Older Adult Spouses with Multiple Chronic Conditions: Challenges, Rewards, and Coping Strategies*

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RÉSUMÉ

Un manque de recherche explore comment les conjoints des personnes âgées avec de multiples affections chroniques confèrent un sense à leur expérience de la prestation de soins. Dans le cadre de cette étude, nous avons posé la question suivante: *Quelle est l'expérience des aidants naturels pour les personnes atteintes de maladies chroniques multiples*? Nous avons appliqué l'approche descriptive interprétative de Thorne, en interviewant 18 conjoints qui ont fourni une riche description de leurs expériences de soins; les entrevues ont été transcrites textuellement et analysées thématiquement. Les thèmes ont été catégorisés en fonction des difficultés rencontrées, des récompenses obtenues et des stratégies de soutien employées par les participants à la prestation de soins pour les conjoints souffrant de maladies chroniques multiples. Les résultats uniques portent sur les défis inhérents à la prise de décision dans le contexte de maladies chroniques multiples. Cet article commence à combler l'écart dans la littérature sur l'expérience des soins dans le contexte de multiples maladies chroniques.

ABSTRACT

There is a paucity of research exploring how spouses to older adults with multiple chronic conditions make meaning of their caregiving experience. For this study, we asked: *What is the experience of spousal caregivers to persons with multiple chronic conditions?* We applied Thorne's interpretive description approach, interviewing 18 spouses who provided a rich description of their caregiving experience; interviews were transcribed verbatim and thematically analysed. Themes were categorized according to challenges encountered, rewards gleaned, and sustaining strategies employed by participants in caregiving to their spouse with multiple chronic conditions. Unique findings relate to the challenges inherent in decision-making within the context of multiple chronic conditions. This article begins to address the gap in the literature regarding the caregiving experience within the context of multiple chronic conditions.

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Chronic conditions can be defined as any persistent condition (including physical, psychiatric, or psychological conditions as well as infectious diseases) that requires ongoing medical management over many years (Goodman, Posner, Huang, Parekh, & Koh, 2013). Although prevalence rates depend on which conditions are measured within a population, the Public Health Agency of Canada indicated that 14.5 per cent of the Canadian population over age 20 reported living with two or more chronic conditions from 2011 to 2012 and 4.9 per cent reported having three or more chronic conditions (Centre for Chronic Disease Prevention, 2014). The prevalence of *multiple chronic conditions* (MCC) increases as the population ages, such that close to half of Americans and Canadians over the age of 65 and almost three-quarters of those over 80 have reported having more than one chronic condition (Broemeling, Watson, & Prebtani, 2008; Denton & Spencer, 2010; Freid, Bernstein, & Bush, 2012). These estimates suggest that a sizable proportion of the older adult population in Canada are currently living with MCC, which may entail overlapping or unique symptoms, management strategies, and patient needs.

Individuals with MCC may require a significant level of care given the potential impacts of MCC: poor health; impaired functioning; lower quality of life (including difficulty balancing different aspects of daily life with illness-related demands); and difficulty living independently (Jeon et al., 2010; Koch, Wakefield, & Wakefield, 2015). Indeed, those with MCC utilize more (and more intensive) health care services than individuals without chronic conditions, and this intensive use of health care services increases with the number of conditions (Broemeling et al., 2008; Denton & Spencer, 2010). MCC can be difficult to properly manage from a health perspective, as one condition may either positively or negatively impact the diagnosis, treatment, prognosis, or general management of other co-morbid conditions (Jeon et al., 2010; Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009). Decisions made around medication use for MCC may be particularly complex, as a medication that is beneficial for the management of one condition may interact poorly with another medication or condition and thereby cause adverse effects (Zulman et al., 2014). In light of this complexity, it has been argued that individuals with MCC require co-ordinated, multidisciplinary care, which integrates information from different health care providers and the patients themselves in order to support patient-centred (as opposed to disease specific) management (Bayliss, Edwards, Steiner, & Main, 2008; de Bruin et al., 2012; Tinetti, Fried, & Boyd, 2012). Unfortunately, gaps in care coordination, case management, and timely access to medical care remain a significant issue for patients with MCC (Schoen et al., 2011).

Although individuals with MCC rely extensively on formal health services, a significant amount of care and support is also provided by informal caregivers (e.g., spouses, adult children, and/or friends). Indeed, informal care is the major form of care for older adults, exceeding that which is provided by the formal health care system (Sinha, 2013). The specifics of this care varies by the individual's medical conditions and level of functioning, but generally involves meal preparation and house-related upkeep and maintenance, assistance with life tasks such as shopping, banking, or transportation, and personal care such as assistance with bathing and dressing (Hollander, Liu, & Chappell, 2009). As individuals with MCC age or their condition(s) worsen, the amount and type of informal care which they require intensifies.

Many of the experiences faced by caregivers of persons with various, individual chronic conditions have been documented in the literature and may include both positive and negative consequences that result from the role of caregiving (Roth, Fredman, & Haley, 2015). Recently, more research has considered the positive aspects of the caregiving journey in order to provide a more balanced, holistic perspective. Positive consequences within caregiving include a strengthened bond between the caregiver and care receiver; a sense of satisfaction with care provided; a way to find meaning; reward from reciprocal relationship; and personal growth (e.g., Lloyd, Patterson, & Muers, 2014; Mackenzie & Greenwood, 2012; Sanders & Power, 2009; Shim, Barroso, & Davis, 2012; Shim, Barroso, Gilliss, & Davis, 2013). It is these positive aspects that may contribute to sustaining a family caregiver in his or her role for longer than might otherwise be expected.

There is, however, a great deal of research literature that speaks to the stressful nature of family caregiving, and which suggests that the toll of providing care (particularly when the care being provided is intensive and time-consuming) may negatively affect the caregiver. The concept of *caregiver burden* has been developed to capture the caregiving-related hardships that many caregivers experience in terms of their psychological and emotional state, finances, relationship with the patient, physical health, and time for themselves and others (e.g., Chappell, Dujela, & Smith, 2014; Garlo, O'Leary, Van Ness, & Fried, 2010; Limpawattana, Theeranut, Chindaprasirt, Sawanyawisuth, & Pimporm, 2012; Pinquart & Sörensen, 2011). These negative impacts may be exacerbated if caregivers are older and have their own health condition(s) (Limpawattana et al., 2012). Moreover, the presence of MCC may further complicate the caregiving role and associated demands, given the increased complexity that comes with managing multiple (as opposed to individual) conditions. Individuals with MCC have described challenges understanding and managing their conditions, including the complexity of medication management and the logistics of accessing care from multiple health care providers (Koch et al., 2015); these issues likely also increase the complexity of caregiving for persons with MCC. Indeed, a greater number of chronic conditions on the part of the care recipient have been associated with higher levels of burden for the individual providing care (Chappell et al., 2014). Given what we currently understand about the potential consequences of caregiving and the unique aspects of managing MCC, research into caregiving experiences in the context of MCC is warranted.

Spousal caregivers are a particularly important population in the context of MCC. Spouses spend a greater number of hours per week engaged in caregiving than other familial or non-familial caregivers, and older spousal caregivers may have their own needs or health conditions which heighten the impacts of caregiving on their lives (Sinha, 2013). Spousal caregivers of older adults report higher physical and financial burden, increased relationship strain, higher levels of depressive symptoms, and lower levels of well-being when compared to adult child caregivers (Pinquart & Sörensen, 2011). Although spousal caregivers appear to experience the same types of caregiver burden in general as non-spousal caregivers, they may understand particular aspects of caregiving differently, and have different caregiving experiences and needs (Chappell et al., 2014; Savundranayagam, 2013; Savundranayagam, Montgomery, & Kosloski, 2011). Despite these indications that spousal caregivers are a distinct (and perhaps in some ways a more vulnerable) population, very little is known about their experiences in the context of MCC and how they understand and cope with this caregiving role.

The purpose of this article, therefore, is to explore the experience of caring for an older adult spouse with MCC. Although the effects of caregiving, in general, have been well-documented (especially quantitatively) in the literature, very little research has attended to the ways in which spousal caregivers to older adults with MCC describe, understand, and make meaning of their experiences. We could locate no other research that has qualitatively considered the experience of spousal caregivers to older adults with MCC. By adopting a qualitative, in-depth approach which is focused on experience, the current article seeks to broaden insight on the topic with this unique population. Thus, the research question driving the current study is, What is the experience of spousal caregivers to persons with multiple chronic conditions?

Methodology

This article presents the analysis of semi-structured interviews conducted with spousal caregivers (*n* = 18) who are part of a larger, repeated-measures embedded mixed-methods study conducted in the Canadian provinces of Alberta and Ontario (results reported elsewhere). Alberta is a western province; Ontario is in east-central Canada. The overall purpose of the larger study was to investigate how social location (e.g., sex/gender, age, education, income, employment status, culture, geography, social connectedness) of family caregivers of older adults with MCC impact quality of life and health outcomes longitudinally.

The design we utilized for this qualitative study is interpretive description (Thorne, 2008). This approach strives to discover patterns and meanings from a description of a phenomenon, which can yield insights to inform health care practice (Thorne, 2008). The focus of interpretive description is on the sharing of, and critical reflection on, the lived human experience in order to produce qualitative representations of a particular phenomenon that are well-grounded in the data; in the case of the present study, the focus was on the experience of caring for an older adult spouse with MCC.

Ethical Considerations

The mixed-methods study received ethical approval from both McMaster University (REB # 2013 104) and the University of Alberta (REB # 00039895) and followed the ethical standards set out by the Research Ethics Boards, such as consent procedures being conducted as approved and data stored in a secure location with only project members having access to de-identified transcripts and demographic information. To protect the confidentiality of participants, we assigned pseudonyms and have used those in presenting our findings.

Given the complex circumstances of the participants, we provided a list of resources to participants at the time of the first data collection. The list was tailored to resources available in the area where the interviews were taking place: for example, a local telephone number of the Alzheimer Society or Palliative/Hospice Care agencies. No participants requested the research assistant to contact a resource on their behalf.

Participants

A total of 194 caregivers of older adults with MCC were recruited in the larger study. The inclusion criteria were (1) patient/care receiver diagnosed with, dementia, diabetes, or stroke in the past six months, in addition to a minimum of two other chronic conditions; (2) participant/caregiver must be actively providing care to an older adult (i.e., age 65 or older) with MCC living in the community; (3) must be 18 years of age or older; and (4) must read, speak, and understand English. The main chronic conditions of dementia, diabetes, and stroke were identified given their prevalence and cause of disability among older adults. To reach and recruit eligible participants, the research team collaborated with a number of community organizations within Alberta and Ontario (e.g., Saint Elizabeth Health Care and Gibrea Centre for Studies in Aging in Ontario, the Alberta Caregiver's Association in Alberta, and the provincial Alzheimer societies). Local newspapers (e.g., the *Metro Edmonton*) also carried advertisements about the study. Recruitment was conducted between July 2013 and June 2014.

Data Collection

All participants from the larger, mixed-methods study participated in two face-to-face or telephone survey interviews, six months apart. A purposive sample of 20 survey participants per province (i.e., n = 40) was invited to participate in an additional third qualitative stage (i.e., a semi-structured interview) following the second survey. The aim of this third stage was to provide an in-depth understanding of how the experience of caregiving is impacted by social location, while also probing the dynamic nature of caregiving for older adults with MCC. These subset participants were selected based on a preliminary analysis of caregiver characteristics, to ensure that those who might typically be both more vulnerable and underrepresented (e.g., lower income persons; those with varying cultural backgrounds; or male caregivers) were well-represented in our sample. The participants that continued on into the third stage included a variety of articulate individuals (i.e., persons who could express themselves clearly and freely to speak to their caregiving experience), such as adult children, grandchildren, and spouses of persons with MCC. The present article reports on the spousal transcripts alone (nine participants from each province for a total of 18 spousal caregivers), as spouses have unique experiences compared to caregivers with other relationships to the care receiver.

Interviews were approximately an hour long and followed a semi-structured interview guide, which included 10 questions related to caregiving within the context of MCC. These questions ranged from broad (e.g., "Tell me about your experience as a family caregiver" or "Please walk me through an average day in your current situation") to more specific (e.g., "What has sustained/kept you going in this role?"). These more-specific questions elicited both positive and negative caregiving experiences, where relevant, that enabled us to explore multiple aspects of caring for individuals with MCC. Interviews were audio-taped and then transcribed verbatim by an experienced transcriptionist. All transcribed data were imported into QSR International's NVivo version 10 software and analysed thematically given the research question posed above.

Data Analysis

The first step of our analysis involved the research assistant (who had not conducted the interviews) and the primary author completing an *open* reading of each transcript, to glean an overall impression of the content shared by spousal participants (Thorne, 2008). The research assistant then conducted initial coding using incident-to-incident coding (e.g., Charmaz, 2006); attention was paid to meaning units within the incident coding. For example, if a particular sentence captured an important idea related to the research question, it was coded using line-by-line coding. In order to develop focused codes, incidents, and their associated codes were constantly compared both within and between transcripts. It was apparent from reading the transcripts that codes corresponded to one of three broad categories: (1) challenges with caregiving, (2) rewards gleaned from caregiving, or (3) sustaining strategies employed. Similar codes were therefore organized into themes under the appropriate category, and findings (i.e., major themes as reflected in greater than half of the transcripts) are presented within these categories.

Trustworthiness of the Data

We undertook a variety of strategies to ensure credibility, auditability, and fittingness of the data (Sandelowski, 1986). Credibility was maintained by closely adhering to the interview transcripts; the primary author undertook coding of three transcripts and compared findings with the research assistant to ensure that similar codes were being generated. Auditability was reflected in the use of an audit trail to record perceptions and subsequent interpretations of the data, as well as changes and decisions that occurred in the present investigation. Fittingness was accomplished by including participants who were living the phenomenon under investigation (i.e., caring for an older adult with MCC), and who were willing and capable of sharing their experiences.

Findings

Of the 18 participants, 17 were legally married, with one participant living with her common-law husband. Nine participants were older than 76 years of age while the other nine were younger than 75 years. Many (n = 8) indicated they had adequate finances, and the majority were Caucasian. Only one participant had less than a high school education, with the remaining participants (n = 17) having completed high school or college/university. Two of the participants were employed (part-time), and all participants lived in urban centres. Half of the care receivers (n = 9) had three to five chronic conditions, with two participants caring for a spouse with greater than nine (11 and 13) chronic conditions. Please see Table 1 for further demographics.

Table 1: Participant caregiver and care receiver demographics

Characteristic	Frequency (*n* = 18)	Percentage (%)
Caregiver		
Gender		
Female	8	44.4
Male	10	55.6
Age		
51–55	1	5.6
56–60	2	11.1
66–70	2	11.1
71–75	4	22.2
76–80	4	22.2
81–85	4	22.2
86–90	1	5.6
Finances meet needs		
Totally inadequately	1	5.6
Not very well	2	11.1
With some difficulty	3	16.7
Adequately	8	44.4
Completely	1	5.6
Very well	3	16.7
Ethnicity		
Caucasian	15	83.3
Asian	2	11.1
Aboriginal	1	5.6
Education		
No high school	1	5.6
High school diploma/equivalency diploma	6	33.3
College/university degree	11	61.1
Care Receiver		
Gender		
Female	10	55.6
Male	8	44.4
Age		
66–70	3	16.7
71–75	4	22.2
76–80	3	16.7
81–85	5	27.8
86–90	2	11.1
91+	1	5.6
Number of chronic conditions		
3–5	9	50
6–8	7	38.9
>9	2	11.1
Main chronic conditions		
Diabetes	5	27.8
Dementia	11	61.11
Stroke	5	27.8

Participants described vivid examples of their caregiving situations that resulted in detailed and rich transcripts. Although the care recipients had different types of chronic conditions, the caregiving experiences were similar across the sample. Some exceptions to this were observed, wherein participants caring for individuals with dementia described some aspects of their caregiving experiences differently than did those caring for a recipient who did not have dementia; we comment on these differences where relevant. Participants' and their spouses' main and total number of chronic conditions are listed in Table 2 to provide this context to the findings. The majority of participants shared experiences of caregiving that varied widely, from feeling alone and isolated to feeling blessed and grateful that they were able to provide care for their spouse. Many other comments related to how participants managed their complex situation or to what they thought they needed in order to cope and carry on in their role. Thus, the following is a presentation of the main themes as they relate to the major categories of (1) challenges with caregiving, (2) rewards of caregiving, and (3) sustaining strategies.

Challenges with Caregiving

The challenges associated with caring for a spouse with MCC dominated the stories of many of the participants, illustrating their significance to the caregiving experience. The following themes reveal the shared challenges faced by participants: (1) life on hold; (2) feeling isolated; and (3) making all the decisions.

Life on Hold

Almost every participant spoke about the need to change their life to the degree that it was now *on hold* in order to focus on the needs of the care receiver. As Melanie stated, "I dislike the fact that I'm, well my life is on hold. … I'm there totally focused on him", while Joseph commented, "You have no life. Your own life gets put on hold." Participants spoke at length about having to make adjustments to their life such as foregoing travel or attending events, organizing their time around the recipient's needs and schedule, and accommodating doctor's appointments with their spouse. Many participants spoke about the impact of caregiving on their employment, and how they had to make adjustments (e.g., taking time off, moving locations, and even quitting) in order to meet their spouses' needs.

The ways in which caregivers described life on hold appeared to relate to the unique caregiving situation and severity of their spouse's conditions. Participants caring for a spouse with dementia spoke to a "lack of freedom as much as anything else … no freedom whatsoever" (Verna) because of being unable to leave their spouse alone for any period of time. Owing to issues of safety, there is the necessity that life becomes intensely focused on a spouse living with cognitive impairment, to the point that freedom to engage in activities that many of us take for granted (e.g., eating out or running an errand) is not possible.

Participants caring for a spouse without cognitive impairment spoke of *negotiations* with the care receiver

Table 2: Care receiver chronic conditions

	Conditions of the Care Receiver			
Spousal Caregiver Participant	**Dementia**	**Diabetes**	**Stroke**	**Total Number of Chronic Conditions**
Alice		✓		8
Anthony	✓			3
Cameron			✓	5
David	✓			5
Ellen		✓		5
Georgia		✓		5
Gerard		✓		3
Helen		✓	✓	11
James	✓			6
Joseph	✓			13
Katherine	✓			7
Leo	✓			4
Matthew	✓			3
Melanie		✓		7
Michael	✓	✓		5
Stewart	✓			8
Verna	✓		✓	7
Violet	✓		✓	6

that led to simply granting what the care receiver preferred, regardless of what the caregiver desired. Georgia described how it is difficult to know what to make for a meal, as her husband will refuse her suggestions, then might ask to wait to eat later: "… and then later is about eight or nine o'clock at night which throws everything off because you think you can get your evening ready." Participants spoke of negotiating multiple aspects of their lives in accordance with the care recipient's wishes, so that they acquiesced to their spouse's desires and needs (e.g., leaving a restaurant before eating) in day-to-day organization and activities. Again, these experiences impart a pervasive sense that participants' lives are on hold to meet the needs and desires of their spouse.

Mobility issues with the care receiver leads to other kinds of limitations. Alice commented, "If I go for a walk with him it's tiny little baby steps and it cannot be long because he's too much in pain, so we turn around. Just limited in all kinds of ways, like living." Multiple participants described changes to their general activity level, as their spouse's MCC limited their ability to engage in the physical activities they were accustomed to and desired. Having a life on hold imposed complex and intersecting limitations on participants that made their caregiving feel challenging, as it interrupted many aspects of their day-to-day lives.

Feeling Isolated

Further to having a life on hold is the lack of time to interact with family and friends; being unable to participate in social activities may leave caregivers feeling isolated and, in some cases, the care receiver (those who are cognitively alert) as well. Helen described how her husband's friends are reluctant to visit them: "People don't know what to do with him, so people he worked with or people that he partied with and stuff don't come around that often." Similarly, Melanie described how the shift to a caregiving/caregiver relationship can alter social relationships: "It's funny, your friends sort of drift away because they realize that … he's become the whole focus." For some participants, going out and being socially engaged with their spouse was still important, yet was sometimes discouraged by other people who were uncomfortable with the care receiver's condition. Matthew described having to give up social activities with his wife, such as a monthly church supper or his class reunions: "The last [reunion] I was at will be my last because of [wife's dementia]. I felt rather isolated, I mean you could feel the tension." Other participants described practical difficulties of trying to attend functions or social occasions with a spouse who has MCC, as the care recipient may not be well enough to attend or may require additional caregiver support to do so.

In addition to difficulties maintaining active social engagement with one's spouse, caregivers described how difficult it was for them to continue social activities on their own. The consuming nature of caregiving for a spouse with MCC can oftentimes mean a progressive isolation, as illustrated by James: "My whole leisure life now is having a cup of coffee with my friend … because I really don't have time for anything else." Participants described being too busy with their added responsibilities given the MCC of their spouse to participate in the social relationships and activities in which they previously took part. Moreover, some caregivers experienced guilt when they did make the time to participate in social activities on their own, as they felt bad leaving their spouse at home. For those spouses caring for fully dependent care receivers, isolation took the form of being unable to leave for extended periods of time. Helen shared that "I would love to go visit [my daughter] … but that means leaving him alone at night, which – who am I going to ask?" Being isolated from people important to the participants, coupled with being unable to obtain a break from caregiving, was frustrating for many participants. Although connecting with family and friends was desired desperately by participants, their isolating circumstances precluded them from being able to engage in those important social activities.

Making All the Decisions

A number of challenges may exist when one spouse is no longer able to participate in day-to-day decision-making. When "the equality is gone … it's not just doing it, physically doing it, it's the decisions" (Helen), reflecting the fact that decisions regarding maintaining the household, what to eat for a meal, which appointment to make, and so on, occupied the minds of participants. Furthermore, spousal caregivers reported that they worry about whether or not they are making the right decisions. James stated, "Now I'm making decisions for myself and for my wife; as a caregiver, it's frustrating in that it doesn't always go the way you want it to", and Helen concluded that "It's really hard to know, [it's] stressful and having to be a boss." The responsibility of having to make all the decisions (both small and large) weighed heavily on participants. Decisions regarding whether to downsize or remain in their current residence also occupied the minds of participants; it was particularly distressing to a couple of participants to even consider moving and add that responsibility to their already long list of (caregiving) decisions.

A number of participants spoke specifically about health care–related decisions given the complexity of health management within the context of MCC. Melanie observed that "It's sort of unilateral decisions. You're not in a relationship anymore, really … you're a health care provider now. You're not a spouse." Not only was getting out to numerous medical appointments for the care receiver challenging, so too was communicating and coordinating with, oftentimes, several different health care providers. Decisions about how to deal with one chronic condition (e.g., starting a new medication) as suggested by a specialist had to be considered in light of how those decisions would influence the other chronic conditions of the care receiver. Participants occasionally found themselves questioning what to do in light of MCC, as illustrated in this quote from Joseph:

> If I could just take care of the Alzheimer's we might be okay, but these other things that she has, are they affecting the Alzheimer's? So you have to figure out, you know, is that from the dementia or does she actually have another, different problem? What do I have to do here, you know? Do I have to get her to the doctor or is it going to go away and will it never go away?

The cognitive impairment from dementia can further complicate situations given the inability of care receivers to express physical or psychological feelings verbally (or accurately); this adds to the challenges for these spousal caregivers. Communication difficulties were expressed, as well, by caregivers of spouses who did not have dementia, in the form of disagreements between the caregiver and care recipient related to decisions about meals or whether to attend an activity or not.

Rewards of Caregiving

The vast majority of participants described experiences in their caregiving that included positive and rewarding components. To elicit such experiences that may not have always come easily to mind, the interview guide included the question: "What have you liked/appreciated about your caregiving experience?" Although there were many challenges, rewarding aspects were also shared over the course of the interview that were not limited to that particular question. The two themes that reveal the rewarding experiences of participants are (1) personal growth and capacity; and (2) gift of fulfilling commitment to spouse.

Personal Growth and Capacity

Many participants spoke of being proud of or even surprised by their ability to take over all the decisions and undertake the physically demanding care of their spouse. Ellen described "just being strong for him … giving him courage [to face his disease]." Husbands frequently reported taking on roles their wives once had in their marriage, such as cooking and other domestic duties. Michael shared that "It's taught me a lot about how to cook, how to bake, do laundries, which I never did, shopping. I do all that now." For wives, new duties were often related to household maintenance or managing the finances, jobs once completed by their husbands. Melanie commented, "It's interesting to try and keep a household going as well, and I learned how to change a filter on the furnace because I had to, right? It's like, wow." Verna stated,

> I've learned things like how to take taps off and fix them and all those kind of things … There's nothing

> I can't do around the house anymore. I know, I take care of everything now and I'm very proud of it.

These experiences illustrate how participants' caregiving role also spurred the development of skills that were not previously within their repertoire, leading to a sense of personal growth and capability. For some participants, taking on their spouse's previous tasks was not only rewarding, but it also provided the realization of all their spouse did in their earlier life together.

Having the physical and mental capacity to provide care to their spouse was also significant for many of the participants. For participants whose spouse was cognitively alert, there was often acknowledgment from the care receiver, illustrated in comments like Gerard's: "Just the fact that I am capable, I am healthy enough to be a caregiver for her … Like she appreciates it." Similarly, Ellen noted that "He always remembers … it's my strength that he sees because I guess we can feed off each other." Recognition of their effort to provide care was a motivating factor to continue in the caregiving role for many participants. For caregivers to spouses with dementia, their capacity to provide care was also important, but an acknowledgement of this care was lacking. Stewart pointed out, "Caregiving involves 100 per cent giving with little expectation of return, and if you can't approach it with that attitude, it's going to be really difficult. That's … I've learnt that over time." Despite not being verbally thanked and acknowledged, the experience of providing care to spouses with dementia could still be meaningful and rewarding. In the case of dementia, sometimes the recognition of the amount of effort caregiving entailed was provided to participants by their adult children or health care providers.

Gift of Fulfilling Commitment to Spouse

Part of the rewards of caregiving centred upon participants' perceptions of fulfilling their commitment to their spouse. Anthony, for example, stated that "I want her to be in good health, to keep her as long as I can … It's my responsibility, and I really want her to be around." Marital vows were often cited as the reason for becoming a caregiver, as Georgia shared: "I love him, that's the important thing. We married for sickness and health and [getting emotional] and that's the way I look at it." Alice similarly commented,

> The wedding vows, and in that it said for better, for worse, for sickness and in health, whatever it says, and that's very important to me, okay? … But we did say that and we tried to live by that, so that's what sustains me.

These participants framed caregiving as part of the marital commitment they had made to their spouse, and, accordingly, they felt that they were responsible for living up to these vows when challenges (such as poor health) arose.

The connection to their spouse and living out that commitment was also important to some participants. Verna, for instance, stated: "He's my whole life. I just … everything I do is for him. If he's happy, I'm happy. And so anything I can do to make his life easier, then I'll certainly do it." As this quote suggests, caregiving could be experienced as an expression of commitment to making their spouse happy. Some participants felt that their caregiving was a way to become closer to their spouse, and deepen their relationship. It is important to bear in mind, however, that while some participants viewed spousal caregiving positively as a gift, for others this commitment was more of an obligation. Moreover, although fulfilling marital vows could be a rewarding experience, it is worth noting that this might sometimes be at the expense of caregivers' own health and well-being considering the mental and physical capacity necessary for intense caregiving in the context of MCC.

Sustaining Strategies

Participants spoke at length regarding the need to remain in their caregiving role and that it was necessary to care for themselves in a way that enabled them to cope with their complex situation. The common themes that reveal the coping strategies that participants acknowledge and/or purposively engage in include these: (1) taking time for self; (2) having a faith/church community; and (3) accessing meaningful formal supports.

Taking Time for Self

An overwhelming response by participants was the absolute necessity to take and make time for themselves in order to remain in their caregiving role. James shared advice he gave to the members of his support group: "You've got to look after you because it may not seem like it, but you're getting tired and you've got to have some time away … because if you don't then there's a problem." There was an acknowledgement by many participants that not taking care of themselves would lead to their own poor health as well as increase the likelihood of their partner needing to be institutionalized. This purposive taking time for *self* includes the following sub-themes of physical activities and connecting emotionally with others.

Physical Activities

Participants specifically spoke about maintaining physical activities as part of taking time for themselves. Many participants suggested that engaging in physical exercise (e.g., going for a run or gardening) was one way to maintain a connection to something they had done for many years before caregiving took more and more of their time. For example, Melanie spoke to being active as a means to deal with the stress of caregiving: "I'm trying to do things to alleviate stress. Running, running on the treadmill is a good thing, right? Increases the endorphins." Some participants lived in homes where physical activity was accessible; for example, Stewart shared, "I'll go down to the gym in the building and work out for half an hour or so, trying to build my walking skills, endurance." These physical activities provided the strength necessary to continue in what is often a physically demanding role as a caregiver while giving participants a break from caregiving.

Participants to spouses with dementia often altered their physical activities so that they could engage in them at home and did not have to leave the care receiver unattended. Verna said, "I make a point of trying to keep myself in shape and I exercise at home" instead of attending yoga classes at a gym. Although participants' commitment to exercising at home is commendable, it is important to note that confining physical activity to home could further decrease participants' social connections.

Connecting with Others

Often participants spoke to the benefits of activities like going for coffee, which helped them to connect with others and get away (even just for a short while) from the responsibilities of caregiving. Matthew noted, "I have a regular coffee group that I get together with", and Helen commented, "Friends, of course, you know, I was telling you about going out to eat or going out for coffee or whatever, that's always helpful." Continued connections with friends were meaningful for the majority of participants.

Again, spouses to persons with dementia experienced additional challenges in order to connect with others. For these participants, attending an activity tended not to be a simple endeavour and involved planning supervision for their spouse; sometimes, the work it took "to get out the door" was not worth the effort. For participants who could get out to socialize and connect with others, this social participation was invaluable. For example, Verna spoke about her friends insisting she continue playing bridge:

> I've always been a great bridge player, and I had to give that up except for once a week in the summertime. And the reason I can do that is because these are friends of mine that insist that I play bridge … Their husbands take [spouse]. The husbands look after [spouse]. So I can play bridge, which is very nice.

By supporting both the caregiver and the person with dementia, friends enabled participants to engage in activities and take time for themselves that might not otherwise be possible.

Support from adult children was also significant for many participants. When Ellen was asked about what helped her most in her caregiving, she simply stated, "Support from family and friends." Adult children provided emotional support, in addition to assistance with some of the physical demands of caregiving. James noted, "You find out how good your family is, and the example I use is my two daughters", who support him with cleaning, menu-planning, and visiting regularly with him and his wife. Participants acknowledged supportive, positive relationships with their adult children that sometimes included assistance with caregiving tasks. However, this may not be the case in every situation as the women did not provide as detailed descriptions about support from adult children with specific caregiving tasks. It is, therefore, possible that there is a gendered component to the support these caregivers received.

Faith/Church Community (Supportive Relationship)

Many participants acknowledged the support they felt and received from their church community. For instance, Leo simply stated, "You know, church has been a major part of our life." Other participants were more specific in the type of support they received. James explained, "The other thing is I have a very strong church community. Very, very helpful, very loving people that, you know, they sit and talk to me and help me out whenever I need help." Attending a place of worship, participating in activities within the church community, and connecting with others enabled participants to foster their faith as well as maintain important social participation, which helped sustain them in their caregiving role.

Occasionally participants were less active in church events (perhaps related to limitations of being consumed with caregiving), and instead they engaged in individual prayer and personal faith. Georgia, for example, shared how she would say "'Okay Lord he's yours today,' and when I say that it just seems to take a whole bunch off me, like 50 pounds, and 'He's yours, take care of him' and that helps a lot." The notion of faith in a higher being was something that could sustain participants in their caregiving, perhaps through the sense that someone else was sharing responsibility for their spouse. Other participants talked about the prayers of others, and their perception that these prayers and their faith have a sustaining effect. Stewart stated, "My faith in God, my prayer life, the support of praying friends and people who really care for us, have kept us going." The prayers of others was another way in which some participants felt supported regarding their spouse's health and caregiving role.

Accessing Meaningful Formal Supports

Many participants spoke about challenges with gaining or accessing appropriate formal supports, yet many also spoke about how important and even essential these supports were in order to sustain their caregiving. Day programs and in-home assistance were invaluable resources to support participants. Many participants positioned formal help as essential, as Violet explained: "You have to seek outside help, as much as possible to be … you almost have to be resourceful and look for all kinds of avenues to get help." Michael similarly observed that "You can't do it by yourself. You've got to have help … you've got to seek the proper people and get the help. You just can't do it yourself." Participants commonly invoked the perception that their caregiving role was not possible to keep up on their own, and required different types of informal and formal supports.

Respite in the way of day programs was useful to allow for extended breaks from the care receiver. David said, "I think a real gift for both of us is the day program, which is supported by [provincial] Health. That's a real gem." A couple of participants described how they would start with one day at a program and then progress to additional days as needed, as Michael related: "This day centre … it's worked fine with her. We started off with two days now, and then we went three days and now we're in the four-day program … and she loves it, but it's getting her there." Day programs allowed participants a chance to rest and carry out other tasks that they found difficult to achieve in the context of intensive caregiving. Violet explained, "After he [leaves] then I can rest a little bit myself and tidy up and slowly get things … organized."

Other participants talked about being thankful for services that came from organizations like home care, Veteran's Affairs, or social services that provided support in their home thus allowing for periods of respite. This is illustrated in a comment by Stewart:

> We've been very fortunate in the people they've sent to us. Most of them, I liked them, and I think one of the big things recently has been the [home care] program in [city], and that's been an absolute lifesaver. It's meant that I can do more things that are three, four hours in duration instead of an hour or so.

At other times these in-home supports provided assistance with the physical demands of caregiving. Verna spoke about individual workers providing key support:

> They're helping me the most, I've got to say yes, for sure. I mean the respite is great but without the other [i.e., home care] I wouldn't be able to go day-to-day. Because like, [name of support worker], when she comes, she gives [spouse] his shower and that's a wonderful help. Two mornings a week, because he's a tall man and I can't.

Despite the effort it took to locate a good in-home support person, participants acknowledged that the right person made their situation manageable for the time being. On the other hand, it is important to note that many participants shared negative experiences they had when accessing formal supports that seemed to lend a stark contrast to the times when appropriate help was used in the past or present.

Without formal supports, both in and outside of their home, participants would not have been able to continue with their caregiving. These were viewed by participants as necessary, in addition to actively taking time for themselves and (for many) having a supportive faith community.

Discussion

To the best of our knowledge, this is the first qualitative study of its kind to explore the experiences of spousal caregivers specific to the context of MCC. The current study highlights the diversity of caregiving experiences, as shared by spouses of older adults with MCC. Although the findings we have described illustrate common themes in caregivers' stories, it is worth noting that some of the challenges of caregiving were more salient when dementia was one of the care recipient's conditions. Participants' experiences of caregiving for their spouses with MCC were generally dominated by challenges, which participants attempted to balance through the use of different sustaining strategies. Importantly, many caregivers also communicated positive or rewarding aspects of their caregiving role. Much of the discussion that follows is completed with studies that are based on specific diseases given the paucity of research that examines caregiving within the context of MCC.

The challenges described by participants included feelings of isolation and the perception that their lives were on hold because of the demands of caregiving. These two themes are closely related; the many behaviours and duties of caregiving may slowly consume the caregiver's time so that they become more and more isolated (see also Hawranik & Strain, 2007). Isolation was also described in relation to increased difficulty in social situations and relationships. These difficulties centred upon the intense shift in the caregiver's focus (from their own life to that of their partner) and changes in the care recipient's cognitive capacity, which altered social activities and relationships. Similarly, Hawranik and Strain (2007) have noted that caregivers may perceive taking the care recipient out as extremely effortful and inconvenient for friends. The disruption and isolation described by participants were significant challenges, and may be extremely detrimental to well-being; caregivers who experience a greater degree of disruption to their lives and minimal social support (both formal and informal) report higher levels of caregiver burden, worse psychological well-being, and a lower perceived quality of life (Alvira et al., 2014; Garlo et al., 2010; Burton et al., 2012; Pinquart & Sörensen, 2011).

Spousal caregivers of individuals with MCC spoke at length about the challenges of making decisions related to the management of the care recipient's conditions. When individuals with MCC (especially if dementia is one of the conditions) require a significant level of care, their caregivers, who do not have the embodied knowledge of living with these conditions nor the expertise of health care providers, may struggle to feel capable and make decisions about condition management. Indeed, Washington, Meadows, Elliott, and Koopman (2011) concluded that many family caregivers of older adults with chronic conditions lack the necessary information about the disease(s) themselves, treatment options, or service or support provision to feel confident in their caregiving ability or prepared for their future. Caregivers found it difficult to interpret symptoms and make health care–related decisions for/with their spouse, which may have been exacerbated by the difficulty of coordinating and communicating with multiple specialists; these caregivers' perspectives spoke to the noted complexity of managing MCC (Jeon et al., 2010; Valderas et al., 2009; Zulman et al., 2014). The present study uniquely identifies how the complexity of MCC exacerbated these challenges, as spousal caregivers were not always certain how to interpret symptoms and best manage the health of the care receiver in the face of MCC.

Making decisions may also be challenging since opinions on health goals, care management, the care recipient's capabilities, and the future often differs between care receivers and caregivers (Hawranik & Strain, 2007; Kuluski et al., 2013; Retrum, Nowels, & Bekelman, 2013). Indeed, some of the difficulty with decision-making that was described by caregivers arose from communication challenges and disagreements between the care provider and recipient, wherein the recipient did not agree with the caregiver's decisions around condition management. This tension related to changes in the equality of participants' relationship, with many caregivers now assuming the primary responsibility for decisions (particularly salient for recipients with dementia, as described by Wolfs et al., 2012) or taking on a more intermediary role that lay between spouse and health care provider. Similar findings were reported by Davis, Gilliss, Deshefy-Longhi, Chestnutt, and Molloy (2011), who found that spousal conflicts arising from caregivers' new role responsibilities or care decisions were a significant source of stress for burdened caregivers to persons with Alzheimer's or Parkinson's disease. In addition to decisions related to condition management, changes in the dynamic of the spousal relationship meant that many caregivers took on increased responsibility for making decisions about day-to-day activities and household management; for some participants, this was also a source of increased stress. As described by Hayes, Boylstein, & Zimmerman (2009) in the context of dementia, assuming more of a "parental" or "boss" relationship can be experienced as frustrating or challenging by caregivers and further alter the spousal quality of the relationship.

Although challenges were salient to participants' caregiving experiences, the vast majority also described positive and rewarding components of caregiving. Echoing previous research on caregiving (e.g., Peacock et al., 2010; Peacock, Hammond-Collins, & Forbes, 2014; Sanders & Power, 2009), participants felt positive about the personal capacity and growth they experienced as caregivers to their spouses with MCC. Both the ability to take care of their spouse as well as to step into other, previously unfilled household roles was a source of gratification for participants. This is consistent with research showing that active helping behaviours (versus general supervision) towards a loved one with chronic illness are associated with more positive caregiver affect (Poulin et al., 2010); a sense of competence, growth, and efficacious helping may be rewarding for caregivers. Other caregivers highlighted the accomplishment of being able to fulfill a commitment to someone they loved as an important and positive aspect of their caregiving role (see Lloyd et al., 2014; Sanders & Power, 2009 for similar findings).

Participants also found sustaining strategies, which allowed them to cope with their situation and care for themselves so that they could remain in their caregiving role. The need to take time for self was described as essential to sustaining their caregiving role. Taking time for self consisted of participation in valued activities, being in a space by themselves, and connecting with others. Sanders and Power (2009) similarly reported that male caregivers to spouses with dementia and other chronic conditions prioritized the need to have some sort of personal time each day to cope with the challenges of caregiving. For participants in the current study, spiritual or religious faith and church community were also important sustaining strategies. Previous research has suggested potential benefits of religious/spiritual coping to caregiver well-being, including the ability to find meaning in caregiving (Harris, Allen, Dunn, & Parmalee, 2013; Hodge & Sun, 2012; Lloyd et al., 2014; Márquez-González, López, Romero-Moreno, & Losada, 2012; Quinn, Clare, & Woods, 2012); the current research suggests that spiritual or religious-based coping strategies may be similarly beneficial for caregivers to persons with MCC. Finally, accessing meaningful formal supports (in-home assistance and day programs) was described as invaluable to participants' caregiving efforts and personal well-being; Donnellan, Bennett, & Soulsby (2015) suggested that knowing one's caregiving limits and accessing formal supports may help foster resilience. It is worth noting, however, that these services may not always be easy to access, and that even when they are utilized, previous researchers have found caregivers to older adults are not always able to fully relax or find genuine respite from their caregiving role (Hawranik & Strain, 2007).

Limitations

There are a few limitations with the study sample. It cannot be concluded that the experiences shared by the spousal participants in this study will be shared by other caregivers to persons with MCC. The sample represents caregivers providing care to their spouse in their own homes (i.e., not providing care in the long-term care setting). Most of the caregivers lived in urban regions; based on the lack of availability of services (such as home care or transportation difficulties), it would be important to explore populations living in rural regions and smaller urban centres. Despite efforts to locate culturally diverse caregivers, the sample reflects mostly Caucasian participants, with many expressing a religious orientation towards Christian values. Further, findings are based on a single qualitative interview which limited our ability to return to the participants and check our understanding and interpretations of what participants shared about their caregiving experience. These limitations highlight the importance of context when interpreting the findings, and speak to avenues for future research such as the experience of caregiving to persons within a long-term care setting. Finally, in an effort to include more male caregivers, the sample in the present study comprised 55 per cent men; in general, there was no discernible difference between the responses of men and women, apart from which household duties were taken on as a result of increased caregiving.

Conclusion

This article presents the experience of caregiving for older adult spouses with MCC, addressing a dearth of information on the experiences of this group. Findings illustrated many points of connection with research on caregiving in other contexts, suggesting that, like other caregivers, spousal caregivers for older adults with MCC may experience challenges (which are mitigated through sustaining strategies) yet also a sense of growth, satisfaction, or reward in their caregiving role. Decision-making was a salient challenge in this group of caregivers, and for the majority of participants, this was directly related to the complexity of the care recipient's MCC. Of note in this study are the challenges with decision-making while dealing with MCC, a unique finding in contrast to studies that consider a specific disease. This aspect of caregiving for older adults with MCC could be more directly explored in future research, as could the perceived utility (or even necessity) of formal supports and barriers to accessing them. The current findings are a useful starting point for such future work, as well as work aimed at understanding and fostering sustaining strategies for caregivers, as they offer an initial exploration of the experience of spousal caregiving for older adults with MCC.

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