




# Women's Caregiving Experience of Older Persons Living With Alzheimer Disease and Related Dementias and Multiple Chronic Conditions: Using Wuest's Theory

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## Abstract

**Introduction:** Care of persons living with chronic conditions rests heavily on women within the context of the family. Research demonstrates that women experience more caregiving strain compared to men, yet less is known about the differences in experiences between women carers: namely, wives and daughters.

**Objective:** The purpose of this study was to examine and compare the experiences of wife and daughter carers of older adults living with Alzheimer disease and related dementias, plus at least two other chronic conditions.

**Methods:** Using qualitative description with Wuest's feminist caring theory of *precarious ordering* as an analytic framework, interview transcripts of women carer participants who were from the control group of a larger multi-site mixed methods study evaluating the web-based intervention My Tools 4 Care were analyzed.

**Findings:** Both wives and daughters experienced daily struggles, altered prospects, and ambivalent feelings around their caring role. Negotiating the role of professional carer was an important part of balancing caring demands and anticipating the future, and women took an active role in trying to harness caring resources. Findings indicated wives and daughters were generally similar in how they described their caregiving, although daughters reported more shared caring and decision-making, and needed to balance paid employment with caregiving.

**Conclusion:** Wives and daughters face similar challenges caring for persons with a dementia and multiple chronic conditions, and actively engage in strategies to manage caring demands. The findings illuminate the importance of accessible, appropriate support from professional carers/health care providers, and suggest that assistance navigating such supports would benefit women carers.

## Keywords

older adults, women caring, qualitative description, dementia, chronic illnesses

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## Introduction

Carers play an invaluable role in the care of persons living with Alzheimer disease and related dementias (ADRD) and multiple chronic conditions (MCC; Ploeg et al., 2017). Caregiving activities depend on the care recipient's conditions and may include assisting with personal care, preparing meals, transportation to

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appointments, managing finances, maintaining the household, and securing formal care (National Alliance for Caregiving [NAC], 2015; Sinha, 2013). In the case of a relative with ADRD and MCC, the complexity of conditions that contribute to added debilitation (Bunn et al., 2014) may create further challenges than caring for a relative with a single condition (Peacock et al., 2017).

Historically, care of persons with chronic health needs has rested heavily on women within the context of the family (Caputo et al., 2017), as women are believed to have a natural aptitude for caregiving (Toepfer et al., 2014). The NAC (2015) estimates that women make up approximately 60% of carers to older adults. Research suggests that women spend more time and provide more care compared to men (Chappell & Hollander, 2013; Pinquart & Sorenson, 2006). Owing to the heavy responsibilities and perceptions of caregiving, women report significantly higher levels of strain, distress, and depression compared to men (Pillemer et al., 2017; Sharma et al., 2016), with wives emerging as the most vulnerable (Chappell et al., 2015). Daughters, however, are a significant group of carers for older adults and are often referred to as the *sandwich generation*, due to the competing demands of caring for their own children in addition to a parent (Steiner & Fletcher, 2017). As the caregiving experience for women differs from that of men, and is considered more stressful, it is important to understand their experiences within a sociocultural milieu in which the bulk of carers are women. Additionally, it is important to explore potential differences between wives and daughters given their unique life stages.

## Review of the Literature

In previous literature, there have been some comparisons of the experience of wives and daughters as carers for persons with ADRD. Comparing wife and daughter carers on lifestyle and health behaviours, McKibbin et al. (1999) found that daughters engaged in smoking more than wives; otherwise, the sample was similar across both positive (e.g., exercise) and negative (e.g., alcohol consumption) behaviours. Rabinowitz and Gallagher-Thompson (2007) found daughter carers of a person with ADRD were more likely than wife carers to report higher rates of high blood pressure or a chronic lung condition, as well as recent weight gain, and concluded these negative outcomes may be related to role multiplicity and the resulting stress on daughter carers. Through comparing wife and daughter/in-law carers, Simpson and Carter (2013) explored the role of mastery (sense of control that one feels) in caring for a person with ADRD, as well as stress and depressive symptoms. Although wives and daughters/in-law reported similar levels of stress and depressive

symptoms, increased carer mastery was strongly related to lower stress and depressive symptoms for wives alone.

Comparative studies of carer experiences in the context of ADRD and MCC between wives and daughters are currently limited and what does exist is quantitative and focused on ADRD alone. The authors could locate no other work that compares the subjective experiences of wives and daughters in the context of caregiving in ADRD and MCC. Given the important role women play in family caregiving, the authors sought to answer the following research question: “*What are the caregiving experiences of wives and daughters to older adults with ADRD and MCC?*” To give voice to women and challenge the context of their caregiving, the use of a feminist theory of women’s caring (Wuest, 2001) as a framework supports the purpose of this study to examine and compare the experiences of these wives and daughters.

## Theoretical Framework

Scholars have previously argued that caring is generally not culturally positioned as *real work*, yet it is a central element of women’s lives and should be highlighted as a key women’s issue (Eriksson et al., 2013; Wuest, 2000). The present research aims to contribute to the body of literature highlighting the complexities of women’s caregiving. This work is grounded in a feminist perspective of caring which brings to the foreground women’s personal experiences, as situated within a broader social, political, and cultural context (Eriksson et al., 2013).

Wuest’s (2001) feminist theory of women’s caring, termed *precarious ordering*, was utilized to understand the experiences of wife and daughter carers to an older adult with ADRD and MCC. This theory was developed with women from diverse caregiving situations, and reflects the relational, social, emotional, and physical processes of women’s caring. Wuest argued that the basic problem for women carers lies in changing and competing caring demands, and that women engage in precarious ordering as they develop strategies to meet these demands and ameliorate negative consequences (fraying connections) they engender. The processes of precarious ordering are setting boundaries (placing limits around caring demands), negotiating (interacting with helpers and systems to facilitate acceptable caring), and repatterning (restructuring care). Within each of these processes, women develop skills and employ ordering strategies in order to alleviate experiencing fraying connections. Wuest’s (2001) feminist theory was chosen because of its strength in considering not only women’s accounts of their situated, embodied experiences, but also how their experiences are embedded within broader social and structural contexts; this is important from a feminist perspective (Eriksson et al., 2013).

Moreover, Wuest's framework is well-suited to explore women carers' agency in navigating their particular caring circumstances: the processes involved in how women negotiate caring is an important focus for research.

## Methods

This study is part of a larger multi-site mixed methods pragmatic randomized controlled trial that was conducted in Alberta and Ontario, Canada. The purpose of the larger study was to evaluate the My Tools 4 Care web-based intervention with carers of community-dwelling older adults with ADRD and MCC (Duggleby et al., 2018). Given the resulting rich qualitative data, the present study consisted of a secondary analysis of the women control group participants' interview transcripts.

### Design

This secondary analysis was guided by qualitative description, which seeks to provide a complete rendering of the phenomenon under investigation (Sandelowski, 2000, 2010). Qualitative description is an appropriate methodology for the study because the aim was to provide a comprehensive description and interpretation of the experiences of women caring for older adults with ADRD and MCC. Furthermore, a qualitative description approach supports the use of theory to analyze data; our present study utilizes a feminist framework, namely Wuest's (2001) theory.

### Sample

The larger study included 199 carers, with the following inclusion criteria: 18 years of age or older; a family/friend caring for an older adult (65 years and older) living with ADRD and at least two other chronic conditions in the community; and have an email address and access to a computer. Further details regarding participant recruitment and data collection, as well as study findings, have been reported elsewhere (Duggleby et al., 2018; Ploeg et al., 2018). The present study involves women in the control group: 15 wives and 18 daughters/in-law ( $N=33$ ; daughters/in-law referred to hereafter as "daughters").

### Data Collection

The protocol for the larger study has been published elsewhere (see Duggleby et al., 2017). Qualitative data were collected by trained research assistants via telephone at 1 and 3 months, using a semi-structured interview guide with questions such as: *In the past three*

*months did you do something to help you deal with the significant changes you experience as a caregiver? What do you feel would help you most as a caregiver?* Audiotaped interviews lasted 30–60 minutes and were transcribed verbatim by an experienced transcriptionist. The present study uses the third month interview data.

### Data Analysis

Transcripts were analyzed by the primary and second author, who initially completed an open reading of each transcript to gain an overall understanding of the content. The authors then did a directed content analysis (Hsieh & Shannon, 2005), using Wuest's feminist theory (2001) as a framework. Data were coded by the second author (codes consisted of the key meaning in each data element) and codes were organized in relation to Wuest's key concepts. Data from the wives and daughters were analyzed separately and then compared. The relationship of codes to Wuest's concepts were agreed upon with the first author, to enhance rigour. Data were subsequently interpreted to illustrate the experiences of the participants in relation to Wuest's theory. Content analysis is a flexible method, and a more deductive, theoretical approach that facilitated comparison of the experiences of wife and daughter carers to persons with ADRD and MCC. Trustworthiness of the data was maintained by transcribing interviews verbatim, using the actual words of participants in the findings, coding non-supporting data pertaining to Wuest's theory, and completing an audit trail (Hsieh & Shannon, 2005).

### Institutional Review Board Statement

The larger study and data collection were approved by the Hamilton Integrated Research Ethics Board in Hamilton, Ontario (#15-309) and the Health Research Ethics Board from the University of Alberta (Pro000048721). The researchers received ethical approval from the University of Saskatchewan (REB #18-49) to complete the present secondary analysis.

## Findings

### Participants

Participants ( $N=33$ ) were primarily Caucasian, with a mean age of 74 years (range 66–88) for wives and 55 years (range 39–65) for daughters. All wives and the majority of daughters were married or in a common law relationship. Most women (73% of wives and 78% of daughters) stated their finances were sufficient to meet their needs. Of the daughters who worked outside the

home, approximately 36% worked full-time, 55% part-time, and 9% were casually employed. Wives indicated being in their caregiving role for an average of 5.5 years (range 2–14), while daughters were caregiving for an

average of 4.2 years (range 1–10). All wives cared for a male spouse while daughters predominantly cared for their mothers; see Table 1 for other key characteristics of the participants.

**Table 1.** Demographic Characteristics of Wives and Daughters.

Variable	Wives <i>n</i> = 15		Daughters <sup>a</sup> <i>n</i> = 18		Total <i>n</i> = 33	
	<i>n</i> (%)	Mean (SD)	<i>n</i> (%)	Mean (SD)	<i>n</i> (%)	Mean (SD)
Region						
Alberta	6 (40.0)		7 (38.9)		13 (39.4)	
Ontario	9 (60.0)		11 (61.1)		20 (60.6)	
Age		73.66 (5.82)		54.88 (6.87)		63.42 (11.40)
What is your marital status?						
Single	–		1 (5.6)		1 (3.0)	
Married	15 (100.0)		13 (72.2)		28 (84.8)	
Widowed	–		2 (11.1)		2 (6.1)	
Divorced/separated	–		1 (5.6)		1 (3.0)	
Common law	–		1 (5.6)		1 (3.0)	
What is your ethnicity?						
Caucasian	15 (100.0)		17 (94.4)		32 (97.0)	
Black	–		1 (5.6)		1 (3.0)	
How many years of education did you complete?		13.10 (2.57)		14.16 (2.00)		13.68 (2.31)
Are you employed?						
Yes	–		14 (77.8)		14 (42.4)	
No	15 (100.0)		4 (22.2)		19 (57.6)	
The number of years caregiver has been in caregiving role		5.53 (3.71)		4.2 (2.28)		4.81 (3.04)
Do you get assistance with caregiving?						
Yes	11 (73.3)		13 (72.2)		24 (72.7)	
No	4 (26.7)		5 (27.8)		9 (27.3)	
Do you have any medical conditions?						
Yes	12 (80.0)		11 (61.1)		23 (69.7)	
No	3 (20.0)		7 (38.9)		10 (30.3)	
Total number of medical conditions of caregiver		2.08 (1.50)		1.63 (0.80)		1.86 (1.21)
Are you actively practicing your religion?						
Yes	5 (33.3)		3 (16.7)		8 (24.2)	
No	9 (60.0)		14 (77.8)		23 (69.7)	
No answer	1 (6.7)		1 (5.6)		2 (6.1)	
What is your estimated annual household income before taxes?						
Less than \$10,000	–		1 (5.6)		1 (3.0)	
\$20,000–\$29,999	1 (6.7)		–		1 (3.0)	
\$30,000–\$39,999	3 (20.0)		–		3 (9.1)	
\$40,000–\$49,999	1 (6.7)		–		1 (3.0)	
\$50,000–\$59,999	2 (13.3)		3 (16.7)		5 (15.2)	
\$60,000–\$69,999	1 (6.7)		–		1 (3.0)	
Greater than \$70,000	3 (20.0)		9 (50.0)		12 (36.4)	
No answer	4 (26.7)		5 (27.8)		9 (27.3)	
Do you live with the person with dementia for whom you provide care?						
Yes	15 (100.0)		8 (44.4)		23 (69.7)	
No	–		10 (55.6)		10 (30.3)	
What is the age of the person you are caring for?		79.06 (8.57)		83.44 (8.05)		81.45 (8.45)
What is the gender of the person you are caring for?						
Male	15 (100.0)		1 (5.6)		16 (48.5)	
Female	–		17 (94.4)		17 (51.5)	

<sup>a</sup>Note: Daughters and daughters-in-law have been combined in the analyses.

## Experiences of Wives and Daughters

A goal of this analysis was to examine the experiences of wives and daughters as distinct groups given their unique social locations, and how they may negotiate care differently. The data illustrated however that wives and daughters were generally similar in their descriptions of caregiving. Findings are therefore illustrative of participants in general, and differences between wives and daughters are described where pertinent. Furthermore, the consequences of ADRD (as opposed to MCC) dominated caregiving experiences. The findings fit well with Wuest's (2001) feminist theory and describe the fraying connections described by these wives and daughters, and the processes that manifested as part of precarious ordering as they adjusted to caregiving demands and their consequences.

## Manifestations of Fraying Connections

Wuest (2001) described fraying connections as women's reactions to changing and competing demands experienced as part of caregiving. These fraying connections are encapsulated by *daily struggles*, *altered prospects*, and *ambivalent feelings*, all of which were described by the women in this study.

**Daily Struggles.** Daily struggles are those which might manifest in the everyday caring work women perform, dilemmas related to caring and competing demands, adversity related to formal systems, and conflicted relationships (Wuest, 2001). Challenges for wives and daughters caring for a person with ADRD and MCC included: balancing caring with other tasks; lack of time for self, family, and friends; financial difficulties; and struggles with care recipients' behaviours. The memory issues and distressed behaviours of care recipients were a major challenge for many carers in this study. One wife described her increasing frustration with her husband's questions: "A lot of repeating . . . he'll ask me what day it is, I tell him, then he'll ask again. I make up a board [with date] . . . He knows that board is there. It would be so easy for him to get the answers himself" (W339).

In line with Wuest's (2001) theory, daily struggles experienced in relation to caregiving could be exacerbated by pre-existing health issues or lead to fatigue, burn-out, and health problems. One daughter explained, "I have rheumatoid arthritis, and I've noticed, I think the bursitis comes out when I'm stressed. So, I haven't been sleeping very well at night just because there's a lot going on" (D307). These issues were not always addressed, and efforts to engage in formal services could also constitute a struggle: "They tell you that, you know, they're going to phone you back and then you don't hear from them

again; sometimes when you do hear back from them, it's not always a practical outlook or solution" (W004). Carers described "jumping through hoops" to attain services that often did not meet the needs of the care recipient or themselves. Some carers did not receive informal support and assistance, which intensified their caregiving responsibilities.

Daughters described an additional struggle, which was balancing caring with employment; this was not an issue for wives. Many daughters described conflict between paid work and caregiving tasks, and how this dual role affected both their ability to provide the care they wanted to and their employment, in terms of financial consequences and performance. Two participants explained how they felt as though their employment was in jeopardy due to caring demands. Another daughter explained: "I have to be honest, it's very hard to do my job. It's really— it's not easy. If I were sitting in an office, I wouldn't be able to do it" (D327).

**Altered Prospects.** Caregiving demands meant that the expected or previous structure of women's lives was altered, which Wuest (2001) referred to as altered prospects. This may refer to unanticipated changes to future plans or personal relationships but is related to the need to psychologically adjust to a new way of thinking about one's future. As a wife stated, "When you sign on as a child or spouse [carer], you don't know this is going to happen" (W318). Altered prospects were primarily evidenced by changes in carers' perceived freedom, and the consequences on their time for self and relationships. Travel was very difficult or impossible: "I don't find that we can go on a holiday. That's hard. We have no freedom" (D017). Other participants described how their priorities had shifted, so that their time and energy for self, their partner, and other family or friends were diminished. One daughter explained: "Some people don't realize that you're just exhausted and some people who aren't going through the same circumstances don't realize. If they're friends, they want you to come out, but you're exhausted, you don't want to pick up the phone" (D309). Sometimes altered prospects were from the intensity and nature of caring demands. Other times the care recipient was unwilling or unable to socialize, which then limited the outings or events the carer attended.

**Ambivalent Feelings.** Wuest (2001) described ambivalent feelings as the mixed emotions which arise from caregiving demands, and suggested they arise from the discrepancy between beliefs about caring and how it is experienced. These feelings reflected in the data were primarily of a negative nature (sadness, stress, and frustration). Key to participants' ambivalent feelings was a perceived lack of understanding from others regarding

their caring role: “I try to explain to people at work, but people at work just don’t get it. I hate to tell you. . . Even though I’m in healthcare they just don’t get it, ‘cause they’re not living it themselves” (D326). This lack of understanding, which some women experienced from other family, friends, or colleagues, made them feel as though others did not acknowledge the challenges they were experiencing. Negative feelings could be offset by caring rewards, such as appreciation from the care recipient or family members and pride in one’s caregiving abilities: “I’m the centre of my family. I know that I give my brothers and sister peace of mind that my mother’s here. . . they see she’s doing well, she’s dressed, she’s clean, she eats, she’s not sick, she doesn’t look like death warmed over” (D314). Several wives also described feeling fear: “Even though he’s 96 years of age, he’s been the strong one and he’s been the decision-maker . . . financially, I’m going to have to really cut back. My future is frightening for me” (W325). For two wives, fear was related to loss and grief; another experienced fear related to the use of formal carers coming into their home.

### Strategies to Manage Fraying Connections

An important aspect of Wuest’s theory (2001) is that women proactively work to manage fraying connections in the face of caregiving demands, and engage in the processes of *setting boundaries*, *negotiating*, and *repat-ternizing* in order to improve their caregiving situation. These processes are iterative and strategies evolve as caring demands emerge or change. Moreover, they are influenced by contextual factors and constraints such as geographical location, availability of formal and informal support, and cultural ideals around care.

**Setting Boundaries.** Boundary setting refers to strategies used to limit the number, type, and intensity of caring demands (Wuest, 2001). Attending to one’s voice (Wuest, 2001) involved carers’ considerations of their limits, as well as whether current caring demands were legitimate and necessary. Wives and daughters balanced their personal needs and limits against the needs of the care recipient and caring demands. This could entail compromises on daily tasks such as doing less/simpler cooking or accepting help from others or making larger decisions. For example, a wife described the decision to move: “I’ve had enough of being out here. We live on the lake and my husband really likes it. . . But I guess it’s him or me; his calmness and happiness out here versus my health risk” (W002). For one daughter, setting boundaries involved restructuring employment in order to better navigate caring demands and support her own wellbeing: “I took a different job. . . under a different manager who understands the situation I have at home” (D329).

Making decisions around formal care was an important part of setting boundaries. Many carers were considering or had decided to access more support or long-term care: “I’m looking at possibly using a bit of respite, I’m a bit frustrated in that I’m the person that is not wanting to do it. I think I need to do it, it’s something that I’m working my way towards” (W008). With the degenerative nature of ADRD and some MCC, carers had to assess when formal care was needed as part of setting boundaries.

**Negotiating.** Setting boundaries was important to negotiating, which Wuest (2001) described as the process of interacting with helpers and formal systems to facilitate caring. Women harnessed resources (Wuest, 2001), which refers to the process of using skills, knowledge, and relationships to interact effectively with resources like professional care. Some women experienced challenges accessing resources and navigating the system, and advocated for more (or more effective) services: “Since I’m moving to the city, I’m only going to get 6 hours a week. I’m really discouraged about that. I’m going to have to do some *pressurizing* to change that. I guess there is a shortage of care workers, let’s face it” (W004).

As suggested above, carers’ ability to harness resources was dependent on resources and service availability. Other carers were dissatisfied with the form of services offered, and perceived them to be of poor quality, poorly organized, or unsuitable (e.g., a female care worker for a male care recipient). A daughter described a “weeding out” process, wherein they tried and rejected different types of services. Making services work well also involved back and forth communication with formal carers: “We have a log for the [workers], you just need to be in constant contact and if there’s an issue you need to talk about it. We’re not afraid to have that conversation, so things are working well” (D304).

Reframing responsibility (Wuest, 2001) entailed considerations of responsibility for specific caregiving demands, which wives and daughters negotiated with other family members. A wife described how she was learning how to delegate caring tasks to others, and ask for help from her family: “I’m learning to ask for more, and I’m learning to say to them when we’re home, ‘You guys need to do this’” (W323). A daughter explained how in addition to ongoing communication, she and other family members sit down formally at least once a year to discuss and make decisions about caring for their mom. While daughters often described family support that involved shared responsibility, wives tended to position themselves as having primary responsibility, with other family in a supportive role.

Another strategy for negotiating care was becoming an expert (Wuest, 2001), which involved learning about

ADRD/MCC and available resources. Speaking with other carers (in a support group setting) and taking courses, such as those offered by the local Alzheimer Society, were perceived as very helpful by the carers who accessed them: "I'm becoming more cognizant as to changes and what to look for. And that's where the [support] group has helped a whole lot too" (D017). Becoming an expert helped carers better understand care recipient behaviours, adjust to caring demands, and harness resources. Some carers also learned skills related to the care recipient's other chronic conditions: "I've had to learn how to take care of a catheter, [so] that he doesn't tug at it, to make it more comfortable. I've learned how to clean the bags and change it from daytime to nighttime" (W325).

**Repatterning.** One aspect of repatterning care involves juggling time; purposeful strategies of combining or ordering activities in order to meet caregiving demands (Wuest, 2001). Juggling time did not feature prominently in wives' descriptions of caring for family members with ADRD and MCC, other than "keeping an eye" on their spouse while doing other tasks and performing tasks while they had substitute care. For example, a few wives described doing their shopping, groceries, or going to appointments while a family member sat with their spouse or they had formal respite. In contrast, daughters spoke of juggling caregiving with other competing life tasks, in addition to employment: "I've still got a lot of things to do. When I need to run errands, I do those on my own, and then when I go to visit Mom I can just devote my time to her (D307).

Setting ground rules for care (Wuest, 2001) entailed decisions around substitute care and what was acceptable. Both wives and daughters described decisions to involve formal carers (or increase the level of care provided), but this care needed to meet particular standards. It was important that care recipients enjoyed the services offered and/or were comfortable with the care providers: "We've probably weeded out anything that doesn't work... my mom does have home care coming and she's happy with the provider. My dad goes to a day program twice a week, he's comfortable there, so it works really well now" (D025). When carers and the care recipient were not happy with services, they tended to avoid their use or try others if problems could not be sorted out through negotiation.

A strategy that was important for repatterning among these carers was anticipating: looking at what caregiving would entail in the future and preparing for eventualities (Wuest, 2001). Women described how they anticipated future physical and cognitive decline in their parent or husband, and many described resources that would be needed in the future: "You just have to be open to the inevitable progress of [ADRD] and you need to deal

with it. We have the backup plan if Mom requires more care that we can't give, then she needs to be in a home" (D304). Some carers already had concrete plans in place for when their current level of support would not be sufficient.

Lastly, when women repattern care, they make conscious decisions around what they will relinquish, and how they will replenish in the face of caring demands (Wuest, 2001). Learning to give things up or purposely choosing activities aided the women in relinquishing and replenishing. A few wives had made the decision to relinquish their house or job due to their husband's ADRD and MCC: "I'm trying to get the house in order because I will have to sell once he has to go into a facility, we don't have enough finances to carry two households" (W333). Women primarily described activities through which they could replenish their energy and sense of self. These varied according to individual interests and values and included both solitary and social activities (exercise, sleep, or attending events, etc.). A daughter explained how riding her motorcycle helped with caregiving-related stress: "I ride my own motorcycle. I hadn't ridden it for a couple of years; I hopped on my bike and went for a little cruise... which was good" (D314). Sometimes replenishing was linked to particular periods of time when caregiving demands were reduced: "It's a demanding role... I read before I go to sleep, so I guess that's kind of when I feel like I have my own time. In the evenings, once everything's done" (W315).

## Discussion

The purpose of this research was to examine and compare the experiences of wife and daughter carers of persons with ADRD and MCC. It is critical that the voices and needs of women carers be heard, as they are doing the majority of care work which is often invisible and undervalued. This study is one of the first that describes the subjective experiences of wives and daughters as carers of persons with ADRD and MCC. In contrast to the published literature on carers of persons with ADRD, the research on caregiving in the context of ADRD and MCC is limited (Peacock et al., 2017). As well, use of Wuest's (2001) feminist theoretical framework has facilitated a unique focus on the processes involved in women's caring for persons with ADRD and MCC. The experiences of women in this study were largely consistent with the concepts delineated in Wuest's framework, with the role of formal services emerging as particularly important for how women set boundaries, negotiated, and repatterned care.

Women in this sample experienced a number of daily struggles, altered prospects, and ambivalent feelings around their caring role, which are consistent with previous ADRD caregiving research (Erol et al., 2016).

Wives and daughters struggled with balancing caring with other tasks, lack of time for self, family and friends, financial difficulties, and struggles with care recipient behaviours. Yet, daughters struggled to manage employment in addition to their caring; this was not the case for wives as none of them worked outside their home. Women also experienced limited ability to travel and diminished freedom to socialize, which impacted their social relationships. Carers often face increased social isolation, including those where the care recipient has MCC in addition to ADRD (Peacock et al., 2017), but relational deprivation may be particularly pronounced for women carers (Papastavrou et al., 2007).

Some of the fraying connections described by wives and daughters were specifically in relation to the care recipient living with ADRD, such as frustration with repetitive or reactive behaviours and limited freedom resulting from the intensive nature of caring required; ADRD may be particularly associated with negative consequences for carers (Kim & Schulz, 2008). Indeed, ADRD predominated over other chronic conditions in the described experiences of women in the present study.

Despite caring demands and frayed connections, it was clear in wives' and daughters' descriptions of caregiving that they were setting boundaries around caring demands, negotiating with helpers and formal systems to facilitate caring, and restructuring their time and care (restructuring). Thus, Wuest's (2001) theory was well-reflected in wives' and daughters' descriptions of their caregiving experiences. This provides further support for Wuest's theory as a general theory of women's caregiving, illustrated among a novel caregiving group where the care recipient is a family member with MCC including ADRD. Moreover, it focuses attention on the processes involved in women's caring, which has often been overlooked in past literature. Our data illustrate women's strengths, via the active work they put into successfully managing caring demands and fraying connections. Despite challenging circumstances, the women in this study continued to work toward achieving a caring environment that was manageable for them as well as safe and positive for the care recipient.

Several strategies were particularly salient for the women carers in this study: considering professional care as part of setting boundaries on caregiving demands, harnessing resources, anticipating the future, and replenishing. Women carers may delay or avoid accessing substitute care or feel ambivalent about receiving such support (Bartlett et al., 2018), which Eriksson et al. (2013) suggested such ambivalence is rooted in gendered and heteronormative assumptions around caring. Many participants in the present study had reached a point where professional caring assistance was desired and were actively working to access services,

although some wives did express ambivalence about these changes.

Difficulties accessing appropriate services (challenges navigating formal systems) were described. As noted by Lethin et al. (2016), navigating formal services and "fighting" for care or services can be frustrating and exhausting for carers. In the present study, harnessing resources emerged as an important strategy for managing caregiving; wives and daughters worked to maximize the effectiveness of resources for their situation. This sometimes involved fighting for service access, but also entailed communication with professional carers, agencies, or social workers to make sure that services were acceptable and meeting carer and care recipient needs. These findings highlight both the sociocultural responsibility placed on women for managing caring demands and the need for accessible and appropriate supports.

Given the degenerative nature of ADRD and to some degree MCC, anticipating the future was an important strategy for one's caregiving trajectory and trying to secure future resources. Indeed, part of transitioning to a caregiver includes securing support and anticipating future needs (Lee et al., 2019). Planning for the future is a common approach among carers in the context of ADRD (Lethin et al., 2016; Truglio-Londrigan & Slyer, 2019) and the present study echoes this important caregiving strategy within a context of MCC as well.

Replenishing was also an important strategy for women carers of persons with ADRD and MCC, involving both solitary and social activities. As described by Strang (2001) women carers may perceive respite to be an internal cognitive process where they can have a break from caregiving duties, regardless of whether they are physically apart from the care recipient. Replenishing primarily involved carers' "own time" although it could involve enjoyable interaction with the care recipient, and was important for sustaining their caring role. Self-sustainment has been linked to higher health-related quality of life among carers (Ekwall et al., 2007), and such activities are important to sustain the wellbeing of carers to older adults with MCC (Peacock et al., 2017).

The analyses suggested few differences in the challenges wives and daughters faced and the strategies they employed to navigate caregiving. Wives presented themselves as the primary informal carer (with others "helping out"), whereas some daughters described a more collaborative arrangement (e.g., with siblings) in how care was negotiated. The main difference between wives and daughters in this study was with respect to many of the daughters having paid employment. Given that more than 75% of the daughter carers were employed, they had to do more work in setting boundaries, negotiating and restructuring given the limits on their time and energy compared to wives. The larger



literature suggests that most carer-employees are women, and although their participation in the workforce provides them with social and financial support, they may struggle with work-life balance and experience mental and physical health issues (Duxbury & Higgins, 2012; Research on Aging Policies and Practices, 2014).

Future research in this area should include examining which interventions can benefit women carers to maintain self-sustainment, and how those interventions might be tailored to optimally benefit wives and daughters. It may also be important to consider the context of daughters caring for a father, and how daughters and daughters-in-law may vary in their caring relationships; understanding the nuances of women's caring will allow for interventions that best meets their needs.

### Limitations

There are several limitations of the present study. First, the semi-structured interviews were reflective of the transitions experienced by women carers and were not originally guided by Wuest's (2001) theory, which precluded our ability to delve deeply into all elements of the theory. A related limitation was that as a secondary analysis of previously collected data, we were not able to return to participants for follow-up interviews. Finally, in this study daughters predominantly cared for their mother and this relationship may have influenced the findings; as well, daughters-in-law were categorized as daughters in this study and the authors cannot infer conclusions about how their experiences may be similar or unique.

### Implications for Practice

The findings of this study highlight the importance of recognizing the needs and concerns of women as carers, be they wives or daughters. As noted by Wuest (2001), the societal attitudes communicated to women influence the way they care and may lead to greater expectations placed on them to take up caring; health care providers must acknowledge and begin to challenge these outdated attitudes. The main area of essential support that women carers identified was assistance navigating the formal care system to secure and locate acceptable services. This was particularly important in light of many women reporting a lack of significant family support with caring. It is essential that women carers be supported to replenish (Wuest, 2001) in order to manage their own well-being. Registered nurses and other health care providers are in the position to recognize the role of women carers and support those needing additional information about ADRD and MCC, as well as to guide women carers to anticipate and prepare for the future.

### Conclusions

This work offers a unique perspective in its use of Wuest's (2001) feminist theory to examine and compare the experiences of wives and daughters caring for a person with ADRD and MCC. Wives and daughters described similar experiences dominated by caring demands and resulting fraying connections, with daughters also needing to balance employment responsibilities. This study highlights the importance of self-care for women carers and the support they require to be sustained in their caregiving role. The findings contribute to understanding the roles of women as carers and highlight the importance of developing specific interventions to improve their well-being during caregiving. From a feminist perspective, findings also challenge societal attitudes about the expectations of women as natural carers, as they illustrate the consequences that caring may have on women. At the same time, however, the findings show participants' strength in developing strategies to navigate the fraying connections they experienced as a result of caring demands. This brings to the fore some of the hidden work that women carers do to navigate caring demands, and illustrates their ability to interact effectively with those around them to minimize fraying connections and maximize resources. For wife and daughter carers of persons with ADRD and MCC, anticipating the future and making plans (e.g., for long term care placement) were important. Carers' involvement of formal carers and the negotiations they had with them around care, were particularly crucial to successfully managing caring demands. Future research should consider the supports wives and daughters require and how to individualize interventions to their context, particularly considering the influence of and challenges with MCC. Registered nurses and other health care providers are in a position to support women carers by helping them navigate the formal care system and acquire the information they need about ADRD and any other chronic conditions that affect their relative.

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