



Being a Husband and Caregiver: The Adjustment of Roles When Caring for a Wife Who Has Dementia

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Michaella Miller¹ , Elena Neiterman¹, Heather Keller² and Carrie McAiney³

¹School of Public Health Sciences, University of Waterloo, Waterloo, ON, Canada; ²Department of Kinesiology and Health Sciences, Schlegel-UW Research Institute for Aging, University of Waterloo, Waterloo, ON, Canada and ³School of Public Health Sciences & Schlegel-UW Research Institute for Aging, University of Waterloo, Waterloo, ON, Canada

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Corresponding author:
La correspondance et les demandes de tirésàpart doivent être adressées à : / Correspondence and requests for offprints should be sent to: Michaella Miller, 200 University Avenue West, Waterloo, ON, Canada N2L 3G1 (m29mille@uwaterloo.ca).

Abstract

As demographics and gender norms shift, more older men will be providing care for their wives living with dementia than ever before. Research on husbands as caregivers is limited and offers an incomplete picture of their role development and how they experience caregiving. This study examined husbands whose wives have dementia and how they provide care and construct their sense of self. Semi-structured interviews with 11 men aged 61–88 were conducted in Ontario, Canada. Data were analyzed using constant comparison analysis and a constructivist grounded theory (CGT) approach. Two categories were developed: *Adapting to the Role of Caregiver* and *Staying a Husband*. Caregiving as a husband for a wife living with dementia required revision of the role of husband to include that of caregiver by reimagining intimacy, being a protector in new ways, and finding new meanings to being a provider and the value of wealth.

Résumé

À mesure que la démographie et les normes de genre évoluent, les hommes plus âgés seront plus nombreux que jamais à s'occuper de leurs épouses atteintes de démence. Les recherches sur les maris en tant que proches aidants sont limitées et présentent une image incomplète de l'évolution de leur rôle et de la façon dont ils vivent la prestation de soins. Cette étude a examiné les maris dont les femmes souffrent de démence, ainsi que la manière dont ils leur donnent des soins et construisent leur estime de soi. Des entretiens semi-structurés avec 11 hommes âgés de 61 à 88 ans ont été menés en Ontario, au Canada. Les données ont été analysées à l'aide d'une analyse comparative constante et d'une approche théorique constructiviste. Deux catégories ont été déterminées: *s'adapter au rôle de proche aidant* et *rester un mari*. Prendre soin d'une femme atteinte de démence en tant que mari a nécessité une révision du rôle du mari pour inclure celui d'aidant en réimaginant l'intimité, en exerçant le rôle de protecteur de nouvelles manières et en trouvant de nouvelles significations au rôle de pourvoyeur et à la valeur de la richesse.

Introduction

Health care systems worldwide rely heavily on unpaid family caregivers and will increasingly do so to support the rising number of individuals living with dementia (Alzheimer Society, 2022; Choi et al., 2023). In 2020, approximately 600 thousand people were living with dementia in Canada and have been projected to increase to over 1.1 million by 2050 (Alzheimer Society, 2022). This increase in the prevalence of dementia is primarily a factor of the aging population in Canada with the 'baby boomer' generation aging into their eighties and nineties (Alzheimer Society, 2022).

Most individuals living with dementia live at home in the community rather than long-term care homes and rely on their family as informal caregivers. As of 2018, approximately 61 per cent of older adults living with dementia in Canada live at home (Canadian Institute for Health Information, 2018). The proportion of older spouses providing care is expected to increase due to the greater longevity of partners and a general preference to 'age in place', the notion of aging in one's own home (Hong & Coogle, 2016).

Historically, women have provided the greatest amount of caregiving for those living with dementia; however, the proportion of men as caregivers has been increasing due to societal shifts in caregiving duties and expectations (Lauderdale & Gallagher-Thompson, 2003). Caregiving responsibilities of women with dementia are transitioning to husbands more frequently than previous generations as lower birth rates result in families having fewer children, especially daughters, to rely on (Shanks-McElroy & Strobino, 2001). In Canada, for older adults, men are as likely to be a caregiver as women and are even more likely to be a caregiver among those aged 85+

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(Arriagada, 2020). This may be due to the longer life expectancy of women. Statistics Canada suggests:

Men aged 85 and older are more likely to live with a surviving spouse than women of the same age. For that reason, older senior men may be more likely to be caregivers for their spouse, while women of the same age have a higher probability of being widowed and, therefore, a lower probability of being a caregiver. (Statistics Canada, 2020)

In fact, the number of male care partners for people living with dementia is projected to grow by nearly 200 percent by 2050 (Alzheimer Society, 2022). Consequently, more husbands will need support in their role as caregivers than in previous generations.

A growing body of literature explores the experiences of men and spouses as caregivers. Previous literature on stress and coping in men as caregivers for persons with dementia suggests that men find stress not necessarily in the care itself, but in the perception of whether care was done well (Hong & Coogle, 2016). Men may also have ‘cushioning effects’ that protect them from negative experiences. Socially, they may have relative freedom from a socialized responsibility or expectations that women face when providing care for a spouse with dementia (Calasanti & King, 2007). They may also experience more praise for their care work, which may act as a protective mechanism in experiencing stress (Calasanti & King, 2007). Other studies have suggested that stress is not a function of gender necessarily, but on the level of care needed by their spouse and whether becoming a caregiver was a choice or a necessity (Hong & Coogle, 2016; Li & Lee, 2020; Sun *et al.*, 2008).

Some research has suggested that the current cohort of older men as caregivers understand gender roles from their upbringing in the twentieth century where men were strongly socialized to perform traditional masculinity and, as a result, construct caregiving in a way that protects what it means to be a ‘man’ (Hong & Coogle, 2016; Robinson *et al.*, 2014; Schwartz & McInnis-Dittrich, 2015). However, caregiving is a feminized role and is not traditionally performed by men. This may mean the men who become caregivers for their spouses are entering into a new role, requiring them to adapt to being a caregiver, navigate a traditionally feminized experience (Hellstrom *et al.*, 2017), and may struggle with this transition.

The current understanding of caregiving by men within the dementia context suggests that men adopt work/task-oriented caring (LaManna *et al.*, 2024), as opposed to the relational and emotional coping strategies typically adopted by women (Robinson *et al.*, 2014). The existing perception suggests that men construct caregiving for their wives with dementia as a task or as ‘men’s work’ (Calasanti & King, 2007; Greenwood & Smith, 2015; Hong & Coogle, 2016), adopting managerial roles and problem-solving in their caregiving to alleviate strain (Hong & Coogle, 2016). However, some literature suggests that categorizing men’s work as ‘managerial’ may miss many men’s experiences in caregiving if they do not participate in managerial roles (Calasanti & King, 2007).

Although the traditional and dominant view of masculinity is pervasive, the embodiment and compliance within it vary considerably between men (Robinson *et al.*, 2014). Hanlon (2009) identified three archetypes of masculinities related to love and care labour: conventional, sharing, and caring. Conventionalists were men who identified with the breadwinner role and were removed from caring work. Sharers balanced their masculine identities with a strong sense of responsibility and caring along with paid work to maintain their sense of self as men. Carers did not define their masculinity through paid work but identified strongly with the

nurturing aspect of caring. Hanlon’s work suggests that gender is a relevant and differentiating component to caregiving and there are variabilities within gendered experiences; however, his work was not conducted with caring for someone with dementia specifically.

Further exploration of husbands’ experiences in caring for a wife with dementia is warranted to better understand their perceptions and needs, as well as provide an understanding of caregiving that captures role structuring beyond assumptive metaphors. Men’s experiences vary, and the adoption of multiple perspectives and experiences is necessary to properly serve their broad needs. The purpose of this study was to explore the experience of husbands whose wives have dementia to gain a better understanding of the process of being a husband caregiver. Focusing specifically on one gender allows the research to acknowledge the existence of gendered differences while pursuing a more nuanced understanding of men as caregivers that may have previously been overlooked.

Method

This study used a constructivist grounded theory (CGT) approach to offer a structured, yet flexible, method to obtain rich data to uncover a social process (Charmaz, 2014). CGT is an inductive qualitative research methodology used to generate knowledge about the main concern of study participants and identify the social process, or how participants manage their concern/phenomenon (Starks & Trinidad, 2007), which lends itself well to explore being a caregiver (social process) as a husband (specific context). This research approach was chosen to provide a structured form of inquiry to explore diverse perspectives of older husband caregivers whose spouses live with dementia and enable them to express their experiences with being a caregiver. CGT allows for exploration of a phenomenon without imposing a specific outcome on the research (McCallin, 2003), which provides an opportunity for dialogue that removes unintentionally influenced considerations. CGT enables an examination of variability within experiences and offers a richness and depth within the data. This study used CGT to develop greater conceptual clarity about the experiences of husbands as caregivers for their wives living with dementia rather than develop a substantive theory (Bryant, 2017; Timonen *et al.*, 2018). Rather, this study aimed to provide further examination into how husbands experience caregiving.

Social constructionism and gender

CGT has strong connections to social constructionism with the acknowledgement of research as a construction of meaning that includes the social reality of the participants as well as the position of the researcher (Charmaz, 2014). Social constructionism understands the underpinning of experience as a production of social norms and the expectations society puts on individuals based on their characteristics, social status, race, and gender (Mallon, 2019).

Gender as a construct refers to ‘the socially constructed roles, behaviours, activities and attributes that a given society considers appropriate for males, females, and other genders’ (Morgan *et al.*, 2016, p. 1.). Gender is a social phenomenon with which meanings of gender are negotiated and vary by social context and histories (Morgan *et al.*, 2016). Gender affects how people relate to one another at all levels, including within health systems. It also can determine power within relationships, including but not limited to vulnerability, decision making, health-seeking behaviours, and

access/utilization of health services (Morgan et al., 2016). Within this study, gender is understood as a socially constructed role. This study will focus on cis-gender experiences, specifically cis-gender husbands and their conformance or non-conformance to traditional gendered norms.

In this context, social constructionism considers predominant discourses of masculinity as a result of cultural norms and not as innately occurring in men. For example, Ribeiro et al. (2007) describe social constructionism as being salient and widely accepted within the literature on masculinity because it emphasizes the diversity of the men's experiences and the different types of masculinities. Essentially, using a CGT approach with parallels to social constructionism allows an acknowledgement of the variability in experience without imposing assumptions and allows space to conceptually explore.

Roles, identity, and self

In addition to understanding gender, the ideas of roles, concepts of self, and identity matter in understanding the experiences of husbands as caregivers. Concepts of self, identity, and roles are inter-related ideas on our positions in the world in relation to others. The 'self' is a term used to refer to a person's sense of who they are, whereas identity is often used to refer to the outward 'social face' and the way in which a person is perceived by others (Hammell, 2006). Both the self and identity are products of the social world, including norms, values, and perceptions of others, society, and social organization which impact how we experience phenomena.

Goffman (1959) described the self as a performance in which people act in a way that manages the social role they have assumed. He believed that it is through roles that society allocates responsibilities. Park (1950) further articulates this point when he exclaims: 'It is in these roles that we know each other; it is in these roles that we know ourselves ... In the end, our conception of our role becomes second nature and an integral part of our personality' (p. 249). Gendered roles, such as traditional masculine roles of 'breadwinners'/providers and leaders/protectors (Blackstone, 2003; Levant & Richmond, 2016), and society's expectations of men in these roles affect how men see themselves. This study uses understandings of roles, identity, and self to examine how the husbands experience caregiving and what has been maintained or altered through caring for their wife.

Recruitment

This study used purposeful sampling, specifically convenience and snowball methods. Recruitment was achieved through connecting with caregiver organizations, support organizations, memory clinics, and social media. Networks of the first author were engaged to share recruitment materials with men's support groups for dementia caregivers. Interested parties contacted the first author and confirmed their eligibility and were invited to an interview. Eligible participants met the following criteria: (1) self-identified as a man, (2) aged 60+, (3) spoke and understood English, and (4) had a wife with dementia who lives within the same household in the community. Individuals whose spouse was in a long-term care home or deceased were excluded from participating. Participants in the study were asked following their interview to share the recruitment materials with men they knew who fit the eligibility criteria and may want to participate.

Ethics and consent

This study was approved by the University of Waterloo Research Ethics Committee (ORE #42861). Participants were given letters of information to review before the interview. Prior to the interview, participants were asked whether they had reviewed the information and consent letter and whether they had any questions. A consent letter was read at the interview, and verbal consent was obtained and recorded before the interview began.

Participants

Interviews were conducted across Ontario, Canada, with 11 husbands who lived with their wives who had dementia (Table 1). All participants lived in the community and were between the ages of 61 and 88 years. Ten participants identified as Caucasian, and one participant identified as Portuguese. Two men expressed that they moved to Canada from Holland, two men were from England, five men identified as Canadian, one man was from Portugal, and one did not disclose their country of birth. One participant completed a high school equivalent, two completed skilled trades, two completed college diplomas, three completed a bachelor's degree, and three

Table 1. Participant demographic response

Participant age	# of participants
60–69	3
70–79	4
80+	4
Urban/rural	
Urban	9
Rural	2
Education level	
High school (or equivalent)	1
Skilled trades	2
College diploma	2
Bachelor's degree	3
Master's degree	3
Self-identified race	
Caucasian	10
Other	1
Country of origin	
Canada	5
England	2
Holland/Netherlands	2
Portugal	1
Unknown	1
Number of years since wife's dementia diagnosis	
1–3 years	3
4–6	5
7–9	1
10+	2

completed a master's degree. Nine participants lived in an urban centre, and two participants lived in rural areas. One participant shared that he and his wife had moved from a rural area due to safety considerations with her dementia. The number of years since their wives' diagnosis ranged from eighteen months to approximately ten years.

Data collection

Semi-structured interviews (approximately 40–90 minutes) were conducted between May 2021 and June 2021. This was during the COVID-19 pandemic when Ontario was in a stay-at-home order. Interviews occurred online through a video conferencing platform or by phone and audio recorded. Audio recordings were transcribed verbatim using transcription software (Otter.ai, 2022, version 3.9.1) and checked by the first author.

Interviews began with an introduction to the research and the first author's background and own experiences with caregiving to help establish rapport. After the first few interviews, the interview guide was reviewed and altered to investigate emerging categories and improve the ease of the conversation between the researcher and the participants. Additional probes and questions were added or changed throughout subsequent interviews as the data emphasized the impact and importance of relationships within the experience of husbands in providing support to their spouse with dementia (e.g. exploring concepts of couplehood through cognitive decline and role changes). Demographic questions were first asked to help ease participants into sharing about themselves. They were then asked to share their experiences from their wife's diagnosis onwards and how it affected them, how it changed over time, and the impacts of caring on themselves. Although gender was an important component to the experiences of husbands, asking about their gender did not seem to illicit meaningful responses; however, asking what would be different if the roles were reversed and it was their wife caring for them became a very emotional question and prompted deep reflection from participants.

Following interviews, memos were written to capture initial thoughts about the interview and provide context to the transcripts, such as intonation of voice and body language (if cameras were on). During the transcript checking and first reading of transcripts, memos were written to capture thoughts and reflections of the researchers. Memos were utilized throughout data collection and analysis to provide reflexivity and offer an analytic tool in constructing abstract thought. Memos captured thoughts, reflections, analytic notes, comparisons, and ideas as they occurred and helped to identify questions and directions to pursue.

Analysis

Constant comparative analysis was used to form categories and iteratively derive the themes within the data (Boeije, 2002). Constant comparison reviews data continuously throughout the analysis and compares between interviews and within interviews, allowing examination into similarities and differences between interviews and contexts and the consequences of these patterns.

Analysis of transcripts, memos, and researcher reflections was iteratively assessed throughout the data collection period and compared at different stages, informing the data collection of subsequent interviews. Analysis began with line-by-line coding of the transcripts, followed by focused coding. Line-by-line coding sticks close to the data, and codes were developed per line using

grunds. Codes were compared at this stage within the interviews during which analytic ideas were written in a memo to accompany the codes (Charmaz, 2014). Focused coding followed and used the earlier codes to define categories and delineate the analytic sense of the data. As each interview was coded, they were reviewed to compare codes and define categories further. This process helped to synthesize and conceptualize the data. Following coding, memos were sorted to assist the analysis, shaped the research, and provided structure to the writing process. Multiple authors reviewed and assessed initial codes, focused codes, and category development.

Findings

The overall experience of being a husband caregiver for a wife living with dementia is one of loss, love, and learning. The process was described as a journey, with continual challenges and disease progressions to navigate while trying to understand and maintain a relationship with their wife. The husbands' experience with their wife's dementia facilitated a re-negotiation of their roles as a husband and what it means to be a husband, while also transitioning to the role of the caregiver. Findings of this study suggest that husbands undergo a process of negotiation of roles and self, in which they experienced changes in social positions in relation to previously held masculine identities. The categories developed were (1) Adapting to the Role of Caregiver, with subthemes of *Relying on Identity to Guide Caring Role* and *Revising Self Because of the Caring Role*; and (2) Staying a Husband, with *Reimagining Intimacy*, *Being a Protector*, and *Being a Provider* (Table 2).

The negotiation of roles and self were different between the husbands depending on how comfortable they were with feminized roles of caregiving and their conformance to masculine ideals. The norms of their marriage and relationship were altered with the progression of their wife's dementia. How the husbands responded to this change and adapted to the role of caregiver depended on their perceptions of self and their role of husband.

Adapting to the Role of the Caregiver:

Adapting to the Role of the Caregiver began with how the husband's perceived caregiving and what this role entailed, followed by how previously held identities were used to move into the caring role, and how the caring role subsequently influenced ideas of the self.

Husbands perceived caregiving as an all-encompassing experience, describing it as relational, emotional, physical, and all-consuming. Participants explained that caregiving, as a concept, was both emotional and physical work, ensuring that their wives' mental health and physical needs were cared for. However, the practical application of caregiving was not always consistent with their definition of caregiving. Although all participants described caring as both physical and emotional work, not all husbands provided personal care (e.g. bathing, continence care).

Table 2. Overview of themes and subthemes

Theme	Subtheme
Adapting to the Role of Caregiver	<ul style="list-style-type: none"> • <i>Relying on Identity to Guide Caring Role</i> • <i>Revising Self Because of the Caring Role</i>
Staying a Husband	<ul style="list-style-type: none"> • <i>Reimagining Intimacy</i> • <i>Being a Protector</i> • <i>Being a Provider</i>

I guess the question was what is the term caregiving mean to me? Taking care of the needs of another person. Taking care of all the needs. I'm not sure whether I qualify to call myself taking care of my wife. I don't take care of her personal needs. I don't think she would let me anyways. (A04)

Discrepancies existed between the concept of being a caregiver and the provision of care. The participant quoted above questioned whether he would define himself as a caregiver even though he was the primary care provider for his wife. The definition of caregiving as 'emotional and physical' can potentially limit the self-definition of being a 'caregiver' if husbands rely on care services and do not provide support in personal care themselves.

Relying on identity to guide caring role

Regardless of whether the husbands considered themselves a caregiver, they all provided some level of care. However, how they provided care differed and was influenced by their unique life experiences. These included their upbringing and learning from women in their lives or their connections to their mothers; generational social or gendered roles; experience with providing care previously; belief systems; previous work and professional skills; and willingness to seek out and use supports. These life experiences impacted how husbands transitioned into the caring role and created variations in how they conceptualized themselves and masculine identities in relation to caring. Participants who had a greater tendency to express feelings and had a history of less traditional gendered roles within their household had an easier time accepting and being influenced by their role as a caregiver. For some husbands, becoming a caregiver for their wives was relatively easy. These husbands shared how they had been socialized to provide care from their families and were influenced by their mothers:

My mother [...] took care of her grandmother and mother [...]. I had heard all these stories of how women deal with these kinds of situations, and it has acted as a model and an inspiration for me to follow the same path. (A05)

This participant shared that becoming a caregiver was easier because he had been exposed to caregiving through the women in his life. In this way, he was able to use those experiences to adjust to the caregiver role. Other participants who had previous caring experience also expressed that their transition into the role of a caregiver was natural for them.

Alternatively, some participants who did not describe a sense of ease with the transition into the role of caregiver relied on metaphors of obligation and morality or comparison to previous careers as a means of understanding their role as a caregiver.

My whole career was in administration at [college]. And we did a lot of staffing and contract administration. And I read a book early on [...] And [it] said, 'I don't know how to provide care to my mother, but I know how to run a business or service from a business perspective'. [...] I'm not trained in personal care. But I do know how to get services to provide and meet [her] needs. (A02)

This participant utilized his professional background to help facilitate care in a way that he understood – through coordinating care. His role became managing his wife's needs through a business perspective. Restructuring their professional roles may enable the transition into the role of caregiver and as a way to protect the norms established earlier in their marriage. Utilizing obligation,

morality, and careers as pathways to providing care can also maintain the previously defined status the husbands held, both socially and within their family dynamics; 'She's one of my own, so and again I feel moral obligation, moralized to do as much as I can, give as much as I can, in order to minimize her suffering' (A06).

Additionally, husbands had a harder time seeing themselves as a caregiver when the role of the caregiver did not match the husband's concept of self and if caregiving was perceived as the more feminized form of caregiving where personal care was central. In contrast, those who had experience caregiving in the past or had grown up with female role models used those experiences to adopt the caregiving role with more ease and provided more hands-on care.

Revising self because of the caring role

The caring role necessitated revising ideas of how the husbands saw their future and, in turn, revised parts of their identity. They spoke of abandoning pieces of themselves when their wives needed more support. Activities that they enjoyed and had brought value into their lives were no longer a priority and were lost to their caregiving role. Some husbands felt a loss of 'the golden years' (A07), or a planned second career (A01), and an inability to travel or be snowbirds (A02). This meant a loss of hobbies, often giving up pieces of their identity to ensure safety and provide care for their wives.

Well, she needs 24/7, care. Like I, I used to curl about three times a week. And so did she. But now to get someone in? [...] Curling takes two hours, and then you got to get there and get home again. So minimum three hours you'd be out. And since [wife] was incontinent, that's a lot to ask of someone else and I wasn't going to pay to have a stranger come in and do it. (A07)

The loss of an idealized future was associated with a loss of independence and personal time as their wives' needs, and subsequently, their caring role became more intensive. In some cases, husbands accepted the loss of their past life and focused on the time left with their wives. This allowed them to move into the preservation of their relationship and to cherish the remaining time with their wives. The participant above continues on to say:

It's just as [wife] progressed to the point where, like I say, I just didn't want to leave her alone and I'm only gonna have so much time with her going in the future. So, I've kind of set my goals to get through this year. So, every time we hit the next month, that's kind of a success. (A07)

Developing into the role of a caregiver required a re-framing of their self-identity to include new skillsets that were previously held by their wives. For some participants, learning the skills of a caregiver, such as cooking, became a sense of accomplishment and pride which prompted positive appraisal of self in the role of caregiver. Many participants expressed how adapting to the role of caregiver facilitated learning their wife's previously held duties in the household, impacting their view of themselves and compelling them to reflect on their role and marriage.

I've become more aware of myself and more aware of my faults and weaknesses. I've tried to work on those, and I think to some, with some success, perhaps quite a bit of success. I've learned a lot of new skills, things like, [wife] always did the cooking and everything else. And now, I'm making meals. [...] But it's more, it's more spiritual. When you look out and you see something beautiful, you think how lucky you are. My

wife is very loving, and we hug and kiss a lot. So that's important. That's still there. (A11)

This participant used positive reflection to come to terms with the disease progression. He chose to construct his experience through a lens of gratefulness of 'beautiful' things, comparing his wife's affection to moments of joy and an appreciation for the skills he learned through becoming a caregiver.

Not all participants had a positive appraisal of their caregiving experiences and had a more negative view of themselves as caregivers. Husbands who experienced more difficulty with caring for their wife often described themselves in self-deprecating ways or experienced internal dissonance.

I'm not as patient as I was. I tried to be. I realize that all the writing say somebody with dementia, don't yell at them. That's very hard not to do. Soon as I've done it, I've regret it. But it's very hard. [...] I think I've changed a little bit; I think I think I'm probably a more nervous person than I was. (A04)

Within the negotiation of roles and in their understanding of themselves was a change in norms. Social positions were challenged with the evolving nature of dementia altering the wife's previously held role in their relationship and the necessity of caregiving placed on husbands. However, husbands did not experience this change uniformly. Among the participants' experiences, caregiving roles were viewed and adopted differently. Some participants who held more traditional masculine positions in their family showed a greater resistance to seeing themselves as a caregiver. One husband described how he did not feel comfortable with providing personal care and that it was a woman's role.

I did some personal care. But quite frankly, that's not the kind of thing that you want to be doing for your spouse. And that may be a man thing as well, as opposed to what a woman might do. (A02)

Masculine identities are presented in various ways in the conceptualization of care. Some referred to having 'strength' to provide care, or when getting emotional, described themselves in derogatory terms, such as 'a sad suck' (A04). One husband described that he now has the strength to provide care: 'I found enough, I found enough strength, enough support to be able to, to carry it forward' (A08). Husbands who felt more confident and comfortable with feminine aspects of caring, or role sharing, leaned towards a more emotionally focused provision of care. While men who conformed to a traditional form of masculinity and division of labour experienced more task-oriented caring or conflict with the role.

Staying a husband

The changes associated with dementia forced husbands to reimagine their role as *husband*. A loss of partnership as it once was occurred for all participants as their spouse's dementia progressed. Husbands maintained a sense of their role as a husband by finding ways to maintain intimacy, offering forms of protection for their spouse, and re-evaluating the meaning of their provider role through the evaluation of finances.

Reimagined intimacy

All husbands experienced the loss of partnership within their marital relationship. Most participants expressed that loss of partnership occurred simultaneously with the progression of dementia and struggled with the loss of the companionship that was the basis

of their marriage; '...Continuous thoughts of I didn't bargain for this, I didn't want this in my later life [...], I want some companionship [...]. I want somebody to talk to' (A03).

In later stages of dementia, husbands had to navigate the loss of recognition of who they were and what their relationship was with their wives. In some instances, they underwent a process of reconceptualization of their partnership and marriage. One participant described that he was not sure who he was to his wife anymore.

She hasn't recognized me as her husband now for a long time. [...] she hasn't called me by my first name in at least a year and a half. And I, even though she says she loves me, and she'll give me a kiss and so on. [...] I'm not sure. I think she's not sure what the relationship is. And I've asked her a couple of times as well. You know, like, Who am I to you? What's our relationship? Just to see what she has to say. And she's never been able to really to come up with an answer other than one time. It was sort of a friend, but no more than that. (A01)

His journey through loss required a reconceptualization of his role in their marriage as a way to cope. He conceptualized her as a figure of his previous relationship but acknowledged that it was not the same and that he could not expect the same companionship and relationship as before.

Husbands often described accepting that dementia was a 'one way journey' and that the person they had married was not the same anymore. Part of the revision of the role of the husband was finding ways to re-establish connection with their wives and accept the disease's irreversible nature. Some participants relied on remembering who she was in the past as motivation to continue with caring. Some reframed conflict to remember that she did not choose to have dementia and that the disease is happening *to* her, not *because* of her. Other participants compared their wives' behaviours to a child to bring empathy forward in their relationship; 'And now she is function, I would say like a four-year-old child. And I have a four-year-old granddaughter, you know, both of them, they are in same, intellectual speaking, they are in same level, problem solving' (A06).

Although there was grief in the experience of losing the relationship they once had, there were also beautiful glimpses into maintaining intimacy (albeit differently). Husbands showed intimacy by employing familiar everyday strategies and holding onto moments of affection. Participants maintained intimacy through paying attention to what their wives enjoyed and being part of that experience together, such as playing music or watching movies she enjoyed. Husbands used strategies when their wives experienced distress or needed a sense of comfort, and engaging her in elements of their wives' life that held meaning to her, such as singing along to music programs.

There's been some music programs that have been available on and off and so able to put them on the computer and some of them are sing along and some of them are just listened to. And my wife's got a music background, sang in choirs and so on. So, music is very important for her. (A08)

Additionally, many husbands described ways their actions promoted feelings of closeness and affection with their wives. One man rubbed his wife's back each morning to start their day, and another focused on being attentive to his wife to facilitate feelings of closeness and connection.

Alzheimer's is, it's like a lighthouse, long, long periods of absolute darkness, and then sudden, sudden beams of brightness. But it's totally, comes randomly. You have to be aware, and when you are aware of that, these moments are great. (A05)

Many husbands held onto their affection and love for their wives and looked for ways to maintain their marriage in new ways, such as carefully attuning to her bids for attention or arranging programs and activities that promoted feelings of affection. Utilizing active forms of affection may have promoted a feeling of closeness for longer with their wives.

However, in some cases, husbands refused to acknowledge their role in meaning-making or their relationship's dynamic. Some stoically assessed their actions as inconsequential and refrained from self-reflection or reconceptualization of their relationship. In these cases, they experienced difficulty navigating relational changes if they denied changes in their circumstances, their wives' needs, or their own emotional difficulties.

The overall [...] scenario, we're all going to die, sooner or later we all die and that's a fact. There's no use weeping about it, that doesn't solve anything, doesn't provide any relief. If you look around, we've got a pandemic with hundreds of dying all over the world. [...] Any little thing that happens between my wife and I, I compare it to that, it's water off a ducks back. She has bad days, bad moods, there's nothing really, I can do except feel sorry for her. And feel sorry for how the world has been. (A09)

Some participants described a withdrawal of intimacy. One participant described that a reciprocal and intimate relationship with his wife was limited and may be typical as dementia progresses; 'So, it's really, it's really pretty limited to tell you the truth, right, at this point, or at this stage, which I think is probably [...] it's pretty typical, I think' (A02). It may be more difficult to share intimate moments if intimacy is perceived as a more sexual or physical act when their wives' dementia had progressed to later stages. Another participant described that the choice of withdrawing from being her primary caregiver was to preserve positive memories of her.

If there's wandering, or if things get physical, which can happen with Alzheimer people. I know men who have gone through that, then that's time. I don't want to destroy the memories that I have of her with having to put up with that and trying to work around physical confrontations or, or wandering. I just can't do that. So and then, when she gets in there, it'll be whatever time it takes until Alzheimer's finally claims her. (A11)

He saw long-term care as a way to preserve his memory of her as she was and their marriage as it was before conflict. In these cases, withdrawal of caring may be a mechanism in which husbands maintain intimacy with their wives by protecting memories of their life and love previous to later stages of dementia and feelings of significant loss.

Intimacy helped to maintain the role of husband as their wives' memory faltered and her perception of their marriage and them as husbands changed. It enabled husbands to feel *like husbands* and offered a sense of connection to their marriage and the relationship they had built. Intimacy also offered a pathway from the role of husband to that of husband *and* caregiver. To do so, intimacy had to be configured in a way that was emotionally driven rather than physically driven, which may conflict with more traditional masculine ideas of intimacy.

Being a protector

The husbands described an increased conflict between their wives and themselves associated with changes in behaviours and needs as dementia progressed. Learning how to de-escalate conflict was a skill some participants developed and enabled a more confident and positive self-perception. Others used validation techniques to

avoid conflict and affirm their wives' realities or implemented environmental changes such as removing the knobs off the stove-top to prevent their wives from turning it on. This action was described as providing protection while also preventing conflict by deterring the spouse from using the stove. Preventing conflict from occurring in the first place enabled the husbands to keep a closer connection with their wives and promoted more positive reflection of their overall relationship.

All our exterior doors now have little chimes on, so when I put those on, I said to [wife], that's in case somebody ever breaks in 'Well, that's fine'. And [she...] took the kettle that we had- one of those electric kettles and put it on the stove and turned on the heat and [burnt] the bottom out of it. So, I took off the knobs off the stove [...]. And if she asks about where the knobs just say, oh, I had to take them off. And it passes, her memory for things like that's 15 seconds. It just disappears very quickly. (A11)

In some cases, husbands used avoidant or distancing techniques to prevent conflict. Some husbands hid from their wives (in a closet, garage, or basement) to avoid eavesdropping or confrontation when they were talking with other people. Some husbands explained that using the words Alzheimer's or dementia could be upsetting to their wives and therefore avoided these terms. Avoiding conflict was a way that husbands could continue to offer protection for their wives and maintain the role of husband and protector.

My wife told me when we're, we're still dating, many years ago, that I should kill her if she will get Alzheimer's. So, I consistently have prevented use of the word Alzheimer's [...] for all this time, yes. I make mistake once, mentioning Alzheimer's in her presence. And she had a very scared look on her face and says, 'I have Alzheimer's?' And after 'Alzheimer's no', she said 'okay'. So, I don't I don't do that that way. (A05)

Navigating the relationship changes that occurred due to dementia included elements of avoiding conflict. Wives' perception of reality was different from that of their husbands, which, without a clear understanding of dementia or what their wives were experiencing, could increase conflict between the couple. To adapt to this process, some husbands used avoidant strategies and deflection to reduce the incidence of conflicting realities and to maintain control of the situation. Other husbands adopted more caring strategies that enabled their wives to experience their reality while maintaining safety.

Being a provider

Additionally, this journey with their wives had fundamentally challenged and changed their view of finances and the role of provider. Many of the husbands described a greater appreciation of the little things and a re-evaluation of the value of money that differed between participants and was conceptualized in a way that affirmed husbands' self-concept and role of provider. For some, the value of accumulating wealth had disappeared. They spoke of the worth of their experiences with their wives as much more meaningful to them, either expressing that they were glad they made choices to travel or use their money as a tool to give her a good life.

We chose consciously to have a mortgage in order to do some other things that we wanted to do. And it makes me so glad we did those things. [...] And so, we were able to do a lot of traveling and do a lot of things that if we'd waited 'til we were 65 simply wouldn't have happened.

We'd have had money in the bank and nothing else. So, it's, it's made me glad for that. (A01)

This participant was grateful that he had spent his money in a way that allowed him to experience life with his wife before later stages of dementia. Another participant expressed that prior to his wife's dementia he had been inclined to save all his wealth.

The value of money has totally changed for me and what I mean by that, before [wife]'s Alzheimer's: save money, save money, save money. Work, work, work, work, save, save, save. And now it's something like, What for? None of the money in the world will bring her brain back, right, and so the value of money has fundamentally changed for me, and it's now a tool, method of keeping her happy or making things easier for her. (A05)

The participant quoted above reflected that his personal values had shifted to provide the best possible care for his wife. Money was now a tool and method for providing care. In contrast, other men shared that money was of utmost importance and enabled them to provide good care for their wives; 'And another thing that I can say-Look, I am providing the kind of care that not so many people can afford to' (A06).

Although the sentiment of using money as a means to provide care was shared by multiple husbands, the values that were reinforced through their reflections differed, which also reflected their caring styles. While some shared that accumulation of wealth became less valuable as their caring journey made them re-evaluate what was meaningful to them, other men shared that their caring journey reinforced the value of wealth as a means to provide care. Additionally, the men who shared money as of primary importance were more inclined to utilize and pay for personal care services, whereas the men who re-evaluated money's worth were more likely to provide personal care themselves.

Discussion

Most literature studies available on the experience of caring for persons living with dementia, especially a spouse, rely heavily on women's experiences (Houde, 2002; Lauderdale & Gallagher-Thompson, 2003). This study contributes to the limited literature on older men as caregivers for someone living with dementia. It offers insights into how husbands adapt and the range of experiences in developing into the role of the caregiver and how they maintain a sense of themselves as a husband. The findings suggest that adapting to the role of the caregiver changes their role of husband as well.

Masculinity and caregiving

The literature on men as caregivers is growing. Previous research suggests that husbands who provided care make sense of caregiving by constructing caregiving as 'men's work' and adopt a task-oriented or work-related model for caring (Calasanti & King, 2007; Greenwood & Smith, 2015; Hong & Coogle, 2016; Ribeiro et al., 2007). LaManna et al. (2024) found in their research that older men work to get the job of caregiving done. However, this was not the sole motivation in caregiving identified in this study. Instead, participants shared multiple motivations and perceptions of caring for their spouse, including wanting to provide the best possible care for their wives, moral and familial obligation, and maintaining the role of husband within their marriage.

Other work has addressed how different masculinities influence men's caregiving personas (Hanlon, 2009). In line with Hanlon's (2009) masculine archetypes for caregivers, some husbands in this study developed the caregiving role in a similar way. Consistent with Hanlon's conventional, sharing, and caring masculinities within caring, the participants in this study existed in multiple masculine identities. Moving into the role as a caregiver was viewed differently by men who held stronger hegemonic masculine identities and instead used work-related business models to provide care. Moral obligation was also used to justify what care they did provide. In contrast, those with masculine identities that were more open to feminine experiences tended to adapt to the caregiving role with more ease and offered more personal care. These levels of masculinity and caregiving identities contrast with most of the caregiving literature on older men caring for a spouse (Calasanti & King, 2007; Greenwood & Smith, 2015; Hong & Coogle, 2016; Robinson et al., 2014; Schwartz & McInnis-Dittrich, 2015). This study suggests husbands offer a range of care provision that is developed through unique life experiences and relates to the level of which their sense of self and social and masculine identity are challenged when becoming a caregiver for their spouse with dementia.

Similarly, Ribeiro et al. (2007) discussed how men's caregiving is negotiated through their current life situation and culturally and socially constructed norms of what it means to be masculine. Other research described personal characteristics that contribute to the variability in experiences for someone caring for a person with dementia, which include 'individual [...] variables that include socioeconomic, demographic, health, personality, and interpersonal factors that are the context in which caregiving is rendered and which influence every caregiving situation in unique ways' (Noyes et al., 2010, p. 10). Additionally, men's involvement in caring is related to their relationships with women (Gerstel & Gallagher, 2001; Hanlon, 2009). Such characteristics and life experiences may explain the variability seen in this and other studies on how husbands provide and conceive care.

The literature on self construction expresses that the social self and construction of identity are responsive to lived experience (Gubrium & Holstein, 2000). The self is a product of engagement with a variety and array of environments around us and that in which we engage in. Self is then reconfigured and reconstructed continuously. The construction of self, in this case, is influenced by the changes brought on by their wives' dementia, the evolving role of husband, and the adoption of the caregiving role. Goffman (1959) argues that the self and social identity are a performance aimed to convey the appropriateness of behaviours in line with the role assumed. Within this study, masculine identities were intertwined into their experiences and impacted the role restructuring and how the caregiving identity was adopted. Goffman (1961, p. 94) also describes an important avenue of understanding this dissonance, through role embracement and role distancing. Role embracing is seen as when the self accepts the situation and acts in accordance with the expected duties of the role. In contrast, role distance is a separation of the individual and the role, otherwise described as the difference between doing and being. Changes to the husbands' sense of self when adopting the caregiving role were met with greater ease in some when their personal identities already supported a caregiving identity.

Role of husband

The role of *husband* was challenged with their wives' dementia changing the relationship dynamic. They often reframed their

relationship to accept that their companionship was different than before. Husbands used new or altered forms of intimacy to connect the caregiving role with the husband's role. Additionally, the experience of caring for their wife through dementia affected the value of wealth, either affirming previous conceptions of the provider role or revising the meaning of wealth as a tool to provide care. Findings also suggest that the role of being a protector as a husband evolved to protect their wives from the impact of dementia, including finding ways to alter environments for safety or employ strategies to avoid conflict caused by discrepancies in their wives' reality.

There are relatively few studies that examine the changes in the role of husband while caring for a wife with dementia. Ribeiro et al. (2007) examine how older husbands care for dependent wives and how their masculine identities changed or did not change with caregiving. They found these older men used dominant ideas of masculinity to maintain a sense of masculinity when entering a feminized role, reinforcing the role of husband, and retaining power in their relationships. This current study shares parallels in some of the husbands' experiences in trying to maintain role of husband. Some participants used the role of husband to move into the adapted role of husband and caregiver, while some did not see themselves as caregivers but viewed their caring as a reinforcement of their role of husband.

Additionally, previous studies on the experience of couplehood through the journey of dementia reflect similar reconstructing processes as seen in this study. Merrick et al.'s (2016) study suggested couples navigate the journey of dementia by continually constructing their relationship. Some literature describes an oscillating process of self-reconstruction that occurs in caring for a loved one with dementia, where caregivers reflect on what they had lost and what remains (Keady 1999; Merrick et al., 2016). Hellstrom et al. identified that the process and phases that a couple engages with during their journey of dementia were 'temporal', but 'not linear and involved a delicate interactive and iterative relationship' (2007, p. 391). Couples may also attempt to maintain their experience of their relationship as it was before they were faced with challenges (Molyneux et al., 2011). Participants in this study adjusted to changes in their roles within their marriage which challenged their previous self concepts and were adjusted to with varying ease. Participants who adopted the role of caregiver with more ease described a variety of adjusting that included learning new skills previously done by their wives, reconceptualizing their marital relationship and their own sense of self. In this case, continuity in relationships may not mean as much or be necessary when role changes occur that alter the previous structure and gender dynamics of the relationship. However, adaption was not uniform and participants adjusted with varying ease. Some experienced more dissonance and discomfort with caregiving and these husbands may attempt to maintain their relationship as it was, as Molyneux et al. (2011) described. Further research on husbands' role restructuring when caring for someone with dementia may further explore the impact on men and their self concepts when entering a feminized role.

Strengths and limitations

The structure offered by the CGT approach enabled a detailed and in-depth examination of the data. However, CGT views knowledge as socially constructed and thus may not be translated into other contexts. Although attempts were made to have a more diverse sample, the final sample was mainly middle-class white men

exclusively in community-based, heterosexual relationships. The experience of these men may not reflect those of men in other countries, care contexts, non-heteronormative relationships, sexualities, ethnicities, or sons as caregivers. More research should be done within these contexts to explore other experiences and unique needs based on an intersectional approach.

Additionally, due to the recruitment constraints of the COVID-19 pandemic, most participants were reached through support organizations. This study may not accurately represent the men who are more likely to be socially isolated or who have not engaged with support services. The pandemic may have also facilitated a level of access. Participants may have expressed interest in participating due to additional time and a desire for socialization. Additionally, the interviews were conducted exclusively over the phone or via online platforms. This may have created a distance from the researcher that impacted the level of disclosure and freedom of expression and may have allowed the husbands to engage more by offering the removal of emotional intensity that can come from in-person interviews.

Conclusion

Husbands' conception of being a caregiver is an all-encompassing process, both physical and emotional. The findings of this study suggest that husbands (re)construct their sense of self and their relationship to adapt to the role of caregiver while attempting to maintain the role of husband even as this role changed. Adoption of the role of a caregiver challenged previous masculine identities and role structuring. Those whose masculine identities enabled crossover with feminized roles had an easier time adjusting to the role of caregiver and provided more personal care. The participants also maintained their sense of self as a husband while experiencing significant loss of partnership in their marriage by attending to their wife through altered forms of intimacy, offering forms of protection that reflected her current stage of dementia, and shifting their views of wealth to provide care.

Competing interest. The authors declare none.

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