iRespite Services iRépit:

Co-designing an app to make in-home respite care more accessible for families with advanced cancers

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Q: Can a smartphone app be designed to improve access to respite care services?

A: Yes.

Quebec cancer and palliative families need better access to in-home respite care services - including easier coordination and guilt-free nudging.

Participatory-designed technologies can help - and iRespite is a formative, bilingual exemplar.

Insights from this research on app design for access can inform the creation of similar appbased services for community health in global oncology.



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Background: Respite care

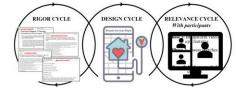
- Respite care is an essential service where homecare workers come to the home to provide care, while the family caregiver can leave and the care-receiver can benefit from new social supports [1,2,3]
- Respite care can reduce family stress and achieve goals of dying at home [1,4,5]
- Cancer respite care needs are rising in Quebec and Canada [6, 10]
- Yet, respite care services are difficult to access [1,5,7,8]
- Only 13% of Canadians die at home with formal in-home palliative supports [9]
- And access to palliative respite has worsened since the pandemic [10]

Background: Smartphone apps

Can facilitate [11-13]:

- Flexible and available scheduling
- Designing for trust





Adapted version of Heyner's Information Systems Research Framework [14]

Rigor Cycle: We published 5 manuscripts: a <u>concept analysis</u> of "informal caregiver", environmental scan of palliative respite care agencies, scoping review of research on respite care technologies, systematic app store search Detailed protocol: Castro et al. 2021, JMIR Research Protocols

Participants:

5 Expert Council key informants

9 nurses, 9 family caregivers, 3 care-receivers with advanced cancers 26 group and individual interviews over 3 research phases: brainstorming, sketching, refining

Key design features of our proof-of-concept Pallium Canac 1) Coordinating direct respite care, CareNOW (~Uber/immediate) CareMATCH (Future scheduling) 3) Information-sharing Palliative care trair Agencies navigator Our navigator of 52 palliative respite care agencies across Quebec is available for sharing now!

Alignment of design features with Lévesque et al. 2013's framework on access [15]





Acceptability / ability to seek Appropriateness / ability to engage Approachability / ability to perceive

Availability / ability to reach

Affordability / ability to pay

Key aspects of availability and affordability cannot be addressed entirely by a rigorously designed technology like iRespite, alone.

→ Need policy, practice, and research advancements on respite care, to truly make these complex services accessible according to all dimensions of access.

Selected sources - Email Castro for full citations
[1] Rao 2021, [2] Whitmore 2022, [3] Thomas 2020, [4]
Nysaeter 2024, [5] Robinson 2017, [6] Brenner 2024, [7]
Leocadie 2018, [8] Wolkowski 2017, [9] CHI 2023, [10] Pesut
2022, [11] Abarca 2018, [12] Currin 2019,
[13] Castro 2023, [14] Hevner 2007, [15] Levesque 2013

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