



The complexity of caregiving for community-living older adults with multiple chronic conditions: A qualitative study

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Abstract

Background: Older adults with multiple chronic conditions (MCC) rely heavily on caregivers for assistance with care. However, we know little about their psychosocial experiences and their needs for support in managing MCC. The purpose of this study was to explore the experiences of caregivers of older adults living in the community with MCC.

Methods: This qualitative study was a secondary analysis of previously collected data from caregivers in Ontario and Alberta, Canada. Participants included caregivers of older adults (65 years and older) with three or more chronic conditions. Data were collected through in-depth, semi-structured interviews. Interview transcripts were coded and analyzed using Thorne's interpretive description approach.

Results: Most of the 47 caregiver participants were female (76.6%), aged 65 years of age or older (61.7%), married (87.2%) and were spouses to the care recipient (68.1%). Caregivers' experiences of caring for community-living older adults with MCC were complex and included: (a) dealing with the demands of caregiving; (b) prioritizing chronic conditions; (c) living with my own health limitations; (d) feeling socially isolated and constrained; (e) remaining committed to caring; and (f) reaping the rewards of caregiving.

Conclusions: Healthcare providers can play key roles in supporting caregivers of older adults with MCC by providing education and support on managing MCC, actively engaging them in goal setting and care planning, and linking them to appropriate community health and social support services. Communities can create environments that support caregivers in areas such as social participation, social inclusion, and community support and health services.

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Introduction

The occurrence of multiple chronic conditions (MCC) or multimorbidity, defined as two or more chronic conditions, has increased globally among adults in the past 20 years.^{1–3} Older adults have high prevalence rates of MCC with as many as 55% to 98% having two or more chronic conditions.^{4–9} Older adults with MCC often experience challenges in caring for themselves and managing their chronic conditions.^{10,11} These individuals often have concurrent physical and mental health conditions,^{2,12} which add to the complexity of their care needs. The presence of MCC in older adults is associated with poorer quality of life, higher rates of healthcare use and costs compared to individuals with no or fewer conditions, and these individuals are at high risk for adverse events such as hospitalization and mortality.^{13–17} Vascular chronic conditions such as diabetes, dementia and stroke are among the leading causes of death and disability in the United States and are linked with high use and costs of healthcare services.¹⁸

Older adults with MCC rely heavily on family and friend caregivers (hereafter referred to as caregivers) for support and assistance with care.¹⁹ It has been estimated that 70–75% of care among older Canadian home care recipients (many of whom have MCC) is provided by family caregivers.²⁰ While caregivers of persons with MCC often experience rewards associated with caregiving, they also experience negative impacts on their quality of life and physical and mental health.^{19,21,22}

A recent scoping literature review of 27 quantitative and qualitative studies of the experiences of caregivers of adults with multimorbidity found that caregivers carried out a range of time-consuming tasks to support the care recipient such as providing physical care, stimulating the older adult, and scheduling and attending medical appointments.²³ The additional burden associated with these tasks often resulted in increased stress, anxiety, and depression.²³ The review found that caregivers were uncertain about how to manage the care recipients' symptoms and conditions and needed more information from health care providers on how to recognize and manage symptoms or side effects. While some studies included in the review identified positive outcomes of caregiving (e.g., enhanced learning and empathy), negative outcomes were commonly described such as lack of time for self-care and decreased social networks and supports. The review also found that caregivers experienced poor communication and coordination between the multiple healthcare providers and teams involved with the care of the adult with MCC, and had difficulty accessing support services to address their own needs.²³ The authors concluded that one of the research gaps is related to

understanding the psychosocial aspects of caregivers' experiences and needs.

There are several recently published qualitative papers on the experiences of caregivers of older adults with MCC that were not included in the scoping review²³ that provide further understanding of the caregiving phenomenon from the perspectives of spousal and male caregivers.^{21,24,25} A study of 18 spousal caregivers of older adults with MCC found that caregivers placed their lives “on hold,” felt isolated, and felt that they now made all the decisions; however, these caregivers also spoke to the rewards of caregiving including personal growth and capacity and fulfilling a commitment to the spouse.²¹ Another study explored the experiences of 19 male caregivers of older adults with MCC.^{24,25} This study found that sex, age, marital status, socioeconomic status, physical capacity, social connectedness, and culture all shaped the experiences and meanings of place while caregiving.²⁴ The authors found that men reported feeling distanced from others as well as feeling intensely connected to others while caregiving.²⁵

Health care services and systems are generally focused on single conditions, often resulting in fragmented and poorly coordinated care that is not person-centered for older persons with MCC.^{26–28} Furthermore, these services are directed to the person living with MCC and seldom address the needs of caregivers.^{29,30} Even guidelines for the assessment and management of MCC have minimal focus on the needs of caregivers.^{31,32} Yet, caregivers play key roles in optimizing chronic disease management to help older adults remain in the community.³³

In summary, caregivers of older adults with MCC face considerable challenges in their caregiving roles. The existing literature^{21,23–25} reflects the need for a deeper understanding of caregivers' experiences and their needs for support in managing MCC, in particular their psychosocial experiences and needs. This understanding is important to inform the development of effective healthcare interventions to support caregivers so they can maintain their own health and quality of life and continue to support older adults with MCC to live in the community.

Research question

The research question for this study was: What are the experiences of family and friend caregivers who care for older adults with MCC living in the community? This paper is a secondary analysis of a subset of data from a larger Canadian study that explored the experiences of managing MCC among older adults with MCC, caregivers and healthcare providers in Ontario and Alberta,¹⁹ and explored in-

Table 1. Sample interview questions.

Topic Area	Sample Questions
Experiences in Managing Multiple Chronic Conditions	Tell me about your experiences in providing care to your family member who is managing more than one condition at a time? How do you make decisions about what chronic conditions or symptoms to manage first?
Facilitators and Barriers in Managing Multiple Chronic Conditions	What helps you to manage your family member's chronic conditions? What are some of the rewards of your caregiving role? What are some of the challenges you face in caring for your family member who has more than one chronic condition?
Health and Social Services	What supports does your family member receive to help them live with more than one condition at a time? What supports do you receive in your caregiving role?
Support from Healthcare Providers in Making Decisions About the Care of the Person with MCC	How have you worked with health professional in making decisions about your family member's care? Can you give me an example of a situation where you did not get the help you needed to support your family member in managing more than one condition at a time?

depth the experiences of caregivers from this larger study. This study is part of a larger program of research from the Aging, Community and Health Research Unit, School of Nursing, McMaster University focused on promoting optimal aging at home for older adults with MCC and supporting their caregivers.³⁴

Methods

Study design

We used Thorne's qualitative interpretive description (ID) approach.³⁵ ID studies are conducted in naturalistic settings and explicitly attend to the value of subjective and experiential knowledge as one of the fundamental sources of applied practice insight.³⁵ The approach attends carefully to the context within which the experience happens. Two philosophical underpinnings of the ID approach and this research are that: (a) the researcher and researched interact to create understandings of a phenomenon; and (b) reality is subjective, constructed, and contextual.³⁵ ID studies are intended to result in positive changes in clinical care.³⁵

Study setting and sampling

Purposive sampling strategies were used to recruit caregivers including criterion sampling and maximum variation sampling.³⁶ Eligible participants met the following inclusion criteria: (a) ≥ 18 years; (b) able to speak English; and (c) provided care to an adult ≥ 65 years, living in the community who had three or more chronic conditions, one of which was diabetes, dementia or stroke. These conditions were selected because vascular diseases are common among older adults with multimorbidity and individuals with these conditions are high users of the healthcare system.³⁷ Maximum variation sampling ensured that there was

diversity among caregivers in relation to age, sex, and geographic location (Ontario and Alberta).

Caregivers were recruited through multiple partner sites in the two provinces such as primary care settings and home care organizations. On-site recruiters at the partner organizations identified potential participants who were then contacted by a member of the research team by telephone to ascertain their willingness to receive further information about the study. If the person expressed interest in the study, they were screened for eligibility and a time was agreed on for an interview. In order to provide sufficient depth and breadth of understanding to address the research question, a sample size of 40 was proposed with 20 caregivers from each province.

Data collection

In-depth, semi-structured one-time interviews of approximately 1 hour were conducted in participants' homes or by telephone and were digitally recorded. Only the caregiver and interviewer were present for the interviews. Interviews were conducted by experienced research coordinators who were trained in consent and data collection processes and had no previous relationship with participants. Participants were recruited and data were collected from July 2013 to May 2014. Interview guides were developed through a review of the literature and discussion among the research team. Interview questions addressed: (a) experiences caring for a person with MCC; (b) facilitators and barriers to caring for a person with MCC; (c) use of health and social services; and (d) support from healthcare providers in making decisions about the care of the person with MCC (see Table 1). Following a pilot interview, questions were simplified and probes were added. Field notes were made after the interviews. Consistent with Thorne's ID approach, data collection ended when we had confidence that the

complexity and variation of caregiver responses addressed the research question.³⁵

Data analysis

Digital recordings of interviews were transcribed verbatim by a transcriptionist and then reviewed by a research team member to ensure their accuracy. Data analysis continued concurrently with data collection, and inductive reasoning, inherent to the ID approach, was integral to this analytic process.^{35,38} Initially, the research team conducted an in-depth review of the transcripts so that they could become very familiar with the experiences of the participating caregivers. Preliminary thoughts and ideas about codes and themes were documented. Short summaries of each caregiver's experience were prepared and reviewed by the team to identify cross-cutting patterns and themes. The analytic process was conducted by a cross-provincial team of eight qualitative researchers with experience in aging, multimorbidity, caregiver and qualitative research. The research team met regularly and the meetings were recorded and involved intensive immersion in and reflection on the data. Open coding, a means of organizing data based on clearly defined structural units within the data, was used to categorize the data into smaller subunits using the qualitative data analysis software program NVivo 10.³⁵ Similar codes were grouped into categories to identify the themes. Analysis was guided by constant comparative analysis, such that data from each new interview were compared with data in previous interviews, both similar and dissimilar.³⁹

Methodological integrity and rigor

The rigor of this qualitative study was ensured using criteria outlined by Thorne including epistemological integrity, representative credibility, and analytic knowledge.³⁵ First, researchers clearly documented their underlying assumptions about the current state of care provision by caregivers to older adults with MCC in field notes. Some of these assumptions, based on personal experiences caring for older family members, as well as experiences in conducting research related to multimorbidity, included: (a) caregivers experience high levels of stress in balancing work, family and caregiving responsibilities; (b) there are both challenges and rewards associated with caregiving; (c) caregivers are seldom included in decision making related to the care of older adults by healthcare professionals; and (d) caregiver needs for support are seldom explored and addressed by healthcare professionals. Throughout the study and analytic process, the researchers frequently re-visited their assumptions to ensure transparency in their influence on the study findings. One of the areas of researcher interest that informed our interview guide and analysis was related to the psychosocial experiences and needs of caregivers of older adults with multiple and complex health conditions. Second, representative credibility

was achieved by using sampling techniques such as criterion sampling and maximum variation sampling, and iterative data collection and analysis, both techniques consistent with the ID approach.³⁵ Finally, analytic knowledge, the clear provision of evidence to support a logical flow of reasoning and decision making, was evidenced by the iterative review of the study transcripts, keeping an audit trail, using participants' phrasing and verbatim accounts from the data, and involvement of multiple researchers across two provinces in data analysis such that themes could be questioned or refuted as necessary.³⁵

Ethical considerations

The study was conducted in accordance with the Tri-Council Policy Statement, Ethical Conduct for Research Involving Humans.⁴⁰ Ethical approval was granted by the Hamilton Integrated Research Ethics Board (#13-411) in Hamilton, Ontario, and the University of Alberta, Health Research Ethics Board (#39559) in Edmonton, Alberta. Written informed consent was obtained from all participants by a research coordinator before data collection and study participants were given a signed copy of their consent form.

Results

Characteristics of participants

A total of 47 caregivers participated in this study (see Table 2). Most caregivers were female (76.6%), ≥ 65 years of age (61.7%), married (87.2%) and were spouses to the person with MCC (68.1%). Care recipients lived with 3 to 15 chronic conditions, with a mean (SD) of 7.1 (3.0) chronic conditions, as reported by the caregivers.

Overview: Experiences of caring for older adults with MCC

Six themes were identified that describe the experience of caring for a community-living older adult with MCC: (a) dealing with the demands of caregiving: "controlling my own stress levels," (b) prioritizing chronic conditions: "the decision is made by what condition he's in at the moment," (c) living with my own health limitations: "I have my own problems," (d) feeling socially isolated and constrained: "I cannot go anywhere," (e) remaining committed to caring: "love more than care because caring is not enough," and (f) reaping the rewards of caregiving: "it fills my soul." Quotations are identified by participant number and province.

Dealing with the demands of caregiving: "Controlling my own stress levels"

Caregivers spoke of their experience caring for an older person with MCC as "stressful," "exhausting," "frustrating," "challenging," "overwhelming," "time-

Table 2. Characteristics of caregiver participants (n = 47).

Characteristics	n (%)
Gender	
Female	36 (76.6)
Male	11 (23.4)
Age	
18–44	4 (8.5)
45–64	14 (29.8)
65–74	17 (36.2)
75+	12 (25.5)
Marital Status	
Single	4 (8.5)
Married/Common Law	41 (87.2)
Divorced/Separated	2 (4.3)
Highest Level of Education Completed	
Some High School	7 (14.9)
Graduated High School	14 (29.8)
Graduated Technical or Trade School	6 (12.8)
Some University/College	3 (6.4)
Graduated University/College	14 (29.8)
Graduate Degree	3 (6.4)
Province	
Ontario	24 (51.1)
Alberta	23 (48.9)
Person to Whom Support was Provided	
Spouse/Common Law Partner	32 (68.1)
Mother	2 (4.3)
Father	10 (21.3)
Other	3 (6.4)
Number of Chronic Conditions of Care Recipient	
Mean (SD)	7.1 (3.0)
3–5	17 (36.2)
6–8	15 (31.9)
9–12	12 (25.5)
13–15	3 (6.4)

consuming,” and “emotional.” They described the complexity of the care required by older adults who had numerous chronic conditions, multiple medications, and many health care providers requiring ongoing appointments. Caregivers identified the many responsibilities they took on to support the older adult including: (a) helping with personal care (e.g., dressing, bathing); (b) taking on daily household activities (e.g., cleaning, cooking, shopping, home maintenance); (c) managing healthcare tasks (e.g., helping with medications, making appointments, communicating with healthcare providers, providing transportation to appointments); (d) managing finances; and (e) providing social and emotional support. They explained the oppressive nature of caregiving and the need for support so they could have “some breathing room”: “I would like somebody just to come in and look after him for a few hours so I could go for a walk . . . have a cup of tea . . . just have some breathing room and to get out into the sunshine and the fresh air” (ON – 24). Some caregivers were working children of older adults and expressed struggles with managing their own homes, families and work, in addition to caregiving: “Staying in control which has been really hard; controlling my own stress

levels . . . I’m so far behind in my work it’s terrible” (ON – 05).

Caregivers described the challenges of living with uncertainty and supporting older adults whose health status fluctuated and often worsened over time. They expressed their concerns about the unpredictable nature of MCC and the necessity of living in the moment, “it’s a day to day thing and, you know, because of everything that’s going on with him, it has to be a daily thing” (ON – 17). Caregivers articulated concern about the frequent transitions that the older person experienced between hospital and home: “(he is) going in the hospital and then I have to worry about him. Now is he going to fall? Is it going to be the big one? Who’s going to be around?” (AB – 11). They described constantly monitoring their loved ones for safety concerns and a pervasive sense of anxiety and worry: “there really isn’t a time when I don’t worry about his safety and his health and his activity” (ON – 05) and “worried. I know . . . you cannot avoid whatever is coming” (ON – 13).

Prioritizing chronic conditions: “The decision is made by what condition he’s in at the moment”

Caregivers described how they supported the older adult in managing their chronic conditions by prioritizing which chronic condition to manage at a given time. They typically spoke to the need to prioritize the management of the older adults’ chronic conditions based on which conditions required their immediate or ongoing attention. Caregivers spoke to various criteria they used for prioritizing, such as the older adult’s safety, their levels of pain, or the unpredictability of the older adult’s health condition. For example, a caregiver spoke about an older adult’s seizures as the preeminent condition, “. . . the priority is around safety and what’s going to get him in trouble first. And what’s going to get him in trouble first is seizure” (ON – 05). Caregivers’ motivation to manage a particular condition also stemmed from the emotional effect it had on the caregiver:

No, not the heart. What bugs me now is that he loses his memory. That’s my number one. Because he’s not my husband anymore, in some ways. Now he sits there and sits there and sits there for hours if you let him and sits and doesn’t do anything; like he’s not here (ON – 13).

The deep emotional impact of particular chronic conditions was always at the forefront for the caregiver and thus took priority in terms of providing support and management. While a cardiac condition may be “silent,” a person’s loss of personality and sense of self had a more immediate impact on the caregiver. In another instance, it was the older person’s delicate eyesight that determined the prioritization of caregiving. A caregiver described, “Well, I think the eyesight is the most important one. I mean, the rest pretty well take care of themselves . . . if the pacemaker goes out of whack, she would tell me if it’s not operating right. But, the sight is

something that it's a constant" (ON – 20). This condition was a priority for the caregiver because it required ongoing, daily, and time-consuming management. While some caregivers prioritized conditions based on their heavy emotional or physical toll, others prioritized conditions that caused the greatest distress for the older adult. In these situations, the caregiver tailored their provision of support to meet the older adult's most pressing need. For example,

I guess the decision is made by what condition he's in at the moment. If his diabetes is acting up, then that gets dealt with or if the arthritis . . . like on methotrexate days he's quite sick so I just kind of leave him to rest and do whatever he needs to do. So we just kind of deal on a needs to needs basis. (ON – 14)

The uncertainty associated with the changing nature of chronic conditions left caregivers on edge, unsure of what to focus on. Fear of recurrence of a health crisis was a common reason for caregivers to focus their caregiving on a particular condition. They described particular concerns such as, "I worry about him having another heart attack; that, I'm petrified of" (ON – 17) and "the stroke's always the top priority because she's had two, we don't want her to have a third" (AB – 01). The unpredictability of some conditions, such as dementia, meant that the caregivers' focus was constantly changing, sometimes based on their own emotional responses to the conditions:

Well, really what is hardest to manage is the frontal lobe dementia. That's the hardest because you live the crazy life all the time and you never know what to expect. You don't because he's so unpredictable, he's so sneaky. But then I guess right now – and it depends what happens as to what takes priority. (AB – 03)

Study findings provide new insight on how challenging and complicated it is for caregivers to set priorities for caring for older persons with MCC. Not only do caregivers make decisions on which of many conditions or symptoms to focus on, but they also consider the fluctuating and often worsening health status of older adults with MCC as well as their frequent transitions from home to hospital. The sheer multitude of issues to address as well as the unending changes in care context create a high level of uncertainty for caregivers in setting priorities for care. In some cases, prioritization was related to the fear associated with catastrophic conditions such as recurrent stroke. In other cases, prioritization was related to the significant emotional or physical toll associated with the condition, such as the emotional impact of caring for a person with memory loss.

Living with my own health limitations: "I have my own problems"

Caregivers described how their own health influenced and was influenced by their experience of providing support to

an older adult with MCC. The needs of the older adults were intensive, time-consuming and often seen as more important than their own needs. They explained how their psychological and physical health made it challenging to provide care to the older person. They also described how their own health was adversely affected by caregiving. They were often pragmatic and stoic in describing their experiences, "I have my own problems besides looking after her, too. I still have some psychological problems that I'm dealing with besides so it's not always easy. I don't sleep well, but we have to do what we have to do" (ON – 02).

Caregivers were also forthcoming about the magnitude of their own health limitations and described how they affected their daily lives, "But it means I can't drive a long distance and I have to wear gloves when I'm driving, otherwise I can't hold the wheel well enough . . . I'm telling you, I'm not in very good shape" (AB – 01). Caregivers reported how the effort they expended in their caregiving capacity exacerbated their pre-existing conditions and led to worsening of their own psychological health such as depression, "So that's why, you get in depression. So I do get frustrated right now because trying to take care of him and then because of my knee, because there's times I go to bed early because I cry; I get depressed because I can't do anything" (AB – 11). Another caregiver explained: "I've always had an endogenous depression but it's worsened with this situation so I'm smart enough to go to my doctor and say, "I'm crying uncontrollably; I cannot sleep" (ON – 24). Their narratives clearly describe the emotional pain and helplessness that caregivers experience when coping with their own ill health while trying to support an older adult with MCC.

Caregivers explained strategies they used to manage their health limitations, ". . . I manage my Parkinson's by not planning too much in a day. I plan one or two things. If I have three things, bang, bang, bang, there's a good chance that at the end of those I'll be exhausted and overwhelmed by doing anything" (AB – 06). Budgeting their available energy enabled them to meet the demands of caregiving while respecting their own limitations. However, caregivers also described experiences where their health crises rendered them unable to care for the person they were supporting. They described situations so grave that they necessitated a role reversal between caregiver and care recipient, "Remember that [name]? I could hardly walk there. I could hardly do anything. And [name] was even looking after me then, I was laid up." (AB – 07). Caregivers tended to downplay the fragility of the caregiver/care recipient relationship, but it was clear nevertheless,

As far as my concerns, now falling down as I did and several times about the house I've fallen down and she [care recipient] has helped me get up. There was once or twice, without help I would really have difficulty getting my legs underneath me to get up. So I appreciate the help I get there. (AB – 10)

Feeling socially isolated and constrained: “I cannot go anywhere”

Caregivers explained that caring for older persons with MCC resulted in social isolation and feeling constrained. The caregiving responsibilities were so all-encompassing and time-consuming, they were often house-bound except for medical appointments. They spoke emotionally about their social isolation: “*I feel like I’m a prisoner;*” and “*I cannot go anywhere.*” One participant explained: “*I find it restrictive . . . I’d like to be off and about, travelling, and we can’t*” (ON – 14). Another caregiver described how their social lives changes with the worsening of MCC: “*We had a very active life . . . now that’s non-existent*” (ON – 17). Participants explained that even when they did leave the home they were often constrained by feelings of worry, “*we leave him alone but my son always has the cellphone and we phone him and see if he’s okay*” (ON – 13).

Caregivers described a loss of autonomy, limits to their personal freedom, and a distancing from people who had once been friends. In some cases, they described immense feelings of being isolated from the world around them, a lack of understanding and compassion from others, and an inability to act with spontaneity. Caregivers explained, “*Right now with me, I miss not going anywhere, not just getting up and going. I’d say, ‘Well, let’s go.’ I can’t. Those are hard for me. Yeah, I just can’t come and go as I please*” (AB – 11). Factors that contributed to caregivers feeling isolated were multifaceted and included time constraints and disease-related constraints such as cognitive decline often associated with MCC. The sense of isolation was also related to the way the caregiver and older adult with MCC were received by the people around them:

A lot of people will think Alzheimer’s right away, memory. And it’s not always memory, it depends really on the type of dementia and most people don’t understand . . . And I find it a real challenge. And people that you’ve known for many years, you get so isolated because they just stay away. Like you get really, really isolated. (AB – 03)

While some of the older adults received home care services, most caregivers did not receive services (such as respite or counseling) to address their own needs. Caregivers felt that formal support could help to reduce their social isolation: “*I sometimes think that it’s a very simple thing, it’s a telephone call, once a week or so to say, ‘Well how are you doing?’ And to help pass the time even for me or her*” (ON – 20).

Remaining committed to caring: “Love more than care because caring is not enough”

Caregivers were committed to their role caring for the older adult with MCC regardless of the challenges they faced. This commitment was chronicled in various ways

and represented caregivers’ unflagging dedication to providing ongoing support to the older adult with MCC. In some instances, commitment was described as originating from an emotional perspective, in others, from a practical perspective. Caregivers, most of whom were spouses, used pragmatic terms such as “*our marriage vows were in sickness and in health,*” “*this is my job,*” “*it’s just what you do,*” and “*it’s just the way it is.*” Others described their commitment in terms of a deep sense of loyalty to the older adult:

Almost fifty-nine years ago, we stood in front of the church and said for better or for worse, for richer or poorer, sickness and whatever; and I think this is probably the worst and this is probably the sickest, you know? And that’s very important to me. (AB – 16)

I think back to our marriage vows and right in your marriage vows it said to look after one another and I think if I didn’t do that, I certainly wouldn’t be fulfilling my obligation when I got married and that’s kind of the way I feel about it. (ON – 20)

These caregivers described the strength of giving their word to their spouse and how they continued to enact this despite their partner’s health challenges and the burdens they experienced themselves. Some caregivers depicted their commitment to care as reciprocity, as giving back to others who had given to them, such as an adult child who said “*When I got home and I needed help to get up and down the stairs, (it was) my mom and dad*” (AB – 08). Some caregivers explained that commitment to care required an underlying and deep love for the older adult:

If you don’t love a person; if you just care about them, it doesn’t work. You’d walk out, pulling your hair out and say, “That’s it. I’ve had enough.” You have to have a lot of love for that person because, otherwise, forget it; it’s not going to happen . . . If you don’t care and love . . . I’m saying love more than care because caring is not enough. (ON – 17)

Another caregiver described their commitment to the older adult as a means to prevent them from being admitted to long-term care, an outcome neither the caregiver nor the older adult wanted, “*because I’m afraid they’re going to tell me he’s got to go in a nursing home and I don’t want him there. Well, because I can look after him and I’m going to miss him. How the hell am I going to snuggle up to him?*” (ON – 17) In contrast to the experiences of those caregivers whose commitment to the older adult was grounded in emotion and loyalty, caregivers also described situations where, “*it’s a matter of this is what I have to do, and this is my job. There is no one else to assist with my mother’s care. I have no other family members*” (AB – 02). For these caregivers, it was an experience of powerlessness, where they were thrust into a supportive role and the option for refusal was not available.

Reaping the rewards of caregiving: "It fills my soul"

Although caregivers reported many challenges associated with caring for older adults with MCC, they also recounted that caregiving was rewarding in terms of their relationships, emotional connections, and intimacy. One commonly reported reward was that they were helping to maintain or restore the health of the older adult: "that he's not getting any worse" (AB – 07) and "seeing the improvement is a big reward" (ON – 21). Sometimes the reward was as simple as having more time with a loved one, "that's the reward... it's time together... our time together" (ON – 11). In other cases, the reward was seeing the happiness of the older adult in response to caregiving: "I noticed she's much happier which brings the house much happier and just overall, everybody's happy. Even the cat's happy" (AB – 09) and "there's no question, it was just so worth it. Just the fact that now I can smile and with this warmth... it fills my soul. To see him happy... he loved having us there" (ON – 04).

Participants described how expressions of love and care from the older adult living with MCC were experienced as rewarding: "lots of loving hugs and words of thanks" (ON – 21) and "he's really kind and looks at me with love and respect" (AB – 07). As one caregiver explained: "When I tuck her into bed and the covers are all in place she will say 'Thank you dear; you're always going to take care of me.' And she'll pat my cheek. What more can you ask for?" (ON – 23). In some cases, the acknowledgment of others was meaningful for caregivers: "just the encouragement I get from others [related to caregiving], as well" (ON – 21).

Caregivers spoke about the rewards of caregiving as including opportunities to know their loved one in new and different ways: "I know my dad in a different way than I would have otherwise ever. I'm a lot closer with my dad. I know more about him and yeah, I think that's a huge reward" (AB – 20). Some participants explained that caregiving provided invaluable opportunities for redemption or restoration of difficult past family relationships:

I enjoy going to visit him because I didn't really know him a lot growing up because of his work ethic and then the fact that when he was home he was a drinker... So lately having him there, getting to know him more, being able to provide him with care has been rewarding. (AB – 13)

This has been actually the most rewarding thing that I've done in my life is taking care of my mother. And it's kind of odd because we never really got along when she was well but we've become very, very much closer now. (AB – 02)

Discussion

Study findings make important contributions to our understanding of the complex experiences of caregivers who provide support to community-living older adults with MCC. In particular, study findings describe the experiences

of an understudied group, caregivers of older adults with a very high level of multimorbidity, in this case, an average of 7.1 chronic conditions. Research indicates that among older adults with diabetes, dementia and stroke, higher numbers of comorbid conditions are associated with higher use of services such as family physicians, specialists, and the emergency department³⁷; this high service use suggests that caregivers of these older adults experience increasing caring demands with increased comorbidity. Study findings also fill a gap in the research, identified by Price and colleagues in their review, related to the psychosocial experiences and needs of caregivers of persons with multimorbidity.²³

Study findings drew attention to three overarching issues related to intense caregiving situations as in the case of caring for older adults with high levels of MCC: (a) the need for a balanced perspective on the effects of caregiving, (b) the need for programs and services to appropriately support caregivers, and (c) the need for recognition that caregiving is a societal issue. Each of these issues are reviewed in the context of existing literature and our findings.

A balanced perspective on the effects of caregiving

Although there are positive aspects of caregiving for older persons with MCC, the negative effects are significant and are often poorly addressed. Study findings support previous research that indicates caregivers of older persons with MCC find the caregiving experience all-consuming and overwhelming, resulting in high levels of stress and anxiety.^{41,42} Caregivers in this study described the emotional pain and helplessness they experienced and how this made it challenging to provide care. The finding that caregivers' own psychological and physical health conditions limit their ability to provide care is also consistent with previous research.^{43,44} This finding may be associated with the fact that many caregiver participants were older spousal caregivers (68%) who were more likely to have physical and mental health conditions that impacted their ability to provide care.

While the social isolation associated with caring for older adults has been identified in the literature, there is little focus on social isolation related to caregivers of older adults with MCC.⁴⁵ The all-encompassing nature of caring responsibilities resulted in some caregivers of older adults with MCC being house-bound and isolated, as supported by previous literature.⁴⁶ Cognitive decline among older adults, often associated with MCC, necessitated extensive care provision and thereby contributed to caregivers' experience of social isolation. The literature indicates that dementia caregivers are at risk for chronic stress and social isolation and that these risks also contribute to increased risk for physical and mental illness.^{47,48}

This study revealed that despite the challenges of caring for older persons with high levels of MCC, caregivers were

extremely committed to their caregiving role and experienced substantial rewards from caregiving. Spousal caregivers identified reward in the time spent together as a married couple, sharing love and commitment, similar to a previous study on spousal caregivers of persons with MCC.²¹ The literature suggests that caregivers may focus on the benefits of caregiving as a means to help them cope with the ongoing challenges they face.⁴⁹ Adult child caregivers spoke of opportunities to relate to parents in new ways, restoring or redeeming previous relationships. The literature suggests that some adult child caregivers welcome the opportunity to reciprocate for the care they received throughout their childhood.⁵⁰ The finding that caregivers have tenacity and a willingness to find the positive in tremendously challenging conditions can inform relational strategies used by health providers who are seeking to support and empathize with caregivers. A balanced perspective that takes into account both the rewards as well as the heavy toll associated with caregiving is needed.

Programs and services to support caregivers

Study findings highlight the need for programs and services to appropriately support caregivers of older persons with MCC living in the community. If caregivers were better supported with services to address their physical, psychological, emotional and social needs they might be better able to cope with the demands of caregiving in a healthy way.

Given the biopsychosocial burden that caregivers in this study experienced and their key roles in helping older adults with MCC remain in the community, it is important to find innovative and effective ways to support these caregivers. However, there is little published literature on such programs or their impact. The Guided Care Program for Families and Friends (GCPFF) involved a combination of support for caregivers together with comprehensive care for older adults with MCC provided by a nurse working closely with primary care providers.^{51,52} The GCPFF included an initial meeting between the caregiver and the nurse, education and referral to community services, ongoing coaching by phone and email, a workshop and support groups.⁵² However, a cluster-randomized trial of the GCPFF found no statistically significant impact of the program on caregiver depressive symptoms, affect or productivity.⁵¹ Our findings suggest that other caregiver-relevant outcomes such as feelings of social isolation, caregiver stress and rewards of caregiving may be important outcomes to be assessed as a result of such interventions.

The use of web-based interventions for caregivers of persons with chronic conditions holds promise to improve their mental health outcomes.^{53,54} Such interventions may be particularly feasible for caregivers of older adults with MCC who experience challenges in leaving their homes. A randomized controlled trial of a self-administered, psychosocial supportive web-based intervention for caregivers of

persons with dementia and MCC, My Tools 4 Care (MT4C), found no statistically significant impact on outcomes of health-related quality of life and self-efficacy, but did find higher hope scores for the intervention group.⁵⁵ In qualitative interviews, caregivers reported that using MT4C encouraged sharing of their experiences, provided affirmation, information and education, and encouraged reflection.⁵⁶

Recognition that caregiving is a societal issue

Study findings reflect the need to consider caregiving as a societal issue that extends well beyond individuals and families to communities and society more broadly. Some caregiver participants spoke of the lack of understanding they received from people in the community, particularly when the older adult had dementia, and the resulting social isolation when friends no longer kept in contact. Consistent with previous research, caregivers spoke of the struggles to manage caregiving in combination with high workplace expectations, suggesting the need for caregiver friendly workplaces.⁴⁶ Caregivers also expressed frustration in having greatly restricted social lives and few opportunities for social participation in their communities. Caregiver needs for support, social connection and recognition of contributions identified in this study are closely related to three key areas of the World Health Organization Global Age-Friendly Cities initiative, specifically social participation, respect and social inclusion, and community support and health services.^{57,58} Study findings could be used to inform further development and refinement of the Age-Friendly Cities initiative, in particular to support active and healthy living of caregivers of older adults.

Implications

Study results can be used to identify how to better support caregivers of older adults with MCC living in the community. First, healthcare providers should use person-centered and relationship-centered approaches to care where caregivers are considered part of the circle of care and are actively involved in decision making processes.⁵⁹⁻⁶¹ Previous research has found that caregivers, older persons with MCC, and providers have differing goals in the management of MCC, particularly when patients had declining cognitive or functional health or safety concerns.⁴¹ This suggests the importance of understanding how each of these groups sets priorities for care and how to support collaborative goal setting and care planning. Further, caregivers could benefit from education and support in deciding how to set priorities for care given the often fluctuating health status of older adults with MCC and their frequent healthcare transitions.

Health and social care providers can also play key roles in promoting self-care among caregivers through what is often a multi-year journey. Counseling services may help

caregivers recognize their need for self-care and assist them to develop techniques that focus on their strengths and available resources.⁶² Caregivers can also be encouraged to maintain participation in activities of interest. Next, it is important to assist caregivers to navigate the confusing array of health and social support services in order to obtain respite and other caregiver support services that best meet their needs. A review of the barriers and enablers to the use of respite interventions by caregivers of persons with dementia (who often have MCC) found that caregivers require considerable support in order to identify the need for and accept respite services.⁶³ Finally, caregiving is a societal issue that will only be magnified as our aging population continues to grow in size and experiences MCC over longer lifetimes. It is important that communities take action to create opportunities to support caregivers such as social inclusion and participation.

Study strengths and limitations

Strengths of this study include a large sample of caregivers who were recruited from two provinces in Canada, and represented diversity in sex, age, education and relationship to the care recipient. Further, the study included an understudied group, caregivers of older adults who had very high levels of multimorbidity, an average of 7.1 chronic conditions. The use of interpretive description with in-depth interviews enabled a rich understanding of the experience of caregivers of older adults with MCC. There was a rigorous data analysis process that involved a cross-provincial research team with expertise in caregiving, MCC and qualitative research. One of the study limitations involved the lack of ethnic and cultural diversity in the sample. Caregivers with different ethnic and cultural backgrounds may well experience caregiving differently and have different needs for support. Exclusion of non-English speaking individuals is also a limitation as they may experience the caring process differently than English speaking caregivers. The use of caregiver self-report for chronic condition diagnoses of the care recipient is a limitation of the study. Further understanding of the experiences of working caregivers of persons with MCC would also be valuable.

Conclusions

Study results indicate that caregivers of older adults with MCC experience both challenges and rewards in their caregiving roles. Health and social care providers can play key roles in supporting these caregivers by understanding their experiences and needs for support, acknowledging the important roles they perform, providing education and support on managing MCC, actively engaging them in care planning, and linking them to appropriate community health and social support services. Communities, through initiatives such as the Age-Friendly Cities project, also play a role in creating environments that could better support not

only older adults with MCC, but also their caregivers. Opportunities for caregiver social inclusion and participation, as well as appropriate caregiver support programs, should be integral to the future design of our communities.

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Author contributions

JP and MMR obtained funding for this project. JP and KDF conceived of the project, wrote the protocol, obtained ethical approval, and supervised data collection. All authors contributed to data analysis. AG and JP wrote the first draft of the manuscript. JP, AG, KDF, LGB, SK, CM, MMR, and SD reviewed and approved the final manuscript.

Availability of data and materials

The data that support the findings of this study are available on request from the corresponding author [JP].

Consent for publication

Caregivers provided written consent for their anonymized quotes to be used in published reports.


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
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