system” as they experienced it and disclosed their hope that their participation might lead to improvements for future daughter caregivers. The women voiced emancipatory remarks that although it was emotional, it was good to talk about their experiences: “I’ve never told anybody all these feelings before, it feels good to talk about it”; and “I didn’t think I had much to say, but the flood waters have opened up—it’s good to remember them [parents] like this.” The primary author remained cognizant of the emotional responses that discussion about recalling the caregiving experience might evoke and made follow-up phone calls to the women a few days after the interview. A social worker was available to the women if there was need for further follow-up, but none availed of this opportunity.

Results

We discovered the anticipated loss of a parent creates Turmoil that is emotional, relational, and societal. The theory of Relinquishing provides an explanatory framework for how daughter caregivers manage the challenge of Turmoil. Relinquishing is a process of daughters’ gradually letting go of a lifelong relationship, as they have known it with their parents, while adjusting to a new reality in a changed family structure. As shown in Figure 1, it is through Keeping Vigil, Navigating Systems, Facing Loss, and Coming to

Terms that a daughter learns to live with her parent’s death. How any one woman moves through the process of Relinquishing depends on personal ideals about her role, her family’s expectations, and the demands of her multiple roles, which we called societal demands.

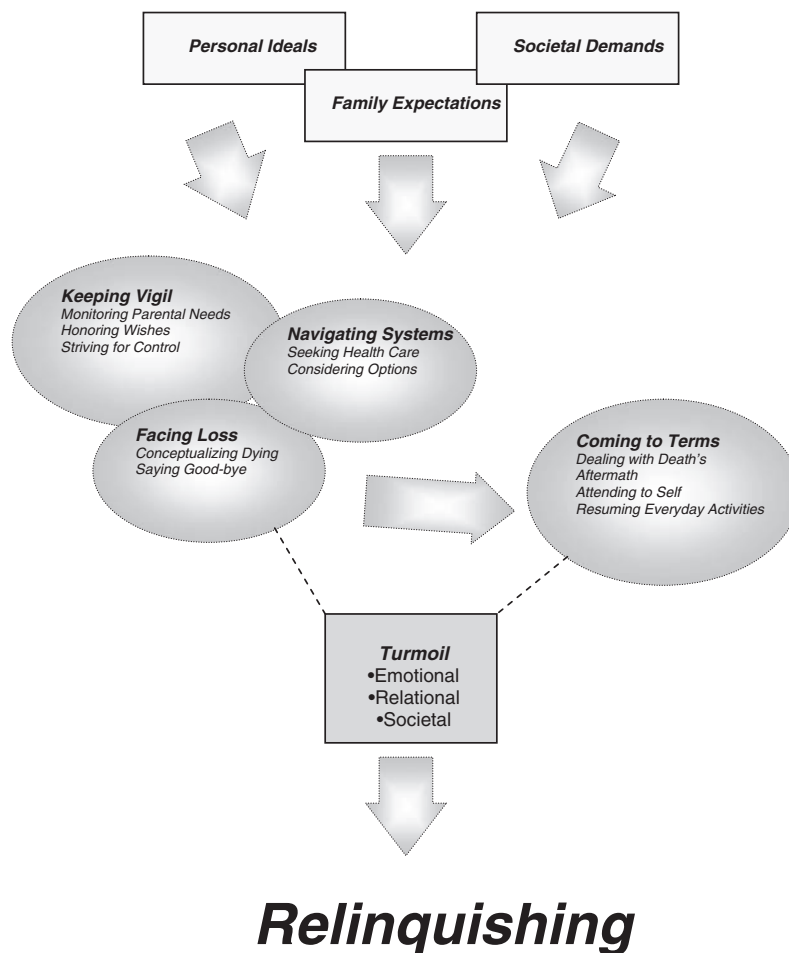
Turmoil: The Core Challenge

Emotional, relational, and societal Turmoil emerged as the core challenge for daughters. The women struggled with Turmoil associated with continuing to fulfill demands of everyday life while meeting personal, familial, and societal expectations around being a dutiful daughter to a dying parent. *Turmoil*, then, is a state of upheaval where normal patterns of life are disrupted for the daughters within immediate and extended families, and in social roles. Perceived disruption of the routine balance of life is associated with daughters’ interpretations and beliefs about dying and the meanings attached to parental relationships. Women in the study exhibited varying degrees of commitment to engage in the care of dying parents. Struggles arose when caregiving demands conflicted with other competing demands of the women, a finding also reported by Wuest (1998).

Emotional turmoil. Emotional turmoil is the tumultuous array of feelings accompanying an awareness of parental health deterioration and the elder’s impending death. Several factors exacerbated a daughter’s emotional turmoil, including her personal ideals, a lack of prognostic or practical information about dying, a belief that the parent was suffering, a sense that nothing could be done, a perceived sense of isolation, and a lack of experience with death and dying. Personal ideals are the characteristics, expectations, values, and beliefs of the daughter that contribute to the daughter’s actions and a sense of obligation to her dying parents, and the extent to which she assumes the role of a dutiful daughter. We found that central to a daughter’s beliefs about her role was an internalized value of needing to be a dutiful daughter attending to the needs of her dying parent. Filial responsibility is endorsed in the literature as an attitude, belief, or sense of personal responsibility that adult children should address aging parents’ needs (Donorfio & Sheehan, 2001). One of the daughters expressed her personal beliefs about being a caregiver:

Caring for Mom when she was dying was something I knew I had to do and I did it. And, Dad was there for me and he’s always been there for me. Now, he’s getting up in age and is having major health problems and I’m looking after him. That is my role in life.

Figure 1
An Overview of the Process of Relinquishing



Among our findings, emotions varied with the daughters, including overall helplessness and feelings of anxiety, sadness, hope, uncertainty, guilt, anger, frustration, despair, bitterness, and loneliness. One woman summed up this sense of vulnerability most poignantly:

It was really difficult, especially when you knew you can't do anything to make her better. Very frustrating. I mean you do what you can, but it's like the end is gonna come sooner than you wanted it to. The feeling that you have like is hopeless and unreal.

On the other hand, interjections of humor and laughter cushioned the roller coaster of emotions, easing tension, as for this family:

In March month he said, "I don't know how much longer I can hang on here." I said, "Father, it's like

this, it's a bad time of the year. I think, if you give it a little bit of go, you can give her another round and you can try to live to a 100." He said, "Well, I don't know." I said, "Well, you'd better not die now because everybody is away and they all gotta come home and to come home here in the month of March. Father, how would you like that?" "OK, then my dear I'll see what I can do for you." And he lasted till June when the weather was good!

Expressions of emotions during caregiving also included pleasure and satisfaction with care. For example, care in the hospital that was perceived as "good" by families lessened Turmoil, a finding supported by Attree (2001), who characterized quality care as individualized and provided humanistically and with involvement, commitment, and concern by staff. In our study, a daughter expressed her relief when her father

was dying; “He had excellent care in the hospital. They really helped him you know. They were right there for anything you needed. They were really good.”

Relational turmoil. Many families approached the time of parental dying with unresolved issues and differing strengths, ideas, beliefs, information, and experiences. Family expectations emerged from the data as the intensity, type, and quality of expectations family members have of one another, and particularly the daughters in the family. Family expectations have an impact on a daughter’s process of Relinquishing her relationship with her parent. As a daughter shared, “Parents are very demanding on their children, even though their children are, you know, doing the best they can.” Realization of a parent’s impending death brought some families together. Conversely, the stress of illness and dying resulted in increased Turmoil for others. Likewise, demands placed on daughters by health and social service providers can conflict with the daughter’s personal ideals and expectations, resulting in relational turmoil. One daughter described her dilemma:

One weekend I thought I was just gonna crack. I just couldn’t take it anymore. It was bad for me too because I had a little baby; he wasn’t even two. And then I was feeling guilty that I was away from him all the time and yet, I wanted to be there with Mom who was dying.

The daughters in our study indicated that Relinquishing was more difficult when emotional and relational turmoil was exacerbated by unequal demands on the daughter. An exasperated woman shared her emotional pain regarding her brother’s lack of support:

My brother phoned one night and I told him, “Mom is in the hospital and she has pneumonia.” I practically cried on the phone and I said, “Look, I’m having a real hard time.” He said, “Life is hard anyway.” I felt so alone. There was just me.

Societal turmoil. Societal turmoil occurs at a level beyond the family structure. It affects daughters’ caring for dying parents and is elicited when dominant societal values and larger social system decisions are imposed on daughters and families. We discovered that societal demands are a reflection of the paucity, fragmentation, lack of universality, accessibility, and comprehensiveness of services from diverse sectors in place to help these families. Within our study societal demands were also reflected in government, health, and social programs available to daughters

and their families. One participant, whose mother and husband died the same year, described her activities in a societal context that does not put supports in place for caregivers:

Trying to put all the drugs in place, alarming the clock to give drugs, sleeping in the chair in the living room, buying all the home care aids, nothing covered on the insurance, trying to bath my husband, to cook, to clean, to wash clothes, make sure he didn’t fall, keep him happy, handling the phone calls, going to the doctor. The list goes on and on until the day comes you’re so frustrated, you could scream or kill the first politician or dignitary you see!

To dedicate vast amounts of time to a dying parent has a rippling effect on her other obligations, such as employment and mother and spouse roles. Each choice to relinquish or sustain a role has enduring consequences for the woman that sometimes last long after the parent dies. Daughters relinquished varying degrees of paid work to care for dying parents. Changes in employment status during and after caregiving were unique to each situation. In our findings, flexibility of employers when an employee’s mother or father was dying mitigated societal turmoil. A daughter shared what was helpful to her:

When my mother was dying, I was based in the hospital. I’d work and go see her on my coffee and lunch breaks. My supervisor was excellent at that time and allowed me to flex my hours.

Societal turmoil created dissonance in daughters who lived away, increasing their emotional turmoil, as in the case of this woman who resided in another province:

We have to deal with the reality that most of us have to move away from outports to find employment. Also we have to accept the fact that we can’t be there 100% of the time when you live away. But most of us, I’m sure, wish we could.

The Basic Social Process of Relinquishing

In response to Turmoil, and mediated by intervening conditions, daughters move back and forth between dynamic processes of Keeping Vigil, Navigating Systems, Facing Loss, and an end process of Coming to Terms. The process of Relinquishing is ongoing and

might take days, months, or years for some daughters to come to terms with the loss of a parent.

Keeping Vigil

Keeping Vigil, an early but ongoing subprocess of Relinquishing, involves monitoring health and illness patterns and emergent needs of the elderly parent. Daughters provide close, protective watchfulness and care for parents in the face of threatening illness or unfamiliar environments. Vigilance is characterized by surveillance and a sense of disruption to the integrity of the family unit. An ethnographic study of vigilance by Carr and Fogarty (1999) involved an exploration of the meanings, patterns, and day-to-day experience of families at the bedside. As in our study, family members demonstrated a commitment to care and resilience as elements of vigilance. By Keeping Vigil, daughters anticipate restoration of some control and positive outcomes for their dying parents.

Critical turning points emerged from the analysis as components of the illness trajectory and influence Keeping Vigil, Navigating Systems, and Facing Loss. These are initial awareness of the illness, diagnosis of a terminal illness, remissions and exacerbations, and the dying event. Initially, a parent articulates being unwell, and the daughter has a sense that something is not quite right with her mother's or father's health. Vigilance of the daughter might increase. It is at this point in Keeping Vigil that the daughter and her parent might begin Navigating Systems, particularly by seeking health care. This period marks the beginning of uncertainty and initially Facing Loss. One of the women shared her experience:

His health changed sort of gradually and then he got very, very weak and was losing a lot of weight. We did not know what was going on, but I think it was a natural progression that my father became ill.

Along the health-illness trajectory there might be periods when the parent seems relatively well, however, a flare-up of new symptoms can occur at any point. During remission of symptoms vigilance might decrease. Resurgence of disease symptoms can trigger more watchfulness and Navigating Systems, especially when illness is prolonged. One daughter cared for her father, who had a 3-year history of cancer and was relatively symptom free while he was living with her until

One night I went to bed and I said, "Dad, make sure you calls me if you gets sick or weak or if you wants

anything." The next morning he came out and I said, "Dad, by, you're not lookin' good this morning, what's wrong?" "I'm not feelin' very good this morning," he said. "Well, this is it then," I said, "Buddy, I'm phoin' the doctor right away." He said, "If you're gonna phone the doctor, you'd better tell him to come quick."

Her father died 2 weeks later, and in this case, the daughter kept vigil at the hospital bedside as much as she was able.

When parental dying is imminent, vigilance by family usually intensifies when possible. The losses associated with dying become real at this time. It is usually at this turning point in the parent's illness that health care professionals send for family members to attend the death. The daughters referred to this point as "he or she took a turn for the worse" or a "downhill turn." Finally, following death, some cultures and religious traditions also keep a final vigil of the deceased parent or loved one before burial or cremation. Thus, critical points along the illness continuum influence Keeping Vigil, Navigating Systems, and Facing Loss. Increased dependence and deteriorating health further influence the process of Relinquishing.

Caregiving demands can be taxing in any woman's caregiving situation (Wuest, 1995), but what intensifies Keeping Vigil in our study is the fact a parent's death was looming near, further straining emotional, relational, and cultural Turmoil. Thus, the extent to which Keeping Vigil reduces Turmoil is affected by the parent's physical and mental condition, the imminence of death, the daughter's availability and willingness to care, her personal philosophy about caring, parental wishes, release from competing demands, and the daughter's perception of the adequacy of and access to suitable assistance. The degree and intensity of daughter vigilance ranged from providing minimal assistance to around-the-clock, 24-hour care and surveillance when possible and needed. We describe strategies for Keeping Vigil as monitoring parental needs, honoring wishes, and striving for control.

Monitoring parental needs. Monitoring parental needs is a way of maintaining awareness of evolving needs of dying parents by identifying which health and illness needs warrant close attention and which require interventions by health and social service providers. Daughters, even at a geographical distance, remain attentive to their parents' changing health status. The responsiveness is highly individual for each daughter with a sense of duty and concern for a parent's welfare central to Keeping Vigil.

Honoring wishes. Honoring wishes means ensuring the care that is provided to meet parental needs coincides as much as possible the expectations of the parent(s) and the daughter. The role of the daughter as dutiful care attendant, advocate, and protector of the parent's best interests is central. There was a strong sense of filial obligation among study participants exacerbated by the fact their parents had developed potentially life-threatening illnesses. Concern for her parent's welfare was evident in the sense of ever-present responsibility, even if the daughter lived far away from her parents. The long reach of the family's arm was omnipresent during the parent's terminal illness and dying. This daughter recognized the importance of routine for her mother dying in the hospital:

You know, she was used to someone catering to her all the time. When you're used to someone getting you a cup of tea at 3:00 . . . so that meant I had to get to the hospital to get that cup of tea for her at 3:00, just to keep things halfway decent because you knew she wasn't going to last much longer kinda thing.

Striving for control. Daughters enact the strategy of striving for control by becoming knowledgeable about their parents' needs and medical condition on diagnosis of a potentially life-threatening illness. There is a sense of impending loss and possibly a sensation of a threat to the family as a whole unit. Likewise, striving for control involves daughters' interpretations of illness symptoms and care provided by others, which are influenced by perceived or actual negative experiences within the health care system. This wariness triggers protective watchfulness in the context of impending parental death in a health care system that offers fragmented support to caregivers. In the process of striving for control, some of the women became knowledgeable about appropriate treatment methods informally, by reading textbooks and health information pamphlets, consulting friends who had some knowledge of health care, and trial and error. Formally, daughters and parents, if able, consulted professionals, usually a family doctor. Once symptoms indicative of a serious, potentially terminal illness occur, daughters and parents react to reduce Turmoil associated with the uncertainty about changed health status.

Navigating Systems

Navigating Systems involves seeking and engaging assistance of helping systems to acquire the care that daughters believe is best for dying parents. Daughters and parents interact with health, social,

financial, legal, political, and spiritual institutions, depending on needs identified. Navigating Systems involves strategies of seeking health care and considering options in an effort to reduce Turmoil.

Seeking health care. Seeking health care occurs when a change in health status of the parent warrants interventions by health care providers. It is a strategy of seeking and acquiring professional and often nonprofessional assistance with care of a dying parent. Seeking health care takes place at the onset of illness and continues throughout the trajectory until death. An exacerbation of illness symptoms precipitates seeking health care. Daughters exercised strategies of making inquiries, parent advocacy, negotiating, and planning ahead. These depend on parental wishes and the daughter's prior experience, knowledge, and resilience. These approaches were also contingent on parental health status, the availability of health care services, especially appropriate terminal illness care, the affordability of supportive services, the relationship with service providers, and the daughter's vigilance.

Making inquiries occurred early in the process of seeking health care and continued throughout the illness. Parents, while able, primarily sought physician advice and medical treatment. Daughters made inquiries about available health services and resources, care options, and symptom management, dependent on parental health care needs. The data suggest that daughters and parents consulted health care professionals to seek answers and treatment to improve care. Early in parental illness, daughters in the study accompanied parents on these visits. One of the daughters explained,

Dad's cancer was back, the doctor told me. Dad said he wanted to go back to see the specialist in the city. And I said, "By, if you wants to go, I'll get you there."

Parent advocacy, or speaking and acting on behalf of the parent, became critical as the parent's health deteriorated. Given the serious nature of decisions that must be made at the end of life, and differing perspectives and values of health care professionals about dying, there were often conflicts or "battles" between daughters and the helpers. One way in which daughters advocated was by encouraging the parent to speak up, as in this case:

My mother would cry, she'd be in pain for so long. And then she'd get angry and clench her fists. But Mom was the martyr-type, she didn't want to admit it or complain. Towards the end, I just went up to the

nurses and said, “Look, my mother needs her medication. Please get in touch with the doctor, she has pain.”

Negotiating is a bargaining strategy useful for enlisting various options to enhance care. Previous experience with illness or dying and knowledge of the health care system helps women in their negotiating endeavors. One of the daughters asserted that a good relationship with the physician was absolutely critical in her negotiations with the health care system:

Mother’s drip would run out and the nurses were so busy it would be ages before they’d [sic] get her hooked up—it seemed like ages, it was probably 10 minutes. At that point in my mother’s health, that 10 minutes was all it took for her lungs to fill up again. That was so frustrating, but once I talked to the doctor about it, she authorized it and . . . she spoke to the nurses and made a note on the chart to say, “. . . if the daughter or husband are there and they say that this is needed, then it should be done and you don’t have to check with me or the doctor on call.” So that was good.

Planning ahead is a strategy used by daughters when there was time to arrange alternate care other than what the daughter could provide. Planning ahead includes obtaining information on long-term care options, institutional or respite care availability, and determining other sources of family assistance among siblings.

Considering options. Considering options is the process of navigating other systems and occurs in response to meeting needs beyond health care, such as financial, legal, spiritual, and funeral arrangements. Daughters and parents become familiar with choices that have to be made to put parental affairs in order as much as possible. Some daughters were receptive to engaging in this process, which also affected Turmoil. Other daughters chose to relinquish this care role: “When my father died I said to my brother, ‘you take over from here. I cannot deal with funeral plans.’” Another woman believed that funeral arrangements were an extension of her caregiving duties: “When my aunt died, I arranged her funeral, too.” Active involvement while considering options resulted in a reduction of daughter Turmoil while Navigating Systems. The closer the parent is to dying, the less time and choice around care decisions that must be made.

Facing Loss

Facing Loss is anticipatory grieving of losses that accrue with the changing relationship of the daughter and her dying parent. Facing Loss can begin at any point during the illness trajectory and thus often occurs concurrently with Keeping Vigil and Navigating Systems. The Relinquishing process was altered for daughters who were not psychologically prepared to face death and were expecting their parents to “get better.” When death is unexpected, daughters might experience increased Turmoil. Conversely, when death is expected, Facing Loss and subsequent Coming to Terms might be less tumultuous for daughters, a finding supported by others. In a study of family caregiving at the end of life, Waldrop, Kramer, Skretny, Milch, and Finn (2005) described the “comprehension of terminality” emerging from concrete information about the illness, observing the disease progression, and observing personality change and role loss (p. 627). Although uncertainty was implicit among study participants, the daughters in our study talked about reducing Turmoil when Facing Loss. Conceptualizing dying and saying goodbye were strategies that emerged from the data, and varied according to the scope of the losses, to enable daughters to face loss.

Conceptualizing dying. Conceptualizing dying is a strategy of rationalizing and attaching meaning to the dying process. The conceptualization process restores some order to the dying event for the daughter. The strategy is based on prior experiences, beliefs about dying, and personal spiritual beliefs. Visualizing the dying person in the bed as not the same as the active parent the daughter once knew, “the essence of him or her was already gone,” eased Facing Loss for some. Some trivialized the body, which helped them understand the physical separation:

To a degree . . . there was this tiny, emaciated, frail woman in the bed, having struggled for each breath, and having to listen to the sound of her breathing was like a witch’s cauldron or something. It was a bubbling, growling sound. That was not my mother.

Saying goodbye. Another way of Facing Loss is saying goodbye, a process of terminating a lifetime relationship by physical or psychological presence. Saying goodbye is associated with vigilance and personal beliefs, as this daughter believed, “You wanted

family to be there when she died. I think people want to be able to say good-bye.”

Finally, saying goodbye at funerals, memorial services, or other related rituals is another way daughters face loss. The choice of ritual is mainly dependent on family expectations, particularly parental wishes. Societal expectations also influence these events. The process of making funeral arrangements can be a tumultuous time by emphasizing the reality of the loss. “Everything was happening and it seemed sort of surreal till the day of the funeral when you saw her in the coffin. Then it seemed sort of real,” said one daughter.

Coming to Terms

Coming to Terms is a maturational stage for the daughter because it indicates her acceptance of the death of the person with whom she had family ties since birth. As in Facing Loss, Coming to Terms might take place over an extended time and at a geographical distance following parental death as the daughter finds meaning in the loss. The loss of a parent is often one of the first times a daughter faces death and, therefore, her own mortality. Through acknowledgment of her finiteness, the daughter can grow emotionally. By tending to her own needs, the daughter resumes the self-care that she might have relinquished while caring for others. Finally, there is a reorganization of her family structure and a reinvestment in other relationships. Strategies enacted include dealing with death’s aftermath, attending to self, and resuming everyday activities.

Dealing with death’s aftermath. Dealing with death’s aftermath involves acknowledging the physical separation of the parent and participating in events that emerge as daughters respond to rituals and ceremonies that preside over the initial loss. The daughter’s role as caregiver ends, and she quickly has to adapt to a role as mourner. If this was the last surviving parent, her role as daughter also terminates. As one daughter stated, “In essence, you are no longer a daughter once both your parents are gone. You become an orphan.” A variation of this concept was described by other researchers as “daughter’s loss of youth” and “you are no longer anyone’s little girl” (Ziemba & Lynch-Sauer, 2005, p. 106). Daughters in our study varied in their reactions to their parents’ deaths by expressing a range of emotions from shock and disbelief to acceptance and a sense of peacefulness.

Attending to self. Attending to self involves managing her own physical, emotional, spiritual, and social

needs that emerge as the daughter responds to her loss. She pays attention to how the emotional, relational, and societal processes of parental caregiving affect her as she comes to terms with her parent’s death. She might engage in caring for herself again if she neglected self-care needs while Keeping Vigil and Navigating Systems. Alternatively, the prolonged stress of providing parent care and her resultant emotional and physical symptoms can now exacerbate because the daughter no longer has to remain the “strong one” in the family; that crisis is over. Some daughters in the sample reported worsening health problems following caregiving. Subsequently, these women sought relief of symptoms by adopting healthier lifestyle habits and seeking medical attention as needed.

Resuming everyday activities. As time passed, daughters busied themselves with resuming everyday activities. The daughter experienced the initial grieving period, attended to self-care needs if previously neglected, and began to merge into a new life without the parent. As adaptation to change is not static, the daughter might be using these strategies simultaneously or at different points along the process of Relinquishing. The caregiving experience and eventual parental death led to a point in the daughter’s life where she was able to integrate the loss and adapt to the life changes. Learning from the death of her parent and the Turmoil inherent in the loss enables a life-affirming separation. New perspectives on life emerged from the data:

Normally, for everyday life, you have to get on and get busy and you don’t forget, but you got to learn to live without [your parents]. You have to do the best you can.

Thus, the strategy daughters cited as most therapeutic was “keeping busy,” which allayed Turmoil. This was referred to frequently as “filling the void.” Some daughters continued caregiving, as caring for a dying parent was just one dimension of competing caring demands. Some daughters who were in the midst of caregiving careers balanced parent care with care of children and care of the surviving older parent. A woman who experienced multiple family deaths stated, “It’s always an empty feeling when someone you love dies, but you do carry on. Life goes on.”

Some women resumed employment soon after the death. Decisions to keep busy by returning to normal activities as quickly as possible or to take time to recover from the caregiving experience influenced Coming to Terms. Over time the major consequence

of Coming to Terms is that the process of grieving allows for reflection and adjustment to the changes that have resulted from the parent's death. The impact of the loss is no less, as "the death of a family member may be the single most difficult crisis that most of us face in our lifetimes" (Steele, 1990, p. 235). Finally, daughters described how they "cherish the memories" of their deceased parents. Daughters repeatedly explained, "You never bring closure to someone you loved that died. You learn to deal with the loss, to come to terms with it, but you never forget."

Discussion

A theoretical explanation for daughters' caring for dying parents as a process of Relinquishing in these study findings has implications for nursing knowledge, practice, education, research, and health policy. Caregiving daughters interface at individual, family, community, and organizational levels and with multiple sectors such as health, spiritual, financial, and legal systems; government agencies, and the funeral home industry. Family caregiving occurs in various settings of home, hospital, hospice, or long-term institutional care. Our findings reveal new understandings of the daughter-parent dyad in the face of the death of an older parent.

The substantive theory of daughters' caregiving conceptualized in our study contributes to nursing's understanding of the art and complex nature of caring. The theory adds to our knowledge of vigilance during caring and provides new understanding of the concept of Relinquishing. The process of Keeping Vigil reiterated the presence and active involvement of daughters and families caring for dying relatives. In a study of male caregivers of a family member with Alzheimer's disease, Parsons (1997) described vigilance as "a major part of the caregiving experience . . . in the form of constant watchfulness" (p. 397). Our study concurs with this finding and applies the concept to care of a dying parent during the process of Relinquishing.

In earlier work of women's caregiving, Relinquishing was identified by Wuest (2000) as a process of consciously choosing which losses to sustain to continue caring for a family member. In the grief literature, relinquishing is captured as letting go (Furman, 2001; Parkes, 1998). Still others considered grief and bereavement as a process of transformation (Romanoff & Terenzio, 1998). Romanoff and Terenzio argued that understanding grief as letting go might be ineffective

and not reflective of the multiplicity of grief pathways and the bereavement process. Findings in our study capture a broader perspective of Relinquishing. Daughters gradually relinquish past relationships with parents but also relinquish their time, energy, and often their health to provide care. Daughters might lose income, job opportunities, and aspects of their lifestyle in their caregiving endeavors. However, there is a paradox of growth and moving on in a changed family structure resulting from these painful and difficult experiences, a finding supported in the literature (Kubler-Ross, 1975).

Nurses ideally offer a holistic perspective to persons in meeting physical, emotional, social, and spiritual needs. To better support daughter caregivers in rural areas, we need to establish positive, vigilant relationships with interventions tailored to meet the needs of caregivers and care recipients. Current formal care and social systems, and primary health care provided by interdisciplinary teams, needs to augment the informal care system. New technologies such as telehealth might link professionals with caregivers of dying persons, especially when traditional support is not accessible in rural and remote areas. Helping daughters navigate health systems and appreciating the consequences of Keeping Vigil for daughters can be a starting point for interventions as the daughters strive to maintain a sense of control and reduce uncertainty. As discovered in our study, when bereaved daughters were able to reflect positively and were satisfied they did everything they could to help their parents, the process of Relinquishing was less tumultuous for them.

Time-honored family values that are central to parent caregiving might establish unrealistic expectations for daughters, even when they or their historically supportive siblings are geographically distant from the parental home and community. Family expectations, including parental wishes, might set caregiving standards so high that daughters find them impractical to attain, thus leading to more emotional and relational turmoil. It is crucial that health and social programs not inadvertently increase the informal care expectations of those left behind in Newfoundland and Labrador to provide parent care.

It can no longer be taken for granted that unsupported family care is best for all involved without depleting the vital resources of daughters who choose to participate in the care of dependent, dying elderly parents. By recognizing that not all daughters are readily prepared and skilled in end-of-life care, nurses can assist and support daughters by teaching skills, encouraging their efforts, and advocating for

additional resources aimed at reducing Turmoil. Recognition by nurses that daughters might be struggling with personal ideals, family expectations, and societal demands enables nurses to intervene to reduce associated Turmoil. Positive support and anticipatory guidance might prevent conflict that can occur while the daughter is Keeping Vigil, Navigating Systems, and Facing Loss. As a result, Coming to Terms might be easier for daughters in their Relinquishing process. In our findings, when parents died within a system where "good" care was provided, the daughters expressed satisfaction about the quality of care. Conversely, when care was fragmented or inaccessible, daughters shared high levels of frustration that care could have been "better."

Furthermore, findings during the processes of Facing Loss and Coming to Terms indicated the need for health professional expertise in bereavement support. Daughters in the study wanted somebody to talk to about their losses but, unfortunately, found few qualified people to aid them in their grief work. This points to a need for accessible bereavement services and also a need for further research to understand the long-term impact of coping with losses such as parental death.

Our study raises concerns about our abilities as a society to care for our dying elderly. At the same time that the population is aging and more people are dying, the supply of informal caregivers, especially in this province, is declining. Fiscal and economic restructuring of health and social services from institutional care to community-based care has not resulted in funding to back the rhetoric that claims that care at home is best for all involved (Frederick & Fast, 1999). Although helping dying elderly parents is generally an act of love and obligation for daughters, Turmoil is a core concern.

An analysis of daughters' caregiving highlights the importance of connecting informal and formal systems. The emotional and physical work of caring is implemented by both families and health professionals, with intermittent help from other systems. Health professionals, at the least, need to be aware of what services caregiving families might need and intersect. This study supports the notion that there appears to be limited research that might facilitate family caregiving at the end of life (McMillan, 2005). Practice and policy decisions for care of the dying, and bereavement support for caregivers need further grounding in the voices of daughters, sons, spouses, and other family caregivers.

A limitation of this study is that it was conducted in rural Atlantic Canada with a small population of women and might not be a reflection of other populations in

larger centers elsewhere. Therefore, future studies might explore determinants of caregiver health, caregiving experiences of men, interventions to ease Turmoil, and strategies to improve and maintain the health of families in both rural and urban areas when caring for a dying family member.

The substantive theory presents a framework for clinical practice and implications for future research. Negative experiences with health care providers and other formal care systems can exacerbate Turmoil, furthering the helplessness associated with the impending loss of a loved one. Conversely, if the daughter and her family feel supported in health care and social systems, Turmoil might decrease. Building on our new discoveries, this research contributes to the women and family caregiving literature, especially care of dying relatives, and will be valuable in informing knowledge, practice, education, and policy.

References

- Allan, G. (1988). Kinship, responsibility, and care for elderly people. *Ageing and Society*, 8, 249-268.
- Aronson, J. (1991). Dutiful daughters and undemanding mothers: Constraining images of giving and receiving care in middle and later life. In C. T. Baines, P. M. Evans, & S. Neysmith (Eds.), *Women's caring: Feminist perspectives on social welfare* (pp. 138-168). Toronto, Canada: McClelland & Stewart.
- Attree, M. (2001). Patients' and relatives' experiences and perspectives of "good" and "not so good" quality care. *Journal of Advanced Nursing*, 33(4), 456-466.
- Bedard, M., Koivuranta, A., & Stuckey, A. (2004). Health impact on caregivers of providing informal care to a cognitively impaired older adult: Rural versus urban settings. *Canadian Journal of Rural Medicine*, 9(1), 15-23.
- Boland, D. L., & Sims, S. L. (1996). Family care giving at home as a solitary journey. *Image: Journal of Nursing Scholarship*, 28(1), 55-58.
- Brakman, S. V. (1994). Adult daughter caregivers. *Hastings Center Report*, 24(5), 26-28.
- Brody, E. M. (1990). *Women in the middle: Their parent-care years*. New York: Springer.
- Carr, J. M., & Fogarty, J. P. (1999). Families at the bedside: An ethnographic study of vigilance. *Journal of Family Practice*, 48(6), 433-438.
- Clark, D. (1997). What is qualitative research and what can it contribute to palliative care? *Palliative Medicine*, 11, 159-166.
- de la Cuesta, C. (2005). The craft of care: Family care of relatives with advanced dementia. *Qualitative Health Research*, 15, 881-896.
- Donorfio, L. M., & Sheehan, N. W. (2001). Relationship dynamics between aging mothers and caregiving daughters: Filial expectations and responsibilities. *Journal of Adult Development*, 8(1), 39-49.
- Faison, K. J., Faria, S. H., & Frank, D. (1999). Caregivers of chronically ill elderly: Perceived burden. *Journal of Community Health Nursing*, 16(4), 243-253.

- Frederick, J. A., & Fast, J. E. (1999). Eldercare in Canada: Who does how much? *Canadian Social Trends*, 54, 26-30. Retrieved June 25, 2007, from <http://www.statcan.ca/english/freepub/11-008-XIE/0029911-008-XIE.pdf>
- Furman, J. (2001). Living with dying. *Nursing*, 31(4), 36-42.
- Gage-Rancoeur, D.-M., & Purden, M. A. (2003). Daughters of cardiac patients: The process of caregiving. *Canadian Journal of Nursing Research*, 35(2), 90-105.
- Gaugler, J. E., Hanna, N., Linder, J., Given, C. W., Tolbert, V., Kataria, R., et al. (2005). Cancer caregiving and subjective stress: A multi-site, multi-dimensional analysis. *Psycho-Oncology*, 14, 771-785.
- Geister, C. (2005). The feeling of responsibility as core motivation for caregiving: Why daughters care for their mothers [English abstract]. *Pflege*, 18(1), 5-14.
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Government of Newfoundland & Labrador. (2005). *Demographic change NL: Issues and implications*. St. John's, NL: Department of Finance.
- Jaffe, J., & Blakley, B. (2000). *Coping as a rural caregiver: The impact of health care reforms on rural women informal caregivers*. Winnipeg, Canada: Prairie Women's Health Centre of Excellence. Retrieved June 23, 2007, from http://www.uwinnipeg.ca/admin/vh_external/pwhce/pdf/projectsComplete.pdf
- Jutras, S., & Veilleux, F. (1991). Informal caregiving: Correlates of perceived burden. *Canadian Journal on Aging*, 10(1), 40-55.
- Kubler-Ross, E. (1975). *Death: The final stage of growth*. Englewood Cliffs, NJ: Prentice-Hall.
- Lewis, J., & Meredith, B. (1988). Daughters caring for mothers: The experience of caring and its implications for professional helpers. *Ageing and Society*, 8, 1-21.
- McMillan, S. C. (2005). Interventions to facilitate family caregiving at the end of life. *Journal of Palliative Medicine*, 1, S-132-S-139.
- Parkes, C. M. (1998). The dying adult. *British Medical Journal*, 316(7140), 1313-1316.
- Parsons, K. (1997). The male experience of caregiving for a family member with Alzheimer's disease. *Qualitative Health Research*, 7, 391-407.
- Pepin, J. I. (1992). Family caring and caring in nursing. *Image: Journal of Nursing Scholarship*, 24(2), 127-131.
- Pohl, J. M., Boyd, C., Liang, J., & Given, C. W. (1995). Analysis of the impact of mother-daughter relationships on the commitment to caregiving. *Nursing Research*, 44(2), 68-75.
- Pohl, J. M., Collins, C. E., & Given, C. W. (1998). Longitudinal employment decisions of daughters and daughters-in-law after assuming parent care. *Journal of Women and Aging*, 10(1), 59-75.
- Raveis, V. H. & Pretter, S. (2005). Existential plight of adult daughters following their mother's breast cancer diagnosis. *Psycho-Oncology*, 14, 49-60.
- Romanoff, B. D., & Terenzio, M. (1998). Rituals and the grieving process. *Death Studies*, 22(8), 697-712.
- Rutman, D. (1996). Caregiving as women's work: Women's experiences of powerfulness and powerlessness as caregivers. *Qualitative Health Research*, 6, 90-111.
- Steele, L. L. (1990). The death surround: Factors influencing the grief experience of survivors. *Oncology Nursing Forum*, 17(2), 235-241.
- Stephens, M. A. P., Townsend, A. L., Martire, L. M., & Druley, J. A. (2001). Balancing parent care with other roles: Interrole conflict of adult daughter caregivers. *Journal of Gerontology: Psychological Sciences*, 56B(1), P24-P34.
- Stern, P. N., & Pyles, S. H. (1985). Using grounded theory methodology to study women's culturally based decisions about health. In P. N. Stern (Ed.), *Women, health, and culture* (pp. 1-24). Washington, DC: Hemisphere.
- Stetz, K. M., & Brown, M. A. (1997). Taking care: Caregiving to persons with cancer and AIDS. *Cancer Nursing*, 20(1), 12-22.
- Stobert, S., & Cranswick, K. (2004). Looking after seniors: Who does what and for whom? *Canadian Social Trends*, 74, 2-6. Retrieved June 23, 2007, from <http://www.statcan.ca>
- Waldrop, D. P., Kramer, B. J., Skretny, J. A., Milch, R. A., & Finn, W. (2005). Final transitions: Family caregiving at the end of life. *Journal of Palliative Medicine*, 8(3), 623-638.
- Ward-Griffin, C. (2004). Nurses as caregivers of elderly relatives: Negotiating personal and professional boundaries. *Canadian Journal of Nursing Research*, 36(1), 93-114.
- Williams, C. (2002). The sandwich generation. *Canadian Social Trends*, 77, 16-21. Retrieved June 23, 2007, from <http://www.statcan.ca>
- Wuest, J. (1995). *Precarious ordering: A theory of women's caring*. Unpublished doctoral dissertation, Wayne State University, Detroit, Michigan.
- Wuest, J. (1998). Setting boundaries: A strategy for precarious ordering of women's caring demands. *Research in Nursing and Health*, 21, 39-49.
- Wuest, J. (2000). Repatterning care: Women's proactive management of family caregiving demands. *Health Care for Women International*, 21(5), 393-412.
- Wuest, J., Ericson, P. K., & Stern, P. N. (2001). Connected and disconnected support: The impact on the caregiving process in Alzheimer's disease. *Health Care for Women International*, 22(1), 115-130.
- Ziamba, R. A., & Lynch-Sauer, J. M. (2005). Preparedness for taking care of elderly parents: "First, you get ready to cry." *Journal of Women & Aging*, 17(1/2), 99-113.
- Zukewich, N. (2003). Unpaid informal caregiving. *Canadian Social Trends*, 70, 14-18. Retrieved June 23, 2007 from <http://www.statcan.ca>

Trudy Read, RN, BN, MN, is Manager, Long Term Care at Western Health, Corner Brook, Newfoundland and Labrador, Canada.

Judith Wuest, RN, PhD, is an assistant dean, Research & Faculty Development, and a professor and UNB research scholar at the University of New Brunswick, Fredericton, New Brunswick, Canada.