



Covenant Health
Network of Excellence in
Seniors' Health and Wellness



Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems

Conversation Circles
Summary

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Network of Excellence in Seniors' Health and Wellness

seniorsnetworkcovenant.ca

Covenant's Network of Excellence in Seniors' Health and Wellness gives voice to seniors through active engagement and makes their priorities, its priorities. It invests in pragmatic research projects through its Innovation Fund grants and strategic initiatives, and then spreads the knowledge gained with targeted communications to expand uptake and increase impact.

By generating ideas in areas of identified need, and disseminating the related knowledge, the Network serves Alberta's seniors with the ultimate goal of 'enabling seniors to live to the fullness of their capacity as active and connected members of their communities'.

The Network's home within Covenant offers an incubator context for the collaborative generation, evaluation and scaling of innovation across the full spectrum of supports and care for seniors, including:

- Acute care and continuing care services in 22 facilities in 15 Alberta communities
- 2,066 continuing care beds in 13 communities
- Covenant Living, an allied, non-profit entity expanding into independent living centres
- The Covenant Health Palliative Institute
- Covenant Care, a non-profit supportive living provider committed to innovative care approaches.

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- Ed Stelmach, Chair, Covenant Board of Directors (Welcome Address)
- Debbie Cameron-Laniga, Program Coordinator, Caregivers Alberta (presenter)
- Cathy Fooks, President and Chief Executive Officer, The Change Foundation (presenter)
- Cecilia Marion, Senior Director Operations, Youville Home & St. Joseph's Auxiliary Hospital, Covenant Health (presenter)
- Norah Keating, PhD, Professor, Department of Human Ecology, University of Alberta (presenter)
- Suzette-Bremault Phillips, PhD, Associate Professor, Rehabilitation Medicine, Occupational Therapy, University of Alberta (conversation circles moderator).

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What issues do family caregivers face?

Family caregivers are defined as individuals who provide ongoing care and assistance, without pay, for family members and friends. They provide invaluable support in the form of personal care, medication, household work and maintenance, financial management, transportation and care coordination. Family caregivers of seniors are an integral part of the healthcare system and vital to its sustainability. However, there is overwhelming evidence that caregiving is being provided at significant physical, emotional and financial costs to family caregivers. They are in need of recognition and understanding by healthcare providers, and of supports to help them manage their caregiver role and to care for themselves.

Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems was a one-day symposium (August, 2016) delivered by Covenant's Network of Excellence in Seniors' Health and Wellness that considered how best to involve and support family caregivers in the healthcare setting, and included discussion on practices, policies, culture, and system change that could improve their experience in these settings. Attendees included family caregivers, healthcare providers, administrators and policy makers who collectively contributed input into 'conversation circles' to identify current issues surrounding family caregivers within acute and continuing care, and to provide recommendations for improving family caregiver involvement and experiences.

Increasing understanding of the vital role family caregivers play in contributing to the health and wellness of seniors is a primary concern and area of interest for the Network of Excellence in Seniors' Health and Wellness. *Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems* built upon knowledge gained through a 2014 event titled *Supporting Family Caregivers of Seniors: Improving Care and Caregiver Outcomes*.

“Care that honours seniors should be truly patient-centered, in action and in word. It should listen to seniors and be inclusive of family caregivers. Care that honours seniors is holistic.... It is accessible, coordinated and transparent and provides seamless transition between hospital, home and care facility.”

-Respondent to Covenant's Shape Seniors Care Outreach (2015)

Overview: Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems

Invited speakers presented on first-hand caregiver experiences, best practices for involving caregivers, and related policy development and training implications. The symposium targeted healthcare providers; members of community organizations that provide seniors' supports; family caregivers; and provincial partners in seniors' care.

Conversation Circles

In addition to the speaker presentations, six conversation circles were facilitated to seek participant input on key topics: this report summarizes the findings from these conversation circles.

The six topics explored in conversation circles were:

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.
6. System change needed from a policy and practice perspective to ensure that family caregiver supports and resources are made available.

Key input from the conversation circles included the need to: expand awareness amongst healthcare providers of the contribution and role of family caregivers; develop mechanisms and tools focused specifically on facilitating and improving communications between healthcare providers and family caregivers; involve and engage family caregivers in planning, care decisions, and co-design of communications and/or education and training regarding engaging and involving family caregivers in our care settings.

Attendees were in agreement that family caregivers play an integral role in seniors' care and that there is a need to review and strengthen current services to support them.

Input: Conversation Circles

1. Orientation and Education of Healthcare Providers to Increase Understanding of Caregiver Needs and How to Assist Them

Issues Identified

- There is limited education and training for healthcare providers specific to increasing their understanding of family caregiver needs, particularly in acute settings.
- The education and training that is available is different for acute and continuing care settings.
- Family caregivers are not necessarily recognized or valued as part of the care team by healthcare providers.
- Communications between healthcare providers and family caregivers are impacted by lack of recognition of the value family caregivers could provide within care settings.

Recommendations for Improvement

1. Educate healthcare providers regarding the value of involving and engaging family caregivers of seniors on care teams and in care settings.
2. Involve family caregivers in the development of education and training materials so their experiences and needs are addressed.
3. Use similar approaches and training tools for all care settings to ensure consistency and increase potential impact across the province.
4. Recognize the importance of developing communication skills in healthcare providers to ensure meaningful communication with patients and family caregivers, and improve information sharing between healthcare providers.

It is time for healthcare providers to connect with family caregivers and treat them as valued members of the care team.

-Attendee of Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems (2016)

2. Culture Change Needed within our Systems to Acknowledge, Respect and Honour Family Caregivers

Issues Identified

- Time pressures leave healthcare providers with little time to engage with family caregivers or provide them with supports.
- Acute and continuing care systems are dominated by a medical model of care more focused on the physical aspects of care, and less on the social and psychological.

Recommendations for Improvement

1. Move to a person and family centred approach to care where communication and dialogue with family caregivers is a normal and standard part of care.
2. Welcome family caregivers in our care settings and recognize, respect and value their contributions.

3. Supports Needed to Engage, Empower and Foster the Resilience of Family Caregivers

Issues Identified

- There is a lack of information and supports for family caregivers to both help them understand - and adapt - to their caregiver role.
- Healthcare providers lack the knowledge on how to engage, empower and foster resilience in family caregivers.
- Healthcare providers are not aware of current resources and community supports available for family caregivers that would support their resilience.

Recommendations for Improvement

1. Healthcare providers need to be proactive in their support of family caregivers:
 - i. Develop and maintain a comprehensive list of resources that support family caregivers that is easily accessible.
 - ii. Create a provincial strategy that supports family caregivers with engagement and empowerment in our care settings.
 - iii. Find ways to help family caregivers navigate the system in a coordinated way.

4. Tools and Processes Available to Help Identify and Assess Caregiver Burden

Issues Identified

- Inconsistencies exist in identifying and assessing caregiver stress/burden.
- Healthcare providers are not adequately or consistently trained in identifying and assessing caregiver stress/burden.
- Conducting multiple caregiver burden assessments is problematic given the inconsistencies identified above, and the time required of healthcare providers to conduct assessments.

Recommendations for Improvement

1. Acknowledge caregiver stress/burden.
2. Train healthcare providers to identify and assess caregiver stress/burden. Review caregiver stress/burden assessment tools to determine the most appropriate and develop a standardized approach to caregiver stress/burden assessment.
3. Build systems and mechanisms for follow up with the necessary supports for those experiencing burden, including respite.

5. Palliative Care and End of Life Supports Desired by Family Caregivers

Issues Identified

- Healthcare providers are 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.
- Healthcare providers are not aware of the palliative and end of life resources available to assist family caregivers or how to access them.

Recommendations for Improvement

1. Educate healthcare providers about the palliative care and end of life supports and how to connect patients and family caregivers to those supports.
2. Train healthcare providers to communicate with patients and family caregivers about end of life, and to support their decisions.

Healthcare providers need to critically examine the supports available to family caregivers and then collaborate with them to maximize the benefits of those supports.

-Attendee to Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems, 2016

6. Systems Change Needed from a Policy and Practice Perspective to Ensure that Family Caregiver Supports and Resources are Made Available

Issues Identified

- Current caregiver support policies and programs have a narrow approach that undervalues the work of family caregivers.
- Current caregiver support policies and programs do not provide adequate financial support commensurate with caregiver contributions.
- Legal constraints related to privacy legislation prohibit family caregivers from obtaining necessary health information about care recipients.

Recommendations for Improvement

1. Develop policies that are comprehensive in scope and cover all needs of family caregivers.
2. Collaborate with and involve family caregivers in developing programs and policies to identify essential financial resources and supports.
3. Change privacy legislation so family caregivers can access the health information they need to inform and provide adequate care.

Next Steps

The conversation circle discussions reinforced the need for healthcare providers to recognize and value the role family caregivers play in seniors' care, and to take on a more comprehensive and holistic approach to better involve and support family caregivers within the healthcare system.

They also recommended a number of improvements to help strengthen support services for family caregivers and to help foster caregiver resilience. These recommendations will be brought forward at the 2017 Fostering Resilience in Family Caregivers of Seniors in Care symposium to explore ways to help family caregivers feel supported and valued in their caregiving role.

Current supports do not adequately compensate family caregivers and they often end up giving and giving until they have nothing left.

-Attendee to Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems, 2016
