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The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia

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ABSTRACT

Objective: Dementia is a terminal illness, and family caregivers play a vital role in providing end-of-life care to their relative. The present study begins to address the paucity of research regarding end-of-life caregiving experience with dementia.

Method: This study utilized Munhall's methodology for interpretive phenomenology. Seven women and four men were interviewed two to three times within a year of their relative's death; interviews were transcribed verbatim and hermeneutically analyzed.

Results: Findings reveal two essential aspects of end-of-life dementia caregiving: *being-with* and *being-there*. Further findings are organized according to the existential life worlds. Examination of the life worlds demonstrates that 1) *spatiality* provided a sense or lack of feeling welcome to provide end-of-life care; 2) *temporality* was an eternity or time melting away quickly, or the right or wrong time to die; 3) *corporeality* revealed feelings of exhaustion; and 4) *relationality* was felt as a closeness to others or in tension-filled relationships.

Significance of results: An understanding from bereaved caregivers' perspectives will help healthcare practitioners better support and empathize with family caregivers. Further research is warranted that focuses on other places of death and differences in experience based on gender or relationship to the care receiver.

KEYWORDS: Dementia, end-of-life care, Family caregivers, Phenomenology

INTRODUCTION

Over the next 30 years, the number of Canadians with dementia is expected to increase 2.3 times, to >1,300,000 men and women (Alzheimer's Society of Canada, 2010). Dementia is a terminal illness (Gill et al., 2010), although it is often not recognized as such. Given the prolonged disease trajectory, family caregivers to persons with dementia may have unique needs and experiences compared with other types of caregivers who care for someone with a steadily progressive disease and a short terminal phase (e.g., cancer) (Hebert & Schulz, 2006; Gill et al., 2010). Little is known about the distinctive experience of providing end-of-life care to a relative with dementia. Research acknowledges the important contributions of family caregivers in providing end-of-life care to those with terminal illness (Andershed, 2006). It is important, then, to understand their experience in order to explore ways to encourage and support family caregivers in this very important role. Therefore, the purpose of this study was to explore the experiences of family caregivers who cared for a relative with dementia at the end of life.

Currently, researchers are beginning to conduct qualitative and quantitative studies that address the experience of caregivers who care for a family member at the end of life (Peacock, 2012). However, there

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remains more to be done to add clarity and understanding within this context, particularly for those who care for a relative with dementia (Allen et al., 2003). Family caregivers to persons with dementia may have unique needs and experiences compared with other types of family caregivers (Gill et al., 2010). Therefore, the context of end-of-life care of family caregivers to persons with dementia calls for a separate investigation from that for family caregivers to persons with a different terminal illness. The concepts of *family caregiving* and *end of life* that were utilized in the study are explained in the following.

Family Caregiving

Family caregiving may be defined as "unpaid or informal care provided to frail or chronically ill family members because they are no longer able to perform tasks themselves." These tasks may include assistance with bathing, dressing, meal preparation, housekeeping, transportation, managing finances, or securing assistance from formal services (Ory et al., 2000; Schulz & Martire, 2004). In addition to these physical tasks, family caregiving can also include sentiment, an emotional connection to the care receiver, and providing psychosocial support (Benner & Gordon, 1996). Specific to the context of dementia, the family caregiving role changes constantly.

Family caregiving is often assumed to be provided to an ill or frail care receiver in their home (Decima Research for Health Canada, 2002; Fast, 2005). However, family caregiving may last for years and continue after institutionalization of the care receiver (Kelley et al., 2000). Although long-term care admission is necessary in the later stages of dementia, deciding to place a relative with dementia in a long-term care home can be distressing and complex for family caregivers (Chene, 2006). Family caregivers often seek continued involvement with care and a way to rebalance family caregiving within the context of long-term care (Gladstone et al., 2006). Time and again, families go *above and beyond* to provide this invaluable care.

End of Life

It may be impossible to definitively identify how and when an individual enters the period known as the *end of life*. Although there is no accepted definition, the research supports two components present at end of life: (1) presence of a chronic disease or impairment that persists but may also fluctuate; and (2) that the resulting impairments from the disease require care provided by others (formal care providers and/or informal caregivers) and ultimately lead to death (National Institutes of Health, 2004). Undoubtedly, the presence of advanced dementia with complete dependence for activities of daily living indicates the likelihood of reduced survival for care receivers (Coventry et al., 2005; Mitchell et al., 2009). The advanced stage of dementia is often characterized by the inability to ambulate or speak and difficulty swallowing, resulting in constant, 24 hour care; this stage may last for years (Volicer, 2001). Research demonstrates that increasingly high levels of suffering (e.g., pain, agitation, shortness of breath, or pressure ulcers) are associated with the end-stage of dementia (Mitchell et al., 2009) and may indicate that the care receiver is entering the last days of life (Aminoff & Adunsky, 2006).

The effect of end-of-life care on the family caregivers to persons with dementia has not been explored sufficiently (Allen et al., 2003). The purpose of this study was to explore the lived experience of family caregivers who provided end-of-life care for a relative who died with advanced dementia. The specific aims of the study were to uncover the meaning of this end-of-life care experience from the perspective of bereaved family caregivers.

METHOD

The study was guided ontologically and epistemologically by the work of Martin Heidegger (e.g., Heidegger, 1927/1962). Heidegger claims that our fundamental way of *being-in-the-world* is to care (Heidegger, 1927/1962; Hoffman, 2006). Our existence is such that it may be humanly impossible and socially unacceptable to not care about someone or something (Benner & Gordon, 1996). Death is the most powerful meaning-giving possibility in life (Hoffman, 2006). "If death moves us to show concern about our life, it is because man's 'basic state' is indeed care" (Hoffman, 2006, p. 228). There seems to be an inevitable connection between death, care, and *being-in-the-world*.

Guiding the methodological approach for this study was Patricia Munhall's (1994; 2007) interpretation of Heidegger's phenomenology. Phenomenology is commonly referred to as the study of the *lived experience* (Munhall, 2007). The aim of interpretive phenomenology is to let things show themselves and seek after meaning that may be hidden (Heidegger, 1927/1962). What makes phenomenology unique from other qualitative methods is that it requires immersion in philosophical literature and looking at the phenomenon of interest with a phenomenological lens (Munhall, 1994; 2007). This interpretive phenomenology undertook a retrospective approach in order to explore the lived experience of caring for a relative with advanced dementia at the end of life. Studying the end-of-life care experience when it was completed allowed for authentic meaning to reveal itself without interrupting participants while in their experience (Munhall, 1994).

Setting and Sample

This study was set in a small urban center of Western Canada where the primary author lives. Purposive sampling was employed as a means to include participants who had experienced the phenomenon of interest and desired to and could articulately tell their story. A heterogeneous sample was desirable to capture diverse experiences of the phenomenon.

Inclusion and Exclusion Criteria

The focus of the study called for a sample of participants who had cared for a relative who died of advanced dementia or some consequence of it (e.g., infection) in the previous year. It was helpful to wait a few months after the death of their family member, as family caregivers required time to sort out initial responsibilities, whereas waiting longer than a year could have reduced recall of events (Addington-Hall & McPherson, 2001). Although care receivers had other comorbidities, it was important to focus on those who predominantly had dementia, as their family caregivers may have had differing experiences compared with those caring for a relative with another terminal illness (Gill et al., 2010). Additional inclusion criteria for study participants were to be $\geq$18 years of age and be able to read and write the English language, in order to give informed consent.

Recruitment

Participants were recruited from a variety of sources, in order to attempt to achieve a heterogeneous sample. The strategies included partnering with a large older adult care community, advertising with a local council on aging, and utilizing snowball sampling with the initial participants. In total, 11 individuals agreed to participate in the study.

Sample

Among the participants were four wives, three husbands, three adult daughters, and one adult son. Spouses' ages ranged from 65 to 89 years; children's ages ranged from 49 to 63 years. The care receivers (ages ranged from 63 to 89 years) all had a confirmed diagnosis of some form of dementia and died in a long-term care home. Therefore, the focus of this study was end-of-life care within the context of long-term care. Length of residency in the long-term care home ranged from as short as 10 days to as long as 4 years.

Data Generation and Analysis

Two or three in-depth, open-ended, audiotaped interviews were completed with each participant, resulting in a total of 27 interviews. Interviews took place in the participant's home or office and lasted between 1 and 3 hours. The first interview began with a very broad question: "*what was it like to care for your dying relative*?" Participants were reminded that there was no right or wrong way to share their story; it was their personal experience, interpretations, and meaning that were sought (Munhall, 2007). In order to glean meaning of the caregiving experience it was occasionally necessary to add more probing questions, albeit sparingly. For example, asking "How were you feeling?" or "What did that do for you?" were helpful in moving the participant beyond description. It was important to think of the interview as a conversation and avoid leading questions that might have imposed structure on the participant's story (Munhall, 1994, 2007). Going back to participants for a second interview allowed them time to reflect and an opportunity to answer the question: "Might there be anything more you would like to share?" (Munhall, 2007). Returning to participants allowed for revealing deeper layers of meaning, and offered a second chance at understanding (Benner, 1994). Interviews were transcribed by either the primary author or a transcriptionist who signed a confidentiality agreement. To clean the data, interview tapes were listened to many times and transcripts reread over and over to be as thorough as possible. All transcript data was hand coded by the primary author.

Analyzing the data hermeneutically took many months and many drafts of writing to complete. There was a constant going back and forth; pausing to reflect and reflecting further when thoughts changed or new insights were discovered. This analysis resulted in creation of a narrative for each participant that reflected that person's experience; second and third interviews provided an opportunity to ensure the researcher had understood and interpreted the participant's narrative accurately. In order to generate the narratives, it was necessary to consider the existential context of the lived experience of the participants, as existential inquiry demands that researchers be attentive to and reflective of the world around them and the participant (Munhall, 2007). Assessment of the four existential life worlds furthered the participants' perspectives, and how that context might have influenced meaning. In comparing the individual narratives with each other, two essences were revealed; namely, *being-with* and *being-there*. For sake of brevity, this article presents the findings in regard to the essences and according to the life worlds.

Trustworthiness of the Data

Fittingness and credibility were utilized to maintain data trustworthiness in this study. In order to achieve fittingness of the data, it was necessary to utilize a sample of participants that could articulately illuminate the phenomenon being studied (Munhall, 2007); therefore, purposive sampling was used to attract individuals who were capable of revealing, and willing to reveal, their story. Adhering to the text of the interview transcript and returning to participants to confirm interpretations maintained the data's credibility. Prolonged contact with participants and validating interpretations with them was necessary for both credibility and fittingness (Sandelowski, 1986). As phenomenology is an emerging process, all changes and decisions throughout the study were recorded. An audit trail using field notes and memos was kept to ensure consistency and auditability of the findings (Sandelowski, 1986).

Prior to undertaking the study, ethics approval was sought and received from two university research ethics boards, as well as the health region where the study took place. Participants provided informed consent and were reminded that they could withdraw from the study at any time if they desired, and pseudonyms were used to protect their privacy.

RESULTS AND DISCUSSION

Using Munhall's (1994; 2007) phenomenological approach, the essence of the phenomenon of caregiving was uncovered along with findings of the four existential life worlds of family caregiving of persons with advanced dementia at the end of life. The following is a presentation of the essences and life worlds.

Essences

An essence is an element related to the ideal or true meaning of the lived experience (Heidegger, 1927/1962). Van Manen (1990) states that essence means "the inner essential nature of a thing, the true being of a thing.... Essence is that what makes a thing what it is" (p. 177). From dwelling with and analyzing the data (i.e., the individual narratives) from the study, two essences were revealed: *being-with* and *being-there.* These essences were interrelated, and permeated the end-of-life caregiving experiences of the participants.

Being-with

Being-with occurred anywhere at any time; it is not a physical presence, but a sensing and feeling with their relative. This sensing and feeling is borne out of an intense caring, concern, and love for another. Buber (1970) shares that, "love itself cannot abide in a direct relation; it endures" (p. 147). *Being-with* was a closeness the participants felt to their dying relative. Further, some caregivers talked about sensing their family member's presence in the room or with them later on during bereavement. For example Grace, an adult daughter, stated while describing the preparation of her mother's body, "Mom was still with us, she's still there." This sensing of their relative was particularly true for participants who stated a belief in an afterlife.

Being-with was essential to the end-of-life care experience because this was the caregiver's connection to the dying relative. The cognitive impairment associated with advanced dementia meant that for most of the participants, communication had been limited for a number of years, and sometimes their relatives no longer recognized them. *Being-with* allowed caregivers to support their relative in the absence of reciprocal communication and recognition.

Being-there

Being-there was the need some caregivers felt to be physically present at death, offering comfort care, keeping a vigil during the last days and hours, or washing the body after death. Nouwen (2005) explains that, "to care for the dying means to make them live their dying as a way to gather around them" (p. 185). Essentially, caregivers were accompanying their relative to the end of their life. This physical accompaniment arose from the need to *be-with*. As their dying relatives were unable to verbalize their needs and discomforts, caregivers felt the need to be present to ensure that comfort care was provided. Many of the participants were very dedicated in their hands-on caregiving, even after their relatives entered long-term care; *being-there* allowed them an opportunity to complete the final leg of the journey. When they were not physically *there* they: (1) were glad another family member was, (2) were comforted that their relatives were at peace at the time of death, or (3) felt guilty about not *being-there*.

Being-there was significant, because as Nouwen (2005) suggested, "Being present to each other is what really matters" (p. 171). This is exemplified in a statement from Laurie, an adult daughter, "it was really just time for her to go and we were with her, she wasn't alone and I think that you take comfort in knowing that you were there. For me I was there all along." *Being-with* and *being-there* were pivotal to the end-of-life care experience of the study participants, and were also found in the life worlds. Further detailed findings will be discussed according to the life worlds.

Life Worlds

Life worlds are where we find ourselves in experience; namely spatiality, temporality, corporeality, and relationality. They are all interwoven, and together they essentially make up our (single) *lifeworld* (van Manen, 1990). Having a grasp of the life worlds aids in our understanding of how a person experiences their world (Munhall, 2007); it helps provide us with the necessary context of experience. A detailed discussion of each life world with supporting quotes from participants explicates the end-of-life care experience with advanced dementia.

Spatiality

Spatiality is felt space; the space where we find ourselves in experience affects the way we feel (van Manen, 1990). It is not related so much to the concrete nature of space, but to the feeling and sense of where we find ourselves. "The first and most obvious quality of a home is its intimacy .... We express a longing for that intimate place that offers us a sense of belonging" (Nouwen, 2005, pp. 146–147).

Participants had many reactions to the physical and social space in long-term care. Some participants felt welcomed, some viewed the long-term care home as necessary for their relatives' safety, and others viewed it as a failure of their own home, whereas a few participants were able to embrace a renewed relationship in the long-term care home.

A Welcoming Space

Participants who viewed the space in long-term care as a welcoming place were positive about many aspects and felt it as a new home for their relatives. A husband, Rudy, talked of how staff would accommodate what he needed for his wife, "the head nurse... she just did everything for me, just beautiful. If I had something she'd sure make sure it was possible, she was very good that way. They all were excellent." Lois, a wife whose husband had early-onset dementia, stated, "this was Bill's home. This was where he was... I just felt like I was part of the whole thing when I went there. I never felt like I was just visiting." Both Rudy and Lois felt included and welcomed to continue to care for their spouses. These responses regarding supportive staff are similar to those expressed in Shanley and colleagues' study (2011) with family caregivers to persons who had died with advanced dementia.

A few participants spoke of long-term care as a necessary move in order to keep their relative safe. Laurie acknowledged the deficits in long-term care homes, yet accepted that it was necessary for her mom. She stated, "it was a tough one. It wasn't her home. It wasn't a place [she] would choose to be. It's not a place that I would have liked her to have to go, but I really didn't have a choice." While Laurie's mother was dying she felt it important to not transfer her mother to a hospital for life-prolonging interventions. She stated, "it's important to leave her at this place that we call her 'home'. Funny that the word home comes into this." Munhall (2007) ponders how space can feel differently at different times as was the case with Laurie, "Our environment... can assume different meanings for different experiences" (p. 194).

An Unwelcoming Space

On the other hand, some participants did not feel welcomed and could not view long-term care as a new home, but as a *failure of their home*. Those who did not accept it as a new home said that caregiving should be done in the community with family, not giving your relative over to others. When talking of how she would have changed her husband's end-of-life care Jane stated:

> I would have somebody living-in. I think that's how they used to do it... Then I could have had someone here to help him because the lucky people in the end of life would have been the ones who had large families. Then no one person would be burdened with something they couldn't handle .... I don't think people should be warehoused. We [had] no intention of warehousing Jim in a nursing home and that's where he ended his life.

Unlike family caregivers of those with other terminal illnesses who often desire and are supported to provide end-of-life care at home, in the community, the prolonged duration of dementia means many family caregivers are not able to care in their own home through to the end of life (Grande et al., 2009).

With a change in the caregiving environment (i.e., from home to long-term care) for some participants there is a feeling of being an outsider now that others are providing the hands-on care to their relatives. This was illustrated well by Tom as he related to the physical separation from his father:

> You go out and you leave and the door behind you locks. All you could see was his new pyjamas and his eye in the door, that cracked double door and you are left with that... It was the hardest thing and the most difficult day of my life.

Perhaps these feelings of being unwelcome related to the cultural and social convention of lived space. Small et al. (2007) comment on the fact that persons with dementia are often hidden away, segregated to a separate area, and that this is viewed as necessary and socially acceptable. This has implications for the end of life as well, perhaps for the view that death is able to be denied or viewed as a failure. Of all the participants, Jane and Tom seemed to consider their relative's death as a failure of their filial obligations or of the environment.

Return to Relationship

Other participants felt that this shifting of care to a new environment allowed them, to a degree, to return to their previous relationship with the care receiver. This was evident in Laurie's case, "after I initiated care from others what happened [was] I became the daughter again." Spouses talked of this as well, Rudy shared that once his wife was in long-term care, "I didn't have to, you know, be on guard all the time which again was freedom within myself... but I looked forward to going up there every day to visit [her]." Therefore, the space offered by long-term care could also mean a renewed relationship between caregiver and care receiver.

Similar to this study's findings, DeMiglio and Williams (2008) described the significance that people attach to space. There are many issues and elements (such as viewing long-term care as a home, feelings of failure of one's own home, or what the social space offered) that influence the study participants' sense of lived space and how that may impact the end-of-life care experience. These issues and elements further supported or detracted from participants' ability in *being-with* and/or *being-there* for their relatives.

Temporality

The traditional sense of time, as in hours or days, does not readily apply when we consider temporality. It may also be important to bear in mind that families have a shared time, a shared family history in which occasions are experienced together (van Manen, 1990); as may be the case with the death of a relative. "When you thought about life, you thought of it as chunks of time, but really it was a series of connected moments, any of which could change you completely" (Rankin, 1999, p. 147).

Participants spoke of time in varying degrees of intensity and awareness. Participants who were aware of their relatives entering the final days of life spoke of it as sensing a change, for example, Lois stated, "something was different" and Rudy stated that he and his children "knew it wasn't going to be long." In the final days, time was of the utmost importance because time with their relatives was now limited. During the last days of keeping vigil, Lois talked about feeling as though, "you think... that it is never going to end." With more specificity, Laurie spoke of her sense of time while her mother lay dying in this way, "so, during the time when she was frothing at the mouth, I mean that couldn't have gone by faster." Laurie further stated, "time at some instances stood still, however in some moments I wish I could hold onto [it]. Like the time I was saying goodbye to her .... The time that I was with my family with her was very meaningful." There was a dichotomy here: time may be viewed as an eternity or time melts away and it is experienced differently by everyone.

Found among the stories was a relation to the *wrong time* or *right time* for the death of their relatives. In some ways this difference is borne out of the differences in relationship to the care receiver; in other words some spouses and adult children seemed to view time of death differently. Some of the spouses wanted more time in that they were not yet ready. This is exemplified in statements such as: "you are never really ready, ever" (Rose) or "you always feel that there could be a magic wand and he'll come back" (Lois). That is not to say that spouses did not want the suffering of their spouse to end, they certainly did. What was happening may have more to do with continuing their own identity as a spouse.

The adult children in the current study seemed to view their parent's death as the right time for the suffering to end. Many of the adult child participants spoke about losing their parent long before the end-of-life phase even occurred; for example, Leona stated with her mother's dementia diagnosis, "So really, we lost our mom just like that." And for Tom, as his father entered a long-term care home 8 months prior to his death, "his life had ended, you know his death at that point of [being my] dad was at that moment." It seemed as though these children were speaking of the social death of their parent (Small et al., 2007), and that that made the physical death the next logical, and perhaps, accepted occurrence.

The discussion of temporality reveals that chronological time is not of significance. Instead, participants felt and sensed time to varying degrees, particularly during the final days and hours of their relatives' lives. *Being-with* became more and more significant as the death of their relatives was approaching. The time spent at the bedside (or the inability to spend time there) influenced how participants could actualize *being-there* for their relatives. The feeling of the wrong or right time for death clearly impacts participants regarding their end-of-life care experience.

Corporeality

We experience the world around us through our body. We reveal things about ourselves through our bodily presence, but we may also conceal elements at the same time. "I myself am my body. The body as a whole functions as a sensorium, a senser, a knower, a perceiver, a digester" (Olthuis, 1997, p. 137).

Participants were experiencing the world around them through their body with physically feeling their own suffering and guilt, through tension and fatigue. Connection of this is heard in the crying and emotion that participants expressed. One man, Dale, could not say his wife's name without crying; he felt her loss so deeply. Speaking about the losses associated with dementia brought out deep feelings for some of the participants. Rudy described it like "re-opening an old wound"; "then at night well, that was the worst part because I couldn't sleep… I was going downhill myself. Losing weight… it was just turmoil really."

During the last few days, when end-of-life care was most intense, many participants spoke about feeling fatigued from the constant vigilance. Leona stated, "We had lots of time. We were there constantly, almost. We would take shifts and stay with her and we were totally, totally physically exhausted, just exhausted." The consuming feelings, emotionally and physically, that participants speak of here may be related to the notion of "total pain" (Saunders, 1978). Dementia is not the only source of suffering limited to the care receiver; instead there is an amalgamation of sensations and feelings that are extended out to the caregivers as well that consumes them in their experience.

In summary, corporeality brings attention to how experience flows and is expressed through our bodies. As was apparent in the other life worlds, *being-with* and *being-there* was impacted by participants' bodily experience. The ability to cope with what was occurring at the end of life and the energy level required to endure the final days influenced how *being-with* and *being-there* might be enacted by participants. Some participants experienced the physical manifestations of end-of-life care very deeply, whereas others experienced it not at all. Similarly, family caregivers to persons with other terminal illnesses may experience comparable physical manifestations during the terminal phase of end-of-life care (Jo et al., 2007; Stajduhar et al., 2010).

Relationality

The quality and intensity of our relationships with others can color how we experience life. Not surprisingly, relationships are intimately interconnected to all the other life worlds. "Only someone who is ready for everything, who doesn't exclude any experience, even the most incomprehensible, will live the relationship with another person as something alive and will himself sound the depths of his own being" (Rilke, 1986, p. 90).

Relationships with others presented, perhaps, as the most significant life world within the end-of-life care experience of the study participants. There were many layers of relationships found in the data: 1) caregiver and care receiver, 2) caregiver and other family members, 3) caregiver and long-term care staff, and 4) caregiver and friends or significant others.

Caregiver and Care Receiver

The relationship between caregiver and care receiver within the context of dementia was constantly changing, given the impairments the care receiver experienced. A few participants were clear about how their relatives changed, and that it was as if there were different people before them as the disease progressed to death. Laurie commented, "You lose them at different stages and you continue to lose them right up to the end."

A strained relationship between caregiver and care receiver was difficult to reconcile at the end of life when dementia was involved, given that the participants lost the ability to communicate with their relatives. Tom shared a great deal about caring for his father despite not receiving fatherly love growing up; he stated, "He had a hard life, and I think that crystallized him so that that would be my experience with him growing up, a person that was very, very hard." Tom found the ability to provide care to his father because, "regardless of what [parents] were for you, growing up they were doing what they were taught to do, and I [felt] that we don't treat people that way." On the other hand, the needs that arose as a result of dementia offered a way to further deepen an already close relationship. For example, Laurie commented how her ability to care for her mother was like being "given a gift. It was a tough one to unpack, but I think that I, I did the best I could with what I had to work with." Unlike the caregivers in the present study, family caregivers to persons with other terminal illnesses are often able to verbally communicate to resolve issues or become closer to the care receiver (Jo et al., 2007; Sutherland, 2009; Waldrop & Kusmaul, 2011).

Caregiver and Other Family Members

Relationships among family members were complex. Tensions among families interfered with the end-of-life care experience in some cases. For example, Tom stated: "[My brother] felt it was important we start to look into a facility for [our father] which I found very hard to do because of what the [long-term care] home is about for Dad… I know what homes are about." With his brother as power of attorney Tom was not included in decisions regarding his father's living arrangements or his end-of-life care. Similarly, Shanley and colleagues (2011) discovered that family caregivers can feel alone in decision-making when other family members pull away from the situation.

On the other hand, some participants described getting closer to their family as a result of their completed journey. Laurie in particular talked about this: "we have a special closeness that didn't exist in the same way throughout the journey with the disease and the death… We have a special connection… now which is really, really nice." Further, Grace echoed a similar result, "I think it got us close, us closer together… there was quite a few of us there. It was very nice to have family all together, to be able to be there together to share that." This experience of closeness to family members is similar to that of caregivers to persons with other terminal illnesses (e.g., Wong et al., 2009).

Caregiver and long-term care staff

Interacting with staff from the long-term care home or from the hospital in some cases held significance for participants. Many participants talked of being supported and welcomed to do whatever is necessary at the end of life. For example, Rudy stated, "you know they looked after her pretty good, so it was nice to have that kind of care." Laurie was particularly struck by the support from the nurse on duty the evening her mother died:

> It wasn't ten minutes and she was in the room and she said that I had asked her to come in and explain to the family what exactly was going on and that time was not something [we had a lot of], as far as Mom being around… So that was wonderful. That person was just fantastic.

A few participants, however, talked about run-ins with staff when they attempted to secure comfort care. Grace, especially, had an unpleasant experience at the beginning of her mother's final days when she was admitted to hospital from the long-term care home. Grace shared: "the doc who came in was a little bit aggressive I thought and not very sensitive, but he basically was pushing us to, you know, just to make that decision not to provide any care for her." Grace and her family opted to have her mother transferred back to the long-term care home to die in a more supportive environment.

Caregiver and Friends or Significant Others

Many of the participants spoke of people outside of their families who assisted them during the final days of their relatives' lives. A few participants mentioned how funeral home personnel were kind and accommodating; as noted in these comments, "the funeral attendants were very good" (Laurie) or "the funeral home out there was just excellent" (Rudy). Lois spoke of her close group of friends, "I think it has to be my friends. Yes, the staff were good, but they [her friends] respected my request to just leave us be…. It was those really good friends that got me through it." This support was important for Lois because it allowed her to spare her daughters from dealing with the physical death of their father.

Another example is Alice, a wife, who was supported by her church family. She stated, "I felt a real support from the church and the church friends as if I was being kind of carried along with their thoughts and prayers… I felt strength from that." Alice was able to call her pastor to accompany her to see her husband moments after he had died in the middle of the night; this was significant to her end-of-life care experience.

As presented, the participants in the current study encountered many types of relationships on the journey with their relatives. These relationships had an impact on them and their end-of-life care experience in varying ways and continued to affect them after their relatives' deaths. For the most part, participants spoke of most relationships as being positive, and they were grateful to have the support from many different types of relationships (e.g., with family, long-term care staff, or significant others). The ability of some participants to offer care, love, and support to their relatives in the final days of life enabled them to fully engage in *being-with* and *being-there* and this influenced their end-of-life care experience positively; those who had challenging relationships were less able to have a positive experience.

Limitations

Findings from this research are applicable only to the participants of the study, as findings from a phenomenology are the result of interaction between the researcher and the participants within a given context. All of the participants indicated that they willingly took on the care of their relatives. Therefore, their end-of-life care experience may differ from that of family caregivers who are far more reluctant to provide care or do so not out of love, but obligation. Another limitation is that all of the care receivers died in a long-term care home. Despite the limitations to the present study, the participants and researcher were able to generate a rich understanding of the complex end-of-life care experience with dementia.

Implications for Practice and Future Research

This research has the potential to inform healthcare practitioners, particularly those who work in long-term care. This is important because of the relationship that nurses and staff have with families, often built up over many years, but in some instances over much less time. It was apparent that some staff members contributed to the positive experience of participants, whereas other staff members were viewed as detrimental. It is necessary to consider the cultural aspects of the physical and social environment during end-of-life care. It may be important to consider how total pain or suffering affects the family caregiver. When healthcare practitioners are able to acknowledge this, they may be better able to support family caregivers to work through all the varied and complex feelings that may arise as their relatives are dying. Grief and suffering are natural reactions to the death of a relative and need not be viewed as needing to be fixed, rather family caregivers may require support to move through and allow those feelings to flow. It is vital that healthcare practitioners understand that family caregivers be met where they are at in their experience and freely allow them to express their needs and concerns in order to assist them to help their relatives to die peacefully.

Given this study was broad in scope and aimed at providing a foundational understanding of the meaning of the end-of-life care experience for family caregivers to persons with advanced dementia, further research is warranted to confirm or contrast the findings. A study that undertakes a comparison of a variety of family caregivers may be beneficial to explore how the end-of-life care experience is the same or different among differing terminal illnesses. And whereas this study highlighted how space influenced the end-of-life care experience, possibly family caregivers will view other spaces (e.g., home, hospital, or hospice) in more or less favorable ways than long-term care.

This work also generated interest in the differences in gender and relationship to the care receiver. Women and men react to and take on differing responsibilities throughout the caregiving journey, and these may have implications for the end-of-life care experience that require further consideration. Perhaps an investigation of differences in experience among wives and husbands is warranted, to further reveal gender and relationship issues and their effects.

CONCLUSION

The present study begins to explore the complex lived experience of providing end-of-life care to a relative with advanced dementia in long-term care. The essences bring to light the end-of-life care experience and make it what it is: a sensing feeling (i.e., *being-with*) and a need to be present (i.e., *being-there*) in any shape or form with their relative as that person is dying, or being distressed when barriers preclude this from happening. Exploring the spectrum of feelings found within the life worlds revealed all the places participants might find themselves. For example, (1) spatiality provided a sense or lack of feeling welcome to provide end-of-life care; (2) temporality may be an eternity or as time melting way quickly, or the right or wrong time to die; (3) corporeality revealed feelings of exhaustion; and (4) relationality was felt as a closeness to others or in tension-filled relationships. Having a better understanding of the lived experience of family caregivers to persons with advanced dementia will help healthcare practitioners to better support and empathize with family caregivers. Further research is warranted that focuses on other places of death and differences based on gender or relationship to the care receiver.

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