

Caregiver-Centered Care for Family Caregivers of People with Dementia – University of Alberta - Final Report

Executive Summary

Family caregivers are the backbone of the health system for people with complexity, frailty, disability, and at the end-of-life. In fact, family caregivers provide 75-90% of the care required for people needing care in the community [1,2] and assist with 15 to 30% of the care in congregate care [3,4]. That backbone desperately needs support. Care has always become more onerous as chronic conditions and acute illnesses progress, or dementia, 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 [1,5,6]. In 2010 15.6% of family caregivers to long-term home care and end-of-life clients in Canada were distressed [7] which rose to 33.3% by 2016 [5] and to 44% in August 2022[8].

Our innovative solution to reduce caregiver distress and support caregivers to maintain their wellbeing was to design, deliver, and evaluate the impacts of Foundational Caregiver-Centered Care Education for the health workforce to identify, engage, and support family caregivers throughout the care trajectory. The Foundational Education is designed to equip healthcare providers with the competencies to engage and communicate with family caregivers as partners in care, recognize the caregivers' own needs, and assist them in accessing services and supports [1,9,10].

Our Foundational Caregiver-Centered Care Education has been co-designed for all healthcare providers and trainees who work with family caregivers and is offered free online (caregivercare.ca). Over one hundred multi-level interdisciplinary people participated on the co-design team. Healthcare providers from five healthcare settings (primary, acute, home, supportive living, long-term care) and trainees in medicine, nursing, and allied health were recruited via email and social media. We used the Kirkpatrick-Barr health workforce training evaluation framework to evaluate the education program, measuring various healthcare providers' learner satisfaction with the content (Level 1), pre-post changes in knowledge and confidence when working with family caregivers (Level 2), and changes in behaviors in practice (Level 3).

Objectives/Implementation

The Foundational Caregiver-Centered Care Education program was co-designed by over one hundred multi-level, interdisciplinary stakeholders including policy makers, researchers, health care administrators and providers, educators, not-for-profit community leaders, and family caregivers. We utilized adult learning theories including constructivism and transformative learning theory, which view learners as active participants in constructing knowledge and meaning through critical reflection upon new information and their experiences. We also drew upon best practices in health workforce education to inform education design. The education consists of six modules that follow the domains in competency framework, including (a) Recognizing the Family Caregiver Role, (b) Communicating with Family Caregivers, (c) Partnering with Family Caregivers, (d) Fostering Family Caregivers' Resilience, (e) Assisting Family Caregivers to Navigate Health and Social Systems and Access Resources, and (f) Enhancing the Culture and Context of Healthcare.

The teaching and learning resources include six videos interspersed with interactive exercises designed to encourage learners to reflect on how the learning might be useful in their role and setting. The education was designed to be delivered flexibly, either facilitated-in-person or virtually. Due to the COVID-19 pandemic preventing in-person learning opportunities, the education is offered free online (caregivercare.ca) and takes about an hour to complete. Participants receive a certificate on



completion. We delivered the facilitated version of the Foundational Education at the Caregivers Alberta Conference in May 2022.

Impact

Since the Foundational Education went online, November 21, 2020, 4552 people have taken the education. 78% of the urban Home Care Palliative Care Staff in the Edmonton Zone have completed the Foundational Education. Learners were primarily healthcare employees (68.9%) and trainees (21.7%) and represented five healthcare settings. Evaluation of the first 161 learners completing the program indicated that on a 5-point Likert scale, the majority were satisfied with the overall quality of the education (Mean(M) = 4.69; SD = .60). Paired T-tests indicated that out of a score of 50, post-education changes in knowledge and confidence to work with family caregivers was significantly higher than pre-education scores (pre M = 38.90, SD = 6.90; post M = 46.60, SD = 4.10; $t(150) = -16.75, p < .0001$). Qualitative results derived from open responses echoed the quantitative findings in satisfaction with the education delivery as well as improvements in learners' knowledge and confidence (e.g., "This module must be incorporated to all Home Care Departments as it is very straight forward and rich in information;" "I have gained better understanding and knowledge regarding the importance of caregiver centered care.")

Health workforce education to provide person-centered care to all family caregivers is an innovative approach to addressing the current inconsistent system of supports for family caregivers. The education program evaluated here was effective at increasing self-reported knowledge and confidence to work with family caregivers.

References

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