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“This is just where I live”: A Situational Analysis of Rural End-of-Life Caregiving

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Abstract

Most informal caregivers in Canada are women (Cranwick, 1997; Fast, Eales & Keating, 2001; Kaden & MacDonald, 1990; MacLean, Cairn, & Sellick, 1998). Women caring for dying persons at the end-of-life have been identified in the literature as those most likely to experience negative physical and mental health outcomes such as declines in health status, depression and anxiety from caregiver burden (Cranwick, 1997). Family caregivers, who do not have access to palliative services including counselling and bereavement services, such as those in rural areas, are in need of more support than other populations (Wilson et al., 2006). Living in rural/remote areas presents challenges for dying persons and their families, such as reduced and difficult access to needed services (Kelley, Sellick & Linkewich, 2003; McConigley, Kristjanson & Nikolette, 2000; Wilson et al., 2009). Additional social and community services are often found only in distant larger communities (Wilson et al., 2006; World Health Organization, 2007). Researchers have noted the paucity of attention to place, particularly rural and

remote locations, upon palliative care (Castleden, Crooks, Schuurman, & Hanlon, 2011). This article contributes to the remedy of this gap; our research study aimed to better understand female provided end-of-life care-giving in rural and remote Ontario communities. In particular, we were interested in the extent to which geography intersects with gender; that is, to what extent (if any) does rural location impact end-of-life care-giving?

Keywords: rural, palliative care, qualitative research

1.0 Introduction

The Canadian government implemented health care reform in the 1990s, amidst a context of resource constraints regarding social spending, and higher demands placed on the health care system given an ageing population. Health care reform has created a shift in care for the elderly, frail and disabled from institutions into “communities”, and the homes of families. The move towards community-based care was based on the political assumption that a home-care focused system would be more cost-efficient than institutional care (Williams, 1996; Purkis, Ceci, & Bironsdottir, 2008). While it is true that many individuals prefer to receive care in the home, this shift in care was not accompanied by adequate resources or formal supports. Much of the burden of care has been placed on families, and the vast majority of that care work taken up by women (Gregor, 1997; Purkis et al., 2008). Changes in the health care system are located in a broader neo-liberal political context, where neo-liberal values and ideas, such as individual autonomy, personal responsibility and self-help enter into policy and result in highly gendered effects. The women who end up taking care of the frail elderly and the dying are expected to do so, and often do it unpaid, largely unsupported by a rationalized health care system (Purkis et al., 2008). The major providers of both formal and informal health care are women, but the gendered nature of care work is rendered invisible in the discourse of “community care” (Gregor, 1997).

While gender-related inequalities exist when it comes to home care provision, inequalities also exist across space. If we turn to the context of Ontario, we see that the distribution of health care provision is highly variable throughout the province, with rural areas experiencing many gaps and challenges, including lower provider availability and accessibility issues due to space, time and socio-cultural constraints (Williams & Cutchin, 2002). Ontario has a formal Home Care Program which is accompanied by informal supports that are provided by family and/or friends, who make up the main proportion of care provided in the home (Williams, 1996). Williams (1996) outlines the historical development of formal home care provision in Ontario and documents evidence of the differential distribution of economic and political power between Ontario’s sparsely populated medically underserved northern region, and the comparatively densely populated fully-served southern region. Home care prevalence has been growing since the 1970s but there was never a comprehensive, strategic plan across the country or the province. Rather, programs have been introduced sporadically over time; they were also modeled for the southern, more densely populated parts of Ontario, and then imported into more remote communities without accounting for specific contextual factors and potential barriers to care accessibility. Northern Ontario has always been served after its urban counterparts, and thus experiences a double burden of

provider availability and accessibility issues, as well as an urban policy bias in the broader political context (Williams et al., 2002).

Home care restructuring in the 1990s has negatively impacted home care practitioners as well as informal care providers; with a simultaneous increase in demand and rationing of services, care practitioners experience increased job constraints and time stress that ultimately decrease the quality of their work life and the quality of care provided (Williams, 2006). The negative health impacts of caregiver burden are extensively documented. Funding cuts have resulted in the increased privatization and the creation of for-profit home care agencies, that creates significant issues for health care providers and clients alike (Leipert et al., 2007). Restructuring has also resulted in the cutting of specialist care services in remote communities, such as palliative care and mental health, as well as has resulted in hospital closures. More broadly, rural communities are undergoing the challenges of sustainability, with increased ageing in place and the out-migration of young people (Williams, 2006). When it comes to health care provision in the rural context, Purkis, Ceci and Bironsdottir (2008) emphasize the importance of inter-professional collaboration and understanding between practitioners; they also emphasize the importance of building health care services that are particular to social, cultural, and physical factors specific to localities involved. The demand for palliative care services is increasing across rural Ontario and rural Canada given the disproportionately large elderly population that reside there, and this demand requires context-specific responses.

2.0 Method

Situational analysis (SA) was the analytic approach selected for this interview study. Considered a post-modern approach to grounded theory, SA's guiding metaphor departs radically conceptually from the action-centred basic social process concept that undergirds traditional grounded theory and replaces it with Strauss's situation-centred social worlds/arenas/negotiations framework (Clarke, 2005, p. xxii). SA offers three main cartographic approaches: situational maps, social worlds/arenas maps and positional maps. Each map is intended as analytic exercise centered on elucidating the key elements, materialities, discourses, structures and conditions that characterize the situation of inquiry. Unlike traditional grounded theory that aims to delineate a basic social process and formal theory, the goal of SA is "to construct processes, sensitizing concepts, situational analytics and theorize" (Clarke, 2005, p. 32). As its name suggests the situation per se is the ultimate unit of analysis and understanding its elements and their relations is the primary goal. SA is unique in its ability to analyze complex situations of inquiry broadly conceived. Ultimately, this approach "enhances our capacities to do incisive studies of differences of perspective, of highly complex situations of action and positionality, of the heterogeneous discourses in which we are all constantly awash and of the situated knowledges of life itself thereby produced" (Clarke, 2005, p. xxiii).

In this study the situation is female provided end-of-life care-giving at home in rural Ontario. In SA data is iteratively collected and analyzed. In this SA we ascertained women's perspectives of caregiving, health professionals' perspectives of the impact of caregiving on women; rural materiality; and discursive conceptualizations of rural end-of-life caregiving. This data enabled us to map the situational elements and the social worlds pertaining to the situation. The simultaneous consideration of these maps yielded thick analysis of this situation.

2.1 Participant's Eligibility Criteria

The primary participants in this study were the women who provided end-of-life care. Professional caregivers comprised a secondary group. The eligibility criterion for the former included: English speaking women over 18 years of age who provided care primarily at home for someone who has died. In addition, participants must have lived within a rural community. In order to maximize inclusion regardless of geographic location prospective participants could live anywhere in rural or remote parts of Ontario. The women recruited were primarily spouses who had been married to the care-receivers for many decades (21-56 years); one ex-spouse, one adopted daughter and one paid caregiver who had provided long-standing care to the same two recipients were also recruited. Care-recipients were predominantly male, elderly, and diagnosed with cancer. End-of-life caregiving transpired over a period of months (4-6 months). With one exception, care-recipients knew, discussed and accepted their dying. Although caregivers mentioned care-receivers' pain as a significant factor, care-recipients were not described as suffering. All of the caregivers affirmed they lived in a rural locale and, with only one exception, had lived in the community in which they provided care from 10-35 years at the time of caregiving. Professional caregivers were key informants as they were another source to inform the experience of women who provided end-of-life care. Eligible health professionals were those who had experience supporting informal caregivers.

2.2 Recruitment

In order to obtain our selective samples of informal and formal caregivers, Web compatible and print recruitment materials were circulated to the Family Health Teams (FHT) in one Ontario Local Health Integration Network (LHIN). FHTs were composed of physicians, nurses (full and part time), and social workers. One of the informants was the nurse who led the FHT's palliative care team. FHTs posted materials in their offices as well as distributed them to women they thought might be interested in participating. Telephone calls to the contact person for each FHT were made to discuss the study. One of the researchers attended a teleconference among all FHTs in this region in order to publicize the study and invite recruitment assistance and direct participation by team members. Thus, caregivers were selectively sampled via direct and snowball recruitment. In the end, 9 informal caregivers and 4 health professionals (3 nurses and 1 physician) were recruited. The health professionals had had long standing experience as clinicians and administrators of community palliative care.

2.3 Data Collection

Data were collected from female caregivers via 2 telephone interviews. The initial telephone interview was an in-depth interview exploring women's caregiving experience. The single grand tour question was—Please tell me what the experience of looking after someone at the end of their life, at home, was like for you. Following analysis of the data from the first interview, secondary structured interviews were conducted to clarify and discuss in-depth issues that emerged from the first interviews. Participants were asked (in the following order): whether they believed they resided in a rural community, what defined a rural community for them, how long had they lived there, did they think living in a rural community had influenced their caregiving experience and finally, how could they account for

the fact that they hadn't identified living in a rural setting as a primary factor in their caregiving experience during their initial interview. All but one informal caregiver participated in the second interview. Health professionals participated in a single unstructured interview designed to ascertain their perspectives of the impact of caregiving on women within their catchment area. Interviews were audio-recorded, anonymized and transcribed. This study was Research Ethics Board approved. Informal caregiver participants were offered a copy of the study's results as well as a \$50 honorarium in appreciation of their time. Health professionals were offered the results but not the honorarium.

2.4 Data Analysis

SA does not deviate from traditional grounded theory in its analytic approach to interview data. Two of us, working independently, constantly compared the data from the unstructured interviews with informal caregivers and health professionals. Memos were created that further probed the data to theorize gendered and rural end-of-life caregiving and its impact on women's health. After the initial interviews were conducted it was apparent that women did not emphasize rurality as a significant component of their experience. This finding came as a surprise to us and constituted what Clarke calls an "analytic turning point"; thus, second, structured interviews were conducted to ascertain caregivers' specific thoughts with respect to the influence of geographic location upon their experience. The research team collaborated to discuss the linkages and relations among the elements of the interviews. This analysis resulted in two maps: an ordered situation map that elucidated the elements in the situation and the relations among them and a map of the social world of gendered rural caregiving that elucidates the collective elements and their intersections.

3.0 Findings

3.1 (Dis)located Self

The sensitizing concept that emerged from caregiver interviews was (dis)location of self.

Dislocation is formally defined as disturbance from a proper, original, or usual place or state. In these findings (dis)location refers to the existential crisis and transformation of one's self in response to the imminent death of a loved one as manifest by the latter's apparent transformation, change and/or deterioration. In this study women experienced (dis)location of self comprised of: (dis)located states of mind, (dis)located identities, (dis)located roles, (dis)located autonomy, (dis)located space and time, (dis)location of social support, (dis)location of formal support, and (dis)location of health. The parentheses are used to emphasize the upheaval of self that is distinct from and supersedes geographic location within this rural end-of-life caregiving experience.

In this section, we present the results of the data analysis based on the experience of female caregivers, taking excerpts from the initial and follow-up interviews to highlight the strong themes that emerged from the telling of their experience. In addition, we augment these themes with the results of the professional caregiver interviews. In keeping with the situational analysis approach, we then present our results in the form of two maps that illustrates the situation of gendered end-of-life

caregiving in rural and remote communities from multiple perspectives. Following this, we discuss our thick analysis of this situation.

3.1.1 (Dis)located states of mind

A common thread throughout most of the interviews was the caregivers' experience of a dislocation or disturbance of their regular state of mind during the caregiving period. Participants described themselves as being in a "dreamlike" state, said they felt as if they were "sleepwalking" through their days of providing care. One other caregiver referred to having "lost my mind." As one spousal caregiver described:

I was thinking this is not real. This is not really happening. Tomorrow I'm going to wake up and it's going to be better. It's like a dream...you're going with it, you're making sure that he's comfortable, but you can't believe it because it's just a nightmare, you're going to wake up and it's going to be fine.

Another caregiver explained:

Well in the beginning, you don't really think about it—I mean this is really your

husband—whom you love—you just do it! You know it was just kind of going...

almost like sleepwalking through the days, because a lot of them were the same.

The metaphors women used to describe their states of mind—sleep/walking, dream/nightmare poignantly exemplify a disturbance in usual states of consciousness. One explained, "*You're not thinking because it's so close to you.*" Caregivers reflected upon their obliviousness to their (dis)location, "*When I was going through it I didn't realize I was in that state...I don't remember going to the bank to pay bills, but I must have.*"

Caregivers also experienced similar alterations in those for whom they cared. Many dying persons became "*progressively more confused*"; others experienced alterations in sleep/dream worlds, "*She would tell me of dreams that she was having and she would have been talking to my dad who had already gone ahead.*" Another reported, "*He was having these hallucinations, he would say that he would be seeing sort of like ghosts, you know. He was seeing people outside the window and they were crying and he would tell me about them, so I knew that his time was getting short.*" Physically, some descended into prolonged sleep states, some lapsed into a coma.

3.1.2 (Dis)located identities

Caregivers were deeply impacted by the impending loss of the care recipient—someone they loved or cared deeply about—particularly as the care recipient's own identity was changing. Caregivers reported that the worst part of this experience was "*watching a loved one die bit by bit*" or, alternatively expressed, "*watch someone I cared about fade away in front of my eyes.*" Another woman concurred, "*So, he got very thin, of course, and it was just a progression—a*

deterioration [crying] which was not very nice to watch.” One wife recalled how “*friends couldn’t bear to see the change*” and another reported how “*hard [it was] for me to see him experience his friends seeing him that way.*” Beyond the physical realm were the “*whole personality*” changes that occurred. Some changes in the care recipient’s identity signalled difference though not necessarily deterioration. For example, one long married spouse recalled seeing the emergence of her husband’s profound religious faith that she had never seen before. A common sentiment was the “*wish to remember him the way he was.*”

Reciprocally, the caregivers’ experienced their own loss of their sense of self. This was particularly evident for those spousal caregivers who regarded themselves as intimately connected to their partner. One wife described how the disruption in her identity was in response to the change in her spouse,

One night he had been quite confused and wasn’t sleeping so I though I’ll just sleep with him for a while, and it was so nice. He had his arm around me and I was crying and he said ‘don’t worry about it.’ And then he had to go to the bathroom and when I went back in I don’t think he knew I was there...I might as well have been a log. So things changed.

Another wife recalled thinking before her husband died, “*I can’t go through life without him.*”

Transitioning from an identity as a couple to a singleton was disruptive. After the death of the care recipient, caregivers had to find a way to move forward without that special person in their life. One caregiver felt lost and alone, and did not know how to begin again. She asked, “*How do you even start a new journey?*” This same caregiver found it difficult to reintegrate into her community after the death of her husband, “*We went to different things they had and now I don’t do that because I have to walk in by myself and so you feel, do you belong?*” Another woman recalled how after her husband died, “*I didn’t want to get out of bed and I didn’t care if I died the next day, you know.*”

(Dis)located identities are further evidenced through the caregivers’ descriptions of reformulation of self after the caregiving experience. As caregivers spoke and reflected back on their care-giving experience, it was evident that their values and approach to life had changed, and that the experience had permanently affected their identities and place in the world. Several caregivers felt that care-giving was a part of life; they accepted this reality, knowing that they would likely need to provide care again, or that they would need to provide emotional support for friends and family providing end of life care:

Well, it’s life, you know. I mean, what else do you do? You do it for family and if a friend is in trouble you reach forward and do what you can. If they have family, you guide and direct them in their caregiving. We’re all hitting that age where we’re looking after somebody.

Caregivers came to place greater value on time and relationships and less on material things. Despite financial hardship, one caregiver shared, “*Once you live through this, you stay tough—material is not important.*” Another emphasized that there is always hope, that one must “*love each minute to the most because when it’s gone is when you’ll really miss it.*” Health care professionals underscored the

transformational nature of the caregiving experience describing how many women “*were thankful that they had the opportunity*” to care for the person; they felt the caregiving experience made them “*a better person*” that they “*learned from the experience, grew from it.*” In addition, newly single women sought to re-integrate social relationships, too. Health professionals recalled that many, many women were looking to volunteer to provide care for, or support, other people.

3.1.3 (Dis)located roles

Caregiving is predominantly done by women and this work is both physical and emotional. As one palliative care nurse described, the daughter is left “*holding the bag*” and that’s not unusual, it is usually the females (though not in every situation), it is “*usually the daughters who step up to the plate; she had done this a few years ago with father and now doing it again for mother*”. In addition, the “*daughter feels the guilt more, the brothers tend to walk away and avoid the situation.*” Caregiving is both physically exhausting and emotionally gruelling but being a caregiver is “*a role they just couldn’t imagine themselves not doing.*” Health care professionals observed that women experienced role disruption. First and foremost was their transformation from their original relational role as wife, daughter to that of the primary caregiver and case manager. Several participants quit their jobs to take up the fulltime caregiver role while others tried to add the caregiver role to their other roles. One nurse observed, “*If they are a younger couple then the wife is trying to balance holding her job and caring for her husband or caring for her parent...*” In some instances women felt they ought to assume the caregiver role but could not because of work obligations; this conflict resulted in considerable emotional distress. As one nurse described:

I have a situation right now where mother is in the hospital and really wants to be home but a young woman and her brother work so there is that whole guilt feeling I really should be doing what mother wants, she doesn’t have much time left.

Caregivers took on new tasks that their husbands would have previously performed such as yard work, house maintenance, and financial responsibilities. Often women never imagined taking on these roles and found them particularly stressful and “*difficult to manage*” especially when disturbed financial management was compounded by loss of income. Most overwhelming, however, is the assumption of nursing tasks. As one nurse described:

If they’re really in tune with the disease and the treatment, they’re told to watch for this and watch for that. One woman said that her biggest worry was that she would miss something...any change in the client’s condition you’ve got to pull the alert and let people know that that’s happening. When they start out these requests are overwhelming but they get very adept.

(Dis)location of role did not just pertain to the caregiver per se but threatened the children in the family as well. One caregiver described how, after the death of her husband, people would tell her teenaged son that “*he was to be the man of the family now*”; she wanted to preserve his usual role and counselled him to enjoy his teen years.

3.1.4 (Dis)located autonomy

Informal caregivers become the “cornerstone of the care team... We can’t do it without them.” Health professionals described this primary caregiving role as isolating and considered this “the number one issue” that threatens caregivers’ health. Isolation results in high levels of stress, anxiety and hopelessness: “because they also have to be the case-manager in the health care system which isn’t very organized to bring in the supports that they require, but before they do that they have to admit that they need assistance.”

Women don’t seek help or support: “they have this concept or mentality that they’re responsible to man it on their own.” One nurse described asking for help “a huge culture shift” and a “huge stumbling block.” According to health professionals “the women who are caring for their husbands tend to ask more questions but still don’t admit that they need any assistance...they reach out and ask what their options are but they still don’t engage in those options.” Not only did women feel responsible to assume the caregiving role, they also felt they were to enact this role stoically. Most caregivers felt that they were expected by others to stay strong in their supportive role, or imposed that expectation on themselves. For example, one spousal caregiver shared:

I had my moments—still do, but I think because you know you have to be strong...you have to take care of it, and you didn’t want him to see you break down, because you wanted to stay strong for him.

Another woman felt this expectation from the care recipient:

I was expected by my mother to be able to be strong, because she knew that I was in the middle. I had my children to explain things to and I had my mother to care for and I had to be strong...I couldn’t be, you know, taking the time to be an emotional wreck.

This suppression of emotions, however, could not last forever and many women felt the impacts after the death of the care recipient. One woman shared, “I’m trying to respect the fact that there is a process that you go through and allow myself that process.” The silence and stoicism with which many women bear the caregiving burden may unintentionally be bolstered by health professionals who may unintentionally re-enforce normalizing social scripts such as the good wife or the dutiful daughter, “my job as an RN is to tell them on a regular basis how wonderful they’re doing—what a gift they are giving to their loved one...dedicate a lot of time just coming to the hospital...absolutely invaluable.” Finally, echoing the devaluation of gendered caregiving work, nurses noted that women don’t “see the value that they have.” Indeed, “no one can die at home without someone being there.”

Female caregivers’ perceived their dislocated autonomy differently from the aforementioned societal perspectives. It’s not that they deliberately disdained assistance, they just weren’t thinking about themselves, “You get out of step with your own being”; “Your state of mind is not on yourself—it is for the betterment of the person who is sick”; “I put myself on the back burner.”

3.1.5 (Dis)located spaces

Several caregivers experienced disruption in their usual spaces. The commonality among this disruption was the desire to be closer to the care recipient: one woman moved from her own home in another city into her mother's home; in addition, she brought her school aged children with her constituting a change in space for them as well. Another caregiver frequently left her own home and family in order to provide care to a former spouse in his home; another caregiver who had provided part time paid care for a man gave up her day job to assume a full time caregiving role in his home. Even women who remained in their own homes while providing care experienced some disruption in home as a place you can freely leave and return to, to a place of confinement and restricted freedom. One caregiver's freedom of mobility within her own home was restricted as her children urged her to remain in her own bedroom at night. Rather than sleeping however, she listened to the sounds emanating out of her husband's bedroom as her children cared for him at night. Certainly there was less time spent occupying social space and more time cloistered with the care recipient. One woman stated, *"I wanted to let him know I always there."* One caregiver also referred to the spatial disruption experienced by her spouse, *"He wanted to stay beside me because he used to always say this is our favourite spot—at night when we cuddled up—and he did not want to go into the hospital bed until he really, really had to."*

For some caregivers providing care at home was highly valued. Home was a place of comfort and familiarity that grounded them despite their otherwise (dis)located state. As one caregiver expressed:

I'm glad I had him at home. I think it wasn't too exhausting because I wasn't travelling back and forth and sitting in a hospital, and people could come in and visit with him...it was just a warmer atmosphere.

Caregivers preferred being able to meet with front-line health care professionals in their home; they felt more comfortable and less rushed. After the death of the care recipient, many caregivers expressed gratitude for being able to stay at home and continue to be part of community life. One caregiver said that she would never want to move because she knows that people close by care about her: *"I live in a small community and if there's something going on, I'm there or I'm invited...you know what's going on and you do it."* Other caregivers expressed feelings of social isolation during and after caregiving, especially if family members lived hours away or were not available to provide support. One family caregiver experienced disruption in her sense of community belonging after the death of her husband.

When specifically asked, most caregivers acknowledged that their geographic location had some impact on their caregiving experience but it was not its most prominent feature. The one exception to this was a caregiver who had migrated from an urban centre to retire in a Northern rural community; she was very articulate about the impact of geographic location upon her experience, *"Absolutely. There's no help!"* Perhaps her previous experience in an urban setting facilitated greater comparison.

We shared our observations from first interviews regarding the lack of emphasis upon geographic location and invited women to help us account for this in the follow-up interview. Caregivers attributed it to *"this is just where we live"* or

“the intensity of a terminal illness within the family becomes the issue.” Indeed, women are habituated to both where they live and how to live. One caregiver described her rural caregiving experience as *“Just the way of our lives.”* Another caregiver said, *“It was my home. It never really crossed my mind. I just didn’t think I was any different. It didn’t jump out at me.”* Similarly, another caregiver responded, *“I was at home, not ‘rural’—you just go with the flow.”* And, *“I don’t think so—it’s hard to compare. I don’t know that it had any difference. It doesn’t really matter where you’re living.”* One nurse adeptly captured the taken-for-granted-ness of location in this anecdote wherein a caregiver described the ease she felt in looking out for her terminally ill father: *“My father lives right next door so he’s close and I don’t have to go far to see him”*. The nurse continued, *“It’s true his property is right next door but there’s a forest between them.”*

Health professionals, on the other hand, recognize geographic remoteness as a dislocation; that is, a disturbance in the ‘normal’ access to services and resources urban dwellers can rely upon. For example, the need to travel from home to other cities and hospitals for care constitutes another spatial dislocation. There are also issues with the more severe winter weather and the impact of this on roads and power. According to one nurse:

People with cancer right now, for example, who need radiation, the bottom line is they have to travel to receive their treatment...no oncologists here...so it’s an hour drive to other cities...they go to wherever their oncologist is and receive their first dose and subsequent doses can be given here and then they have to go back occasionally for follow up...it means a lot of travel for them; just navigating the system is a huge stress...try to navigate those buildings, navigate a city they’ve never been in, travel adds an extra burden.

3.1.6 (Dis)located Time

Co-incidental with disrupted space was disrupted time. Caregivers recall how their experience of time was so different from objective time; generally, time slowed, *“The day to day seems to go on forever.”* Considering the short number of months between diagnosis and death, one caregiver reflected, *“So it was kind of fast—and when you’re living it—it’s not so fast!”* One woman explained, *“I think when you’re in it, you don’t...well, I didn’t look at it from a long range view. When it’s over, you sit and you think of from day one to day whatever it was—the last day—so much goes on. You can sort of see it as an overall picture—the day to day seems to go on forever, but the overall picture is more like a capsule.”* Another caregiver referred to wanting to make the most of the time left, *“You want to value every second you have.”*

3.1.7 (Dis)location and Social Support

Health professions reported their experience with the changing demographics of rural life and the impact of this upon family support:

I find in a lot of rural communities, because there was farm like employment in the past, the family support networks (cause we’re talking off reserve) have moved away due to lack of employment or the group has come here to retire and are now in a situation that they have to care for their loved one

because they're retired and they're dying so all the young family that would normally step in more of an urban centre are not around and therefore they can't lean on that group as much as we would in the city.

Vagaries of family dynamics

Family is an idealized construct in the literature; that is, family is assumed to always be a positive resource. The reality, however, is that families may function well or not and these dynamics are accentuated in the caregiving experience and greatly influence women's experience of caregiving. Health professionals perceived that family dynamics could be either supportive to the caregiver or burdensome:

Every family's unique. Some I can just picture they would do absolutely anything for their wife and mother, the kids came home they all kind of pitched in...you know supported each other, it went really well, but situations with a loved one ill at home brings out the best in some families and brings out the worst in others—whatever was dysfunctional before the situation seems to be amplified and the brother and sister who don't get along and now they're trying to make decisions together.

When families function well their provision of social, emotional and practical support provides great relief for the caregivers both during and after the caregiving experience. Thus, caregivers who had strong support from family, whether in the form of siblings and/or children, were able to tell a much more positive caregiving story. One woman had her sons come live with her for the last two months of her husband's life and, although it was an extremely difficult, emotional experience, she was able to be there for her husband without worrying about other details; responsibilities such as cooking and looking after the home, were taken care of by her sons, who also provided her with emotional support. She fondly remembered one son taking her out for a drive and when she finally broke down and momentarily wept he suggested, "*Mom, you know you can cry for more than 25 seconds.*" Another woman described how depressed and lost she felt following the death of her husband, and how her sister came and stayed with her, encouraging her to get up and go for walks when that was the last thing she wanted to do. She acknowledged how much this helped her get back into step with life.

One nurse observed how the quality of the relationship between the caregiver and the recipient of care potentiates or ameliorates the caregiving burden. This nurse observed:

The stronger the relationship with the person they're caring for the less stressful it is for them...when there is a real close loving relationship and they know each other very well they can draw energy from each other, but if it's a really close relationship and its coming to an end that is very stressful as well...as an RN walking into a situation if they didn't function very well before a situation, we're not going to fix that dysfunction we have to work within it in this situation.

Presence of friends

Supportive friends or organizational members, such as church congregations, offer a strong resource to caregivers, in particular, they allow the caregiver to leave the house. Nurses noted the importance of such a social network. The caregivers themselves

underscored the importance of the support they received from their friends. In some cases, it was the woman's friends who provided emotional support, lending a listening ear or providing a chance to get out. Another caregiver emphasized the value of support: "*Just knowing there's somebody out there that'll listen to you and have a good cry once in a while is a good deal.*" In other cases, the care recipient's friends provided support, taking time to sit and chat with them; this allowed the caregiver to take some time away. One woman highlighted the importance of friends: "*your friends...women friends...they just, they stick by you come hell or high water no matter what happens in your life.*" One caregiver was able to go away for a weekend thanks to a friend who offered to take over the caregiving.

Absence of friends

Those caregivers who did not have support missed it very much. One woman had to move away from where she lived, requiring both her children to move schools in order to move into her mother's home in a rural community to provide care. There, she felt isolated and did not have an established network of friends to reach out to. Another woman found that friends stopped calling and visiting because they were not comfortable seeing her late husband in his weak condition; further, they did not connect with her as a single woman following his death, as she was no longer part of a couple. One woman, who had very few social supports in her experience, expressed her emotions through writing and found this to be therapeutic:

I spent so many hours alone when he was sick and sleeping, that I wrote poetry. And I never wrote poetry before in my life, but I was putting my feelings on paper and it would come out in poetry...it is good for people to write feelings down on paper.

3.1.8 (Dis)location and Formal Support

A strong theme throughout the interview data was the importance of support from the formal care system. Front-line health care professionals whom caregivers came in contact with included: nurses, family doctors, surgeons, specialists, social workers, personal support workers, and physiotherapists. It was not just the existence and availability of health care services that mattered to these female caregivers; it was also the nature and home setting of the support, and how care professionals communicated with the family caregiver and care recipient.

Vagaries of Health Care System

Some caregivers were fortunate to have access to their community's family health team for palliative care service provision. In one woman's case, "*Pretty well anything I needed for [spouse, care recipient] was there. The doctor came once a week...she was the most wonderful doctor you could ever ask for.*" This woman also had support from a hospice coordinator, a nurse, and a social worker who followed up with her after her husband's death. She articulated that this team-based care should be available to anyone who ends up in her situation. It was especially important for caregivers to receive support in the home setting, as well as to have continuity of care so that a trusting relationship could be built with the same set of front-line health care professionals. Family caregivers found it helpful when they knew the health professionals personally. One nurse echoed this advantage for medical service delivery in small rural communities, where family doctors still make home visits.

Not all caregivers, however, had a positive experience with the formal support system; some front-line health care professionals did not reach out and caregivers responded by trying to provide the majority of care on their own in the home. One participant expressed that she did not know about a support system and did not research what was available: *“You don’t actually pursue the support system...you don’t know what’s available and you’re so busy dealing with so many things that...you just get through it the best you can.”* Similarly, health professionals observed that navigating the system is confusing for many caregivers, *“sometimes during treatment the family doc is left out of the loop, so who does she (sic) call? Does she (sic) try to get the oncologist? Or my family doctor?”* Family caregivers mentioned certain gaps in the health care system. Due to the distance required for travel to run errands or get away, having a home care worker in the home for three hours was not enough for caregivers to leave and do what was needed. Caregivers also expressed frustration regarding the lack of communication and clarity of communication of health professionals, as well as issues regarding the dispensing of medication.

Health professionals described how living in rural communities means access to care is variable depending on times of budget years and presence or absence of health care professionals:

Just because of funding and availability of personnel to do the work, there are times of the year that CCAC has a nice flush budget and they are liberal and provide lots of care but as you get near the end of the budget year they will restrict the amount of service they can provide so in some ways it’s not consistent...and being in a rural area they don’t always have the bodies to do the work.

Caregivers themselves also mentioned the drastic drop in supports once the care recipient passed away. One woman, who had an extremely positive experience with the palliative care team that supported her husband, shared what happened after the death: *“everybody was, you know, getting their stuff out and then they’re gone! From your everyday constant people in and out... gone to absolutely nothing. And you didn’t have your husband there either.”* Several caregivers mentioned that they needed and/or were seeking grief counselling; in addition, many had their own health issues to deal with.

3.1.9 (Dis)located Health

The consequences to women of providing end-of-life care in the home were highlighted by the participants. Many shared the physical and mental health sequelae of caregiving that were manifest during and after the caregiving experience. One key informant described caregivers as being *“out of their routine”* by which they mean their normal activities of daily living such as eating and sleeping are disrupted. In addition, anything else they used to do is replaced with caregiving described as a *“24/7”* responsibility. Thus, caregiving disrupted self-care routines. Women caregivers seem to lack insight into the toll caregiving takes on their health and well-being. According to one nurse, *“they present with distress and anxiety and a physical symptom that they don’t understand why they’re having it.”*

3.2 Physical (Dis)location

Caregiving is physically exhausting. Nurses cite lack of sleep, the unrelenting day/night nature of caring required and the emotional toll that care-giving extracts, *“the worry that goes along with that.”* The most common negative health impact that all caregivers mentioned was a lack of sleep and an inability to sleep. Family caregivers either lost sleep because of attending to the care recipient overnight, or could not fall asleep because they were too worried and anxious about the state of the care recipient, *“So I quit taking my medication because I was afraid that if I didn’t hear him he was going to fall.”* Similarly, cessation of eating was reciprocal, *“I quit eating because I didn’t cook for myself, and I didn’t feel like I should be eating in front of him because he kept saying he wanted to eat but he couldn’t.”*

Lack of self-care is the cardinal characteristic of caregiving it seems. Nurses described this cessation of self care as *“the first thing they don’t do anymore because they’re caring for their loved one”* and/or *“they don’t have the opportunity to leave the home to get it done.”* So, women no longer keep up with their usual screening tests such as pap smears etc. If women had pre-existing health conditions, they neglected these during the caregiving experience. For example:

I quit taking my meds for my headaches and my own problems increased—I couldn’t eat properly, which didn’t help any. My weight went way down. Sleeping? You can forget about sleeping! Until this day, I haven’t slept in my bed.

Health professionals describe how women “come into the clinic complaining of headaches—a lot of chronic pain or headaches”; women also mentioned an increase in blood pressure, pain, and depression. One nurse observed that women lack insight into the correlation between caregiving and these alterations in health. Rather, they see such illness as poorly timed interferences that risk undermining their ability to provide care. According to one nurse:

When they do come in they’re less concerned about their health and more concerned with the situation that they are living in, so social worker gets involved and provides psychosocial support and tries to rally other family support and allows the individual to come to the realization that they need assistance.

Some caregivers reported that caregivers did not observe a decline in their health; a few of these same caregivers were better able to acknowledge the impact they felt after the death of the care recipient:

It wasn’t too long after caring for my mom and then getting back to work and...I really just kind of—turned into soup, I guess, you know, just let it all catch up with me. Like, you can only go so long.

Several caregivers also described a period of depression following the death of the care recipient, where they were prescribed anti-depressants or felt little motivation to get out of bed in the morning.

Financial wellbeing also played a role in the caregiving experience. For women who had secure employment or who had savings available, there were fewer financial stresses as a result of the caregiving experience when compared to those who didn't have access to these resources.

Several caregivers experienced compromised financial wellbeing due to taking unpaid time off or quitting work to provide care; most of these caregivers had no safety net to bounce back on. Caregivers who were receiving government assistance expressed that this was not enough to cover all of their expenses and that financial insecurity was a source of stress.

3.2.1 Emotional (Dis)location

Nurses used the metaphor “*roller coaster*” to describe the dynamic emotions experienced by caregivers:

Guilt, emotionally charged hurt, fear, anxiety, grief, loneliness, impatience, resentment, anger, overwhelming sense of loss, love, sense of wanting to protect this person, sense of being out of control, terms I've heard most from families and care-providers: rollercoaster, good days/bad days; hope/hopelessness.

Caregivers themselves reported having experienced many difficult emotions as they watched someone they cared about deteriorate; they described the experience as “*heart-wrenching*”, as being in “*mental anguish*.” Participants found relief in being able to express their emotions, whether they had a friend to confide in, or whether they were able to talk openly with their family and/or the care recipient.

4.0 Discussion

This research aimed to theorize the situation of gendered end-of-life caregiving in rural Ontario and in particular, the extent (if any) to which geography exerted any influence upon this experience. Our findings assert the significance of subjective geography rather than physical geography; that is, the predominant sensitizing concept of this situational analysis is (dis)location of self. This is not to negate the influence that rural location (as well as other factors) exerts upon the multiple disruptions that constitute this central experience, however. As researchers, we expected that the importance of place, specifically the rural context, would be strongly reflected in the caregiver data; surprisingly, we found that it did not. This constituted what Adele Clark calls the “analytic turning point”; our analysis turned from the health implications of caregiving in a rural location—a dislocation of place—to the health implications of (dis)located self, ameliorated or potentiated by location. As such, our findings are highly congruent with the body of literature regarding the experience of end-of-life caregiving. Our findings are noteworthy, however, in this similarity of caregiving experience regardless of location as far as caregivers are concerned. Our findings add to other feminist studies that emphasize specific similarities such as “intimate connections and continuities between different sites and contexts in which caring occurs” (Bondi, 2008, p. 258).

The sensitizing concept of (dis)location is very similar to what others have referred to as “a total disruption” in caregiver's lives (Farber et al., 2003; Houdin, 2007), and “turmoil” (Read & Wuest, 2007) defined as a “state of

upheaval where normal patterns of life are disrupted for the daughters within immediate and extended families and in social roles” (p. 935). (Dis)location of self, however, is distinguished by its interiority—in addition to the disruptions of life and turmoil our caregivers experienced, this concept emphasizes the profound upheaval of the self that occurs when confronted with the imminent death of a loved one. Indeed, although we did not specifically seek spouses or others who loved the dying person they cared for, these are the very participants who responded. Only one of our participants referred to her sense of filial obligation, reflecting Read and Wuest’s (2007) discovery that daughters feel a “responsibility” or “moral duty” to care for their parents. Spousal love, then, may be significant to our findings. However, others have elucidated an intrinsic emotional bond within caring relationships generally (Lawson, 2007); it would appear that this emotional bond in the end of life caregiving relationship is critical to the (dis)location of self.

(Dis)location of self marks the cleaving of a dyad by dying. It is analogous to ‘existential crisis’ fraught with severe emotional distress and life and death concerns. The grieving of this imminent loss is the key process of this study and transformational for both caregiver and care recipient: both are dying, though, for the caregiver, with penultimate finality. Scott (1997) describes two paradigmatic interpretations of the “letting-go processes of grieving”: critical social theory and depth psychology (p. 41). Social theorists view personal transformation as either a dialectic in social interaction and action, or a by-product of the social forces at play (Scott & Schmitt-Boshnick, 1994). A large proportion of caregiving research is situated within this paradigm—women caregivers are particularly conceptualized as being constructed by social forces, especially gender, as well as economic trends that have shifted care from hospitals to informal caregivers at home. Certainly, the transformation of women to caregivers is a social accomplishment. In addition, the transformation of caregivers occurs in social interaction with the care recipient—they experience parallel disruptions, like the “existential plight” experienced by both daughters, and their mothers who were newly diagnosed with breast cancer (Raveis & Pretter, 2005). In our study, as our data reveals, when the caregivers were asked to describe their experience, they inextricably described both their own disruption and the parallel disruption in the care recipient. Bondi (2008) explains that change is relational, “selves are shaped and re-shaped in relation to others” (p. 262).

By contrast, analytic depth psychology focuses upon personal transformation through expanding consciousness. Whereas critical social theorists regard the self as primarily a rational entity whose primary function is to promote intellectual and rational capacities, by contrast, in analytic depth psychology, the self also includes the unconscious. Transformational grieving is not a rational process although it includes rational abilities. Asking why the caregiver does not take care of herself conceptualizes the caregiver as a rational self. To ask why the caregiver doesn’t verbalize e.g. ask for help, assumes the transformational capacity of dialogue as a way to “sort out the meaning of our loss” (Scott, p. 46). A depth orientation emphasizes “the profound emotional experiences that force us to grieve the loss of what used to be a meaningful state of being before we move into another state that is deeper, wise, and more in tune with body and souls, and the material world” (Scott, p. 45). Transformation from the depth perspective is facilitated by explication of “internal and subjective experience rather than external, objective experience” (Scott, p. 46). According to Scott:

That does not mean that we do not engage in dialogue or seek out helpers in the grieving process, but because the transformation process is fundamentally extra-rational and intensely personal, the “sitting” (listening or waiting) within the images requires us to descend into a kind of darkness...This fall is a going deeper into the self” (p. 46).

Women caring for loved ones at the ends of their lives experience, too, this type of transformational grieving. This deeper engagement with one’s self may explain the many of the disruptions they experience: their apparent isolation from society—what has been referred to as cocooning (Dawson & Kristjanson, 2003), their inability to conduct themselves rationally e.g. look after themselves, despite the assumption of rational abilities such as learning to give medications. Even the inability to sleep may be indicative of this.

Existential crisis is transformational in the sense that when the crisis resolves, people are changed. Caregiver transformation may be characterized as spiritual in the sense that their main concern in life is altered—Scott (1997) asserts that people who have experienced the loss of a loved one have “a heightened sense of what is essential and what is not essential” (p. 8)—our findings suggest a greater valuing of relationships than materiality. Caregiving at end of life is spiritually transformative—soul work. In sum, (dis)location of self is transformational grieving accomplished both rationally through social forces that induce disruption, as well as extra-rationally, induced by the existential crisis of imminent loss.

The results present a significant disjuncture between the discourse around rurality and rural health care whose textual representation of care provision in rural communities emphasize the rural location and lack of health care services, and the actual embodied experience of women providing end-of-life care. Although physical geography is discursively conceptualized as the biggest issue, in fact (dis)located self seems to be. It would appear then that although women are aware of the implications of geographic location upon their caregiving experience these are peripheral to the (dis)located states induced by the caregiving experience itself. This habituation to rural life in addition to gendered roles may have implications for degree of burden, subsequent adverse health and compromised self-agency.

Caregiver habituation to gender role and rural life is situated within a social world of palliative care characterized by liberal individualism and allopathic medicine. These factors conspire to put the burden of care on the woman providing care at the same time as it undervalues this work; similarly, the focus is upon the dying person while the woman herself and her health and well being are barely regarded. Although palliative care by definition incorporates the family as the unit of care, in practise it is still very much focused on the patient only. Our analysis has revealed that women in rural and remote regions providing end-of-life care in the home are the backbone, the primary actors in the care provision of the dying person. They are doing this intensive work with comparatively less formal support and resources than their urban counterparts; they are not, however, aware that this is the case and continue to provide care until they can no longer go on. They exemplify what Wuest & Hodgins (2011) termed the precarious ordering of caregiving agency taking on this role quietly and successfully, learning new skills and performing tasks they never would

have imagined performing. Their agency for the care recipient however is different from their own self-agency; they silently suffer health consequences (physical, emotional and financial), both during and after the caregiving experience. Our liberal-individualist culture in North America neglects the inextricably relational nature of care provision and receipt—for example, the identity and well-being of the caregiver is intimately connected to that of the care recipient; the caregiver cannot imagine life apart from this person, and when death results in separation, the caregiver is left with more than the loss of a significant other in their lives. Thus there are two deaths: the physical end-of-life of the care recipient and the dislocation of self or the end-of-life as it was known by the care provider. This dislocation of self and requisite reformulation happens without acknowledgement or support from the health care system.

The distance of rural women from health care services could be paralleled with the distance between womens' experience of self during caregiving and their former self. In a rural setting, the greater distance of both may raise the risk of caregiver burden, and result in unintended, long-term consequences on the caregiver's health and wellbeing. In recognition of the (dis)located state of women during this experience, it is important for health care providers and policy-makers to ask the question: what are we doing for her? It is not enough to provide practical support to the dying patient during their last days. Women caregivers do not take care of themselves or mobilize supports for themselves because their selves are (dis)located.

Although there is evidence that demonstrates the vulnerability of rural communities, it is important to consider who is being impacted by these realities, and to acknowledge the totality of their situation. In so doing, strategies to minimize caregiver burden can be holistically addressed. Rural women take on the role of end-of-life caregiving and are doing the work on their own, for the most part. The results of this analysis demonstrate the gap between the assumptions of the majority of stakeholders involved in the analysis of the health care system, and the actual experience of female caregivers. Caregivers' appreciation of providing care at home does, in fact, reinforce the current policy direction around "ageing in place", specific to the advocacy work being done to insure that patients die in the location of their choice. Although caregivers preferred to care at home, it is evident that the health care system is not adequately supporting caregivers to be able to do so while maintaining their health and quality of life. Figures 1 and 2 provide a visual representation of the situation of rural female women providing informal care to someone at end of life; Figure 1 is ordered, while Figure 2 demonstrates the intersecting social worlds for women providing end of life care in rural communities.

<p>Individual Human Elements/Actors</p> <ul style="list-style-type: none"> • Self (the woman) • The person who is dying • Her best friend/his friends/ their friends • Her family/his family (children) 	<p>Discursive Constructions of Individual and/or Collective Human Actors</p> <ul style="list-style-type: none"> • The devoted wife, caring daughter • Emphasis on biomedical model • Focus on human actors as “individuals” rather as interconnectedness between patient, caregiver, family
<p>Collective Human Elements/Actors</p> <ul style="list-style-type: none"> • Formal care system – Family health team/palliative care team, including doctors, nurses, personal support workers, social workers, specialists, hospice, grief counsellors • Funeral homes • Community • Church 	<p>Implicated/Silent Actors/Actants</p> <ul style="list-style-type: none"> • Bodies • Minds • Emotions • Pain
<p>Political/Economic Elements</p> <ul style="list-style-type: none"> • Neoliberalism – de-institutionalization • Policy focus of “ageing in place” and “care in the company” • Strained health care resources • Individual responsibility • Work – paid versus unpaid 	<p>Discursive Construction of Nonhuman Actants</p> <ul style="list-style-type: none"> • Rural discourse – idealization of social cohesion: constructed as “under-served”
<p>Temporal Elements</p> <ul style="list-style-type: none"> • Patient’s health status (declining over time) • History between caregiver and care receiver (length of time in a relationship) • Length of time providing care • Seasons – winter 	<p>Sociocultural/Symbolic Elements</p> <ul style="list-style-type: none"> • Gender – women providing care in the home • Idealization of family, marriage, home
<p>Major Issues/Debates</p> <ul style="list-style-type: none"> • Death in home versus death in hospital 	<p>Spatial Elements</p> <ul style="list-style-type: none"> • Home • Geographical location • Rural context: distance to travel to access specialist health care: distance fro practitioners to visit homes • Rural health care services piecemeal and imported from urban models • Proximity in relationships – closeness
<p>Non-human Elements: Actors/Actants</p> <ul style="list-style-type: none"> • Palliative care • Medications, pain and symptom management, medical technologies • Finances • Multiple responsibilities – paid work, caregiving, household chores 	<p>Related Discourses (Historical, Narrative, and/or Visual)</p> <ul style="list-style-type: none"> • Gendered roles, expectations of women to be caregivers • Choice versus conscription? What is our obligation to the other? • Salt of the earth – stoicism

Figure 1. Ordered Situational Map

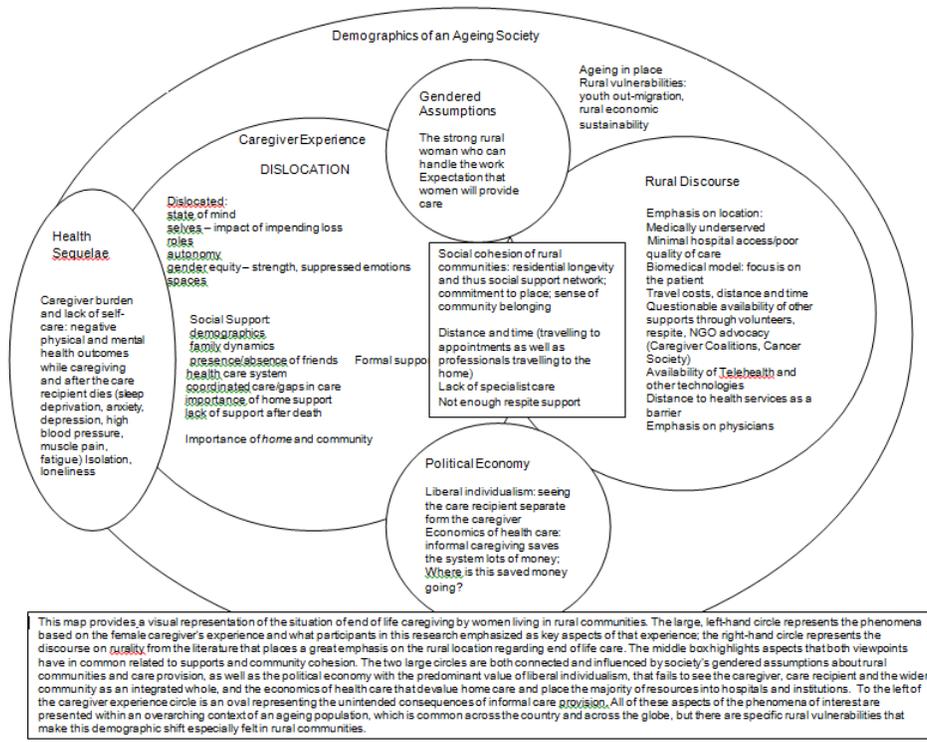


Figure 2. Social Worlds of Rural Caregiving Map

5.0 Conclusions

Situational analysis is a cartographic approach that facilitates the consideration of multiple perspectives such that any one does not dominate but is kept in view with all others. It facilitates to visualize the data differently provoking new ways of seeing. For example, considering pain as an element in Map 1 allows us to consider pain in both the caregiver as well as the person who is dying. Instead of traditional linear thinking exemplified by consideration of one thing or another, SA permits seeing data in relation with each other. Such juxtapositions facilitated consideration of female caregivers' actual experiences versus the social discourse that exists about them. This is critically important in the case of female provision of end-of-life caregiving in rural and remote Ontario communities. Dominant discursive representations of this experience emphasize the rural characteristic as if it is the defining feature of the caregiving experience. We expected that women's rural location would be an important feature in their telling of their caregiving experience. Stunningly, however, unstructured interviews with 9 caregivers who shared their experiences in interviews lasting 1-2 hours barely mentioned location as a noteworthy factor. According to the caregivers in our study, the predominant feature of their experience was not their dislocation from urban settings, and hence a dislocation from services, but rather a (dis)location of themselves. For female caregivers in rural and remote settings, place is taken for granted. Rurality is a constant given that the caregivers had 'always lived here' and 'know everyone'. Women caregivers did not specifically mention rurality as having any influence on their experience, "Just where we live our life." However, the (dis)location of caregiving may be influenced by rurality insofar as it affects ameliorating or

potentiating factors, such as access to professional health care supports. Indeed, one caregiver advised that services should be “*offered to people*” since women are “*going through the motions in a shocked state.*” Rural women just “*going with the flow*” may be unwitting perpetrators of the conditions that exacerbate their vulnerability and invisibility.

In the literature and policy discourse, place is at the forefront; consequently, there seems to be a lack of awareness or emphasis on the centrality of the (dis)located state end-of-life caregiving induces as well as its unintended consequences. Similarly occluded are the deeply contextualized experiences of family, friends, relationships and rural life itself. Despite their discursive idealization, these elements may add further dimensions to the burden of caregiving that women must silently bear. These are indications for future research. Women are acknowledged as the cornerstone of end-of-life caregiving at home. It is the responsibility of the system to bring her into view and set their sights on her physical, emotional and financial support; local public and health programs need to not only provide such supports but make them known and available. Further, ongoing advocacy for state-provided services such as specialized interdisciplinary palliative home care services and caregiver-centric programs, such as the Compassionate Care Benefit and grief counselling among others, are necessary such that all constituent elements in her (dis)location are addressed.

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