

Assessing the Need for Caregiver Support in Saskatchewan, Canada: Gathering Perspectives and Setting Priorities



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ABSTRACT

Background

An ageing population corresponds with a need for informal caregivers. Caregiving burden is the most compelling problem affecting caregivers of older adults. Previous research efforts have explored predictors of caregiving satisfaction and interventions for caregiving support. Our study aimed to set priorities for the future development of interventions for caregivers in Saskatchewan. Our objective was to engage caregivers in setting priorities for accessible interventions and support. The specific research question we sought to answer was: “What do the experiences of caregivers have to offer in setting priorities for caregiver support?”

Methods

We conducted an environmental scan of caregiver intervention programming in Canada. We then held two focus groups with caregivers to older adults, defined as 55 years or older for this study. Twenty-three caregivers attended the first focus group, and 10 caregivers participated in the second. We used a qualitative descriptive approach and data were analyzed using thematic analysis.

Results

Caregivers of older adults were eager to share barriers and facilitators of their role. Themes derived from data include: 1) lack of access; 2) conflict with self and others; 3) the burden of caregiving; and 4) declining health and wellness.

Conclusion

Caregivers may struggle to find resources to support them in their caregiving role. Findings from this study indicate that there is a need for more interventions to support caregivers. Furthermore, our data highlight what outcomes caregivers in Saskatchewan want from those interventions.

Keywords: caregivers, support interventions, older adults, focus groups

INTRODUCTION

In 2019, almost one-fifth of Canada’s overall population was 65 years of age or older.⁽¹⁾ Moreover, a third of Canadians aged 80 years or older have at least four chronic conditions,⁽²⁾ and most older adults who are chronically ill rely on informal caregivers seven days a week.⁽³⁾ The role of caregiving is multifaceted and the caregiver often has to engage in not only physical but psychological, social, and spiritual support.⁽⁴⁾ With the rising prevalence of chronic illnesses,^(2,4) the role of family caregivers has become critical to address this societal challenge.⁽⁵⁾ In fact, the majority of care services are provided in the community by family members or friends, rather than health-care professionals.⁽⁵⁾

Caregiver stress, role strain, and burden are recurrent findings within studies.⁽⁶⁾ Rates of caregiver burden are significantly higher among those who provide 21 hours of care per week and those who are caring for older adults with symptoms of depression, cognitive decline, or behavioural changes.⁽⁷⁾ The role of caregiving can be very demanding, leading to fatigue, stress, or physical strain,⁽⁸⁾ as well as depression and social isolation.^(9,10) Caregiver stress has been associated with the decline of the caregiver’s health, overlapping domains of physical, mental, and psychosocial health.⁽⁹⁾ Caregiving spouses are at heightened risk for declining health as they often place self-care as secondary to the care of their spouse.^(11,12)

Complicating matters further, many caregivers are older adults themselves,⁽¹³⁾ and some caregivers live with chronic conditions and multimorbidity.^(13,14) These individuals have to harness strength to care for another individual while also engaging in managing their own care.⁽¹⁴⁾ Therefore, caregivers require comprehensive support to foster resilience and ensure they can maintain their well-being while simultaneously acting in their caregiving role.⁽²⁾ Predictors of caregiving satisfaction and interventions for caregiving support continue to be explored through research. However, a clear idea is still lacking of what the goals of interventions for caregivers should be.⁽¹⁵⁾

Purpose and Aims

It is essential to consider the multiple sources of support needed by caregivers when developing interventions.⁽¹⁶⁾ Our purpose was to gather the lived experiences of Saskatchewan caregivers and subsequently inform priorities for community support interventions and services in our province. Our specific research question was: “What do the experiences of caregivers have to offer in setting priorities for support interventions and services in Saskatchewan?”

METHODS

Qualitative description^(17,18) is the methodology underpinning this study due to its naturalistic inquiry, which generates an understanding of the meanings participants ascribe to a phenomenon.⁽¹⁹⁾ The phenomenon of interest in this project was the caregiver experience in Saskatchewan. Our methods are reported herein in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ).⁽²⁰⁾

Setting and Sample

An environmental scan (Table 1) was conducted in January 2020 to assess the availability of caregiver support interventions and services in Canada. Results of the scan showed that Saskatchewan had much room for growth in the level of support provided to caregivers. Our initiative took place in the city of Saskatoon in the province of Saskatchewan, Canada. Saskatoon is the largest urban centre in Saskatchewan. Saskatchewan’s older adults (aged 65 yrs or older) make up about 15.5% of the entire province’s population.⁽²¹⁾ Participants were recruited through word-of-mouth, as well as from posters placed in the community. The World Health Organization⁽²²⁾ defines older adults as individuals who are 60 years or older. However, since we were using a convenience sampling method, we set inclusion criteria for participants that they had to be a current or past caregiver to someone 55 years of age or older. They did not have to be a family member of the care recipient to participate.

Screening and Informed Consent

This project was considered to be a quality improvement (QI) initiative. We conferred with the Research Ethics Board (REB) at the University of Saskatchewan and received an exemption from REB review. Ethical conduct recommendations for QI initiatives⁽²³⁾ were followed. Participants were made aware during the introduction to the focus group that the purpose of the gathering was not to serve as a support group, but rather to set priorities for future support to caregivers. We also informed the group members that they were free to leave the room at any point if they felt uncomfortable.

Data Collection

We chose focus group discussion as our method of approach. Group discussions were facilitated by fourth-year nursing students during their community health clinical. Discussions were focused on three topics: what caregivers find helpful in their role; what they find is lacking in support and resources; and what their ideal solutions are for expanding support and facilitation for the role of caregivers. Discussion prompts are presented in Table 2. Two nursing students acted as notetakers, using Morse and Field⁽²⁴⁾ as a guide for field note data collection. Although the field notes collected were rich and detailed, few quotes from the focus group were transcribed verbatim. A total of two focus groups were held (n = 2) with a total of 33 participants. No relationship was established with participants prior to the focus groups. An iterative process was employed, where feedback was collected after the first focus group. The facilitation of the second focus group was subsequently tailored to the feedback received. During both focus groups, demographic data were collected on written forms.

Data Analysis

We used the method thematic analysis⁽²⁵⁾ to analyze field notes taken at the focus groups. Notes were imported into NVivo 12 software (QSR International (Americas) Inc., Burlington, MA) and were thematically coded through discussion amongst six fourth-year community nursing students. The codes

TABLE 1.
Environmental scan of caregiver support interventions and services, January 2020

<i>Services</i>	<i>BC</i>	<i>AB</i>	<i>SK</i>	<i>MB</i>	<i>ON</i>	<i>QC</i>	<i>NS</i>
Caregiver support line	✓	✓	✓	✓	✓	✓	✓
Caregiver workshops	✓	✓	✓	✗	✓	✗	✓
Access to support groups	✓	✓	✓	✓	✓	✓	✓
Webinars and online courses	✓	✓	✗	✗	✓	✗	✓
Central office / Physical address	✓	✓	✗	✗	✓	✓	✓
Funded by Ministry of Health	✓	✓	✗	✗	✓	✓	✓
Caregiver navigator role/Facilitator training	✓	✓	✗	✗	✓	✗	✗
Caregiver advisor	✓	✓	✗	✓	✓	✓	✓
List of resources	✓	✓	✓	✓	✓	✓	✓

were then evolved into subthemes and overarching themes concerning each focus group topic. Rigor⁽²⁶⁾ was ensured through peer debriefing with the nursing students which occurred after each focus group to discuss the assessment of participant reactions, behaviours, and the recorded field notes. As well, the nursing students analyzed the data simultaneously as a team to ensure the clarity of all themes.

RESULTS

Participant Demographics

Due to an overwhelming amount of interest in participation, our first focus group had a total of 23 attendants. The second focus group had 10 attendants. Although attendee numbers were unbalanced, the discussion in both focus groups was rich and enthusiastic. Demographic forms were distributed at both focus groups but not all attendants of each focus group returned their demographic forms. Table 3 displays the demographic data that we were able to obtain from attendants. In total, our collected demographic data showed that participants were 82% female. All participants had received at least high school education, with 63% having pursued post-secondary studies. The years of experience that participants had as caregivers ranged from 1 to 50, with a mean of 12.76 years, and 22.7% had received formal training for their caregiving role.

Qualitative Findings

The overall intent of the focus groups was to conduct a needs assessment of what caregivers want from support services. Four overarching themes were created by the nursing students from the data collected at the focus groups: 1) lack of access; 2) conflict with self and others; 3) the burden of caregiving; and 4) declining health and wellness.

Lack of Access

Caregivers reported lack of access to clear concise information, respite, and financial assistance. They shared that information is not well publicized, such as where to go for help or what is available to caregivers. It was reported that, when their care recipients were admitted to hospital, they had greater accessibility to resources that were often seemingly hiding while living in the community. Participants shared stories

TABLE 2.
Focus group questions

What are some of the challenges you experience as a caregiver?
In your role as a caregiver, where have you found help in the community?
Have you ever found that you have needed help and not been able to find it?
If you could make a change that would make caregiver support better, what would you do?
If we were to develop a tool to help caregivers access support and services, what would that tool look like?

that echoed each other, including the stress of dealing with opinions of others and not having a place to vent frustrations or people with whom to share their experiences. Many shared the concern of not knowing where to go for their psychosocial needs. Support from family and friends and access to support groups was reported to be lacking. Participants stated that they would appreciate and utilize online discussion boards and moderated forums, as well as in-person support groups. Lastly, lack of access to finances was prevalent. For example, the ability to afford care in a retirement residence or long-term care facility was a concern for many of the caregiver participants. Furthermore, for the caregivers who did not live with their care recipients, the ability to afford transportation and travel was another noted financial burden.

Conflict With Self and Others

Conflict was an overarching theme that was derived from analysis of the facilitators' notes. Caregivers noted they experience conflict within themselves, sharing feelings of guilt and inadequacy. One recorded caregiver response was, "Am I doing it right?" Many did not understand how taxing caregiving can be, and wished they had received more knowledge prior to taking on the role. There was also conflict within oneself through the difficult experience of losing their [the caregivers'] independence. Balancing the needs of the care recipient with those of the caregiver were also conflicts that were mentioned.

Conflict also ensued with the care recipient. This was especially agreed upon for individuals who were caregivers to older adults with dementia and cognitive impairment. These caregivers talked about the conflict that ensues due to the responsive behaviours and agitation related with dementia. Some caregivers reported struggling with family members who live out of town, who they referred to as "secondary caregivers". In these situations, the external

TABLE 3.
Participant demographics^a

Variable	Focus Group 1		Focus Group 2	
	n = 14	%	n = 8	%
Gender				
Male	1	7.2	3	37.5
Female	13	92.8	5	62.5
Age (mean)	79.5			
Male (mean)	98		87.3	
Female (mean)	78.2		81.6	
Education				
High school	5	35.7	3	37.5
Post-secondary	9	64.3	5	62.5
Years of Caregiving (mean)	11.7		14.3	
Formal Training Received?				
Yes	2	14.3	3	37.5
No	12	85.7	5	62.5

^aNot all participants returned their demographic forms after the focus groups.

secondary caregivers were not supportive of the primary caregiver or seemed to imply the person receiving care did not really need it. This initiated conversation regarding the variation and liability of the emotional and mental state of the care recipient, especially when other family members were present. Additionally, primary caregivers stated that sometimes the person receiving care would take their anger out on them and would be kinder to the secondary caregivers or family members external to the situation. Primary caregivers ultimately felt as though they were “bearing the full burden” (recorded field note), especially when it came to deciding on proper living arrangements for the care recipient. Interfamilial conflict was part of the discussion. Some caregivers who had gone through the experience of their care recipient entering long-term care discussed that it was difficult to make decisions like this when secondary caregivers were not as involved but were also stakeholders in the decision.

The Burden of Caregiving

Social isolation and neglect for self-care were the largest discussion points associated with this theme. The greatest resource reported by participants was when family and friends of the caregivers were made available to listen to their situations and provide support when possible.. Those with lack of support felt overwhelmed, alone, and abandoned. Caregivers also struggled with giving oneself permission to engage in self-care, which involved them giving up things they like to do. As previously mentioned, caregivers at the focus groups faced a great challenge trying to decide where the best place was for the person receiving care to live. Caregivers also stated that they were confused as to how to maintain their care recipient’s autonomy, while still supporting them in their time of need.

Declining Health and Wellness

This theme came from two distinct points that arose in focus group discussion: the progressive cognitive decline of the care recipient, and the functional decline of the caregiver. Regarding the care recipient, responsive behaviours, such as taking out their anger on their caregiver, was noted to be become more prevalent as time progressed through the caregiving experience. This also coincided with further dependency on caregivers occurring over time. One caregiver noted that her care recipient would often call late at night for help with small tasks like fixing the television remote. These actions would lead to less sleep and higher anxiety in the caregiver, which relates to the functional decline of the caregiver that was discussed. Caregivers realized their own physiologic process of aging. Their health status, and their health conditions and comorbidities, played a role in their ability to act as a caregiver. Quotes that were recorded in field notes were: “I’m getting old too!” and “I’m tired all of the time.” Some caregivers noted there was also concern with their physical strength and ability to assist with transferring, lifting, and repositioning their care recipient, or helping in emergencies such as in cases of falls. Overall, caregivers reported “feeling worn out” (recorded field

note), not receiving enough sleep, and not taking adequate care of their own chronic conditions.

Participant Recommendations

Participants offered opinions on what they thought was most important for programming caregiver interventions and services in Saskatchewan. Firstly, they agreed overall that more external support was needed. They recommended moderated online forums, live discussions with other caregivers or trained staff, regular caregiver meetings, and the implementation of a neighbourhood ambassador role, someone who would coordinate assistance for caregivers in a community. Emotional and informational support were the two types of support participants recommended prioritizing. A central resource, such as a streamlined website, was requested by participants. Educational opportunities, including seminars and workshops, were also popular suggestions. Lastly, respite in the form of a break for a couple hours a week, or organized retreats and self-care activities, were recommended as high priorities. Participants were asked on their demographic forms what they thought was the most important priority discussed. Responses are presented in Table 4.

DISCUSSION

Caregivers in our focus groups were eager to share their experiences in group discussion. Lack of access to information, respite, and financial assistance was prevalent. Conflict was another central topic within the group discussions, in both the context of conflict with self and conflict with others. Caregivers spoke about bearing the full burden, neglecting self-care, and feeling overwhelmed, and the added stress of their own declining health. Despite the negative aspects to our overarching themes, caregiving is not always burdensome. Caregiving has many positive aspects, such as providing a

TABLE 4.
Priorities identified by caregivers

<i>What do you think is the most important priority that was discussed today?</i>	
Focus Group 1	Access to supports for caregivers & advocacy with government agencies for supports. The need for better access to caregiver information. Resources for caregivers. Getting messages to people in need for emergency help. Support and accessing info. Losing their independence. We all need support and understanding. What is available right now, those of us who are caregivers need that information NOW!
Focus Group 2	Caregiving for the caregiver. What to do next. The need for training programs for caregivers. Support and provision for caregiver training. How to access help.

sense of giving back to loved ones, or an increased sense of meaning and purpose in life.⁽²⁷⁾

Participants provided key insight on what support interventions and services they would be interested in accessing and benefiting from. In fact, many of the recommendations offered by participants have already been validated as interventions for caregivers.⁽²⁸⁻³⁰⁾ A previous study identified that caregivers prioritized wanting to learn first aid for orientation to the caregiving role.⁽³¹⁾ An interesting finding of this study was the unique activities participants were interested in for orientating to caregiving, specifically a course on body mechanics. Therefore, the data derived from this initiative provide direction for the implementation of support interventions and services that are targeted for our Saskatchewan's population of caregivers.

With respect to our first theme, two noteworthy points were the lack of access to finances and transportation. Many caregivers have to bear the burden of costs associated with medical services and supplies, medications, and transportation to the care recipient.⁽²⁾ Support provided by caregivers can range from a few hours a week to round-the-clock care,⁽¹¹⁾ which can be detrimental to maintaining employment and steady financial income. In a Saskatchewan study, 22.7% (n = 409) of caregivers reported spending between 0.5 to 10 hours per week performing unpaid caregiving work.⁽¹²⁾ However, the same study found that those living in rural Saskatchewan were more likely to spend more than 40 hours a week in unpaid caregiving activities. To add to the complexities, those who live in rural areas have less access to health-care professionals, additional care services, and respite, meaning rural residents need to find transportation into urban centres for assistance.⁽³²⁾ This highlights the need to explore the needs, perspectives, and experiences of rural Saskatchewan caregivers in future studies.

Some of our participants noted the difficulties and feelings of isolation they experienced when not receiving support from family members. This phenomenon of broken connections is not unique to our participants. A participant in a study by Abendroth *et al.*⁽¹⁰⁾ stated: "Nobody sees my husband's full condition... Somebody just needs to stay with him a week or maybe 24 hours. I think they'd be shocked that he's lost so much of his abilities" (p. 52). This disbelief on the part of family members external to the primary caregiving scenario is detrimental, and can further add to the burden of caregiving and worsening health outcomes.⁽⁶⁾

A novel finding in this study was the participants' description of tiering caregivers into primary and secondary roles. Despite being a previously explored notion,⁽³³⁾ caregiving tiers can often be overlooked in recruitment for caregiving research. Dilworth-Anderson, Williams⁽³³⁾ describe primary caregivers as having the highest level of responsibility regarding care, performing the largest number of caregiving tasks, and investing the most time in their caregiving role. Secondary caregivers may perform tasks at a similar level to that of the primary caregiver, but are not typically in charge of making decisions about the care recipient's support and care, and only provide care in conjunction with primary caregivers.⁽³³⁾

Although these definitions are likely not encompassing of all caregiving exchanges, the recognition of these tiers by our participants highlights the potential for differences in the perspectives of caregivers at different tiers of involvement.

Lastly, balancing the needs of the care recipient with those of the caregiver was also reported to be difficult for caregivers in our study. Caregivers can sometimes be 'invisible patients,' meaning their health and wellness is overlooked by providers, as the focus is on the patient.^(13,34) Caregiving spouses are at a higher risk of declining health because of deprioritizing self-care to be able to support their spouse,⁽¹²⁾ meaning it is critical that professionals need actively to assess and evaluate the risk for health decline in the caregiver.⁽⁴⁾

Limitations

Regarding the timing of this project, focus groups were held in January and February of 2020, prior to the COVID-19 pandemic. The picture of the caregiver experience has evolved significantly since the onset of the COVID-19 pandemic.⁽³⁵⁻³⁷⁾ Furthermore, caregivers have been found to be at greater odds of experiencing role overload as a result of stress related to the pandemic.⁽³⁷⁾ Loneliness has also been a significant challenge during COVID-19, and being a caregiver throughout the pandemic has shown to have increased reports of loneliness.^(35,36) Since social isolation was already discussed in depth during the focus groups with Saskatchewan caregivers, it is worthwhile to investigate how the pandemic affected these pre-existing feelings of loneliness. Therefore, an updated iteration of this project is well-warranted.

CONCLUSION

Our findings present what a sample of caregivers in Saskatchewan, Canada want for support in their caregiving role. Saskatchewan caregivers reported their priorities are to receive clear and concise information on their role as caregivers, respite from their caregiving duties, and financial assistance. Emotional and informational support in the form of online forums, live discussions, seminars, workshops, and other educational opportunities are examples of programming that Saskatchewan caregivers want to access.

Carstairs and Keon⁽¹¹⁾ shared in their report: "If we do not support them [caregivers], we may end up with two users of our health-care system" (p. 119). The perspectives of those with lived experiences provide critical information when directing intervention development and implementation, which holds true in the case of caregivers and support interventions. In Saskatchewan, the support network for caregivers is in its infancy, but gaining insight from those with lived experience can help to grow a successful program for residents within the province.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal's* policy on conflicts of interest disclosure and declare no conflicts of interest.

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