
CONFERENCE ABSTRACT

Engaging and Empowering Young Carers: Shifting the Focus for Public Awareness and Intervention in Canada

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Over 8 million Canadians provide care to chronically ill or disabled family members. While most caregivers are between the ages of 45 and 54 (24%) and 55 and 64 years (20%), the third largest group is young carers. Carers between the ages of 15 and 24 account for 15% of all caregivers in Canada. This group of carers are those under the age of 25 that provide significant and ongoing unpaid care to a family member or friend. However, despite these known figures, very little attention has been paid to the existence of young carers in Canada except for scant emerging research. Our two-phased study aimed to first gain a better understanding of how young carers interact with the health system [how they are included in discussions and how is information shared with young carers]. The second phase focused on building on this body of knowledge by engaging young people and partnering with caregiver organizations in a more participatory, active manner to identify potential solutions to improve their involvement in supporting their family member's healthcare use. In phase one, we applied a deductive analytical approach to identify touch points and pain points as perceived by participants. Our findings demonstrated that young carers interacted with the healthcare system at touch points spanning the home and community sectors, hospital and rehabilitation care, and primary and palliative care services. We also identified five types of pain points that the young carer participants experienced in their caregiving roles: 1) desiring acknowledgement; 2) seeking information and communication; 3) managing system navigation; 4) engaging in balancing acts; and 5) performing point-of-care tasks. Phase two consisted of a virtual co-design event with the young carer participants, members of the partnering support organizations, and the research team. During the meeting, the group engaged in a brainstorming activity to identify priorities for our proposed project. The two priorities identified by our event were to 1) Build awareness of young carers for both healthcare organizations and healthcare practitioners and identify challenges in their recognition and support at point-of-care. And 2) Support the co-design of a prototype program that recognizes the needs of both young carers and healthcare workers during their healthcare interactions and that addresses the identified pain points. These results will inform the next steps that intend to explore to what extent are health care professionals aware of young carers and their support needs. Our program of research is adding to

the national literature on Canadian young carers and provides more evidence to develop support provisions and interventions for young carers.