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When one is sick and two need help: Caregivers' perspectives on the negative consequences of caring

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Cover Page Footnote

The health experiences research and development of the online module (www.healthexperiences.ca or www.experiencessante.ca) were possible thanks to the generous contribution of all the participants we spoke to who care/cared for someone with a chronic physical illness, St. Mary's Hospital Foundation and the Women's Health group for their financial support, and to the members of our Expert Advisory Panel for their encouragement and support throughout the project.

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Abstract

Informal or family caregivers contribute significantly to individual care, and to the Canadian healthcare system, yet receive limited support from governments, institutions, and healthcare professionals in recognition of their role, or in response to their health and social care needs – often due to the negative consequences of caregiving. Learning about the diversity of others' experiences can positively influence personal decision-making, reduce feelings of isolation, as well as promote adjustment to a personal situation. For caregivers, however, few resources exist that provide reliable information on others' experiences. We collected the narratives of caregivers' experiences of caring for someone with a chronic physical illness and produced an evidence-based web resource. Through purposive variation sampling, 42 caregivers were recruited across Canada for interviews in their homes or alternate location using video/audio recording. Qualitative data analysis followed a constant comparison approach. 29 thematic pages were developed for the web site (www.healthexperiences.ca) featuring the diversity of lived experiences, and presenting topics important to the caregivers with illustrative video/audio clips, along with other sources of information. Key themes related to caregivers' perspectives on the negative consequences of caregiving included: the impact upon personal health; challenging interactions with professionals; inconsistent information, limited support from family and friends, and unhelpful societal views. These results contribute to existing evidence of caregiver burden, but uniquely in the voices of caregivers themselves – with constructive insights for understanding the causes of ill health related to caregiving burden and for informing policy and practice.

Keywords

Qualitative methods, caregiver, caregiver burden, informal care, online health information, video recording, narrative research

Note

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Introduction

As Canadians age, the reliance on informal or family caregivers to support those with chronic illness at home becomes increasingly important to individuals, the healthcare system and to society more broadly¹. Informal caregivers are those who provide care and assistance, without pay, for family members and friends and play a crucial role in maintaining the health, well-being, and

quality of life for people otherwise at risk of losing their independence^{1,2}. In 2012, about 8.1 million individuals, or 28% of Canadians aged 15 years and older, provided care to a family member or friend with a long-term health condition, disability or needs related to aging in general³. The term 'caregiving' is used to describe a wide range of activities, such as driving someone to appointments, preparing meals, helping with bathing and dressing, and/or administering medical treatments, and may involve

relatively low to high intensity engagement of the caregiver³. Informal caregivers provide approximately 80% of these care needs for people with chronic health issues, valued in 2009 at around \$25-26 billion in Canada as a contribution to our healthcare system, including around \$5-\$6 billion in unpaid work each year in Canada²⁴.

In studies of caregivers' perspectives, participants have reported many positive consequences and personal benefits related to caring for a spouse, family member or friend, when ill^{5,6}. The negative consequences have also been documented and are substantive, including physical, psychosocial and financial burdens, such as reduced work hours, that potentially interfere with the sustainability of caregivers' contributions^{6,7}. Many studies have demonstrated that providing care for aging family members imposes a burden upon caregivers' health^{8,9} with negative health outcomes including depression and overall poor health such as compromised immune systems, higher blood pressure, sleep difficulties, fatigue, cardiovascular disease, poor immune functioning, or burnout⁸. Most alarming, however, is the evidence that identifies caregiving, particularly for older caregivers experiencing mental or emotional strain, as a risk factor for mortality¹⁰, although there is some debate about this¹¹. And more recently studies in the UK, USA and Australia have demonstrated that youth caregivers are substantially more absent from school due to family caregiving responsibilities¹² and in Canada about 12% of people under 18 years old are involved in caregiving¹³. Further, caregivers are at a greater risk for abusing the care recipient as a consequence of stress and burden¹⁴. Caregivers experience a range of psychological complications as well, including fear, hopelessness, mood disturbances, anxiety, and depression at rates which often surpass those of the patients for whom they provide care¹⁵. As well, time taken to perform caregiving responsibilities is time away from other responsibilities, social activities and personal relationships, all of which may add to a caregiver's emotional stress, sense of isolation, and feelings of being overwhelmed¹⁵. Finally, caregiving is often associated with enhanced financial pressures, particularly when they may be required to limit working hours or turn down career opportunities due to unpaid caregiving duties^{2,16}.

The limited recognition of these challenges in policy formulation¹⁷ in Canada suggests that caregivers are primarily conceptualized as a 'resource' in today's healthcare system rather than a valued partner in the provision of care, or as a 'co-client' potentially in need of care^{16,18}. Despite their crucial role in supporting the health of older adults, practical, social, emotional, informational and financial support for unpaid caregivers is lacking or inconsistently available, which can have a negative impact on the quality of care that they provide¹⁹. It is not

surprising that as a result, caregivers are often dissatisfied with their limited level of involvement²⁰.

Despite the overall recognition of the negative health and social consequences of caregiving, we know less about caregivers' self-identified reasons regarding *why* and *how* their health is negatively affected. From a patient-centered perspective there is also a need to better understand caregivers' perspectives on potential solutions to reduce or prevent these negative experiences and impacts.

In this article, we present key findings from a qualitative study of caregivers' narratives with respect to factors contributing to the negative health and social consequences of caring. Although caregivers shared many of the joys and benefits of engaging in their role (as can be viewed in the online presentation of results at www.healthexperiences.ca), here we focus on how they spoke about underlying causes of ill health and other negative impacts experienced as caregivers.

Design and Methods

Design

This study adopted a phenomenological approach to qualitative inquiry which enables a focus on subjective, lived experiences²¹.

Methods

In-depth, qualitative interviews^{22,23} were conducted with a diverse sample of caregivers across Canada using audio/video recording as per standardized procedures established by the Health Experiences Research Group at Oxford University²⁴. Inclusion criteria included adult caregivers (18 years of age or older) who cared or had cared for a family member or friend with a chronic physical illness, (caregivers of care recipients who had cognitive problems or a diagnoses of mental illness as their primary diagnosis were excluded). We employed a participatory research approach to ensure the relevance of this work to caregivers and clinicians' roles in real life, and to promote learning with respect to the conduct and use of research amongst our team members^{25,26}. We established an expert advisory panel to meet over the course of the project that included clinicians, researchers, and caregivers who had expertise in family caregiving and elder abuse, qualitative research methods, and family caregiving. All members of the group were involved in discussions about recruitment, analysis, topic page development and dissemination.

Recruitment

Information about the study was sent out through national, provincial and local caregivers' and patients' organizations, health care professionals, and via personal and professional networks. An expert advisory group established for the study (involving clinicians, caregivers,

and methods experts) assisted with identifying potential participants. Interested caregivers contacted the project coordinator who checked for eligibility, provided more detailed information, and arranged an interview if agreement to proceed. 40 interviews were conducted (38 individual and 2 with couples) between September 2011 and October 2012. Of the 42 participants, 3 did not return their transcripts (sent for their review) for unknown reasons and so were lost to follow-up, leaving 39 interview transcripts for analysis. We aimed for a diverse, maximum variation sample²⁷. The strategy for sampling sought variation on two dimensions: caregiver's individual characteristics (e.g. age, sex, ethnicity, socioeconomic status); and, attributes of related to the caregiving experience (e.g. chronic condition of the care recipient, years of caregiving)²⁷. Ethical approval was received from the Research Ethics Committee (REC) of St. Mary's Hospital Center and also from the Comité d'éthique de la recherche des établissements du CRIR et CIRRIIS, and CSSS Cavendish.

Informed Consent

We employed a two-stage consent process: at the point of interview and when approving use of the final transcript. Following the interview, participants received their transcript and were invited to strike out any text they were uncomfortable with being used for analysis or presentation on the website. The 'marked-up' transcript was then returned to the research team together with a signed copyright form giving permission for the research team to use the material in video, audio and/or text form for the web site, for educational purposes and for future research.

The Interview

Interviews were held predominately in participants' homes or at a preferred community-based location. Qualitative audio or video- recorded interviews were conducted by a senior qualitative researcher, as per the protocol developed for DIPEX UK²⁴. Participants could choose whether to use their own name or an alias. Interviews took between 25 minutes and 2.5 hours, and began with an unstructured narrative where participants were invited to tell their story from when they first started caregiving, followed by semi-structured questions where specific issues related to caregiving were explored.

Analysis & presentation of interviews on the website

Interviews were professionally transcribed. Thematic analysis of the interviews was conducted, using NVivo 10 software to help organise emergent (i.e. unexpected) themes as well as those that were anticipated, involving the method of constant comparison^{28,29}. The first 10 interviews were coded independently by two researchers (IO and SL) who then developed an initial coding framework and discussed differences or problems of interpretation, in order to ensure consistency and data quality. A modified grounded theory approach, using the

'one sheet of paper' method, ensured that all of the coded extracts within the theme were included and compared in the analysis³⁰. Topic pages presenting the key descriptive themes were prepared for the publication on the www.healthexperiences.ca evidence-based information website³¹ (see Table 1) including illustrative video, audio or text clips from the interviews. Each topic page was reviewed by 2-3 members of the expert advisory panel to enhance readability, ensure accuracy, and identify evidence-based resources as appropriate. All participants were offered an opportunity to view the website and results before the public launch. Our team conducted further analysis of the data to explore caregivers' perceptions of factors related to the negative impacts on their health and social well-being.

Results

Interviews were conducted in English and French across Canada with participants from East, Central and West Canada, in both rural and urban settings. The sample (n=39) consisted of both males (28%) and females (72%) ranging from 23 to 88 years of age. Table 2 presents the personal characteristics and caregiving status of the study participants. The majority of caregivers were married, and the age when caregiving began varied from 5-60 years (most were 50-59 years old). The majority of caregivers were Caucasian and English-speaking, although there was some diversity of ethnic and cultural backgrounds amongst participants, as well as diversity in their personal situations and types of care recipients. Table 3 presents the illnesses and conditions of the care recipients as described by the caregivers. Several care recipients were reported to have multiple chronic health problems, and despite focusing on chronic physical illness, many participants indicated that they were caring for someone who also had cognitive decline.

In this section, we present key themes from the analysis related to caregivers' perceptions of factors related to the negative impacts on their health and social well-being. This includes: perceived causes of negative impact; the invisibility of the caregiver; unhelpful societal views; and, the lack of resources and timely consistent information. This is followed by a summary of some of the potential solutions identified by the caregivers to help address these issues. Finally, we present emerging ideas about variation of perspectives within the sample across demographic categories that arose in our analysis (within the limitations of the sample and sampling strategy).

Perceived causes of impact on health and social well-being

While some participants described the positive effects of caregiving on their own health and life, most emphasized to a greater extent the negative impacts ranging from minor health issues to those more serious. For example,

Table 1: Key themes and topic pages as presented on healthexperiences.ca

Key themes	Topic pages (or sub-themes)
Advice for others	Advice for friends and family Advice for other caregivers Advice for professionals and society
Being a caregiver	Becoming a caregiver Providing support Society and caregiving Support from family and friends Uncovering why and how caregivers care What is it like to be a caregiver? When care changes over time
Impact on the Caregiver	Financial impact The future and caregiving Impact on health Impact on professional life and career Personal growth and transformation Social impact and lifestyle changes
Personal challenges in caregiving	Adapting to new roles and key issues for spouses Caring for yourself Challenging emotions and feelings Effect of the care recipients' behavior Legal issues Travelling, holidays, and respite Trying to find the right balance
Resources & Professional Services	Health system issues Home care and live-in caregivers Hospitals and facilities Interaction with professionals Navigating the system Resources

the help that Marlyn provided for her husband demanded an increasing level of physical effort to a point when she hurt her back; it took her two years to recover. She has since learned that she should stop before she injures herself again.

Caregivers also spoke about what they perceived to be the underlying causes of their health problems and the

consequences. Val cared for her husband who had chronic obstructive lung disease in the final phase of his illness.

I think you sleep less and less, and the anxiety gets more and more, and the burden gets more and more. (...) I wasn't about ever to tell him, "No, I wouldn't do it," that I wouldn't lift him, that I wouldn't pick him up push or pull him. (Val, 58 years old, cared for her husband)

Table 2: Characteristics of 39 participant's caregivers and their care recipients

Age at Start of Caregiving Duties (years) , n=39	N	%	Current age (years), n=39	N	%
<20	3	7.7	<20	0	0
20-39	13	33.3	20-39	5	12.8
40-59	22	56.4	40-59	14	35.6
60-79	1	2.6	60-79	18	46.2
80+	0	0	80+	2	5.1
Caregiver Status, n=43*			Caregiver Gender, n=39		
Current Caregiver	32	74.4	Female	28	71.8
Post-caregiver	11	25.6	Male	11	28.2
Time Spent Caregiving (Years), n=39			Age of Care Recipient (years), n=43¹		
0-9	14	35.0	<20	1	2.3
10-19	15	38.5	20-39	2	4.7
20-29	6	15.4	40-59	8	18.6
30-39	4	10.3	60-79	22	27.9
40-49	0	0	80+	1	25.6
50-59	1	2.6	Deceased	9	23.1
Care Recipient Designation, n=43*			Caregiver Employment, n=39		
Mother	12	27.9	Full-time	12	30.8
Father	2	4.7	Part-time	8	20.5
Wife	5	11.6	Retired	13	33.3
Husband	17	39.5	Lost job due to caregiving duties	1	2.6
Friend	3	7.0	Sick leave	1	2.6
Child	4	9.3	Not working	4	10.3
Care Recipient Residence at the time of interview , n=39			Marital Status at the time of interview, n=39		
Another household	1	2.6	Married	27	69.2
Same household	23	59.0	Widowed	5	12.8
Health care institution	6	15.4	Separated	1	2.6
Deceased	9	23.1	Single	6	15.4
Mother Language of Caregiver , n=39			Ethnic Background, n=39		
English	26	66.7	Aboriginal	2	5.1
French	4	10.3	Asian	2	5.1
Bilingual	4	10.3	Black	1	2.6
Other	5	12.8	Caucasian	34	87.2

* N=43 as some caregivers took care or had cared for more than one person

Anne was brought to the hospital with what was thought a heart attack but it turned out to be stress.

They made me stay in for a week, which was great because I just slept for a whole week. It was really nice. Isn't that terrible? That you have to get to that point to take a break? (Anne, 62 years old, cares for her husband and daughter)

Two caregivers, both caring for a spouse with reduced mental capacity, spoke about the impact of abusive behavior by their care recipient, and a few mothers mentioned the negative consequences for children when one spouse cares for another who is ill.

Um no I remember one time I was, I won't say who I was talking to on the phone it was some company and the lady heard him blow up and she said "Do you want me to call the police for you?" And I said no, I said he's got a brain

Table 3: Illnesses or health conditions of care recipient as reported by the caregiver

Care Recipient Illness(es)	N	%
Neurological Conditions		
Multiple Sclerosis	8	14.3
Parkinson's	5	8.9
ALS	1	1.8
MSA	1	1.8
Brain Damage	6	5.4
Epilepsy	2	3.6
Cerebral Palsy	2	3.6
Stroke	5	8.9
Hemiparesis	1	1.8
Dysphagia	1	1.8
Quadriplegia	1	1.8
Muscular Dystrophy	1	1.8
Chronic Physical Condition		
Back Issues	2	3.6
Fibromyalgia	1	1.8
Rheumatoid Arthritis	2	3.6
Scleroderma	1	1.8
Heart Conditions		
Pulmonary Conditions	4	7.1
Renal System	5	8.9
Visual Impairment	1	1.8
Cancer	3	5.4
Cancer	2	3.6
Multiple Unspecified Chronic Conditions	6	5.4
Care recipients with 1 reported condition	29	
Care recipients with 2 reported conditions	4	
Care recipients with 3 or more reported conditions	8	

injury and in half an hour be'll calm down. (Alyce, 47 years old, caring for husband)

They get to a point where they've just had it and that happens to them and ... the professionals should talk to people about that kind of stuff. To make sure that they take breaks every once in a while and also maybe look at the family a bit closer to see that the kids don't suffer because of all this that they're going through too. (Anne, 62 years old, cares for her husband and daughter)

Regarding the causes and consequences of caregiving related to their personal health, participants spoke about the increasing burden of care and the resultant fatigue and exhaustion. They described the inability to take breaks or have any respite from their caregiving responsibilities, and their inability to recognize mental or physical health consequences because of their situation, until the problems were more advanced. Caregivers felt invisible

and unrecognized in their tasks. They also spoke about experiencing stress caused by societal expectations related to their caregiving role, as well as the lack of resources and information to support them in specific tasks.

Invisibility of the caregiver

Invisibility was expressed in different ways: family and friends focused on the care recipient; health care professionals sometimes forgot to include them in the coordination of the care; and resources and information were scarce and hard to access. Fernanda speaks about this issue from her experience.

So if there can be more of an awareness of what it is that caregivers do out there (...) what they go through, what they experience. If they can be heard, if there can be somebody to take the time to hear what they go through and the toughness it is for them, perhaps this will (...) perhaps it gives caregivers (...) it can give a caregiver the

thing of "I'm not there alone". And so, even though today's a really bad day, it's okay. Like, I can make it through that day; I've just got to do it one minute at a time, one hour at a time. Just like everybody else, we all want to be heard. (Fernanda, 49 years old, cares for her mother)

Several caregivers had become advocates to different degrees for better recognition in their role as a caregiver and their contribution to the public health system more broadly. Drew had been involved in the care for his mother since she had a stroke when he was 5 years old. He spoke about his expectations concerning support and recognition.

Whether it's a little extra support in terms of accessing respite, accessing support groups, accessing really anybody with practical, hands-on experience, we feel that we should be able to do that – again, for us, if nothing else, we have, by making a decision to keep her at home, we are materially saving the wider public purse quite significantly. And that, I think, is worthy of a little bit of leeway as far as accessing the assistance when we do need it, because we don't do it that often. (Drew, 38 years old, cares for his mother)

Caregivers described feelings of isolation with few opportunities to socialize due to their situations. But it is not only the inability to find time to socialize; caregivers felt a general lack of understanding and acknowledgement in their role amongst friends and colleagues, causing further feelings of isolation.

Unhelpful societal views

Despite the above statement, most caregivers received valuable support from at least one or two close friends or family members. However, they also spoke about painful reactions and unrealistic expectations. Several spousal caregivers spoke about the incongruence between their experiences and the expectations that others have of them.

I think that a lot of people think that the family of a victim should all be Wonder Woman and Superman. Well, you just can't. There's a limit to your resources, there's a limit to your own capabilities, and there's just a limit to what you can do. (Sheni, 56 years old, cares for her husband and son)

Kai, a youth caregiver, spoke about his difficulties to be present at work while he was worrying about his father being alone at home. At the same time, he did not feel comfortable speaking about his caregiving responsibilities with his employer.

It's definitely a stigma. You don't want to tell the world that your family isn't perfect.... You want them to think that you have a perfect family, there's nothing wrong. But

it came to the point where work was really suffering, and I was eventually fired. (Kai, 28 years old, cared for his father)

These challenges – social isolation, the felt obligations of their role, managing challenging relationships with family, friends and healthcare professionals, personal physical and emotional health consequences – together with the demands of caregiving made it hard for caregivers themselves to acknowledge their own need for help when feeling unwell. Many of the people we interviewed felt that caregivers were invisible to the public and society in general – this was in addition to feeling invisible to the health system, institutions and providers involved in the care of their family member or friend.

Most caregivers spoke about positive and supportive interactions with health care professionals but also described negative situations. Examples of negative encounters most frequently involved professionals who appeared to lack empathy or an understanding of their situation, or made painful or insensitive remarks, or when healthcare professionals seemed to have unrealistic expectations of what the caregivers should or could do. Dealing with disagreements with healthcare professionals was challenging for most caregivers. It sometimes added to feelings of anxiety, anger, frustration, and reduced trust.

I was sitting-in in a meeting with a nurse—and I had a cup of coffee for myself and my wife in one hand and I had something else in another hand and I got up to help my wife get up from the chair and told my wife, "I can't grab your hand because my hands are full." (...) And the medical person said to me, "Ah you men, you cannot multitask as we do." And I didn't really appreciate that. Considering that the night before I had been up maybe a couple of times because my wife had fallen. And I just thought it was totally uncalled for. Now, this is one small detail and, of course, as you get more and more tired one becomes more vulnerable. So, I don't want to blow this out of proportion. This is just like one incident out of dozens of more positive experiences. But just, the feeling I have is that caregivers are just (...) not that important; we're an invisible minority. And so, if I can help give a voice to this invisible minority, then so be it. (David, 68 years old, cares for his wife)

Specific groups of caregivers described their own unique challenges. Youth caregivers appeared to be particularly vulnerable, and possibly the most invisible of all. A younger caregiver we interviewed was told by a professional that because she had a limited IQ, it was unlikely she would ever be able to live on her own, yet she looked after her mother full-time and had for years. She was involved with a support group for young caregivers in her community.

A lot of people look at me and my mom and they think "Oh, she's obese because she doesn't get out much," and "there's something wrong with her." But it's not her fault. She can't walk. I mean, she goes like maybe 15 feet to the bathroom and she's already buffing and puffing when she comes back, and so...

If they see me on the street and I'm picking up pop tins, it's not because I want to; it's because I need the extra cash. I get harassed by teenagers for doing so. Normally, I just wear baggy sweatpants, and my top here, and they say "Oh, you don't have nice clothing. You should wear nice clothing." Well, I don't have the money for that. (Snoopey, 23 years old, cares for her mother)

Lack of resources and timely consistent information

Drew, like many others we interviewed, highlighted the importance of providing caregivers with targeted hands-on information, respite services, and access to support groups. These were three key issues that emerged in our analysis of the challenges for caregivers. The constant changing nature of responsibilities, together with the progression of the illness and associated care needs, caused a continuous search for relevant information, resources and potential solutions. Not knowing about existing resources, whom to reach out to, or how to find answers to particular worries were constant themes in caregivers' stories. In general, the caregivers we interviewed had put a lot of effort into finding the right information leading to appropriate resources in the health care system.

And so every number they gave me, I was running into a brick wall and I thought, "How could you possibly give me those numbers and not know that they would not be able to provide the service that I specifically discussed with them." They're obviously not doing their job if they're giving this information to me and telling me to set something up with these people. What is wrong with a system that puts that burden on somebody and doesn't even do the research? (Sheni, 56 years old, cares for her husband and son)

Marc, a caregiver for over 30 years described how he finally came across a 'pivot' nurse (a term used in Quebec for an oncology nurse with a care coordinator role) and how this helped him to find his way in the system. Rowdyneko speaks about the importance of having resources for people that are still relatively young and in the workforce. As an experienced social worker, she didn't realize she could ask for home care services until someone mentioned it to her.

Respite services were considered another essential resource, enabling caregivers to take a break from their day-to-day responsibilities. Participants spoke about the demands of providing continuous care, some involved 24/7 care, and as Shayna said "Nurses have time off, caregivers

don't". Arrangements for respite were challenging and depended largely on the availability of local services, or via private organizations at the caregivers' expense. While most caregivers recognized the need to take a respite in order to remain healthy, it was difficult to find appropriate places.

So we have, you have to have the supports all in place. It takes a lot of work to get up there because you'll see there's all kinds of notices [pointing to bulletin board]; there's a schedule of who's going to work because we have to have 24/7 coverage. So it takes a lot of work, but again, once you've got that system in place (...) you can just brush it off and use it every year. (Michael and Lillian, 55 and 56 years old, care for their son)

Moving towards solutions

Caregivers spoke about different ideas and hopes for things to change. For example, to be able to access a single point of service for caregiving information right from the beginning, such as a care coordinator or a place or professional within the health care system that automatically provides information – to help people realize that what they are doing is caregiving.

I would hope that sometime, some day, right away, it would be an automatic thing: "Well, these are the services available for the person you're caring for, but also these are the services available for you that are very important." You always hear, "Oh, you can't do it alone." You can't, and you don't realize it until either you're right in it and you don't know where to turn, or it's too late. (Christine, 61 years old, cares for her husband)

Barbara felt it was important for doctors to recognize that caregivers are an important part of a patient's circle of care.

And it's one of the things that I would love doctors to know and to recognize is that in this caregiving circle of which they are a part—as are their nurses, as are hospitals, as are all of those things—there's also the family caregiver in that circle. And if that link breaks, if that family caregiver drops off the circle or the chain of caregiving surrounding their patient, it's like a whole domino effect where suddenly you're missing this huge chunk of caregiving for your patient. And so, the more they can do to support that family caregiver in that circle of care, the better they are, the better their patient is. (Barbara, 62 years old, cared for several people)

Caregivers also spoke about the importance of a better societal recognition, for example through raising awareness of the caregiving role, developing adequate policies that support caregivers, and attention to more vulnerable caregiver groups, such as youth caregivers and

employees, so that policies and practice reflect these particular needs.

All of the continuum of care, there are caregivers involved. And I think that caregiving is noticeably absent from policy in all the sectors. So, I would hope that there would be influence from researchers. And once again, we're very fortunate in this province because we do have people who do research on caregiving and they're also involved in the province; they actually have an opportunity to influence policymaking, but I would hope that happens in all jurisdictions. Also, I think there's a noticeable absence of caregiver... appreciation of caregivers in employment; not government policy but employment policy, both private and public sector. (Susan, 58 years old cares for her mother)

Variation within the sample

In our analysis, we observed some patterns in the experiences of caregivers that were associated with particular demographic characteristics such as age (whether relatively young or much older), relationship to the care recipient (spouse, parent or other), and employment. We are limited here given that our sampling strategy was to ensure maximum variation in experiences rather than representativeness of particular groups or types of caregivers, but we describe below some of these trends that would be interesting to pursue with further research.

Young caregivers (n=5)

While we did not interview caregivers under the age of 18, we did interview 5 adults that started caregiving as a child or young adult (before the age of 25). These participants described missing out on social activities with peers, and having to interrupt their education or go to a local university to be able to continue their caregiving responsibilities.

I was going to university and my selection as to where I went for university was extremely difficult for me because all my friends are going out east and I really wanted to go out east, my dad had gone to [university] and I wanted to go to [university] and all my friends are going to [university] but money was tight and I didn't feel comfortable leaving her. So I ended up going to [a different university] and I remember being okay with the decision once I made it but I had probably a week of just crying about it, not knowing what to do because I knew even though I was 16 at the time that wherever I ended up going to school would have a great impact on the rest of my life. (Rachel, 27 years, cares for mother)

It was tough like it's a lonely experience youth caregiving. The home you know you grow up thinking that the home is supposed to be a safe, secure happy place but I'm assuming that for most youth caregivers home can really become like a prison because this is what we have to do. (...)

I'm very socially awkward. I'm more [comfortable] to hang out with adults than I am people (with) my own age because I was with doctors a lot more than with my own friends and busy with like at the time I was working but you know because my mom was also working I wanted to make sure that she had time to herself. So I was either with dad or tidying around the house so social life was, it was there it was present at that time, but it was, it wasn't as strong as it could be. (Kai, 28 years, cared for father)

Also, whereas most adult caregivers assumed specific tasks and engaged more directly with the health care system, some describing the valuable support and guidance from health care professionals, participants who were youth caregivers did not have this kind of contact and therefore lacked this kind of acknowledgement, support and advice.

So I think at that dark time in my life I wasn't with people who could handle what I was going through. They weren't in a place where they were centered enough to carry a little bit of my pain as well and now I just only surround myself with people who know my story and are open to having the discussion with me and offer me support. So there's a core group of people who have really been my family over the last 5 to 7 years and who I can call with anything and who offer not only me support, but my mom support. (Rachel, 27 years, cares for mother)

Several spousal caregivers expressed their concern for children in the caregiving situation because of the expectations for involvement in caring for the sick person (from the care recipient), the reduced time and attention from the healthy parent, and general burden of caregiving.

I had to teach my children that it's okay to say "no" to their father, who would call them every 2 minutes to pick up a pen that dropped or get something. It's just, you can't do that to a child; they're not your caregiver. That's a whole different piece. And you as a mother watching this—seeing how it affects your children, seeing how your children are so ambivalent between wanting to help and hating to help, and how it affects them—and trying to deal with that, that's a whole different volume. (Sheni, 56 years old, cared for husband)

Spouses [n=22] and parents [n=4] – societal norms and concerns about the future

One spousal caregiver for example described how it affected her loss as a woman and wife.

I remember once we were invited to a party and all the wives were dropped off as I dropped off my husband and went to park the car with all the men. And then came back and again the invisibility and everybody chatting how wonderful it was to see him and then all the husbands and I went to get the cars and shoveling off the snow and warming up the car and then as these women are waiting

for their husbands to drive up and go into the warm car as I drove up frozen to get my husband in the car and it just bit me. There's a whole piece of feminism and that is a very integral part of being a woman and in a marriage that is gone, it's really gone and uh that's another loss that you mourn. (Sheni, 56 years old, cared for husband)

In a chronic illness, you cannot do what's normative. It's not a crisis illness that's going to go away in 6 months; this is the rest of your life and this is the rest of your family's life, and you have to handle it in a way that makes sense for your family. And if you expect your relatives who are not around, your friends or strangers to understand, you're going to be very, very disappointed. Most people have no idea what's involved. (Sheni, 56 years old, cared for husband)

This dialogue between parents as part of the interview highlights their concerns about their own future as well as that of their son's.

You asked the question about future fears. I guess we have future fears about getting older and who's going care for him when we're gone you know. But again part of that, assembling those resources now is the hope that this hockey player will still be in his life when we're no longer in his life. ...

Father – And, of course his aunt who absolutely adores him and he absolutely adores (her) who comes and visits us regularly so there are people in his life who I know will, and his older brother and others, so there's family members as well as.

Mother – But how many resources are going to be enough resources? See we talked about retiring

Father – Yes that's scary, that is terrifying.

Mother – So how can we possibly retire because we have no idea how much he's going to need over the course of his life?

Father – Nor do we know how much the state is going to provide and again so there were cutbacks this year in our province and this is when one of our colleagues said 'hum I think I'm going to have to quit and I'm going to have to look after my child full-time because ... there's no program'. And so this is, that's really terrifying. So at any time these programs could get cut and at any time whatever we think is a sufficient reserve, so we're not only planning for our future and our retirement, but we've got another which is this huge amount of money that we've got to put aside for somebody ... [and] ... he's likely to live a very long life. (Michael and Lillian, 56 and 55 years old, care for son)

Donovan, age 76 having cared for his wife for 17 years, spoke about feelings of abandonment by a society that leaves him few options for the remainder of his life.

There aren't enough facilities as a result there are, they are crowded, they are inadequately staffed. There are facilities that are privately run by corporations and they are great. I saw a few of those maybe 3, they are just great places but you have to be able to put out about \$8,000/month to afford them and we can't do that. So we don't have any options, we are stuck with what the government can offer and it's not much of an option. It's a hell of an option quite frankly. That's the way I feel about it. It's ... a very bad situation to end up being in – it really is and there's nothing can be done about it; we have to accept it. We either accept it or we go the other route, get out of it. My wife has even mentioned and she still does every few months, a couple times/year she'll say you know why don't we just drive up the [highway] someday and drive off it, finish it? You know I'm not the only one that thinks that way. She does at times also because she knows there's no end, no end in sight for either one of us. She's going to gradually get worse (...) you might say she's paralyzed. The only thing that she can move, she can move 2 things her head and her right hand, that's all. She can't move her torso even; she can't wheel herself because this hand is over here dead and this one she is losing the function in it she's only got about half the function. She can raise her arm up a bit but her hand function is only about half there. So it gets extremely discouraging for her you know, it gets very discouraging for me also. (Donovan, 76 years old, cares for wife)

Employment and caregiving (n=17)

Caregivers who were employed described the effect of caregiving on their professional development and career choices. Working adult caregivers described having to reduce their work commitment to be more available during the daytime; many used all of their vacation days to fulfill their caring responsibilities. On the other hand some caregivers described how the benefits of having work and being able to go out of the home to their job helped them cope better.

Health care professionals, interviewed as caregivers, are an interesting case. In this study, these participants described many challenges in navigating the healthcare system and worried about how others less familiar with health care managed.

We're two professionals who are supposed to be insiders in that world and we find it really hard. I can't imagine what it would be like if we made a fraction of what we make now, if we didn't have the education that we have now, if we didn't have the connections ... that we have. (Michael and Lillian, 56 and 55 years old, caring for son)

Discussion

Contributions to existing knowledge

This study presents a unique approach to understanding caregivers' lived experiences in Canada. Although the findings are consistent with existing evidence about what matters to caregivers, the challenges, and their needs, we believe that there are additional insights from this work regarding the perspectives of caregivers on the underlying determinants of poor health and negative consequences of caring. The need to understand the particular health risks for caregivers in more depth had been identified in previous research³². The results of this study offer further support for the existing body of research advocating for better support and resources for caregivers, as well as a better response from the healthcare system to address the impact on health of caregiving. Similarly, the diversity of experience represented in our variation sample, supports the need to tailor information and services to respond to caregivers' needs³³. Finally, the public web site we have produced contributes a unique online resource, where other caregivers, families and healthcare professionals can see, read and hear caregivers speak about a range of lived experiences (see: <http://www.healthexperiences.ca/en/caregiving/index.aspx>).

Strengths and limitations

The particular and unique strengths of this study revolve around the approach and the diversity of caregivers' voices in the sample, where we did achieve a satisfactory level of saturation in terms of emergent themes reflecting caregivers' perspectives. We adopted a novel approach involving: a combination of narrative and semi-structured interviews to elicit caregivers' stories and perspectives on their lived experiences, the use of video recording, and the production of a web resource in English and French for other caregivers and healthcare professionals. This form of 'experience as evidence' is now available to inform decision-making by other patients and families, professional education and policy relevant to caregiving and patient-centered care. This approach may also have contributed to the limitations of the study given the use of video, and the explicit knowledge translation objective for a web-based 'product'. It is possible that only certain types of participants volunteered for this study that may have inhibited those less interested in a more 'public' form of engagement in research, although efforts were made to increase participants' comfort level, such as having the option to choose an alias, reviewing the transcript to remove portions as preferred, and the choice of video and/or audio. We also note the large proportion of participants in this sample caring for people with neurological problems in addition to chronic physical illness. While the recruitment was deliberately broad and via multiple sources, and aimed for diversity, it is possible that there was some bias in our approach; it is also

possible that caregivers of people with long-term multiple chronic illnesses may be more attracted to this type of study to share their story. The findings however, are consistent with previous research eliciting the perspectives of caregivers. Finally, although we did not exclude any potential participants given their location, and we did travel to a number of rural locations, we did not receive any requests to participate from northern or remote or from Indigenous people. This will be addressed in future research. So, although we had diversity of experience in the sample, we had some but perhaps not maximum diversity on relevant personal attributes of participants across the sample. We explicitly excluded caregiving for people whose initial diagnoses was related to cognitive and mental health problems given the evidence and clinical perspective that this entails substantially different experiences for caregivers – this will also be the subject of a future research proposal from our team.

Implications for policy, practice and future research

The results of this study have important implications for policy, practice and future research. There is strong evidence emerging from this study and others, that support for caregivers must be strengthened given health system resource constraints and changing societal demographics, but also given evidence of the benefits of patient-centered care, emphasizing choice and place of care as part of an effective and efficient healthcare system. The development of new policies from some provincial governments¹⁸ to provide financial compensation and enhanced services for caregivers are promising and necessary interventions, but likely insufficient to address the range and depth of health and social care needs expressed by caregivers. Recognition of caregivers role and personal as well as social care needs at the service level and the burden created by health and social services³⁴ also requires strengthening; this has implications for training healthcare professionals, the design of facilities and services to not only accommodate but support caregivers, and for training caregivers themselves. Healthcare teams that are better equipped to acknowledge and engage with caregivers in response to the sorts of needs identified in this study, but targeted to individual needs and concerns, will contribute to the overall reduction of the caregiving burden, and related health and social consequences. Promising interventions include the appointment of case managers, or pivot (or navigation) nurses that would support caregivers³⁵, training for caregivers³⁴, self-directed financing options^{18,36} and respite services for caregivers¹⁸. Further evaluation of such programs and interventions will contribute to a better understanding of which programs work well for whom and why. Finally, descriptive and comparative research on various policies and approaches adopted by different countries and jurisdictions to support caregivers will increase our understanding of the costs and benefits of such efforts.

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