

# Supporting Family Caregivers of Seniors Within Acute and Continuing Care Systems



Jasneet Parmar, MBBS, MCFP(CAC)<sup>1,2</sup>, Jacqueline Torti, PhD<sup>1</sup>, Suzette Brémault-Phillips, PhD<sup>3</sup>, Lesley Charles, MBCHB, CCFP(COE)<sup>1</sup>, Karenn Chan, MD, MSC, CCFP(COE)<sup>1</sup>, Peter George J. Tian, MD, MPH<sup>1</sup>

<sup>1</sup>Department of Family Medicine, University of Alberta, Edmonton, <sup>2</sup>Covenant Health-Network of Excellence in Seniors' Health and Wellness, Grey Nuns Community Hospital, Edmonton, <sup>3</sup>Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, AB, Canada

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## ABSTRACT

### Background

Family caregivers who provide care to seniors at no cost to the healthcare system are an integral part of the healthcare system. Caregiving, however, can cause significant emotional, physical and financial burden. We held a one-day symposium on how to best involve and support family caregivers in the healthcare system. The symposium brought together caregivers, healthcare providers, administrators and policy-makers to identify needs and make recommendations to address these issues.

### Methods

Participants engaged in conversation circles which were audio-recorded and transcribed. Data were qualitatively analyzed alongside written notes provided by participants.

### Results

Symposium participants identified a lack of both orientation and education for healthcare providers about family caregivers and standardized processes for assessing caregiver burden. They highlighted a need to ensure that the family experience is captured and included as an essential component of care, foster a culture of collaboration, expand the notion of the healthcare team to include family caregivers, provide more integrated palliative care, and enhance policies and programs to acknowledge family caregivers.

### Conclusion

There is a need to recognize the essential role of family caregivers in seniors' health and well-being, and to take on a more comprehensive approach to patient care.

**Key words:** family caregivers, seniors, acute care, continuing care, health care

### Introduction

Family caregivers are individuals who provide ongoing care and assistance, without pay, for family members or friends in need of support due to physical, cognitive, or mental health conditions.<sup>(1)</sup> As of 2002, almost 4 per cent of Canadians identified as a family caregiver of individuals with disabilities, chronic conditions, or frailty.<sup>(2)</sup> This percentage translated to approximately one million individuals caring for a family member in an informal capacity. This survey also found that most care recipients were elderly, with approximately 57 per cent of all care recipients being at least 65 years of age, and 17 per cent being 85 years or older.<sup>(2)</sup> The highest percentage of care was being provided for age-related needs or frailty.<sup>(3)</sup> The most recent survey of family caregiving, conducted in 2013 by Statistics Canada, found that approximately eight million Canadians (28% of the population) over the age of 15 years provided care to family members or friends with a long-term health condition, a disability or problems associated with aging.<sup>(3,4)</sup> As these most recent statistics are from 2013, one can reasonably speculate that family caregivers have increased in prevalence, given that an even greater percentage of the population is now over the age of 65.<sup>(5)</sup> With an aging population comes increased longevity and multi-morbidities which can require complex care.<sup>(5)</sup>

Family caregivers of seniors are an integral part of the healthcare system and vital to its sustainability. By providing care that would otherwise need to be delivered by the healthcare system, family caregivers save the system time, money, and resources. In 2009, it was estimated that family caregivers in Canada contributed \$25 billion in unpaid work to the Canadian healthcare system.<sup>(5)</sup> This most recent estimate is expected to be much higher, given the growing number of family caregivers. Although it has been expressed that many

unpaid family caregivers enjoy caring for a loved one and that caregiving was associated with positive outcomes,<sup>(6)</sup> family caregiving also comes with many challenges. As the complexity of care expands and the prevalence of family caregivers rises, it will be all the more critical that caregivers be supported. Since caregivers have proved vital to the healthcare system, it is essential that the experience of family caregivers is improved, their health sustained, and the health of the seniors they care for well-managed and maintained.

There is overwhelming evidence that caregiving is being provided at significant physical, emotional, and financial costs to family caregivers. Several studies have found that family caregivers have poorer physical health compared to the general population.<sup>(7,8)</sup> In addition, caregiving is associated with measures of poor psychological health including distress, anxiety, depression, and low levels of self-efficacy and self-esteem.<sup>(7,9)</sup> This negative effect on health can have implications for healthcare expenditure and the provision of care.<sup>(10)</sup> In addition to negative health implications, caregiving can also come at a significant financial burden. Many family caregivers balance time spent in their paid employment with unpaid time caregiving. It is estimated that providing full and competent care to a frail and elderly individual as a primary caregiver equates to full-time employment.<sup>(11)</sup> The level of responsibility assumed by caregivers often leads to family caregivers taking time off from their paid employment to care for their care partner; some individuals even leave their job altogether to provide full-time care.<sup>(12)</sup>

A one-day symposium on supporting family caregivers of seniors within acute and continuing care systems was held in Edmonton on August 31, 2016 by Covenant Health's Network of Excellence in Seniors' Health and Wellness. This symposium aimed to make a difference in the lives of family caregivers of seniors by: (1) raising awareness of the role of family caregivers of seniors, their challenges, and needs for support; (2) identifying gaps in family caregiver supports and share current practices; (3) examining ways to enhance health provider education to better support family caregivers; and (4) reviewing caregiver assessment tools for consideration in practice. As a first step toward ensuring that family caregivers feel supported and valued in their role, this symposium focused on identifying strategies to involve and support family caregivers in the healthcare system, and informing policies and practices that are reflective of their important role in the larger system. This paper highlights the ideas generated in areas of identified need, and offers recommendations to address these issues.

## METHODS

The symposium brought together 106 participants. There were 38 frontline healthcare providers (physician, nursing, allied health, administrative support staff), 36 healthcare managers, 16 senior service organizers, 8 family caregivers, 5 academics, and 3 policy makers from 21 stakeholder organizations. We identified these attendees as stakeholders in family caregiving from a list of previous attendees to a 2014 CIHR-funded

conference on supporting family caregivers of seniors and from the Network of Excellence in Seniors' Health and Wellness' lists for community organizations, family caregivers, and e-mail correspondence. The symposium consisted of a series of presentations followed by conversation circles. Presentations, which aimed to provide participants with current information about family caregivers, included first-hand caregiver experiences, best practices for involving caregivers, training needs of service providers, and policy and practice implications. Conversation circles stimulated thought and facilitated discussion among participants regarding the current state, gaps, and barriers, as well as recommendations specific to the following topics: (1) Orientation and education of healthcare providers to increase understanding of caregiver needs and how to assist them; (2) Culture change needed within our systems of care to acknowledge, respect, and honour family caregivers; (3) Supports needed to engage, empower, and foster the resilience of family caregivers; (4) Tools and processes available to help identify and assess caregiver burden; (5) Palliative care and end-of-life supports desired by family caregivers; and (6) System change needed from a policy and practice perspective to ensure that family caregiver supports and resources are made available.

Conversation circle participants exchanged ideas, learned from one another, and confirmed priorities for supporting family caregivers of seniors. Attendees recorded their thoughts and ideas on index cards. Upon completion of the discussions, participants summarized key insights on note-taking template pages. Brief summative presentations highlighting key emergent themes from each conversation circle were provided to the larger group by table moderators. These were audio-recorded for later analysis. The symposium received ethics approval from University of Alberta's Health Research Ethics Board—Health Panel (Pro00069056).

## Data Analysis

All symposium data, including the contents of the question/comment cards, index cards, participant summary pages, facilitator feedback pages, and audio-recordings, were analyzed utilizing thematic content analysis. The audio-recordings from the symposium were transcribed verbatim by an experienced transcriptionist (JT). Qualitative thematic data analysis was then undertaken following phases outlined by Clarke and Braun.<sup>(13)</sup> This included listening to the audio-recordings and reading over source data several times. Each document was then reviewed in detail, preliminary analytic notes were taken, and relevant codes were collected and grouped into themes. The codes were developed inductively from the primary data source (documents and transcripts). Preliminary analytical notes were used to further refine our thinking around open axial coding. Themes were iteratively modified to ensure that they accurately captured the codes, made sense in relation to one another, did not inherently overlap, were distinct enough to stand alone, and were adequately supported by the data. To improve the rigour of the analysis and trustworthiness of the

data, the qualitative analyst (JT) met with study investigators (JP, PT) for peer-debriefing of the preliminary analysis.

## RESULTS

Findings from the data analysis highlight key topics and themes. These include: (1) orientation and education of healthcare provider; (2) facilitation of culture change toward respect and honour of family caregivers; (3) enhancement of resilience among family caregivers; (4) identification of caregiver stress and burden; (5) provision of palliative care and end-of-life supports; and (6) facilitation of policy and practice change. Each of these is described below, including associated current issues, needs, and recommendations for improvement.

### Theme 1: Orientation and Education of Healthcare Provider

Attendees noted that, when engaging with family caregivers, “Every interaction is an opportunity.”

#### Issues Identified

There is a need to increase understanding among healthcare providers about family caregiver needs, and how to support and assist them. Limited education and training is currently available for healthcare providers specific to increasing their understanding of family caregiver needs, particularly in acute settings. The education and training that are available are different for acute and continuing care settings. Given the paucity of training and orientation, family caregivers are not necessarily recognized or valued as part of the care team by healthcare providers. As such, communications between healthcare providers and family caregivers are impacted by a lack of recognition of the value family caregivers could provide within care settings.

#### Recommendations for Improvement

It was recommended that healthcare providers be educated regarding the value of involving and engaging family caregivers of seniors on care teams and in care settings. This includes engaging family caregivers in the development of education and training materials so that their experiences and needs are addressed. In addition, it was recommended that similar approaches and training tools be used in all care settings to ensure consistency and increase potential impact across the province. Lastly, the communication skills of healthcare providers need to be further developed to ensure meaningful communication with patients and family caregivers, and to improve information sharing between healthcare providers.

### Theme 2: Facilitation of Culture Change toward Respect and Honour of Family Caregivers

Participants emphasized the need to, “See the caregiver as part of the team and take the time to connect with them.”

#### Issues Identified

There is a need to facilitate a culture shift within our systems of care toward more intentionally and explicitly acknowledging, respecting and honouring family caregivers.

At present, time pressures, competing priorities, and a strong task-focus within the system leave healthcare providers with little opportunity to engage with family caregivers or provide them with support. In addition, acute and continuing care systems are dominated by a medical model of care that is more focused on physical, and less on social and psychological, aspects of care.

#### Recommendations for Improvement

It was recommended that systems move toward a person- and family-centered approach to care, where communication and dialogue with family caregivers is a normal and standard part of care. This includes welcoming the family into the care environment and recognizing them as part of the care team.

### Theme 3: Enhancement of Resilience among Family Caregivers

Participants noted that, “... these conversations may take time initially, but will save time in the long run as one builds rapport, understanding, and the beginning of a partnership between caregivers and care providers.”

#### Issues Identified

There is a need to foster the resilience of family caregivers. Currently, there is a lack of information and support available to family caregivers to help them understand and adapt to their caregiver role. Healthcare providers generally lack knowledge regarding how to engage, empower, and foster resilience in family caregivers. They are also often unaware of resources and community supports available for family caregivers that might support their resilience. While evidence-based strategies and resiliency skills-training programs have been developed to help build resiliency-capacity, such programs have not been tailored to the specific needs and circumstances of family caregivers.

#### Recommendations for Improvement

Healthcare providers need to be proactive in their support of family caregivers. This includes developing and maintaining a comprehensive, easily accessible list of resources that support family caregivers, creating a provincial strategy that supports family caregivers with engagement and empowerment in our care settings, finding ways to help family caregivers navigate the system in a coordinated way, and adapting resiliency skills-training programs that might meet their specific needs and enable them to build or maintain their resilience.

### Theme 4: Identification of Caregiver Stress and Burden

Participants highlighted that it is essential for service providers to “capture the authentic experience of caregivers.”

**Issues Identified**

At present, inconsistencies abound regarding the manner in which caregiver stress and burden are identified and assessed, as well as tools and processes used to do so. Healthcare providers are not adequately or consistently trained in identifying and assessing caregiver stress/burden, neither is it clear whose responsibility it is to conduct these assessments. As a result, multiple caregiver burden assessments can be administered on any one caregiver, adding undue burden on the caregiver, and unnecessary time and cost to the system.

**Recommendations for Improvement**

It is critical that caregiver stress/burden be acknowledged. Therefore, healthcare providers need to be trained on how to identify and assess caregiver stress/burden. This would involve a review of caregiver stress/burden assessment tools to determine those that are most appropriate, and the development of a standardized approach to caregiver assessments. Lastly, mechanisms should be put in place to follow up with those experiencing burden so that the necessary supports, including respite, can be offered.

**Theme 5: Provision of Palliative Care and End-of-life Supports**

Participants suggested that we “look at the supports we have, and take another look and critically examine the benefits by asking those affected”. We need to ask family caregivers how they are doing, what they need, and how the system can best support them.

**Issues Identified**

Family caregivers desire palliative care and end-of-life supports. Healthcare providers, however, are generally not trained to support patients and their family caregivers at end of life, and are often uncomfortable discussing end of life with patients and family caregivers. In addition, healthcare providers are unaware of the palliative and end-of-life resources available to assist family caregivers and how to access them.

**Recommendations for Improvement**

It was recommended that healthcare providers be educated about palliative care and end-of-life supports, and how to connect patients and family caregivers to those supports. In addition, healthcare providers need training on how to engage with patients and family caregivers about end-of-life issues and supports, and how to best support their decisions.

**Theme 6: Facilitation of Policy and Practice Change**

An attendee noted that: “When we consider the family as a caregiver instead of a partner, they are expected to give and give until they have nothing left.”

**Issues Identified**

Systems change is needed from a policy and practice perspective to ensure that family caregiver supports and resources are made available. Currently, caregiver support policies and programs have a narrow approach that undervalues the work of family caregivers, and do not provide adequate financial support to family caregivers. In addition, legal constraints related to privacy legislation prohibit family caregivers from obtaining necessary health information about their care partners, which can impede their ability to appropriately or adequately provide for their care needs.

**Recommendations for Improvement**

Symposium participants advised that policies be developed that are comprehensive in scope and cover all needs of family caregivers. They also suggested that family caregivers be involved in development of programs and policies so that their needs are addressed, including the provision of essential financial resources and supports. Lastly, a change in privacy legislation is needed so that family caregivers can access the health information needed to be informed and better able to provide adequate care.

**DISCUSSION**

Family caregivers of seniors play a vital role in the healthcare system, and it is essential that they feel supported and valued in their caregiving role. This symposium took first steps toward ensuring that family caregivers of seniors are seen as valued and respected members of the care team by raising awareness about family caregivers, identifying issues, and making recommendations for improvement. This research found that there is a need for orientation and education of healthcare providers on family caregivers. This finding is not unique, as other studies have alluded to the fact that healthcare providers require education in order to properly support family caregivers. For example, a study found that healthcare providers lacked the skills necessary to address family caregivers’ needs and to support them.<sup>(14)</sup> Education on family caregivers, however, has received little attention, and there is a strong desire among stakeholders of this symposium to incorporate mandatory education for healthcare providers regarding family caregiver needs and how to support them.

By providing healthcare providers with knowledge and skills, we can better cultivate a culture of care within our systems that acknowledges, respects, and honours family caregivers. Family caregivers often go unrecognized, both in the care and support they provide and the burden they may be experiencing. Sherman and colleagues speak to the importance of family-centered care and the need for healthcare providers to interact with family caregivers in order to facilitate “taking them out of the shadow of the patient” (p.3).<sup>(15)</sup> To provide true family-centered care, we must acknowledge family caregivers, listen to and communicate with them, assess their needs, support their resilience, and provide them with the support they need to work through issues they might be experiencing in relation to their caregiving role.<sup>(14)</sup>



Assessing family caregivers needs involves identifying caregiver stress and burden. Our research indicated that healthcare providers are unclear about who should be conducting caregiver assessments and when, and spoke to the inconsistencies involved in this process. It is our recommendation that one individual on the healthcare team be assigned the responsibility of assessing caregiver stress and burden in order to streamline the process and ensure that a proper assessment is completed. Regardless of who conducts this assessment, performing the task recognizes family caregivers and the valuable role they play in patient care.

Future directions include engaging acute and continuing care sites in building structures that support family caregivers of seniors. This can be achieved by exploring ways in which we can educate healthcare providers to help them meaningfully engage and communicate with family caregivers, incorporate family-centered approaches as a standard part of care, cultivate resilience among family caregivers, and support family caregivers identified as experiencing caregiver stress and burden. This will involve conducting a mini-symposium to disseminate study findings and recommendations, further engaging sites and symposium participants in strategic planning to support caregivers, identifying programs, policies, and practices that might better support family caregivers, and advocating for change.

## CONCLUSION

This report has focused on the current state, gaps, and barriers, and the recommendations on a variety of topics relevant to family caregivers. Through this research, we have raised awareness, identified gaps and opportunities, and enhanced health providers' understanding of family caregivers. By identifying effective strategies to guide and support family caregivers, we have built on the current body of evidence and expanded the notion of family caregivers in the healthcare context, thereby creating an opportunity to reflect on current practices and make recommendations for the future. It is recommended that healthcare providers recognize the essential role family caregivers play in seniors' well-being, and that the healthcare system develop a more holistic care model that takes into consideration the patient in their entirety, including the patient's family caregiver. Such a model of care has the potential to have a broad impact on both the health and well-being of family caregivers, as well as on the health outcomes of the seniors for whom they care.

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## CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

## REFERENCES

1. Canadian Caregiver Coalition. A caring voice newsletter: respite. Ottawa: Canadian Caregiver Coalition; 2001.
2. Health Canada. National profile of family caregivers in Canada—Final Report [Internet]. Ottawa, ON: Health Canada; 2002 [updated 2004 Oct 1; cited 2017 Aug 22]. Available from: <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiver-interven/index-eng.php>
3. Sinha M. Portrait of caregivers, 2012. Ottawa, ON: Statistics Canada; 2013 [updated 2017 Aug 22; cited 2017 Aug 22]. Available from: <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm#a3>
4. Turcotte M. Family caregiving: what are the consequences? Insights on Canadian Society series. Ottawa, ON: Statistics Canada; 2013 [updated 2013 Sept; cited 2017 Aug 28]. Available from <http://www.statcan.gc.ca/pub/75-006-x/2013001/article/11858-eng.pdf>
5. Wolff JL, Mulcahy J, Huang J, *et al.* Family caregivers of older adults, 1999–2015: trends in characteristics, circumstances, and role-related appraisal. *Gerontol.* 2017;gnx093. [Epub ahead of print]
6. Hollander MJ, Liu G, Chappell NL. Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Law Gov.* 2009;12(2):42–49.
7. Ashworth M, Baker AH. 'Time and space': carers' views about respite care. *Health Soc Care Community.* 2000;8(1):50–56.
8. Pinguat M, Sørensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging.* 2003;18(2):250–67.
9. Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *J Soc Work Educ.* 2008;44(Suppl 3):105–13.
10. Roth DL, Perkins M, Wadley VG, *et al.* Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults. *Qual Life Res.* 2009;18(6):679–88.
11. Bauer JM, Sousa-Poza A. Impacts of informal caregiving on caregiver employment, health, and family. *J Popul Ageing.* 2015;8(3):113–45.
12. Schulz R, Mendelsohn AB, Haley WE, *et al.* End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med.* 2003;349(20):1936–42.
13. Clarke V, Braun V. Teaching thematic analysis: overcoming challenges and developing strategies for effective learning. *Psychologist.* 2013;26(2):120–23.
14. Hudson PL, Aranda S, Kristjanson LJ. Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *J Palliat Med.* 2004;7(1):19–25.
15. Sherman DW, Austin A, Jones S, *et al.* Shifting attention to the family caregiver: the neglected, vulnerable, at-risk person sitting at the side of your patient and struggling to maintain their own health. *J Fam Med.* 2016;3(7):1080.

**Correspondence to:** Dr. Jasneet Parmar, MBBS, MSFP(CAC), Grey Nuns Community Hospital, 416 St. Marguerite Health Services Centre, 1090 Youville Drive West, Edmonton, AB, T6L 0A3 **E-mail:** [Jasneet.Parmar@covenanthealth.ca](mailto:Jasneet.Parmar@covenanthealth.ca)