

CONFERENCE ABSTRACT

Developing a Smartphone Application for Co-ordinating Respite Care Services for Families with Palliative-Stage Cancer: A Research Proposal

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Aimee Castro¹, Antonia Arnaert¹, Karyn Moffatt², John Kildea³, Audrey-Jane Hall⁵, Vasiliki Bitzas^{1,4}, Argerie Tsimicalis¹

1: Ingram School of Nursing, McGill University

2: School of Information Studies, McGill University

3: Gerald Bronfman Department of Oncology, McGill University

4 Department of Geriatrics and Palliative Care, Jewish General Hospital

5: Société de soins palliatifs à domicile du Grand Montréal

Introduction: Families coping with palliative-stage cancer need comprehensive community services to support death at home. One such service, respite care, allows family caregivers to experience short breaks from their intensive role while giving patients new opportunities for social and care support. Respite care can be invaluable to families, especially when services are flexible and staffed by trusted care providers, such as nurses. However, many families forego respite because the available services are difficult to schedule and not staffed by providers with palliative care training. Other industries (e.g. transportation, travel accommodations) are using mobile applications (“apps”) to optimize service delivery, but there is limited research on apps for palliative respite services. We aim to develop an app to foster the integrated care co-ordination of nurse-provided respite care services for families coping with palliative-stage cancer in Québec, Canada.

Methods: A user-centered design study will be conducted, guided by Hevner’s Information Systems Research Framework. 20 nurses, 15 adults with palliative-stage cancer, and 20 of their caregivers will be recruited from one palliative home-care community partner and two palliative oncology departments. Remote data collection will occur over three phases: brainstorming potential app features for addressing the needs of both caregivers and care recipients; evaluating the proofs-of-concept; and usability testing of the prototype. Qualitative and quantitative data will be descriptively analyzed and triangulated to identify key app features. An Expert Council of key informants, including patient and caregiver advocates, will be consulted throughout the study to guide further data collection, app design, and dissemination.

Highlights: To our knowledge, this will be the first app collaboratively designed to co-ordinate nurse-provided respite care for families with cancer. While this research is primarily digital solutions research (Pillar 7), this study also aligns with Pillar 3, “People as partners in health and care”. The mHealth app will be developed in partnership with: patient, family caregiver, and nurse participants; community partners; and our transdisciplinary research team composed of nurses and computer scientists, several of whom have lived experience as family caregivers and palliative homecare workers. The creation of this app may empower families to use these optimally co-

ordinated respite care services with available nurse providers, allowing them to personalize their requested respite care services (such as through scheduling, and nurse skillset), leading to improved family and carer support in the community. Preliminary results for this ethically-approved project will be available for the conference.

Conclusions: We will design an app to facilitate the delivery of respite care services in Québec, where cancer is the leading cause of death, and where respite care services are often fragmented. Once pilot-tested and launched, this app could improve the delivery of respite care services, reducing demand on institutional services while facilitating death at home, where most patients wish to be.

Limitations and Implications: Anticipated study limitations are related to the risk of palliative care participant attrition. While the findings will be contextualized to Québec, the innovative methodological approach and app results may be transferable to other caregiving populations and settings.