

# A qualitative exploration of how gender and relationship shape family caregivers' experiences across the Alzheimer's disease trajectory

Dementia  
2021, Vol. 20(8) 2851–2866  
© The Author(s) 2021



Article reuse guidelines:  
[sagepub.com/journals-permissions](https://sagepub.com/journals-permissions)  
DOI: 10.1177/14713012211019502  
[journals.sagepub.com/home/dem](https://journals.sagepub.com/home/dem)



## Kristina M Kokorelias

Rehabilitation Sciences Institute, University of Toronto, Toronto, ON, Canada

## Gary Naglie

Department of Medicine and Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada; Department of Medicine, Rotman Research Institute, Baycrest Health Sciences, Toronto, ON, Canada

## Monique AM Gignac

Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada; Institute for Work and Health, Toronto, ON, Canada

## Nira Rittenberg

Department of Occupational Therapy and Occupational Sciences, The Temerty Faculty of Medicine, University of Toronto, Toronto, ON, Canada

## Jill I Cameron

Department of Occupational Science and Occupational Therapy, The Temerty Faculty of Medicine, University of Toronto; Rehabilitation Sciences Institute, University of Toronto, Toronto, ON, Canada

---

### Corresponding author:

Jill I Cameron, Department of Occupational Science and Occupational Therapy, The Temerty Faculty of Medicine, Rehabilitation Sciences Institute, University of Toronto, 500 University Avenue, Suite 160, Toronto, ON M5G 1V7, Canada.  
Email: [Jill.cameron@utoronto.ca](mailto:Jill.cameron@utoronto.ca)

## Abstract

Caregiving experiences are not static. They change across the disease trajectory and care continuum. However, it is not clear how caregiver gender or relationship type is related to evolving caregiver experiences over time. This qualitative study informed by constructivist grounded theory and framework analysis explored the experiences over time of men and women who were adult children and spousal caregivers to persons with Alzheimer's disease. Forty spousal (10 husbands and 10 wives) and adult children (10 sons and 10 daughters) caregivers to persons with Alzheimer's disease were interviewed using a semi-structured interview guide. Our findings suggest the experiences of caregiving, examined through a gender and relationship type lens, are complex and variable. The caregiving experience was not related to gender or relationship type alone, but often to a combination of the two. For instance, spousal caregivers did not immediately accept the diagnosis, with wives being more optimistic than husbands about a slow progression of the disease. Adult children caregivers were concerned about the ways the caregiving role would impact their personal and career obligations and sought ways to mitigate the changes to their daily lives. Sons and husband caregivers largely utilized home and community health services to assist with personal care tasks, whereas daughters and wives utilized the same services to allow them to complete other caregiving tasks (e.g., housekeeping). Recognition of the complex inter-relationships among gender and relationship type on caregiving experiences supports the need for family-centered interventions. This article also extends sex and gender research as it highlights that an in-depth understanding of the caregiving experience cannot be understood by gender alone and relationship type must also be considered.

## Keywords

qualitative, gender, community, caregiving, dementia, Alzheimer's disease

## Introduction/background

Family caregivers play a central role in the care and support of people with dementia across the disease trajectory. Caregivers are commonly spouses (Barber & Pasley, 1995; Wawrziczny et al., 2018) and adult children (Stommel et al., 1994; Tatangelo et al., 2018). Providing care can negatively impact caregivers' physical and psychological health (Abreu et al., 2020). For family members who assume the caregiving role for a relative with dementia, the potential impacts are especially great. Dementia, including Alzheimer's disease, is a syndrome whereby there is progressive deterioration in cognitive function (e.g., memory, orientation, comprehension, and judgment) that interferes with a person's ability to function independently (Wong et al., 2016). We define family caregivers (described here as caregivers) as family members such as spouses and adult children, who provide unpaid care for a person with Alzheimer's disease.

Caregiving experiences may differ depending upon whether the caregiver is a spouse or adult child. A meta-analysis by Pinquart and Sörensen (2011) of 168 empirical studies (not specific to dementia but including dementia caregivers) compared caregiving spouses with adult children or children-in-law and found that spousal caregivers reported lower levels of psychological well-being and higher levels of financial and physical burden than adult child or child-in-law caregivers. In contrast, a study of family caregivers to persons with dementia found higher levels of caregiving burden and more negative outcomes among adult child caregivers compared with spousal caregivers (Chappell et al., 2014). In comparison to husbands, wives' levels of strain have been found to be significantly worse than husbands' as both men and women believe wives have a greater obligation

to care (Collins & Jones, 1997). Yet, other researchers have found no difference in the level of burden between spousal and adult child caregivers to elders with cognitive impairment (Chumbler et al., 2003). Consequently, existing literature has shed contradictory light on how gender or type of relationship (e.g., spouse and child) is related to caregiving experiences as they evolve over time with different phases of dementia.

Internationally, there is growing demand for the improvement of sex and gender integration into dementia health research, policies, and programs (Johnson et al., 2014; Wyndham-West, 2020) and that this be accomplished in a systematic manner (Greaves, 1999). Researchers are also becoming increasingly aware that sex (biology) and gender (a sociocultural construct) can influence health and illness experiences (Johnson et al., 2014) and that this has implications for caregivers. One of the most consistent findings in the caregiving literature has been that the majority of family caregivers are women (Amanullah et al., 2020; Stone et al., 1987), although more men are assuming the caregiver role (Mott et al., 2019). Seminal literature theorizes that gender may influence the type of care provided by caregivers, caregivers' access to health and social care resources, and the level of support that they receive (Kramer & Kipnis, 1995; Miller & Cafasso, 1992; Pinquart & Sörensen, 2006). Much of the literature on gender differences in caregiving stems from quantitative methods, rather than qualitative methods, which can allow for more in-depth understandings of people's experiences. Findings from gender analyses can help healthcare providers and community organizations tailor support and services to their clients (Gahagan et al., 2015). A review of 93 articles on gender differences in dementia caregiving studies concluded that women experienced more distress and used more services than men (Baker & Robertson, 2008). However, within this review, several studies also reported no gender differences (Baker & Robertson, 2008; Baker et al., 2010). Researchers suggest that a flaw of many caregiving studies is that they tend to make comparisons between men's and women's caregiving experiences by highlighting the challenges women experience without the same in-depth understanding of men's experiences (Fromme et al., 2005).

Illnesses, like Alzheimer's disease, are rarely static, and, as a result, the caregiving situation changes across the disease trajectory and across the care continuum (Cameron & Gignac, 2008). Caregivers often experience multiple and complicated transitions over the course of their caregiving journey including changes to their environment, occupational roles, social relationships, and physical, emotional, and mental health (Duggleby et al., 2011; Farina et al., 2017; Zakrajsek et al., 2018). The caregiver-identified phases of Alzheimer's disease (CIP-AD) care framework is the first conceptual framework to describe changes in caregivers' experiences and support needs across the disease trajectory from the perspectives of male and female caregivers (Kokorelias, Gignac, Naglie, Rittenberg, & MacKenzie, 2020). The CIP-AD defines five phases of Alzheimer's disease caregiving: (1) monitoring initial symptoms; (2) navigating diagnosis; (3) assisting with instrumental activities of daily living; (4) assisting with basic activities of daily living; and (5) preparing for the future (Kokorelias, Gignac, Naglie, Rittenberg, & MacKenzie, 2020). Each phase of the framework also emphasizes caregivers' needs for informational, emotional, instrumental (e.g., tangible assistance), and appraisal supports (Kokorelias, Gignac, Naglie, Rittenberg, & MacKenzie, 2020). The CIP-AD has been expanded to outline the health and social care service needs and/or use corresponding to each phase (Kokorelias, Gignac, Naglie, Rittenberg, Cameron, 2020).

Research completed to date has identified changing support, services use, and needs of caregivers across caregiver-identified phases of Alzheimer's disease caregiving (Kokorelias, Gignac, Naglie, Rittenberg, & MacKenzie, 2020; Kokorelias, Gignac, Naglie, Rittenberg, Cameron, 2020). To date, this work has not considered the nuances in experiences that may be related to gender and relationship type over time. In the context of the larger caregiving literature, few studies have explored experiences in caregiving by both gender and relationship type (Abdollahpour et al., 2018; Chappell

et al., 2014). The exceptions have primarily focused on caregiver burden. Understanding the nuances in caregiving experiences can be used to tailor programs to specific groups of caregivers (e.g., adult children, spouses, females, and males). Therefore, the goal of this article was to explore the influence of gender and relationship type on caregiving experience in relation to the key elements of the CIP-AD framework as the framework can be used to explore caregivers' changing experiences across the disease trajectory (Kokorelias, Gignac, Naglie, Rittenberg, & MacKenzie, 2020). The research question guiding this study was "How do caregiver gender and relationship type shape caregiving experiences across the Alzheimer's disease trajectory?"

## Methods

### *Design*

The foundational study that identified CIP-AD used a grounded theory approach by Charmaz (2006; Kokorelias, Gignac, Naglie, Rittenberg, & MacKenzie, 2020). This method combines an inductive approach with the researcher's existing knowledge, including the use of an existing conceptual framework to guide data analysis. In this study, framework analysis was employed to explore how gender and relationship shape caregivers' experiences over the CIP-AD (Srivastava & Thomson, 2009).

### *Participants*

Participants were wives, husbands, daughters, and sons centrally involved in providing care to someone with Alzheimer's disease without financial compensation (see Table 1 for inclusion/exclusion criteria).

Participants were recruited through word-of-mouth, social media (e.g., Twitter), and from community organizations. To obtain a breadth of caregiving experiences, we purposely recruited caregivers at different phases of their experience (e.g., caring for family members in earlier or later stages of the disease and a minimum of 1 year post-diagnosis) and were interviewed. We also made efforts to ensure that, across phases of caregiving, there was diversity in gender and relationship type. To do so, we recruited from gender- and relationship-specific support groups (e.g., support groups for sons only).

Interested participants contacted members of the research team who explained the study and obtained verbal consent. Participants provided verbal re-consent prior to data collection. Institutional research ethics boards approved the study protocol.

### *Data collection*

We conducted semi-structured interviews with caregiver participants residing in Toronto, Ontario. The first author conducted all interviews. Each participant was interviewed at least once using a semi-structured interview guide that focused on the overall caregiving experience (see Supplemental Table 1 for the interview area key topics guide). Participants were asked to discuss their experiences of caregiving and how this evolved over time. Participants were also asked to describe their needs for support and health and social care services. Interview questions were semi-structured and left ample opportunity for respondents to generate themes and issues that were relevant to them. As themes emerged, later interviews were probed on some topics. This also resulted in five participants being interviewed twice to further explore their experiences.

**Table 1.** Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ol style="list-style-type: none"> <li>1. Fluent English speaker and be able to provide informed consent</li> <li>2. Be the spousal or child caregiver to a family member with Alzheimer's disease</li> <li>3. Self-identify as being centrally involved in providing care and/or the organization of care to someone with Alzheimer's disease</li> <li>4. Have been in the caregiving role for a minimum of 1 year</li> <li>5. Assisting, or had been assisting, with at least one of the instrumental activities of daily living (IADLs) or activities of daily living (ADLs) to a spouse or parent with Alzheimer's disease at least once a week A list of the IADLs and ADLs was provided to potential participants for reference</li> <li>6. Caring for someone with Alzheimer's disease who is living in the community, or has been admitted to complex continuing care, long-term care, or assisted living (such as a retirement or nursing home), within the past 3 months</li> </ol>	<ol style="list-style-type: none"> <li>1. Being a licensed healthcare provider who provides treatment to persons with Alzheimer's disease</li> </ol>

ADLs: activities of daily living; IADLs: instrumental activities of daily living.

We interviewed 20 spousal (10 husbands and 10 wives) and 20 adult children (10 sons and 10 daughters) caregivers. Interviews were conducted in person ( $n = 12$ ), using videoconferencing systems ( $n = 3$ ) and via telephone ( $n = 25$ ). All interviews lasted between 43 and 133 min and were conducted by a trained female qualitative researcher (Blinded for Review) (see [Supplemental Table 2](#) for participant characteristics). Interviews were audio recorded, transcribed verbatim, and transcripts were checked for accuracy by the first author. Data were collected in each participant group until theme saturation. Theme saturation was reached in some groups sooner than others (i.e., daughters), but we continued interviewing to obtain equal numbers of participants in each group. Additional data helped to further test the level of saturation ([Thomson, 2010](#)).

Demographic data also were collected including age, income, length of time providing care to someone with Alzheimer's disease, length of time using community services, and previous caregiver experience.

### Data analysis

As with the foundational study, data were analyzed using principles of grounded theory constant comparison ([Charmaz, 2006](#); [Kokorelias, Gignac, Naglie, Rittenberg, & MacKenzie, 2020](#); [Srivastava & Thomson, 2009](#)). Framework analysis supported a concentrated investigation of the participants' lived experiences over time using the CIP-AD, while also allowing other themes to emerge ([Srivastava & Thomson, 2009](#)). In line with framework analysis ([Srivastava & Thomson, 2009](#)), the codes were repeated for each phase of the framework identified in the foundational

grounded theory study (i.e., CIP-AD) and participant group (e.g., the code “acceptance-wife” was used once for each phase of the CIP-AD framework such as “acceptance-wife-monitoring initial symptoms,” “acceptance-wife-navigating diagnosis,” etc.). Data that did not fit with the framework were coded without a phase-based code, so that the findings were grounded by participants’ collective experiences. Data analysis also followed principles of grounded theory, including the constant comparative method consisting of ongoing comparisons of coded data and of categories from one case to the next (e.g., comparing initial interviews with daughters to other later interviews with daughters) until theoretical saturation was achieved. Next, looking within and across cases (e.g., comparing the experiences of daughters to sons then daughters to wives), the first author extracted several overarching data patterns pertaining to the lived experiences of male and female and spousal and adult children caregivers. Throughout the coding process, [Blinded for Review] and [Blinded for Review] met regularly to ensure consistency in the interpretations of the codes and data. NVivo qualitative software was used to organize data (NVivo, 2002). The findings follow the general structure of organizing the experiences of caregivers using the CIP-AD.

In-person member-check interviews occurred with 12 participants (3 wives, 3 husbands, 3 daughters, and 3 sons) approximately 10 months after the initial interviews. No changes to the findings were deemed necessary.

## Findings

Our gender and relationship type analysis highlights that the caregiving experience cannot be described by a simple dichotomy of men and women or spousal and child caregivers. Both gender and relationship type were interwoven and were important to the caregiving experience over time. However, at times during the caregiving and disease trajectory, one or the other variable—gender or relationship type—appeared to be more relevant. Below, we outline the varied experiences of adult children and spousal caregivers over the CIP-AD. [Supplemental Table 3](#) provides a summary of findings for the different phases. Sample quotations from participants are provided to illustrate key points. Quotations are referenced using the relationship the caregiver has to the person with Alzheimer’s disease followed by their participant identification number.

### *CIP-AD-phase: Monitoring symptoms*

Participants described a gradual recognition of the severity of symptoms in the person with Alzheimer’s disease. While all participants attributed some of the early symptoms to aging, perceptions related to severity differed by participant groups (i.e., wives, husbands, daughters, and sons). Adult children caregivers tended to express greater concern about the symptoms than spousal caregivers. Adult children described believing the symptoms needed to be attributed to an emerging medical condition. Some adult children described becoming frustrated with their parents (including the parent with Alzheimer’s disease) or other family members for not being concerned about the symptoms. Adult children reported that their uneasiness prompted them to conduct their own research, further noting that the deterioration had occurred over a period of several years. Spousal caregivers, on the other hand, often spoke of the symptoms as occurring over a shorter period of time or even “overnight” (Wife Participant 1). Some wife caregivers described not recognizing the symptoms and relying on other family members or friends to identify changes in their spouse. Participants who were wives all described feeling misunderstood by a family member or friend for not being alarmed about the changes occurring in their spouse. Both husband and wife caregivers

attributed the symptoms to age. However, unlike wives, husbands of care recipients described noticing the symptoms on their own.

### *CIP-AD-phase: Navigating diagnosis*

Adult children participants obtained a preliminary diagnosis of dementia for their parents earlier in the caregiving trajectory compared to spousal caregivers. Most of the adult children responded to the diagnosis of dementia without much surprise and with acceptance since they suspected dementia as a possible explanation for their parents' symptoms. Daughter participants often displayed empathy for their parents' medical condition. Son participants repeatedly described this phase as being met with worry that they would now have to "parent the parent" (Son Participant 8). Most of the adult children who were employed indicated that they were concerned about trying to find a way to balance their responsibilities between work and home, emphasizing that they were concerned that they would no longer be able to perform well in their careers.

The acceptance of the diagnosis was harder for spousal caregivers, with both wives and husbands reacting with shock. Husband Participant 5 stated "*I did not accept it. All of a sudden, she went from healthy to sick. Of course, I was in shock. She was fine.*" Husband participants shared that they were eventually able to get past the shock and urged for, and in some cases demanded, further testing and extensive investigations to confirm the diagnosis and/or the type of dementia. Some husbands also expressed feelings of guilt that their initial inability to view their spouses' symptoms as a medical condition delayed the diagnostic process. These husbands made it explicit that they were not "*necessarily in denial*" (Husband Participant 5) but had a lack of awareness that dementia could be a plausible explanation for their wives' symptoms.

Wife participants remained skeptical of the dementia diagnosis during this phase. Some wife participants even questioned the physicians' ability to diagnose the disease or the veracity of the diagnosis. Two of our wife participants described not accepting the physician's referral for further testing until several months following the initial diagnosis. While talking about her experience retrospectively, Wife Participant 25 said that she "*put [her] head in the sand and denied something this serious was wrong.*" Other wife participants described more of a "partial-denial" where they described first rejecting, then accepting the diagnosis as somewhat plausible, admitting that they "*were in denial and did not want to accept it*" (Wife Participant 28).

While most of the participants relied on multiple healthcare providers to obtain the diagnosis (e.g., geriatricians), male participants described being referred to dementia specialists sooner than female participants, even when both genders pushed for a clear diagnosis. In some cases, female caregivers described calling memory clinics themselves (without prior physician referral) to obtain a more specific dementia diagnosis. For many of the female participants, the diagnosis of Alzheimer's disease took years to obtain after receiving the preliminary dementia diagnosis, unlike male participants who described receiving a diagnosis much sooner.

### *CIP-AD-phase: Assisting with instrumental activities of daily living*

Both spousal and adult children caregivers described being motivated by love and obligation to provide hands-on care for their family member. Participants shared that caring for their family member would provide continuity in the relationship. In this phase, daughters began to reflect on the impact that caregiving for their parent would have on their own lives, specifically on their ability to care for their families (extended and immediate) and themselves. In some cases, sons' and daughters' stress was further exacerbated by their concerns about the impact caregiving would have on their

careers. Adult children described maintaining a responsiveness to their parents' needs and a readiness to be available in case of unforeseen circumstances. Some adult children caregivers obtained support from their employer for flexible work schedules so they could meet the needs of their parents. They also obtained support from their spouses or friends. This was in sharp contrast to husband caregivers, who explicitly stated that they did not plan for the future, but rather took caregiving "*day-by-day*" (Husband Participant 26). Some husbands made it clear that not looking too far into the future was a coping strategy that helped them alleviate some of the stress associated with their caregiving role.

The increase in caregiving duties in this phase resulted in the lack of physical and emotional intimacy for spouses. Husband participants noticeably brought up intimacy more frequently, more candidly, and earlier on in the interviews than wife participants. In some instances, wife participants only mentioned intimacy when probed on their changing spousal relationship due to providing increased levels of care. Husband participants discussed physical intimacy more often, whereas all but one wife participant focused on emotional intimacy.

Some participants reported attending support groups during this phase of caregiving. Although some adult children caregivers described feeling alone in this phase, they stated that their primary goal of attending support groups was gaining information. Spousal caregivers described using support groups for emotional support as they assumed that other people in their social network did not understand the emotional toll of caring for a spouse with Alzheimer's disease.

When asked to reflect on providing assistance with instrumental activities of daily living, two noticeable differences between adult children and spousal caregivers emerged. In several cases, spousal caregivers described feeling guilty and criticized themselves for some of the ways they provided assistance. Adult children did not express these sentiments. Examples of spousal caregivers' perceived wrongdoings included not allowing the person with Alzheimer's disease to be more independent or leaving them home alone at times:

"I just feel so bad. Guilty. I didn't really want my husband to leave the house. I could do the grocery shopping, the banking, I just wanted him to stay home at that point" (Wife Participant 20).

This is in contrast to the adult children caregivers who did not describe their experience with blame but rather stated that they acted to the best of their ability. Moreover, adult children caregivers described some positive aspects of providing care including becoming closer to their parent, despite all the changes that occurred. Reasons provided for a closer relationship most often included spending more time with them and becoming familiar with their personal needs, habits, and other information (e.g., routines and finances).

### *CIP-AD-phase: Assisting with basic activities of daily living*

Participants described that assisting with basic activities of daily living left them feeling resentful of other family members. The assistance roles of other family members was discussed by adult children caregivers, but not spousal caregivers. Adult children believed that their siblings or parents should assist with caregiving. Daughter participants reported that they had to justify their decision to engage with services to their family members, and many expressed feeling angry for having to do so. As one daughter expressed, "*I was so mad. Why did I have to tell my sister what I was doing when I was doing everything*" (Daughter Participant 14). Some daughter participants described needing to rely on services for respite as their other family members were unable to assist. Other daughter participants explained that their family members had conflicting opinions of what to do in relation to the



care of their parent. Son caregivers described making few demands on other family members to participate in caregiving or had no family support.

Experiences in this phase were largely marked by caregivers' experiences with health and community services. Adult children participants described their use of services as a source of respite and an opportunity to carry out their own health needs, to attend work, go to appointments, or run errands. Spouses did not speak about services in terms of respite. Daughters and sons felt comfortable leaving their parent in the care of personal support workers (PSWs). Daughters described their experience of services as putting them in a care management role, whereby they instructed professionals in the care tasks what their parents required or specific details in how to perform the tasks. Sons ascribed their use of services as a means to avoid having to engage in household and personal care activities (e.g., bathing and toileting), which they felt would be embarrassing for them and their parent. Daughters described mostly being willing to complete such personal tasks and other caregiver duties (e.g., housekeeping).

Control over their husband's care was important for wives. Many of the wife participants recounted choosing to use services at the urging of their family members or physician. Some wives discussed using services in a process of trial and error, whereby they would ask to try a service once before enrolling in frequent sessions. Many of the wife participants expressed that they were comfortable completing the personal care tasks their husbands required (e.g., bathing) and would have preferred more assistance with home-related tasks (e.g., housecleaning):

"I wish they would have cleaned my house or something. I know how to take care of my husband. I didn't really need help with that. I just needed help doing everything else" (Wife Participant 28).

In contrast, husband participants reported using services to gain support for personal care tasks for their wives. Husbands described feelings of embarrassment having to help with these tasks for their wives, similar to caregiving sons. However, unlike sons, all of the husband participants stated that they typically ended up bathing their wives, despite their discomfort, if a staff worker was unable to do so. Husbands described using the presence of support and service workers in the home to allow them to catch up on their own instrumental activities of daily living (e.g., finances and housekeeping). They were not reluctant to receive services and were willing to accept help once the idea had been raised by their children or their own or their spouse's physician. Both husband and wife participants were not comfortable leaving their spouses home alone while support and service workers were present and, thus, rarely did.

### *CIP-AD-phase: Preparing for the future*

The differences related to how female and male participants discussed their experiences were prominent in this phase. Female participants expressed more emotion in discussing their plans for the future and many cried during interviews.

Although participants had been in the caregiver role for various lengths of time, they all questioned the sustainability of keeping their family member at home. As a result, they discussed long-term care facility placement as being part of their caregiving experience either now or in the future. Spousal and adult children caregivers had differing opinions on long-term care facilities. Adult children participants primarily believed that they could not sustain care at home because they had limited time to participate in their own meaningful activities (e.g., employment and fitness). As a result, they believed that institutionalizing their parent would allow them to return to their normal routines and reengage in some meaningful activities. For these participants, institutionalization was

considered inevitable due to their understanding of the increasing care responsibilities required as a person with Alzheimer's disease progresses through the disease trajectory:

"I will be heartbroken when it's time for a home, but I also try to think about going back to work or even back to my photography classes" (Daughter Participant 12).

Spouses reported having more doubts about long-term care placement than adult children caregivers. All spousal caregivers contemplated their ability to sustain care at home, but many believed that they would be able to do so for a while longer. Some shared that they had made previous promises to their family member about not placing them in a facility. Wife participants were less enthusiastic about long-term care placement than husband participants and considered it "[*their*] *worst fear*" (Wife Participant 20). Husbands described not wanting to place their wives in long-term care but saw it as a viable option to ensuring their wife was being taken care of. Husbands described the idea of "taken care of" as attending to the medical needs of their wives and reducing the risk of harm (e.g., their wife wandering). Most spousal caregivers' concerns about long-term care placement were based on listening to other caregivers' experiences. Husbands and both groups of adult children caregivers frequently discussed benefits of long-term care placement including increased supervision for the person with Alzheimer's disease. Only two wife participants expressed this same interest in long-term care.

## Discussion

An understanding of how best to care for caregivers of persons with Alzheimer's disease is among the most important challenges for health service researchers. Previous research finds that caregiving is often gendered with women—daughters and wives—predominantly taking on the caregiving role, although this may be changing (Seidel & Thyrian, 2019). This study is among the first to qualitatively examine the role of gender and relationship type over the caregiving trajectory to better understand the perspectives and experience of wives, daughters, husbands, and sons. The findings suggest that gender and relationship type are important concepts in understanding the caregiving process and that they are often interwoven. For example, there were differences in recognizing the seriousness of dementia symptoms with adult children caregivers, regardless of gender, recognizing the symptoms of Alzheimer's disease sooner, and wives being particularly reluctant to recognize and accept the disease diagnosis. Sons expressed concern about the impact of caregiving on their own lives earlier than daughters and spousal caregivers. Health service access also differed with sons and husbands gaining access to dementia specialists sooner. Service use and perceptions of services illuminated key differences related to gender and relationship type with adult children seeking access to services and recognizing their importance for their parent and their own well-being. On the other hand, spousal caregivers often delayed service use and felt guilty about using services because it suggested they could not provide adequate care. Wives often monitored personal care services to their husbands instead of taking time away from caregiving responsibilities. These findings highlight the importance of examining the entire care trajectory and the value of looking further at gender and relationship type in caregiving. The findings also suggest new areas of potential research into the caregiving experience.

One of the key findings of our work was the difference in the acceptance of the dementia diagnosis related to gender and relationship type. Specifically, there were differences in recognizing the seriousness of dementia symptoms between the different groups of caregivers. Adult children caregivers, regardless of gender, recognized the symptoms of Alzheimer's disease sooner than

spousal caregivers. Spouses respond to the diagnosis of dementia with shock, and husbands were more likely to recognize and accept the diagnosis than wives. Existing literature suggests that men are less likely to admit negative feelings (Baker et al., 2010) in relationship to caregiving (Gollins, 2001). An extensive body of literature also describes Alzheimer's disease caregiving experiences at the time of diagnosis (e.g., Robinson et al., 2011; Byszewski et al., 2007). Our findings are consistent with previous findings that spouses deny cognitive changes and consequently delay help seeking, including obtaining a diagnosis (Adams, 2006). However, our research extends previous findings by highlighting the interplay of gender *and* relationship over time. Exploring the caregiving experience across the disease and caregiving trajectory allows for gender and relationship differences to emerge.

A number of intervention strategies can be implemented to help support family caregivers across the disease trajectory. The diversity in caregiving experiences observed across the disease trajectory by relationship and gender suggests that it would be very difficult to address the nuances of caregivers' needs in any single intervention/program/service. Family-centered approaches to care can help meet the needs of complex and varied groups of individuals. In a broad sense, family-centered models of care aim to consider the unique family situations (Gilmer, 2002; Kokorelias et al., 2019) and can be applied to various populations and settings (Kokorelias et al., 2019). Key characteristics of family-centered approaches include collaboration between family members and healthcare providers, consideration of unique individual and family contexts, and education for healthcare professionals and family members (Kokorelias et al., 2019). Within a family-centered care approach, support and service providers remain cognizant of the uniqueness of caregiving situations (e.g., relationship of the caregiver to the care recipient) and consequently support tailoring their approaches to meet the specific needs of individual caregivers. For instance, wife caregivers may benefit more than husband and children caregivers from illness-specific education focused on symptoms of dementia as they struggled to identify symptoms on their own. On the other hand, male caregivers may benefit more than female caregivers from education on completing personal care tasks (e.g., bathing) to help them become more comfortable providing this type of care. Multiple methods of support, where at least one intervention involves individualized education based on a caregiver's need(s), have been found to improve caregivers' outcomes (Berwig et al., 2017; Hendrix et al., 2013; Lautrette et al., 2007). Expanding on existing models of family-centered care with a gender and relationship lens can provide the foundation for developing, testing, and implementing interventions to meet the diverse and complex support needs of family caregivers to individuals with Alzheimer's disease across the disease trajectory.

Gender analyses are recommended in health research (Morgan et al., 2016). Gender, defined as the socially constructed role and behavioral dimensions of femininity and masculinity, is evident in the diverse ways individuals engage in Alzheimer's disease caregiving (Johnson et al., 2014; Morgan et al., 2016). Within seminal theories on gendered caregiving, care has often been defined through general cultural ideas about those who provide the care and the gender differences that impact the way caregiving burden is experienced and managed (e.g., Aronson, 1991). Feminist theory posits gender is a powerful influence on the caregiving experience (Neysmith, 1995). For example, our study observed that male caregivers are reluctant to perform personal care tasks. This is consistent with previous research (e.g., Hibbard et al., 1996), which suggests that men do not have the emotional acumen to tolerate burdens of personal care within the context of caring for an individual with dementia (Gold et al., 1995). Literature on the gendered cultural meanings of caregiving suggests that male caregivers negotiate their caregiving role by maintaining gender scripts that are present in their culture, such as not showing emotion (West & Zimmerman, 1987) and not providing personal care (Parsons, 1997). However, previous findings suggest that male spousal caregivers are more willing to perform hands-on tasks than previously reported (e.g., Russell, 2001).

In our research, we found that husbands will bathe their wives despite embarrassment. This may be the result of more men taking on caregiving roles (Harris & Long, 1999). In contrast, son participants in our study discussed not bathing their parents. Our study extends previous theories on gender and caregiving by suggesting it is not sufficient to just consider gender in the context of understanding caregivers' experiences, but the influence of relationship to the care recipient should also be considered. Other characteristics such as socioeconomic status, ethnic background, sexual orientation (Bowleg, 2008; Hankivsky et al., 2010; Weber & Parra-Medina, 2003; Windsong, 2018), and other social factors (e.g., education) may also influence caregiving experiences over time. These characteristics seldom have been considered in the research on gender differences in caregiving (Sharma et al., 2016). Future research exploring these variables is needed to better understand caregiving experiences that in turn can inform the development of caregiver support services.

### **Limitations**

Several limitations may impact the overall understanding of this research and its implications. The CIP-AD framework guiding this study may not account for the dynamic nature of caregiving. Our study did not set out to explore the gendered nature of caregiving or its influence on caregivers' experiences. The majority of the interviews were conducted via telephone, and thus, nonverbal cues could not be noted. The study sample was homogeneous as participants were predominantly white, well-educated, fluent in English, and commonly used services. This study did not explore other factors that may interact with gender, such as ethnicity and socioeconomic status. Last, all participants in this study were from one urban city in Ontario that may not be representative of the caregiving experience in other regions. Thus, future research with a diverse group of caregivers should explore the dynamic and gendered nature of caregiving and the influence of gender on caregivers' experiences. Such research may help us to obtain a fuller understanding of male, female, and gender-diverse caregivers' experiences across their caregiving trajectory.

### **Conclusion**

Gender and relationship to persons with Alzheimer's disease are both important factors to enhance our understanding of caregiving experiences and needs over time. Formal care providers, support program planners, and policy makers should be cognizant of the diversity in experiences of family caregivers to meet their needs. Our findings describe the various ways male and female caregivers, as well as spouses and adult children caregivers, experience caregiving across caregiver-identified phases of caregiving. Our findings highlight that the evolving caregiving experience cannot be described by gender or relationship alone. As a result, this article adds to our understanding of the caregiving experience over the caregiving and Alzheimer's disease trajectory. Similarly, this article extends sex and gender research as it highlights that in health contexts, such as caregiving, experiences cannot be understood by gender alone and relationship and other lenses may also be needed (e.g., socioeconomic class and ethnicity). Future caregiving research is needed to explore the nuances of gender, relationship, and culture on caregivers' experiences over time to further inform care models. Family-centered care may address the complexity and variability of caregiving experiences across the disease trajectory (Kokorelias et al., 2019). Our findings indicate that future research efforts should continue to consider caregivers as a heterogeneous group and evaluate ways to implement family-centered care to offer support services tailored to individual caregiver needs.

## Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: G. Naglie is supported by the George, Margaret and Gary Hunt Family Chair in Geriatric Medicine, University of Toronto.

## Ethical approval

The University of Toronto Health Sciences Research Ethics Board approved the study protocol.

## ORCID iD

Kristina M Kokorelias  <https://orcid.org/0000-0002-1277-472X>

## Supplemental material

Supplemental material for this article is available online.

## References

- Abdollahpour, I., Nedjat, S., & Salimi, Y. (2018). Positive aspects of caregiving and caregiver burden: A study of caregivers of patients with dementia. *Journal of geriatric psychiatry and neurology*, *31*(1), 34-38.
- Abreu, W., Tolson, D., Jackson, G. A., & Costa, N. (2020). A cross-sectional study of family caregiver burden and psychological distress linked to frailty and functional dependency of a relative with advanced dementia. *Dementia*, *19*(2), 301-318.
- Adams, K. B. (2006). The transition to caregiving: The experience of family members embarking on the dementia caregiving career. *Journal of Gerontological Social Work*, *47*(3-4), 3-29.
- Amanullah, S., Vithianathan, A., Snelgrove, N., Ghuloum, S., & Shivakumar, K. S. (2020). Women as caregivers in the elderly. *Mental Health and Illness of Women*, 3-18.
- Aronson, J. (1991). *Dutiful daughters and undemanding mothers: Constraining images of giving and receiving care in middle and later life. Women's caring: Feminist perspectives on social welfare* (pp. 138-168).
- Baker, K. L., & Robertson, N. (2008). Coping with caring for someone with dementia: Reviewing the literature about men. *Aging & Mental Health*, *12*(4), 413-422.
- Baker, K. L., Robertson, N., & Connelly, D. (2010). Men caring for wives or partners with dementia: Masculinity, strain and gain. *Aging & Mental Health*, *14*(3), 319-327.
- Barber, C. E., & Pasley, B. K. (1995). Family care of Alzheimer's patients: The role of gender and generational relationship on caregiver outcomes. *Journal of Applied Gerontology*, *14*(2), 172-192.
- Berwig, M., Heinrich, S., Spahlholz, J., Hallensleben, N., Brähler, E., & Gertz, H.-J. (2017). Individualized support for informal caregivers of people with dementia—effectiveness of the german adaptation of reach II. *BMC geriatrics*, *17*(1), 286.
- Bowleg, L. (2008). When black+ lesbian+ woman ≠ Black lesbian woman: The methodological challenges of qualitative and quantitative intersectionality research. *Sex roles*, *59*(5-6), 312-325.
- Byszewski, A. M., Molnar, F. J., Aminzadeh, F., Eisner, M., Gardezi, F., & Bassett, R. (2007). Dementia diagnosis disclosure. *Alzheimer Disease & Associated Disorders*, *21*(2), 107-114.
- Cameron, J. I., & Gignac, M. A. M. (2008). "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient education and counseling*, *70*(3), 305-314.
- Chappell, N. L., Dujela, C., & Smith, A. (2014). Spouse and adult child differences in caregiving burden. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, *33*(4), 462-472.

- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London/Thousand Oaks: SAGE.
- Chumbler, N. R., Grimm, J. W., Cody, M., & Beck, C. (2003). Gender, kinship and caregiver burden: the case of community-dwelling memory impaired seniors. *International journal of geriatric psychiatry*, 18(8), 722-732.
- Collins, C., & Jones, R. (1997). Emotional distress and morbidity in dementia carers: a matched comparison of husbands and wives. *International journal of geriatric psychiatry*, 12(12), 1168-1173.
- Duggleby, W. D., Swindle, J., Peacock, S., & Ghosh, S. (2011). A mixed methods study of hope, transitions, and quality of life in family caregivers of persons with Alzheimer's disease. *BMC geriatrics*, 11(1), 88.
- Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia*, 13(5), 572-581.
- Fromme, E. K., Drach, L. L., Tolle, S. W., Ebert, P., Miller, P., Perrin, N., & Tilden, V. P. (2005). Men as caregivers at the end of life. *Journal of Palliative Medicine*, 8(6), 1167-1175.
- Gahagan, J., Gray, K., & Whynacht, A. (2015). Sex and gender matter in health research: addressing health inequities in health research reporting. *International Journal for equity in health*, 14(1), 1-4.
- Gilmer, M. J. (2002). Pediatric palliative care. *Critical Care Nursing Clinics of North America*, 14(2), 207-214.
- Gold, D. P., Cohen, C., Shulman, K., Zucchero, C., Andres, D., & Etezadi, J. (1995). Caregiving and dementia: Predicting negative and positive outcomes for caregivers. *The International Journal of Aging and Human Development*, 41, 183-201.
- Gollins, T. (2001). Male carers: a study of the inter-relations between caring, male identity and age. In *Sheffield online papers in social research shop*. University of Sheffield.
- Greaves, L. (1999). *CIHR 2000: Sex, gender and women's health*. Vancouver, BC: Centre of Excellence for Women's Health.
- Hankivsky, O., Reid, C., Cormier, R., Varcoe, C., Clark, N., Benoit, C., & Brotman, S. (2010). Exploring the promises of intersectionality for advancing women's health research. *International Journal for equity in health*, 9(1), 1-15.
- Harris, P. B., & Long, S. O. (1999). Husbands and sons in the United States and Japan: Cultural expectations and caregiving experiences. *Journal of Aging Studies*, 13(3), 241-267.
- Hendrix, C. C., Landerman, R., & Abernethy, A. P. (2013). Effects of an individualized caregiver training intervention on self-efficacy of cancer caregivers. *Western Journal of Nursing Research*, 35(5), 590-610.
- Hibbard, J., Neufeld, A., & Harrison, M. J. (1996). Gender differences in the support networks of caregivers. *Journal of Gerontological Nursing*, 22(9), 15-23.
- Johnson, J., Sharman, Z., Vissandjee, B., & Stewart, D. E. (2014). Does a change in health research funding policy related to the integration of sex and gender have an impact?. *Plos One*, 9(6), Article e99900.
- Kokorelias, K. M., Gignac, M. A., Naglie, G., & Cameron, J. I. (2019). Towards a universal model of family centered care: a scoping review. *BMC health services research*, 19(1), 564.
- Kokorelias, K. M., Gignac, M. A. M., Naglie, G., Rittenberg, N., MacKenzie, J., D'Souza, S., & Cameron, J. I. (2020). A grounded theory study to identify caregiving phases and support needs across the Alzheimer's disease trajectory. *Disability and rehabilitation*, 1-10.
- Kokorelias, K. M., Gignac, M. A., Naglie, G., Rittenberg, N., & Cameron, J. I. (2020). *Caregivers' decision making for health service utilization across the Alzheimer's disease trajectory*. Manuscript Submitted
- Kramer, B. J., & Kipnis, S. (1995). Eldercare and work-role conflict: Toward an understanding of gender differences in caregiver burden. *The Gerontologist*, 35(3), 340-348.
- Lautrette, A., Darmon, M., Megarbane, B., Joly, L. M., Chevret, S., Adrie, C., Barnoud, D., Bleichner, G., Bruel, C., Choukroun, G., Curtis, J. R., Fieux, F., Galliot, R., Garrouste-Orgeas, M., Georges, H., Goldgran-Toledano, D., Jourdain, M., Loubert, G., Reignier, J., ... Azoulay, E. (2007). A communication strategy and brochure for relatives of patients dying in the ICU. *The New England Journal of Medicine*, 356(5), 469-478.
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: fact or artifact?. *The Gerontologist*, 32(4), 498-507.

- Morgan, R., George, A., Ssali, S., Hawkins, K., Molyneux, S., & Theobald, S. (2016). How to do (or not to do)... gender analysis in health systems research gender analysis in health systems research. *Health policy and planning, 31*(8), 1069-1078.
- Mott, J., Schmidt, B., & MacWilliams, B. (2019). Male caregivers: Shifting roles among family caregivers. *Clinical Journal of Oncology Nursing, 23*(1), E17.
- Neysmith, S. M. (1995). Feminist methodologies: A consideration of principles and practice for research in gerontology. *Canadian Journal on Aging/La Revue canadienne du vieillissement, 14*(S1), 100-118.
- NVivo, Q. (2002). QSR International Pty Ltd.
- Parsons, K. (1997). The male experience of caregiving for a family member with Alzheimer's disease. *Qualitative Health Research, 7*, 391-407.
- Pinquart, M., & Sörensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 61*(1), P33-P45.
- Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and aging, 26*(1), 1-14.
- Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., Samsi, K., & Manthorpe, J. (2011). The transition to dementia - individual and family experiences of receiving a diagnosis: a review. *International Psychogeriatrics, 23*(7), 1026-1043.
- Russell, R. (2001). In sickness and in health. *Journal of Aging Studies, 15*, 351-367.
- Seidel, D., & Thyrian, J. R. (2019). Burden of caring for people with dementia - comparing family caregivers and professional caregivers. A descriptive study. *Journal of Multidisciplinary Healthcare, 12*, 655-663.
- Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family - caregivers of people with mental illnesses. *World Journal of Psychiatry, 6*(1), 7.
- Srivastava, A., & Thomson, S. B. (2009). *Framework analysis: A qualitative methodology for applied policy research*.
- Stommel, M., Collins, C. E., & Given, B. A. (1994). The costs of family contributions to the care of persons with dementia. *The Gerontologist, 34*(2), 199-205.
- Stone, R., Cafferata, G. L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist, 27*(5), 616-626.
- Tatangelo, G., McCabe, M., Macleod, A., & Konis, A. (2018). I just can't please them all and stay sane: Adult child caregivers' experiences of family dynamics in care-giving for a parent with dementia in Australia. *Health & Social Care in the Community, 26*(3), e370-e377.
- Thomson, S. B. (2010). Sample size and grounded theory. *Journal of Administration and Governance, 5*(1), 45-52.
- Wawrzynicz, E., Berna, G., Ducharme, F., Kergoat, M.-J., Pasquier, F., & Antoine, P. (2018). Characteristics of the spouse caregiving experience: Comparison between early- and late-onset dementia. *Aging & Mental Health, 22*(9), 1213-1221.
- Weber, L., & Parra-Medina, D. (2003). Intersectionality and women's health: Charting a path to eliminating health disparities. *Advances in gender research, 7*(3), 181-230.
- West, C., & Zimmerman, D. H. (1987). Doing gender. *Gender & Society, 1*(2), 125-151.
- Windsong, E. A. (2018). Incorporating intersectionality into research design: An example using qualitative interviews. *International Journal of Social Research Methodology, 21*(2), 135-147.
- Wong, S. L., Gilmour, H., & Ramage-Morin, P. L. (2016). *Alzheimer's disease and other dementias in Canada: Statistics Canada*
- Wyndham-West, M. (2020) Gender and dementia national strategy policymaking: Working toward health equity in Canada through gender-based analysis plus. *Dementia, 10*(6), 1471301220964621.
- Zakrajsek, A., Schuster, E., Wells, C., Williams, J., & Silverchanz, P. (2018). Caregivers of older adults during care transitions: insights into positive aspects of caregiving. *Innovation in Aging, 2*(suppl\_1), 896.

**Kristina Marie Kokorelias** was a PhD Candidate in the Rehabilitation Sciences Institute at the University of Toronto and is a current post-doctoral fellow at Sunnybrook Health Sciences Centre, St. John's Rehab. Kristina's research expertise is in the areas of gerontology, qualitative

methodologies and health service research. Her primary research interest is to understand how family caregivers use services to support their caregiving role across the disease trajectory. Kristina's PhD research includes a study of family caregivers to individuals with Alzheimer's disease to understand caregiving phases and caregivers' corresponding needs for support across the disease trajectory.

**Gary Naglie** received his medical degree from McGill University, specialty training in Internal Medicine and Geriatric Medicine at the University of Toronto, and graduate training in Clinical Epidemiology at McMaster University. He is a Professor in the Department of Medicine and the Institute of Health Policy, Management and Evaluation at the University of Toronto, and he holds the George, Margaret and Gary Hunt Family Chair in Geriatric Medicine. He is the Vice President of Medical Services and Chief of Staff, and Chief of the Department of Medicine at Baycrest Health Sciences, and is a Scientist at Baycrest's Rotman Research Institute and the Toronto Rehabilitation Institute-University Health Network.

**Monique Gignac** is Scientific Co-Director and a Senior Scientist at the Institute for Work and Health and a Professor at the Dalla Lana School of Public Health at the University of Toronto. Dr. Gignac's research expertise is in the areas of health and social psychology, including health models of disability. Her research examines psychosocial factors like stress, coping, and adaptation and their importance in understanding the impact of chronic conditions on the lives of adults across the life course. Of particular interest is research on workplace communication, privacy, and accommodation needs among individuals living with chronic, episodic conditions.

**Nira Rittenberg** is an Occupational Therapist, who graduated from the University of Western Ontario in 1985. After a brief period in acute care, she has worked for over 30 years in geriatrics, both in the hospital and community setting. She has developed an expertise and focus on geriatric mental health and dementia care in her years as a case manager on a Community Psychogeriatric service. There, she was involved in clinical care, as well as teaching and research through the University of Toronto. Nira has had an active interest in research, exploring the caregiver role and the experiences of men and women caring for persons with dementia. She has co-authored and published a guide book for caregivers, "Dementia: A Caregivers Guide". Nira authored a biweekly column in the Toronto Star, called Caregiver SOS, which provided education and advice to caregivers addressing practical and emotional challenges of elder care. Additionally, Nira was a consultant and participant in the CBC documentary, "The Caregivers Club," which explored the journey of dementia with families she worked with. Currently, Nira works in her private practice where continues to advocate, engage and collaborate with individuals, families and key stakeholders involved in the ageing process.

**Jill Cameron** is a Professor and Vice Chair Research in the Department of Occupational Science and Occupational Therapy and Rehabilitation Sciences Institute in the Faculty of Medicine at the University of Toronto and an Affiliated Scientist at Toronto Rehabilitation Institute - UHN. Dr. Cameron has published over 70 peer-reviewed articles, held 3 career investigator awards, and held over \$2 million in research funding as principal investigator. Her primary research interest is to understand the experiences and needs of family members who assume the role of informal caregiver for individuals with disability. Dr. Cameron aims to develop timely and relevant programs to assist them with their care-giving activities and pursuit of other valued activities and interests. The ultimate goal of her research is to support families as they transition across care environments with the aim of optimizing life in the community.