


The Predicament of Caring: Work Interferences and Health of Family Caregivers of Persons With Multiple Chronic Conditions

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Abstract

Providing caregiving to family members with multiple chronic conditions (MCCs) can interfere with employment status and have a negative impact on caregivers' well-being. The qualitative analysis of 13 Canadian employees who were also simultaneously providing unpaid care (carer-employees) identified three themes that highlight work interference, negative impacts on well-being, and workplace culture. The findings call for employers to provide health promotion strategies and a supportive workplace culture that reduce workplace interference while being responsive to the unique needs of carer-employees.

Keywords

carer-employees, work interferences, qualitative research

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Introduction

The growing elderly population living with multiple chronic conditions (MCCs) affects the family caregivers who provide care for them. Undertaking most costs and burdens associated with caregiving, family carers in Canada provide up to 80% of the care for community-living older adults with MCC (Canadian Institute for Health Information, 2010). Regrettably, this often results in losses to their own well-being, with the level of carer strain shown to have a direct relationship with the number of chronic conditions that the older care recipient has, increasing negative health outcomes and health service use for caregivers (Canadian Institute for Health Information, 2011; Lehnert et al., 2011; Williams et al., 2016).

Caregivers are heterogeneous in the intensity of their caregiving commitments, demographic profiles, and labor force patterns (Lilly, 2011; Ryan & Kossek, 2008; M. Sinha, 2012; Swody & Powell, 2007). Given Canada's aging demographic, a growing concern is caregivers' ability to remain productively employed and financially stable while providing additional support to their dependents (Angelo & Egan, 2015). Carer-employees (CEs) are people in the workforce who provide care and assistance to individuals living with debilitating physical, mental, or cognitive conditions. CEs can be caring for a parent, a parent-in-law, a spouse, a life partner, an adult child, or a friend.

The latest evidence highlights employment-related economic consequences for CEs. These include loss of wages and benefits (medical and/or pension), having to withdraw from savings due to quitting or leaving jobs, taking unpaid days away from work, or working part-time (Hilbrecht et al., 2017). Other examples of losses that CEs face when trying to balance work–life conflict include relinquished management positions, refused promotions, and unfair treatment by coworkers and managers (Hilbrecht et al., 2017; Rosenfeld, 2007). Furthermore, CEs lose social interaction, emotional well-being, personal empowerment, and respite from caregiving when decreasing or quitting employment. One obvious approach to mitigate this is to implement strategies to better enable CEs to better balance paid work and unpaid caregiving. To do this, we need to better understand how paid work affects the unpaid caregiving role and vice-versa, the latter often occurs through work interferences (WIs).

Although limited, there have been a few studies focused on CEs who are caring for patients with MCC.

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Arnsberger et al. (2012) found that, in terms of self-assessed health status (SAHS) of caregivers caring for patients with MCC, several characteristics were found to be predictors of a higher SAHS level. These included a higher educational level, being employed full-time, being male, not living with the care recipient, caring for a female, and caring for an older adult. In contrast, lower SAHS was associated with high emotional stress, providing support for activities of daily living (ADL) or medical care, lower income, unemployment, being female, caring for a male, and caring for a younger recipient (Arnsberger et al., 2012). The authors also found that moderate to high income was the next best predictor (to the absence of MCCs) of better SAHS.

Lack of financial resources affects the ability to hire help or pay for institutionalized care, consequently contributing to negative health outcomes for CEs. This is particularly concerning for patients with MCCs, who may be required to spend a higher proportion of their income on medical and nonmedical expenses related to their multiple diagnoses, than individuals with only one condition (Valtorta & Hanratty, 2013). Furthermore, women who have lower incomes are also found to exert more physical and mental effort in their caregiving roles (Juratovac & Zauszniewski, 2014). It may be the accumulation of costs—both direct and indirect—that is implicated in creating economic hardship for caregivers and their care recipients (Valtorta & Hanratty, 2013).

Using a qualitative approach, the purpose of this article is to discuss the WIs for Canadian CEs caring for older persons with MCC. Following a short methods section, an overview of the results precedes a discussion specific to research implications and conclusions.

Method

The data presented herein are a subset of a larger embedded mixed-methods study, the methodology which is presented elsewhere (Williams et al., 2016). For the qualitative interview stage of concern herein, a subset of 40 survey participants who elected to participate in the interview were chosen based on their degree of vulnerability to carer burden and negative health outcomes, as indicated by their social determinants of health. Thirteen of the 40 qualitative interview participants were CEs and are the focus of this article given the comparative greater carer burden they experienced.

Sample

Participant demographic characteristics are outlined in Table 1. The eight female and five male participant CEs were in the sample. Six were working full-time, five were employed part-time, and two were self-employed. All the participants were providing care to a family member with three or more chronic conditions.

Table 1. Participant Sample Characteristics.

Characteristics	N = 13
Caregiver age	
<30	1
41–45	1
46–50	1
51–55	3
56–60	4
61–65	2
76–80	1
Caregiver gender	
Female	8
Male	5
Marital status	
Single	4
Married	5
Divorced/separated	3
Other (common-law)	1
Ethnicity	
Caucasian	10
Black	1
Chinese	1
Other	1
Level of education	
High school diploma (or GED)	2
College or CEGEP	3
University degree	8
Employed	
Yes	13
No	0
Self-employed	
Yes	3
No	10
What is your employment type?	
Full-time	6
Part-time	5
No answer	2
What is your relationship to the care recipient?	
Husband/wife/life partner	2
Son/daughter	9
Parent	1
Other	1
What is your estimated annual household income?	
Can\$10,000–Can\$19,999	1
Can\$30,000–Can\$39,999	4
Can\$70,000 or more	6
Prefer not to answer	2
Do your finances meet your needs?	
Totally inadequately	0
Not very well	1
With some difficulty	5
Adequately	4
Very well	0
Completely	3
Residency/geography	
Urban	13
Rural	0

Note. GED = general educational development.

Data Analysis

Charmaz's (2006) constructivist grounded theory was used to develop initial or open codes, selective or focused codes, categories, and themes. As with most traditional grounded theory approaches, it was not our purpose to formulate a theory. To develop initial codes, segments of data were studied closely and then named in short concise terms (such as "feeling physically tired" or "quitting work"). Initial codes were then combined (such as "feeling physically tired" was combined with "having a headache") to produce a focused code "physical well-being." Similarly, codes such as "feeling depressed" and "crying" were about emotional well-being and were grouped under "emotional well-being." Focused codes were combined to produce categories. For example, "physical well-being" and "mental well-being" codes were combined to produce a category "physical and mental well-being." To form analytical themes, we combined categories—for example, the "physical and mental well-being" category was combined with the "negative impacts of caregiving" category to produce the theme named "impacts of caregiving on well-being." As suggested by Charmaz, the constant comparison method was used throughout the analytical process, where data were compared with data, and codes were compared with codes.

Qualitative Findings

Below we present three key themes related to the article: (a) WI; (b) impacts of caregiving on well-being; and (c) workplace culture:

Theme 1: WI

This theme identifies how caregiving interfered with participants' employment status and/or ability to engage in paid work. Overall, the findings from the participant interviews suggest that caregiving interfered with their work in varying intensity, regardless of whether they were employed full-time (AP535; AP593; AP622; AP638; OP013; OP093), part-time (AP569; AP581; OP077; OP101. OP042), or self-employed (OP033; OP055). Gendered and cultural expectations to care were strong forces in CEs' ability to manage both care and paid work.

OP077, a single woman working part time who had been taking care of her mother for 3 years, discusses the sacrifices that come with caregiving demands. As the only caregiver to her mother, the caregiving greatly affected her work status:

Yeah, because I am not working full-time. And I was offered a job full-time, but I can't take it because of this (caregiving). My part-time job is even gone. I used to work half (you know 20 hours a week), now it is down to sometimes zero hours a week. You know, I worked maybe five days last school year. So, it really went down a lot. (OP077)

Although she understands that her hours decreased due to her mother needing constant care, including having to take her to 20 or more appointments, tests, X-rays, and blood work, she feels guilty about not working. She was also quite resentful about her decision:

So, I know I was upset about the fact I quit, right? [crying] . . . cause I don't quit . . . So, I had to sacrifice to help my mom and the boys (her two brothers) didn't have to sacrifice, you know? So, it seemed like I was the one always missing out. (OP077)

Although AP569 does not verbalize it as guilt, she was unable to refuse her mother's demands when caregiving first began: "I was there almost every day and I just felt I couldn't say no; I was working full-time and taking part-time courses." She had to drop down to part-time work due to the lack of support received from her siblings:

It was expected and not asked. It was just, you're a girl and girls care-give and boys don't . . . So I definitely saw, like, oh, you know, the gender divide and the expectations kind of just thrust upon me. No training, no nothing. You're just pushed into it. I didn't like that at all. (AP569)

Her experiences of gendered caregiving resonate with AP593, AP638, and OP077 who, as indicated earlier, were also expected to make career and/or financial sacrifices while their brother(s) were not.

From a male perspective, AP581 believes that caregiving comes easier to women. Although he lives with his mother, which covers his living expenses, he is sensitive to the issue:

I feel a bit sometimes sensitive to the fact that, like, I'm a male doing it, right? I mean I don't know if it's because of my ethnic background or because in general, you know? Like it's a bit unusual, you know? And I've had a few friends say, ". . . it's unusual for a man to be living at home with your mom," you know, kind of a thing. And so I'm a bit sensitive about that, to be honest, you know? I find it a bit annoying, actually.

One male participant (AP581) only works part-time, but had to quit his master's degree and give up teaching English as a second language due to the physical and psychological demands of caregiving. Likewise, AP535, a divorced/separated male taking care of his parents and working full-time, is very familiar with the sacrifices of being a caregiver:

What I don't like about it (caregiving) is the sort of time commitment. It's a lot, right? And you're always sort of making that decision whether you go over there and see them tonight and you're tired and you got stuff to do for work, you know, and there's always that sort of balance. You know, you feel guilty if you don't go over. . .

In addition to gender, culture also played an important role in career sacrifices. One visible minority CE who was a Black immigrant woman, was raised to take care of her elders and felt honored to take care of her mother. This cultural expectation was strongest felt on her career when her mother needed 24/7 care: "She's 24/7 care, so I mean, I'd love to go out and work, but I just can't, because of the circumstance" (OP033). However, being self-employed assisted her with the caregiving demands: "I'm also glad that I can be at home, that I don't have to go out to work. I'm here to care because it's a 24/7 care." But the transition from full-time employment to self-employment came with some financial sacrifices. Making barely Can\$10,000 to Can\$19,000, she met her financial obligations with some difficulty: "Affordability plays a part, so I know I have to downsize on everything, right? . . . So I've downsized a lot."

As a full-time health care consultant (nurse), OP013 also found it challenging to balance full-time caregiving and full-time paid work. As both her parents had MCC, it seemed she was always on call. She observes, "I was already working 20 hours a day, because I was carrying huge work contracts, and there is no negotiating on deadlines when you are a consultant" (OP013). She explains how she juggled paid work and unpaid caregiving:

So, if I had a deliverable due on a certain date, I would have to do it and I would work, even at night. That's why I would have to take work to the house, my dad's house, so that I was at least there. I could have done the work in a quarter of the time, if I was on my own.

Increasingly, she found it difficult to balance paid work and unpaid care: She notes, "I am taking no long-term contracts. I had huge contracts I was carrying last year, and I never would have taken them on if I would have known that my mother would start deteriorating" (OP013).

Like OP013, AP593 found it difficult to manage full-time paid work and attending to increased frequency of her mothers' medical appointments and emergencies. Often, it required her to leave very early to visit her mother at the hospital before going to work. Even with her husband working, she was not able to leave her work or work part-time due to financial hardship. In addition to providing emotional and physical help, she was also financially assisting her mother who was on a limited senior income. Her brother, who was earning more than her, was largely disengaged from any form of caregiving.

Theme 2: Impacts of Caregiving on Well-Being

This theme highlights the impacts of caregiving on participants' physical and/or mental well-being. Due to the family's complete dependence upon her for caregiving,

one full-time CE (OP013) could not even take time off on a work retreat. She notes,

I tried to go away for a three-day re-treat for work, I was back at the same day. So I took a trip to the United States in the morning and I came back that day because my mother had a fall, and my son felt terribly that he had to call me, but she was in the hospital. (OP013)

Ultimately her health deteriorated: "Physically I was very, very sore. My arms were sore, my back was sore . . . muscle strain, tension, constant worry."

Although, AP622, a full-time social worker, made every effort to be on time for the morning medical rounds at work, the caregiving demands of her husband caused her to be often late. She rationalizes her reasons for being late at work: "But anyway, I just have a hard time and it's a mixture of that I'm really tired, like people say, 'Well why don't you just get up earlier?' Well I'm so exhausted, you know?" (AP622). Similarly, in trying to manage paid work, family responsibilities (taking care of her children), and caregiving, OP042 too feels tired and unable to sleep at night.

As a 21-year-old Chinese female who was the oldest child in the house, fluent in English and the first generation to get a university education, there were a lot of responsibilities and expectations on OP101's young shoulders. As the oldest child, she is "expected to earn money and bring it back to the family" (OP101). She is expected to know everything (all material related to caregiving) in English first and then translate it in Chinese for her family. Despite the hardships of managing school, part-time work, and caregiving demands, she is not supportive of putting her grandfather in a home: "That's not an option. We'll always find a way" (OP101). The stress of managing multiple tasks took its toll:

The stress as well, yeah. And so I wasn't . . . for like a good period of time I wasn't being productive. My own life kind of went down and I didn't feel like doing anything, but eventually, you know, I learned to deal with it.

As a self-employed caregiver older than the age of 60, OP055 is concerned:

I gotta watch what I do because I got my own physical problems and I don't think my dad realizes how sometimes, how much it bothers me to lift him and help him into the car, in the wheelchair, out of the wheelchair, doing this and that, but I never say anything to him.

Managing paid and unpaid work was physically and mentally taxing for the 13 caregivers who also were employed. One participant who worked part-time confided, "So you cry every night and it affects you because, with the full-time job I had, I closed the door and cried and [laughing] a couple of employees saw me and it's embarrassing" (AP569).

Furthermore, the qualitative data reflected how time was implicated in the changes experienced. As the frequency of emergencies and hospital appointments increased over time due to the care recipients having MCC, it was harder for full-time CE participants to integrate paid work with caregiving commitments (AP593; AP638). As noted in the data above, a number of CEs experienced negative impacts on their well-being, from muscle strain to blood pressure problems and stress.

Theme 3: Workplace Culture

This theme highlights the importance of workplace culture in caregivers' ability or inability to stay employed. When AP622, who had originally worked full-time hours as a social worker, received modified work hours for a while, she found her work situation eased. But when the new supervisor insisted that she attend rounds, she complained to Human Resources (HR) who supported her: ". . . they (HR) told him about this new way of thinking called 'duty to accommodate'; that, I really knew nothing about before, [laughter] and so they have to try and meet your needs." In spite of support from HR, she experienced "being sort of squished between two places," that is, between caregiving and paid employment. Finally, as her husband's condition worsened and he became more ill, she changed her place of employment and found work closer to home. She was cognizant of the fact that the many tensions on her time—paid work, caregiving, and travel time—affected her work performance: "So I think I was aware that I wasn't doing as good a job, and I know that I don't do as good a job as I did before all of this. . ." (AP622).

Travel time was also a problem for AP638, a full-time employee and primary caregiver to her mother. As discussed in Theme 1, AP638 complains that her brother only does some yard work and goes on frequent vacations. She adds,

He's the darling little boy. That's a hard thing too, that he seems to be the favourite [crying] when I do everything. Like every time I, every day, I work those bad weeks. I'm taking her, I'm going to work early, I leave work to go pick her up, bring her, stay if I have to stay to see the doctor, get her back home, then I have to go back to work 'til 9:00 or so.

She is grateful to her boss who was accommodating to her caregiving needs. However, she was mindful that she could not continue to expect to be allowed to leave work early indefinitely. Alike AP638, AP535 is very grateful for the support of his employer:

Great employer, very understanding. I can phone my boss and say, "I gotta run, it's ten o'clock, I've got a problem at the old folks' home," and [snap] you know, you pass off the on-call cell phone pager, whatever, you go, right? So it's been, there's been no real challenge there, you know?

Although her immediate supervisor understood, AP638 notes, "The boss above her is not understanding at all, and that's a whole other horrible story [laughter]." The difficulty this participant has in managing paid work and family caregiving is expressed in the following sentiments: "So I do feel like I'm not a good mother, I'm not a good daughter, I'm not a good enough friend, that I'm not a good enough employee [very emotional]." Clearly, this CE was very thinly spread. The data suggest that the workplace culture (i.e., whether the supervisor and/or colleagues were empathetic, and if there were workplace accommodations available for caregivers) was critical in the participants' ability to remain employed.

Limitations

As a qualitative study with a small sample, the findings are not generalizable to the larger population. Most of our sample consisted of White Caucasian caregivers and thereby was not diverse.

Discussion and Future Directions

A wide range of strategies were used by participants to best meet the demands of caregiving for recipients with MCC. Two were contemplating quitting work due to the time commitments of caregiving (AP525; OP036), while others took employment closer to home to be available to the care recipient (AP622). One participant (AP631) took early retirement, and another moved closer to the care recipients (parents) after retiring (AP567). Others reduced their workload (OP013) or dropped down to part-time hours (AP638). Finally, one participant mentioned that they had to put their educational goals on hold (AP581). These various strategies were self-imposed, suggesting that the workplace itself had little flexibility in accommodating CEs or assisting CEs in better managing the demands of their caregiving role. This suggests Canada has much to do in making their workplaces caregiver-friendly.

The gendered aspect of caregiving is well established in literature (Sethi & Williams, 201; Williams et al., 2016), and was confirmed again herein given the expectation that female members of the household were expected to be the primary carers. Our findings suggest that the gendered division of labor specific to providing care to elderly family members is still predominately weighted as women's work. Women continue to bear the brunt of the responsibility, although more men are stepping up. We are making progress, but it is slow. The data also revealed that caregivers suffered negative impacts on their well-being due to trying to integrate work and care obligations. These were wide ranging, from muscle strain to blood pressure problems, and inability to sleep.

This study adds to growing literature on the employment and WI related to CEs. Often, participants felt marginalized at the intersection of work and home life. The data highlighted a range of WIs, such as being late to

work (AP622)—alike that reported on by Gautun and Hagen (2010), through to reducing work hours and sometimes quitting work. These findings corroborate other work on how caregiving can negatively influence work status and job situation (Gautun & Hagen, 2010; Pavalko & Henderson, 2006; S. K. Sinha, 2013). There is, indeed, a relationship between WI and caregiving (Fast, 2015; Hilbrecht et al., 2017; Keating et al., 2014). Johnson and Lo Sasso (2000) suggested that “trade-offs between work and time assistance (caregiving) may become evident once we control for other factors affecting labor supply and caregiving” (p. 20). Related to this, it is concerning that employment status has a negative effect on the willingness to provide informal care (Carmichael et al., 2010). What is not clear from the findings is how the decisions were made to change work status, whether moving from full-time to part-time, to reducing work hours, or leaving the labor market altogether. Future research addressing this issue will provide further insight while determining how well-being is implicated in these decisions.

The data in our study also highlighted the significance of workplace culture. It was clear from caregivers’ quotes that a supportive workplace culture and an understanding employer supervisor eased the burden of caregiving. A supportive workplace culture likely contributes to CEs remaining employed.

Conclusion

Framing the qualitative study within Charmaz’s constructivist model (Charmaz, 2006) provided findings grounded in participants’ voices from multiple perspectives. As our population ages and caregiving demands rise, employment policies that help caregivers best manage their caregiving responsibilities is an important strategy to reduce employment costs related to caregiving. Currently, most policies are “treatment oriented,” in that they provide accommodation only when the caregiver is often in the middle of providing care, and sometimes on the verge of losing employment. To prevent caregivers from being forced out of the labor market, and to make it easier for employees to combine work life and care responsibilities, we need to be thinking upstream, using a preventive approach to maximize CEs’ ability to sustain both roles and minimize burnout.

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Ethical Approval

This study was approved by IRB: McMaster Research Ethics Board: Approval: 2013 104. It contains no HIPAA identifiers.

Declaration of Conflicting Interests

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