

Caregiver-Centered Care

“Fundamental changes are needed in the way we support family caregivers.”

Family Caregivers, the ‘Submerged Iceberg’

Family caregivers have been referred to as “invisible,” the “shadow workforce” and “the submerged iceberg” because their work is largely invisible.

They arrange healthcare appointments, assist in routine and high stakes treatment decisions, coordinate care and services, perform medical procedures (medication management, wound care, cathysis), do the driving, help with daily tasks (dressing, bathing, meals), and manage finances and housing (cleaning, home maintenance).



25% of Canadians are family caregivers.

Family Caregivers provide

- 75- 90% of the care to people living with frailty, complex chronic conditions, and impairments in the community
- Assist with 30% of the care in LTC (pre-Covid).

Stress is increasing: In 2013/14, one-third of caregivers of long-term homecare clients experienced distress, anger or depression in relation to their caregiving role, or were unable to continue in that role. That was double the rate of distress in 2009/10.

Why increased stress? Family caregiving typically becomes more onerous as illness, frailty, and impairments become more severe, however in the last two decades medical advances, increased longevity, shorter hospital stays, as well as the push for community care have made family caregiving even more complex and longer lasting.

At the same time, demographic change, family structure and gender role changes, and health and continuing care practice reforms have increased the demand for care while threatening the supply of family caregivers.

Stakeholder Consultations: How do we support family caregivers?

The University of Alberta and Covenant Health Network of Excellence in Seniors’ Health and Wellness led consultations with over 400 multilevel, interdisciplinary stakeholders. **They said that healthcare providers are well positioned to support caregivers.** At all stages of the care journey, family caregivers interact with healthcare providers. Health care providers are highly trusted.



Caregiver Centered Care

At the 2018 symposium, stakeholders recommended **Caregiver-Centered Care**. They suggested that caregiver-centered education and training should be shaped by competencies specifically related to working with family caregivers.

While providing person-centered care is a key goal for provincial and territorial health systems in Canada, the term “family caregiver” or “carer” is not currently associated with definitions of person-centered or person- and family-centered care. Thus, the need for person- centered care for caregivers may not be formally recognized by professionals within health and social systems.

We use the term “Caregiver-Centered Care” to specifically focus on person-centered care for family caregivers.

We emphasize that caregiver-centered care is not the shifting of care, care management, or advocacy responsibilities to families, but rather a collaborative working relationship between families and health and social care professionals, with professionals supporting family caregivers in their caregiving role, decisions about services, care management, and advocacy.

Why are competencies important?

All health and social care professionals now look to a set of competencies to define their curricula and inform their scope of practice.

Caregiver-Centered Care Competencies

Six competency domains were identified through a literature review, environmental scan, and thematic analysis of 2018 Symposium data. The competency domains and indicators were validated by an Expert Panel in modified Delphi Process January- March 2019.



- A. **Recognizing the Caregiver Role.**
- B. **Communicating with Family Caregivers.**
- C. **Partnering with Family Caregivers.**
- D. **Fostering Resilience in Family Caregivers.**
- E. **Navigating the Health and Social Systems and Accessing Resources.**
- F. **Enhancing the Culture and Context of Care.**

We asked our stakeholders, “*How should Caregiver-Centered Care education be delivered?*”

What is the best way to teach Caregiver-Centered Care competencies?

The competency domains, competency indicators, and level of learning will need to be tailored to learner’s role. Stakeholders recommended there were core competencies that everyone should be exposed to and then a curriculum tailored for specific roles.

“I think anybody that intersects at all with a family or resident or patient, need some level of understanding of the philosophy and what we're trying to do, the environment we're trying to create.”

How will we spread and scale Caregiver-Centered Care Education?

Professional societies, accreditation bodies, academics in educational institutions, and employers such as Alberta Health Services and Covenant Health should support education and training development. **CHAMPIONS** play critical roles in leading change.

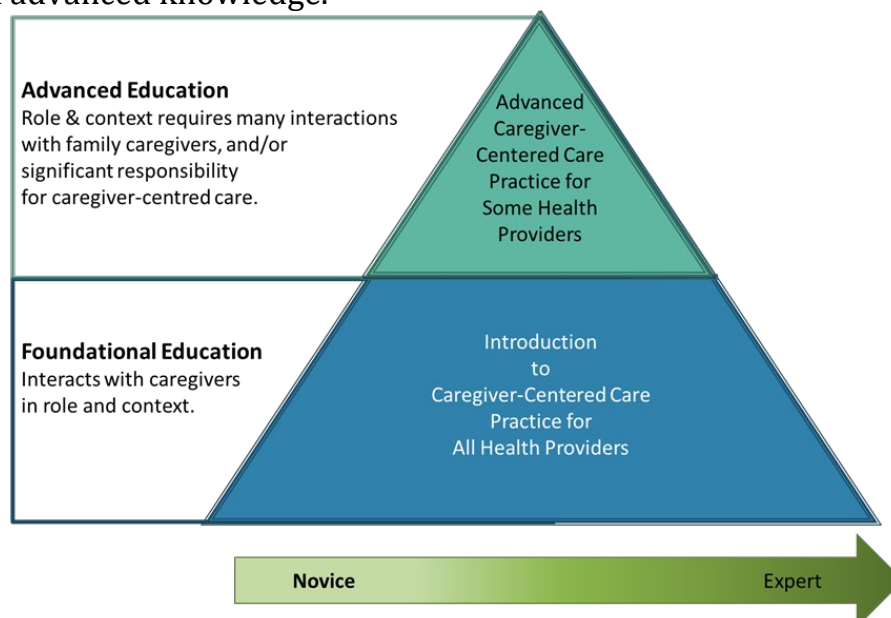
“Many people here are already committed. So at least for Alberta, you've got a group of people at that level who are probably champions already. In other provinces, we don't have that yet, at least not in our setting.”

Do we need multiple levels of competency-based Caregiver Centered Care Education?

“You might want your unregulated workforce to have a level of awareness but then your regulated workforce to be educated to a greater skill level or knowledge level, and then the policy makers might need an awareness but something else as well.”

Two Competency Levels

The competency triangle is divided horizontally into two competency levels, Foundational and Advanced. All health providers who work with family caregivers benefit from foundational knowledge. The healthcare providers who have more responsibility and interactions with family caregivers will need advanced knowledge.



What is important in designing education?

Caregiver-Centered Care Education should be effective at changing attitudes and the culture of care around caregivers.

"I think we've got to be innovative. We've got to do something that makes the difference. If we have somebody for 15 minutes, we've got to 15 minutes to really make a difference. We should get really innovative and try to make people understand in their soul."



COMING SOON

Foundational Level

Caregiver-Centered Care: Competency-based Education for the Health Workforce

Funders:



Centre for Aging + Brain Health Innovation: SPARK

Alberta Health, Seniors Strategic Clinical Network Community Funding

Co-designed by over 40 multi-level interdisciplinary stakeholders including Family Caregivers, Researchers, Educators, Doctors, Nurses, Social Workers, Recreation Therapists, Healthcare Administrators, Policy Influencers, Professional Associations Representatives

- Curriculum
- Facilitator's Guide
- Multimedia media resources: Six instructional videos
- Caregiver Centered Care Website.

See Dr. Jasneet Parmar's Caregiver-Centered Care ICCER Presentation

<https://www.youtube.com/watch?v=usohpisp5E&feature=youtu.be>

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