Caregiver-Centered Care Competency Framework©

Education for Health Providers to Support Family Caregivers

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### CIHR Planning Grant Team

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### List of Organizations at Engagement Meetings

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<tr>
<th>Agecare Communities of Care and Wellness</th>
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<td>Covenant Health</td>
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<td>Early Onset Dementia Alberta</td>
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<td>Edmonton Oliver Primary Care Network</td>
<td>Mount Saint Vincent University</td>
<td>University of Saskatoon</td>
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<td>Edmonton Seniors Coordinating Council</td>
<td>MS Society of Canada, Central Region</td>
<td>University of Toronto</td>
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<td>Edmonton West Primary Care Network</td>
<td>Norquest College</td>
<td>Voices of Toronto</td>
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<td>ElderCare Edmonton</td>
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<td>World Health Organization</td>
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Background

In Canada, recent efforts to adopt family caregiving as a public health concern have led to increased interest in how to support family caregivers’ health and capacity [1]. We recognize that “family caregiver”, “caregiver”, “carer”, “informal caregiver”, “unpaid caregiver”, “care partner”, and “care provider” are synonymous terms or descriptions often used in literature to describe the person who assumes an unpaid care role. We use “family caregiver” broadly defined as any person who takes on a generally unpaid caring role providing emotional, physical, or practical support in response to an illness, disability, or age-related needs.

While providing care can be uplifting, there is extensive evidence of the negative impacts on the family caregiver’s own health, employment, finances, and social life. Specifically, family care is associated with back pain, high blood pressure, depression/distress, and higher mortality rates [2]. On average, family caregivers incur an average of $7000 in out-of-pocket expenses yearly [3,4]. Employed family caregivers often reduce their hours of work or withdraw from the labour market entirely which reduces their income and pensions [2,5]. They lose work-related skills, self-esteem, and social contacts [6]. Many family caregivers are socially isolated.

Family caregivers play a critical role in meeting the health, social, emotional, and practical needs of Canadians with illness or limitations in their health, employment, finances, and social life. Specifically, family care is associated with back pain, high blood pressure, depression/distress, and higher mortality rates [2]. On average, family caregivers incur an average of $7000 in out-of-pocket expenses yearly [3,4]. Employed family caregivers often reduce their hours of work or withdraw from the labour market entirely which reduces their income and pensions [2,5]. They lose work-related skills, self-esteem, and social contacts [6]. Many family caregivers are socially isolated.

Despite family caregivers’ contributions and a plethora of policy, practice, and guidance reports and research recommending support for family caregivers, they are often marginalized by the health and community systems that could support them [2,11,12]. Support, capacity building, and promoting family caregivers’ resilience should be part of health professionals care mandate [13-15]. In fact, in 2018, American caregiving scholar Schulz and colleagues specified, “Educational and workforce development reforms are needed to enhance the competencies of healthcare and long-term care service providers to effectively engage caregivers” (p. S36).
Competencies

Canada has been a leader in competency-based education for the health workforce. Competencies are a way of capturing the knowledge, skills, attitudes, and behaviours required for successful practice. They are the foundation of learning and assessment in educational programs; workforce recruitment, selection, and career and leadership development; and, evaluating success [16-19].

Health workforce competencies are not limited to clinical-technical skills, such as assessment, diagnostic procedures, and clinical interventions. Relational skills: communication, collaboration, self-awareness, reflection, role clarity, and working in teams are also critical elements of care and improving the quality of care.

Definition of Competence
There are numerous conceptualizations and definitions of competence [20,21]. We are using Parry’s (p. 60) definition of competency: “It’s a cluster of related knowledge, skills and attitudes that affects a major part of one’s job (i.e. one or more key roles or responsibilities); that correlated with performance on the job; that can be measured against well-accepted standards; and that can be improved via training and development” [22]

Features of Competencies
Competencies are complex. Over time, health care providers have the opportunity to move from being a novice to an expert in their role and context. Progress from novice to expert is facilitated through practice, education, mentoring, and reflection. We should assume that as caregiver, patient, and population needs change, competencies will also need to change and improve [23].

Competency Levels
The competency triangle is the foundation of the framework (Figure 1). It is divided vertically into three competency levels, Foundational, Advanced and Champions. All health providers who work with family
caregivers benefit from foundational knowledge and the healthcare providers who have more significant responsibility and interactions will need advanced knowledge. Champions are the health care leaders who model and mentor other providers to progress from novice to expert within either the foundational or advanced level (i.e., horizontal progression). Changing categories (i.e., vertical progression) is not necessarily the goal. For example, a health care provider working on a medical ward could move from novice to expert in providing caregiver-centered care and remain in the Foundational Level. SOME healthcare providers will work in roles and settings in which they have more responsibility for family caregivers. They are also a resource for colleagues within their local environment. Healthcare leaders in organizations who are responsible for health care providers who interact with family caregivers also need to ensure the culture and context of care in their setting supports family caregivers. These healthcare providers and leaders require Advanced and/or Champions Level of education.

**Competency Development Process**

The Caregiver-Centered Care Competency Framework development process was a multi-step iterative consensus building process that culminated in a Modified Delphi Process with a panel of experts validating the competency indicators.

Dr. Parmar and the research team, supported by the Covenant Health Network of Excellence in Seniors’ Health and Wellness, hosted five meetings with over 400 stakeholders to facilitate practical change in caregiver supports. The first meeting in 2014, *Supporting Family Caregivers of Seniors: Improving Care and Caregiver Outcomes [24-26]* resulted in research projects evaluating services for family caregivers [27-29] and a toolkit for HCPs [30]. Stakeholders at the 2016 *Supporting Family Caregivers of Seniors within Acute and Continuing Care Systems*[31] and 2017 *Fostering Resilience in Family Caregivers of Seniors in Care*[32] meetings clearly stated that health and social care professionals should be educated to support family caregivers within existing health and community systems [33]. The competency domains were identified and validated at 2018 *Healthcare Workforce Training in Supporting Family Caregivers of Seniors in Care*.

An Expert Panel of multi-level, interdisciplinary caregiving experts (n=42), including researchers, academics, policy makers, provincial government leaders, front-line health and social care professionals, non-governmental organization leaders, and family caregivers participated in a Modified Delphi Process to guide competency indicator identification and valuation. The competency indicators underwent two rounds of revisions online in January and February 2019. Then, the Expert Panel met face-to-face on March 14, 2019, at the “Health Workforce Education and Training to Recognize and Support Family Caregivers of Older Adults” symposium in Edmonton. Participants (n=42) met in facilitated groups (n=6) for 1.5 to 2 hours. They reviewed each competency indicator to ensure the meaning was clear. Participants then rated the inclusion of the competency indicators as either green (essential/ important) or red (somewhat important, not important, don’t know). All competency indicators, but one, were rated by 95.2 to 100% of participants as essential. The competency indicator considered “not important” was similar to another indicator. The final competencies were emailed to participants for further comments. Participants approved the competency framework.
What is Caregiver-Centered Care?

While providing person-centered care is a key goal for provincial and territorial health systems in Canada [34], 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 [35,36].

There are many definitions of person-centered care and all embrace ensuring that people are involved in, and central to, their care [37,38]. Person-centered, patient-centered, or family-centered are associated with care that includes:

• putting people at the center of care and respecting their values,
• taking people’s preferences and expressed needs into account,
• coordinating and integrating care,
• customizing communication, information, and education,
• providing emotional support and eliminating fear and anxiety, and
• making sure people have access to appropriate care when they need it [38,39].

We will use the term “caregiver-centered care” to refer to this specific focus on family caregivers, recognizing that “family” can refer to family, friends, partners, neighbours, and other people deemed by the person needing care as fulfilling the care role [40].

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 [41,42].

This approach respects and meaningfully involves the person’s family caregiver in the planning and delivery of supportive services. It also recognizes and addresses caregiver needs and preferences and integrates family caregivers as partners in care[43,44].
The Caregiver-Centered Care Competency Framework

Six competency domains highlight the knowledge, skills, attitudes, and values that shape caregiver-centered care practice. While they are portrayed individually, in practice the domains are interdependent.

The six competency domains are:
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
Competency Domain A: Recognizing the Caregiver Role

Competency Indicators
1. Demonstrates understanding of the value of family caregivers’ contributions to society and the healthcare system.
2. Demonstrates knowledge of the consequences of caregiving on family caregivers.
3. Demonstrates awareness of, and identifies the family caregivers, their roles and responsibilities in supporting the care recipient.
4. Understands the diversity among family caregivers (e.g., age, gender, culture, where they live, work).

Competency Domain B: Communicating with Family Caregiver

Competency Indicators
1. Communicates in a manner that demonstrates respect, empathy, and compassion toward the family caregiver.
2. Demonstrates ability to listen actively and respectfully to family caregivers.
3. Provides timely information to family caregivers in ways they will understand.
4. Supports coordinated care by providing consistent documentation and information amongst providers and family caregivers.
Competency Domain C: Partnering with Family Caregivers

**Competency Indicators**
1. Understands the benefits of including family caregivers on the care team.
2. Establishes collaborative relationships with family caregivers.
3. Includes family caregiver’s knowledge of the care recipients in assessments and care planning.
4. Understands conflicts and works to de-escalate conflict.

Competency Domain D: Fostering Resilience in Family Caregivers

**Competency Indicators**
1. Identifies and assesses family caregiver’s needs and goals on an ongoing basis.
2. Recognizes the dynamics of the caregiver-care-recipient relationship.
3. Enhances family caregivers’ skills and abilities through education and support.
4. Promotes the health and wellbeing of family caregivers and encourages self-care.
Competency Domain E: Navigating the Health and Social Systems and Accessing Resources

**Competency Indicators**
1. Works collaboratively with caregivers to access applicable supports in a timely manner.
2. Communicates with, and makes referrals to other providers, in accordance with family caregivers' preferences.
3. Works with family caregivers to overcome barriers to access services and supports.

Competency Domain F: Enhancing the Culture and Context of Care

**Competency Indicators**
1. Recognizes that care and caregiving are affected by societal views (e.g., ageism, stigma, discrimination).
3. Engages in self-reflection to improve interactions with, and support of, family caregivers.
<table>
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<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Ableism/disablism</td>
<td>Ableism is the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior. Disablism can be defined as discriminatory, oppressive, abusive behaviour arising from the belief that disabled people are inferior to others. What is the difference between ableism and disablism? Both terms describe disability discrimination, but the emphasis is different. Ableism is discrimination in favour of non-disabled people. Disablism emphasizes discrimination against disabled people.</td>
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<tr>
<td>Ageism</td>
<td>The stereotyping of, and discrimination against, individuals or groups because of their age. Ageism is multifaceted and manifests itself in multiple ways, such as prejudicial attitudes toward older people, old age, and the aging process; discriminatory practices against older people; and institutional practices and policies that perpetuate stereotypes about older people.</td>
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<td>Diversity</td>
<td>“Diversity” refers to any and all differences between and among people[45]. Diversity means different things to different people. Generally, in common use, diversity refers one of three things: demographic diversity (our gender, age, race, sexual orientation, education, religious affiliation), experiential diversity (our affinities, hobbies, and abilities), and cognitive diversity (how we approach problems and think about things)[46].</td>
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<tr>
<td>Family</td>
<td>We are using the Vanier Institute of the Family broad definition of family: Any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibilities for variant combinations of some of the following: 1) Physical maintenance and care of group members; 2) Addition of new members through procreation or adoption; 3) Socialization of children; 4) Social control of members; 5) Production, consumption, distribution of goods and services; and 6) Affective nurturance – love. Our definition of family is deliberately broad to ensure that it captures all families and family experiences. It is a functional definition of family that focuses on relationships and roles – what families do, not what they look like.[47]</td>
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<tr>
<td>Family caregiver</td>
<td>Any person who takes on a generally unpaid caring role providing emotional, physical or practical support in response to an illness, disability or age-related needs.</td>
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<td>Health care team</td>
<td>Health care teams are primary health care organizations that include a team of family physicians, nurse practitioners, registered nurses, social workers, dietitians, and other professionals who work together to provide primary health care for their community. They ensure that people receive the care they need in their communities, as each team is set-up based on local health and community needs (Ontario Ministry of Health and Long-Term Care, 2016).</td>
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References


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34. Canadian Institutes for Health Information. How Canada compares: Results from The Commonwealth Fund’s 2017 International Health Policy Survey of Seniors. Canadian Institute for Health Information: Ottawa, 2018; 978-1-77109-673-7 p 2979.


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