

Who can you call when you suddenly need respite care, but your loved one is very ill and living with palliative-stage cancer?



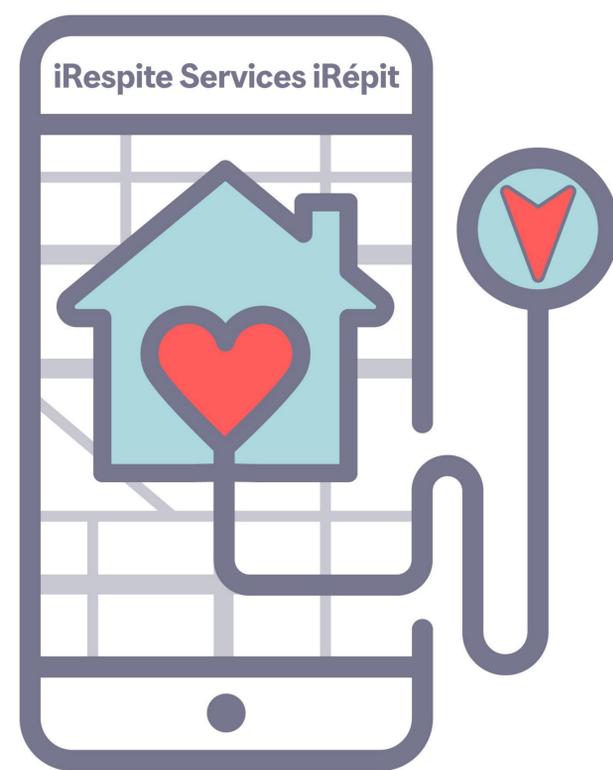
Jade and her father:
Sandwiched care



Pablo and Ray:
Work/Financial concerns



Anya and her grandmother:
Young carer, burning out



iRespite Services iRépit
<https://aimeecastro.com/irespite-services-irepit/>

BACKGROUND

Cancer caregiving is one of the top 3 most labor-intensive forms of family caregiving [1,2]

Families want in-home respite care → need flexible and trusted **respite care providers**, who have the skills to provide the necessary care supports for several hours while **patients and caregivers can take breaks from each other and their family dyadic roles** [3-7]

Families with complex medical needs, like families coping with palliative stage cancer, need highly trusted and flexible respite care services [6,7]

For such families, nurses may be the optimal respite care service providers [5,6,8]

The presence of an overnight respite care nurse may be the key factor in whether a family has the capacity to continue with a patient's wishes to die at home [3,5,8,9]

Can ubiquitous smartphones be used to better coordinate respite care services, by collaboratively designing a respite care app with stakeholders?

PURPOSE: To develop an mHealth app prototype, **iRespite Services iRépit**, for coordinating flexible and trusted in-home respite care services, provided by nurses to families coping with palliative-stage cancer in Quebec.

METHODOLOGY

Methodology: User-centered design & Hevner's 3-cycled Information Systems Research Framework

Methods: Triangulating qualitative and quantitative data using content analysis techniques to identify key respite care needs and app design features

The protocol has been published in *JMIR Research Protocols*:

Castro, A. R., Arnaert, A., Moffatt, K., Kildea, J., Bitzas, V., & Tsimicalis, A. (2021). Developing an mHealth Application to Coordinate Nurse-Provided Respite Care Services for Families Coping With Palliative-Stage Cancer: Protocol for a User-Centered Design Study. *JMIR research protocols*, 10(12), e34652.



Sample size over 3 research phases

Phase	Participants
Phase 1: Brainstorming respite care challenges and the possibilities of app coordination	Individual interviews Expert Council #1 (6 key informants) 10 nurses 10 family caregivers 10 patients N= 7 nurses, 2 caregivers, 1 patient
Phase 2: Wireframing several designs & discussing	Focus groups and/or individual interviews, as participants prefer Same participants as Phase 1, with additional recruitment for expected attrition
Phase 3: Usability testing of the final design	Same 10 nurses + 5 new = 15 nurses Same 10 caregivers + 5 new = 15 caregivers

DISCUSSION

Preliminary findings align with other research on the need for improved, **integrated coordination** of community respite care in the palliative context [9, 3, 10]

Transdisciplinary research to construct a new app-based respite care service together, to improve service coordination for families coping with cancer

Next steps: Summer 2022 (Finish Phase 1 interviews and brainstorming). Fall 2022 (Phase 2 wireframing discussions). Winter 2023 (Phase 3 usability testing)

Eventually → practicing nurses, other providers, and homecare agencies could coordinate their services through an app based on this co-developed prototype.

RESULTS: App features

Sign-up:

Separate dashboards: family caregivers, respite care contractors (self-employed), agencies
Skillsets: region; language(s); specific care support needs; credentials

Co-ordination:

Schedules showing provider availabilities, with map showing ETA
Easy-to-navigate list of other services available for respite care
Notifications sent out by hospices & day centres to families and nurses when a space becomes available

Managing expectations up-front:

Cost transparency: list of prices shared early-on
Families choose: urgent respite support vs continuity of care

Security & trust:

Fingerprints > passwords
Respite care provider rating options
Don't sell user data or have ++notifications

RESULTS: Contextual themes for respite care needs

Respite care needs:

All agree: need better respite care coordination for families

Implementation - marketing:

Common challenge: families unaware, need time to accept need for respite Timing & promotion: early marketing of app & respite care services

Implementation - financing:

Public-private partnerships; Cost transparency

Service - training:

**Training is necessary, as is matching appropriate skillset
**Unlike literature: nursing credentials may not be necessary
Key: managing family expectations

Service - multiple respite care options:

On-demand respite care
Easy-to-navigate database of existing services
Hospice and day centre timeslots available

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SELECTED REFERENCES:

[1] Sinha, 2013. [2] Lambert et al., 2016. [3] Robinson et al., 2017 [4] Strang, 2002. [5] Barrett et al., 2009. [6] Buscemi et al., 2010. [7] Lambert et al., 2019. [8] CCS: Caring for life, 2014. [9] Rao et al., 2021. [10] Thomas et al., 2021.

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