Designing a proof-of-concept of an app to facilitate access to in-home respite care services for families with advanced cancers: A user-centred design study

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Abstracts

Abstract

Introduction: Respite care provides temporary relief for families coping with advanced cancers. This service offers numerous benefits for both family caregivers and care-receivers. However, existing respite care services are often inaccessible. Smartphone applications (“apps”) present a promising avenue for addressing key challenges of access to respite care for these families.

Aim: To rigorously design a proof-of-concept of a bilingual app that families and nurses perceive to be relevant for facilitating access to in-home respite care services for families coping with advanced cancers in Quebec, Canada.

Study design: This user-centred design research was guided by the cyclical Information Systems Research Framework, which was adapted to incorporate three distinct research phases of the app design process. The original study protocol was published in 2021 (Paper 1).

Data collection and analyses: Each study phase was overseen by an Expert Council. Participants included *family caregivers* of adults with advanced cancers, adult *care-receivers* with advanced cancers, and registered *nurses* with expertise in oncology, palliative, or home care nursing. Participant data were remotely collected during each phase through individual interviews and focus groups, to discuss the iterative data analyses and app design developments.

Phase 1 involved conducting knowledge syntheses to inform interview guides, followed by brainstorming sessions with participants about respite care needs and potential app features. Phase 2 consisted of sketching low-fidelity wireframe features with participants. Phase 3 consisted of refining the proof-of-concept design with participant feedback.

Analyses involved qualitative content analyses of interview data and descriptive statistics following each phase, to prioritize and refine app goals and features across the three phases. The final Phase 3 proof-of-concept design was analyzed post-hoc for its alignment with a public health framework describing factors affecting access to healthcare services.

Results: To commence Phase 1, the following knowledge syntheses were initiated: a concept analysis that highlighted informal caregivers' support needs (Paper 2), an environmental scan of palliative respite care agencies in Quebec (Paper 3), a scoping review of respite care technologies (Paper 4), and a systematic search of the Apple and Android app stores for respite care apps (Paper 5). Following ethical approvals, participant data collection across the 3 phases resulted in 3 Expert Council meetings with n=5 key informants, and 26 individual interviews and focus groups with n=21 additional participants: 9 family caregivers, 3 care-receivers, and 9 nurses. During the design cycles of each phase, we developed and refined ideas for the proof-of-concept, incorporating data analyses from each prior phase to refine the app features. The final iRespite Services iRépit ("iRespite") app design facilitates access to respite care via flexible direct coordination of respite care services, between families seeking respite care and self-contracting respite care providers who have palliative care training (Paper 6). The proof-of-concept also integrates a chatbot for support and engagement, and shares information on relevant Quebec resources, including a palliative respite care agencies navigator. Participants noted feasibility issues for future consideration related to recruiting providers and ensuring affordable services. Overall, they considered the app design to be acceptable and appropriate for supporting their respite care needs.

Conclusion: This research suggests potential for iRespite to improve key factors affecting access to respite care for families with advanced and palliative cancers. This research will benefit nurses, who will be able to share the launched agencies navigator, as well as the future iRespite app with families in their care, helping these families to access respite care services across Quebec. Future research will focus on usability, feasibility, and pilot testing for coordinating respite care visits using the iRespite app.

Abrégé

Introduction : Les soins de répit offrent un soulagement temporaire aux familles confrontées à un cancer avancé. Ce type de service offre plusieurs bienfaits, autant pour les aidants familiaux que pour les bénéficiaires de soins. Cependant, les services de répit existants sont souvent inaccessibles. Les applications mobiles représentent un moyen prometteur de relever les principaux défis liés à l'accès aux soins de répit pour ces familles.

Objectif : Concevoir rigoureusement une preuve de concept d'une application que les familles et infirmiers.ères perçoivent comme étant pertinente pour faciliter l'accès aux services de répit à domicile pour les familles confrontées à un cancer avancé au Québec (Canada).

Méthodologie : Ce projet de recherche de conception centrée sur l'utilisateur a été guidée par le cadre de recherche cyclique sur les systèmes d'information (Information Systems Research Framework), qui a été adapté afin d'incorporer trois phases distinctes de recherche du processus de conception de l'application. Le protocole de recherche initial a été publié en 2021 **(article 1).**

Collecte des données et analyses : Chaque phase de l'étude a été supervisée par un conseil d'experts. Les participants comprenaient des *aidants familiaux* d'adultes atteints de cancer avancé, des *bénéficiaires de soins* atteints de cancer avancé et des *infirmiers.ères autorisés.ées* ayant une expertise en oncologie, en soins palliatifs ou en soins à domicile. Les données des participants ont été recueillies à distance lors de chaque phase par le biais d'entretiens individuels et de groupes de discussion, afin de discuter des analyses itératives des données et des développements de la conception de l'application.

La phase 1 a consisté à réaliser des synthèses de connaissances afin d'informer des guides d'entretiens, suivies de séances remue-méninges avec les participants sur les besoins en matière de soins de répit et les caractéristiques potentielles de l'application. La phase 2 a consisté à esquisser des fonctionnalités de basse fidélité avec les participants. La phase 3 a consisté au perfectionnement des preuves de concept, tenant compte des commentaires des participants.

Les analyses ont comporté une analyse qualitative du contenu des données d'entretiens et des statistiques descriptives après chaque phase, afin de prioriser et de peaufiner les objectifs et les caractéristiques de l'application au cours des trois phases. La conception finale de la preuve de concept de la phase 3 a été analysée a posteriori pour vérifier sa conformité avec un cadre de santé publique décrivant les facteurs affectant l'accès aux services de soins de santé.

Résultats : Pour amorcer la phase 1, les synthèses de connaissances suivantes ont été réalisées : une analyse conceptuelle qui a mis en évidence les besoins de soutien des proches aidants (article 2), un scan environnemental des agences de répit palliatifs au Québec (article 3), une revue de la portée des technologies de soins de répit (article 4) et une recherche systématique des applications de soins de répit dans les boutiques d'applications d'Apple et d'Android (article 5). Suite à l'approbation éthique, la collecte de données au cours des 3 phases a donné lieu à trois réunions du conseil d'experts avec cinq informateurs clés, et à 26 entretiens individuels et groupes de discussion avec 21 participants additionnels, soit 9 aidants familiaux, 3 bénéficiaires de soins et 9 infirmiers.ères.

Au cours des cycles de conception de chaque phase, nous avons développé des idées et raffiné celles-ci pour la preuve de concept, en incorporant les analyses de données de chaque phase précédente pour peaufiner les caractéristiques de l'application. Le conception finale d'iRépit facilite l'accès aux soins de répit grâce à une coordination directe et flexible des services de répit, entre les familles à la recherche de soins de répit et les prestataires de soins de répit indépendants ayant reçu une formation en soins palliatifs (article 6). La preuve de concept intègre également un chatbot pour le soutien, l'engagement et le partage de ressources québécoises pertinentes, y compris un navigateur des agences de répit palliatifs. Les participants ont souligné des enjeux de faisabilité, liés au recrutement de prestataires formés et à la garantie de services abordables, à prendre en compte à l’avenir. Dans son ensemble, les participants ont jugé que la conception de l’application était acceptable et appropriée pour soutenir leurs besoins de soins de répit.

Conclusion: Cette recherche suggère que iRépit a le potentiel d’améliorer les facteurs clés qui influencent l’accès aux services de répit pour les familles confrontées à un cancer avancé ou palliatif au Québec. Ce projet va bénéficier les infirmiers.ères, qui pourront partager avec les familles dont elles s’occupent le navigateur d’agences de répit actuellement disponible et la future application iRépit, afin d’aider ces familles à accéder aux services de répit dans l’ensemble du Québec. La recherche future portera sur les tests de convivialité, sur les évaluations de faisabilité et sur les essais pilotes pour la coordination de visites de soins de répit à l’aide de l’application iRépit.

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Both care and research take a village, and this caregiving dissertation was no exception. This work started with my mother, **Marianne, and my grandmother, Angela**, who together showed me that caregiving and care-receiving can be hard but meaningful seasons in life that help to make us fully human. Dad, **Joe**, you always believed in me and my craft, whether it was my track practice or my research; I am so thankful for your ongoing support.

To my supervisor, Dr. **Argerie Tsimicalis:** I am grateful for your encouragement, brilliance, and contagious enthusiasm. I wouldn't have embarked on this PhD if I didn't know I'd have you on my team to guide me in turning my vague entrepreneurial ideas into a full-blown doctoral study. What a privilege, challenge, and adventure this has all been!

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Contributions to Original Knowledge

This dissertation offers distinct contributions to theoretical, methodological, and empirical knowledge. This work contributes to *theoretical* knowledge on designing complex digital health service coordination platforms with the concepts of partnership and access in mind. This work contributes to *methodological* knowledge by showing how to conduct participatory, transdisciplinary, and integrative research when designing an app to facilitate access to a complex health care service. Finally, this work contributes to *empirical* knowledge on digital health design for facilitating access to community support services like respite care, and on respite care support needs for families with advanced and palliative cancers. These contributions are further described in the six manuscripts and the discussion section of this dissertation.

Contribution of Authors

There are multiple authors on each of the six manuscripts included in this thesis. I am first author on all six manuscripts. I am co-first author on Paper 3. The contributions of each author for each manuscript are briefly described below.

Paper 1 (published): Study protocol

Cite as: **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. (A. Castro et al., 2021)

Contributions: I conceived of this project for my doctoral studies. AT and AA provided significant input for the preliminary study design, with all co-authors contributing critical refinements to the protocol based on their various expertises: AA (digital health design), KM (age-tech design), JK (oncology digital health design), and VB (palliative care). AC and AT drafted this manuscript, with all co-authors contributing to its refinement.

Paper 2 (published): Concept analysis of "informal caregiver"

Cite as: **Castro, A. R**., Arnaert, A., Moffatt, K., Kildea, J., Bitzas, V., & Tsimicalis, A. (2023). "Informal caregiver" in nursing: An evolutionary concept analysis. *Advances in Nursing Science*, *46*(1), E29-E42. (AR Castro et al., 2022)

Contributions: I designed the study with AT and AA. I collected and analyzed the data. I discussed the preliminary and final data analyses with AT, JK, and KM. All authors made substantial contributions to the interpretation and discussion of the data, and to the final drafting of the manuscript.

Paper 3 (published): Environmental scan of Quebec palliative respite care agencies

Cite as: ***Castro, A.**, *Lalonde-LeBlond, G., Freitas, Z., Arnaert, A., Bitzas, V., Kildea, J., Moffatt, K., Phillips, D., Wiseblatt, L., Hall, A.J., Després, V., & Tsimicalis, A. (2024). In-Home Respite Care Services Available to Families With Palliative Care Needs in Quebec: Novel Digital Environmental Scan. *JMIR Nursing*, *7*, e53078. (Castro, Lalonde-LeBlond, et al., 2024)

*Co-first authors. GLL agreed in writing to give me the use of this publication as part of my manuscript-based dissertation. This manuscript was part of GLL's course-based Master's work, which I co-supervised with AT from 2021-2024. GLL has since graduated, and as hers was a course-based Master's degree, she did not need to use this manuscript in a thesis.

Contributions: I designed the study with GLL and AT. We confirmed the study design with AA, JK, and KM. GLL was primarily responsible for collecting the data, while I provided ongoing feedback and methodological direction. I analyzed the data with GLL and AT. We confirmed our environmental scan findings with clinician and caregiver key informants, DP, LW, AJH, VD, and VB. All authors contributed to the final drafting of the manuscript.

Paper 4 (published): Scoping review of respite care technologies

Cite as: **Castro, A. R.**, Brahim, L. O., Chen, Q., Arnaert, A., Quesnel-Vallée, A., Moffatt, K., Kildea, J., Bitzas, V., Pang, C., Hall, A.J., Pagnotta, A., & Tsimicalis, A. (2023). Information and communication technologies to support the provision of respite care services: scoping review. *JMIR Nursing*, *6*(1), e44750. (Castro et al., 2023)

Contributions: I designed the preliminary study protocol, with feedback from LOB, AQV, AA, and AT. AQV co-supervised me with AT for an independent study course to conduct this research. I was primarily responsible for data collection, with support from LOB, QC, and AP. I was primarily responsible for data analyses, with support from LOB, and AP. All authors contributed to writing the manuscript, finalizing the discussion points, and/or approving the final submission.

Paper 5 (published): Systematic search of respite care apps

Cite as: **Castro, A.,** Londono Velez, J. B., Nghiem, T., Moffat, K., Arnaert, A., Pagnotta, A., Gautrin, A., & Tsimicalis, A. (2024). A systematic search of publicly available mHealth apps for respite care coordination. *Canadian Journal of Nursing Informatics*, *19*(1). (Castro, Londono Velez, et al., 2024)

Contributions: I designed the study with AT. I provided guidance and methodological decisions while JLV, TN, and AP collected the data. JLV, TN, AP, and AG conducted preliminary data analyses, with ongoing feedback from me. All authors contributed to writing the manuscript, finalizing the discussion points, and/or approving the final submission. I revised and submitted the final draft of the manuscript for publication.

Paper 6 (in preparation): Results manuscript of the formative iRespite design

Cite as: **Castro, A.,** Moffatt, K., Lalonde-LeBlond, G., Arnaert, A., Kildea, J., Bitzas, V., Tsimicalis, A. (in preparation). iRespite Services iRépit: Formative design of an app proof-of-concept to accessibly coordinate respite care services for families with advanced cancers. To be submitted to the Journal of Medical Internet Research.

Contributions: I designed the study with AT, with feedback from KM, JK, AA, and VB. I collected the data across the three research phases, with support from GLL for conducting interviews in French. I analyzed all data, with feedback from GLL for confirmation of themes, and research team and Expert Council guidance following each research phase. I drafted and revised this manuscript, with all co-authors contributing feedback.

List of Figures and Tables

Note: Most figures and tables have two labels: one in brackets, for its placement within this dissertation, and a following label outside the brackets, for its placement within the manuscript.

Chapter 1: Introduction

Chapter 3: Paper 1: Published Protocol of Planned Methods

Chapter 4: Paper 2 – Concept analysis

Chapter 5: Paper 3: Environmental scan of Quebec palliative respite services

Chapter 6: Paper 4 – Scoping review

Chapter 7: Paper 5 – App store search

Chapter 8: Paper 6 – iRespite design

List of Abbreviations

App: Smartphone application

CG: Caregiver

CINAHL: Cumulative Index of Nursing and Allied Health

CISSS: Les centres intégrés de santé et de services sociaux

CIUSSS: Les centres intégrés universitaires de santé et de services

CLSC: Les centres local de services communautaires

CR: Care-receiver

GIS: Geographic information system

ICTs: Information and communication technologies

iRespite: iRespite Services iRépit

N: Nurse

UX: User experience

1.0 Introduction of this Dissertation

Respite care is an essential support service for families coping with functional dependencies caused by health challenges like advanced cancers (Rao et al., 2021). Without adequate support services such as respite care, family caregivers are at higher risk for negative role consequences, including mental distress, depression, sleep deprivation, and early-onset mortality (Adashek & Subbiah, 2020; AR Castro et al., 2022; Ochoa et al., 2020; Rao et al., 2021). Simultaneously, care-receivers[1] are at higher risk for inadequate care, hospital re-admissions, and ultimately, institutionalization when their care becomes impossible to manage at home (Adashek & Subbiah, 2020; Rao et al., 2021). With cancer as the leading cause of death in Canada, respite care needs during cancer care are rising (Brenner et al., 2024; Pesut et al., 2022; Thomas et al., 2020). Such respite care needs are particularly heightened during the advanced and palliative stages of cancer care, when symptoms management is prioritized over curative treatments (Nysaeter et al., 2024; Rao et al., 2021; Robinson et al., 2017).

Respite care services can provide family members with necessary reprieves from their intensive family caregiving and care-receiving roles (Rao et al., 2021; Robinson et al., 2017; Whitmore, 2022). There is growing research that respite care services at end-of-life can reduce family stress and reduce hospitalizations, helping to achieve families' goals of dying at home (Nysaeter et al., 2024; Rao et al., 2021; Robinson et al., 2017). However, homecare services like respite care are examples of complex health service interventions (Renyi et al., 2022; Wolkowski & Carr, 2017). Consistency in delivering appropriate respite care is difficult, as each family's needs are unique and sometimes conflicting within the family unit (Leocadie et al., 2018).

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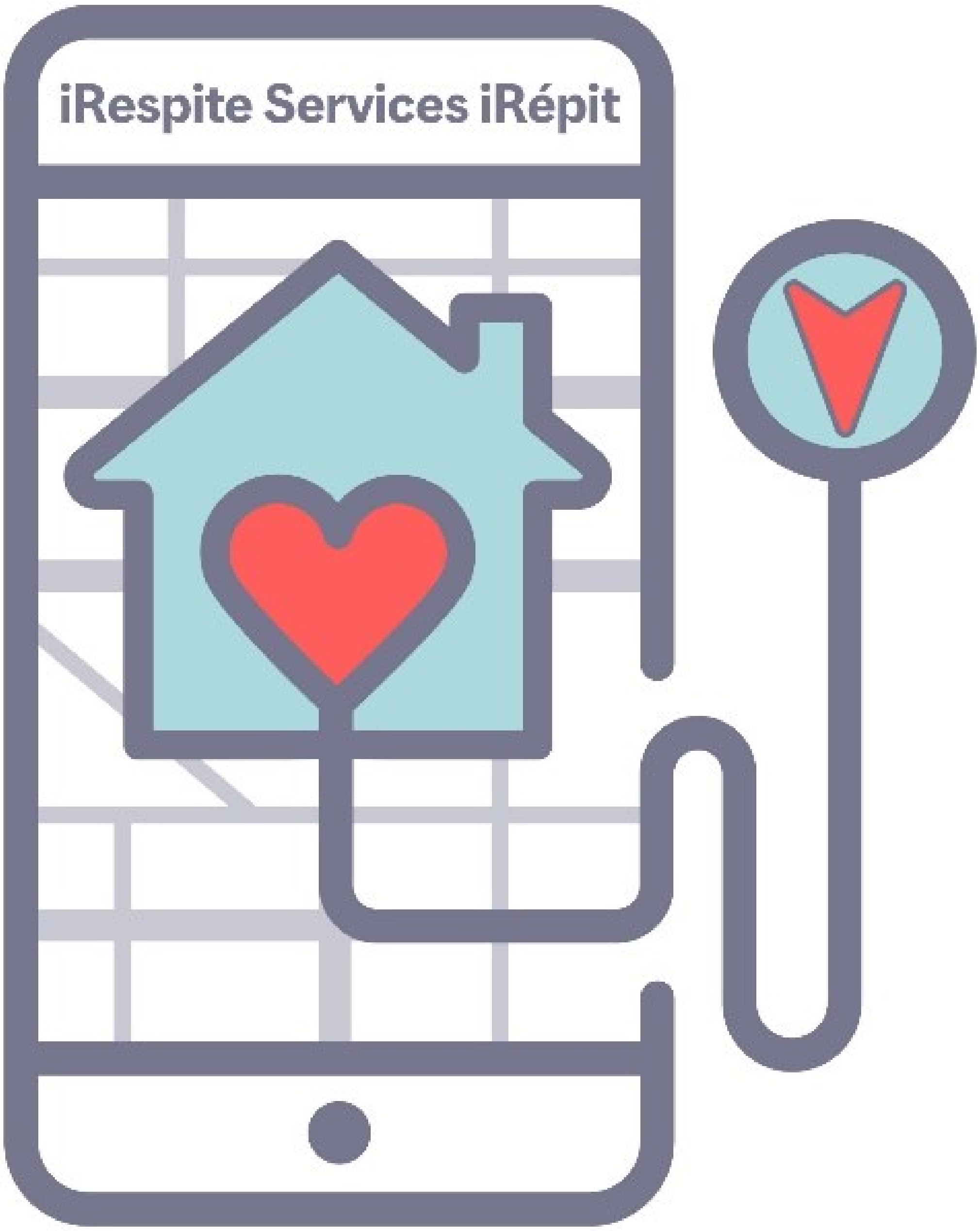
[1] Consistent with the focus on dyadic partnership highlighted in my concept analysis (Paper 2), I predominantly employ the more active terminology of "care-receiver" instead of "patient" or "care recipient" when addressing family care relationships within this dissertation.

Families' needs may also conflict with the capacities of under-resourced respite care organizations, as well as with the needs of respite care providers and the priorities of other health systems stakeholders in delivering the service (Leocadie et al., 2018; Renyi et al., 2022; Rousseau et al., 2019; Wolkowski & Carr, 2017). Combining these standard respite care challenges with the needs of families coping with advanced cancers creates additional complexities, as families cope with the uncertainties of the amount of time they have left, and with guilt for wanting respite care (Becqué et al., 2021; Rao et al., 2021).

Furthermore, respite care services are frequently difficult to access. Key barriers in accessing current respite care services are inflexible coordination systems (e.g., synchronous phone calls, voice mails, and pre-visit assessments) and inflexible scheduling (Castro et al., 2023; Phongtankuel et al., 2018; Robinson et al., 2017; Schurgin et al., 2021), with few options for urgent, overnight, and weekend care (Leocadie et al., 2018; Rao et al., 2021; Robinson et al., 2017; Rose et al., 2015a; Wolkowski & Carr, 2017). Another challenge is perceptions of inadequate respite care staff training, with families too often finding that when respite care providers arrive at their homes, they do not have the appropriate skillsets to support their families' needs (Rao et al., 2021; Robinson et al., 2017; Wolkowski & Carr, 2017). As a result of these complex challenges, even when respite care services are technically available, they may go unused, rendering them inaccessible (Leocadie et al., 2018; Robinson et al., 2017; Wolkowski & Carr, 2017).

Smartphone applications ("apps") present an innovative digital health opportunity to overcome some of the accessibility challenges of scheduling and trust in community-based health services like homecare and respite care (Abarca et al., 2018; Currin et al., 2019). There is burgeoning evidence that family caregivers of adults with advanced cancers and other palliative care conditions are invested in more flexible and asynchronous forms of support that can be delivered through smartphone apps (Heynsbergh et al., 2019; Phongtankuel et al., 2018). Service providers in other sectors are using such apps to improve service delivery scheduling, and to find appropriate matches between clients' needs and service providers' skills or offerings (e.g., Uber, TaskRabbit). However, our scoping review of respite care technologies (Chapter 6, Paper 4) (Castro et al., 2023) and appraisals of the iOS and Android app stores (Chapter 7, Paper 5) (Castro, Londono Velez, et al., 2024) revealed a notable gap in the delivery of respite care services across these international reviews: no appropriate app currently exists that was designed specifically to facilitate access to respite care services with trained providers for families with advanced cancers. This dissertation describes my iRespite Services iRépit ("iRespite") app design research that was undertaken to address this gap (Figure 1.1).

(Figure 1.1) iRespite Logo



1.1 Objectives of this Dissertation

The original aim of this iRespite research was to rigorously design a proof-of-concept of an app that families and nurses perceive to be relevant for facilitating the coordination of flexible and trusted respite care services between families seeking respite care and contractors providing respite care services. This platform design would be similar to an Uber-for-respite care model. However, with feedback from our Expert Council and participants, the purpose of the app design evolved beyond solely direct care coordination, to harnessing other aspects of smartphone capabilities to facilitate broader access to respite care services. Therefore, the final goal of this research was to rigorously design a bilingual proof-of-concept of an app that, once fully programmed, families and nurses would perceive to be relevant for facilitating access to in-home respite care services for families coping with advanced and palliative cancers in Quebec.

Key objectives for this PhD dissertation were determined by the research activities across the Rigor Cycle (knowledge synthesis activities), Relevance Cycle (participant feedback), and Design Cycle (artifact creation) of the methodological framework (Hevner, 2007). These cycles are further described in the Chapter 2.3 Methodology section. The objectives were as follows:

(1) For the Rigor Cycle, the objective was to synthesize relevant literature and knowledge on caregiving and respite care support needs, digital health design for respite care, and accessible service design, to inform the interview guides and proof-of-concept design.

(2) For the Relevance Cycle, the objective was to explore with nurses, family caregivers, and care-receivers, how to best design an app that is relevant for addressing families' respite care needs when they are coping with advanced cancers.

(3) For the Design Cycle, the objective was to sketch and refine across the research phases, a proof-of-concept design of an app that facilitates access to respite care services, which could meet the needs of families coping with advanced cancers in Quebec.

2.0 Comprehensive Review of the Relevant Literature

This Chapter 2 literature review provides an overview of the three distinct areas of research that my doctoral research is situated within. These three areas are: (1) understanding the respite care requirements of families, particularly those coping with advanced cancers and palliative care needs, both globally and in Quebec (Chapter 2.1); (2) designing digital health tools, such as websites or apps, to address key challenges for families in accessing respite care services (Chapter 2.2); and (3) describing the methodological contexts of this participatory design science research (Chapter 2.3). These three areas informed the creation of the Chapter 3 (Paper 1) published protocol, as well as of Chapters 4-7 (Papers 2-5) consisting of knowledge syntheses that delved further into these three areas.

2.1 Respite Care Needs for Advanced Cancer Care, Especially in Quebec

2.1.1 The paradox of respite care: High demand, yet under-utilized

Respite care is a healthcare service that is intended to provide temporary relief of caregiving responsibilities to family caregivers, while simultaneously offering supportive care to care-receivers (Evans, 2013b; Rose et al., 2015a). A concept analysis of "respite" found that respite care is both, the provision of the service, as well as the ideal outcome of that service, conducted in partnership between respite care providers, family caregivers, and care-receivers (Evans, 2013b). Respite care services benefit family caregivers by providing temporary breaks from their intensive family caregiving roles, allowing family caregivers to engage in their paid work and leisure, attend medical appointments, and catch up on sleep (Rao et al., 2021; Wolkowski & Carr, 2017). Respite care services can benefit care-receivers by offering them access to and choice in additional supports from others outside of their family unit. These respite care services can help provide care-receivers with physical, mental, and emotional supports, without feelings of burden that sometimes accompany care-receivers in family caregiving dyads (Evans, 2013b; Wolkowski & Carr, 2017). Respite care can be provided in-home, in community day centres, and in healthcare institutions, although in-home respite care is often preferred by families (Rao et al., 2021; Robinson et al., 2017; Rose et al., 2015a). Respite care providers can be volunteers, trained homecare workers, or nurses, depending on the level of care needed (Barrett et al., 2009; Rao et al., 2021; Rose et al., 2015a; Whitmore, 2022).

Beyond providing temporary relief to families from their intensive family roles, respite care may also lead to improvements in quality of life and societal benefits for families and communities, including strengthening family units, and delaying or reducing the need for institutionalized care (Rao et al., 2021; Utz, 2022; Whitmore, 2022). Quantitative and economic analyses of respite care services are more limited with mixed results on the benefits of respite care, due in part to the challenges of measuring the effects of complex and fragmented respite care services (Rose et al., 2015a; Whitmore, 2022). However, qualitative studies and knowledge syntheses, as well as community health and long-term care stakeholders, all consistently emphasize that in practice, respite care services are crucial support services for families coping with intensive caregiving and care-receiving roles (Rao et al., 2021; Thomas et al., 2020; Utz, 2022; Whitmore, 2022).

These methodological challenges contribute to the known paradox of respite care: while respite care is in high demand and considered an essential support service for families, respite care services are also often under-utilized by families, even when they are apparently available (Leocadie et al., 2018; Rose et al., 2015a; Whitmore, 2022). Reasons for this under-utilization of respite care include inflexibility in scheduling, lack of trust in the respite care providers' training and skillsets, lack of affordable services, and feelings of guilt among family caregivers for wanting respite care (Leocadie et al., 2018; Rao et al., 2021; Robinson et al., 2017; Thomas et al., 2020; Viens, Éthier, et al., 2024). When inadequate but available respite care services are nonetheless used by families, such families are at risk for experiencing additional new stressors due to the services' inadequacies, rendering the services less approachable and therefore less accessible (Robinson et al., 2017; Wolkowski & Carr, 2017). If this paradox is to be resolved, services need to be truly accessible and designed to meet families' diverse needs.

Later in this chapter (section 2.2), as well as in the knowledge syntheses conducted for this dissertation (Chapters 4-7), I delve further into possibilities for addressing this paradox by designing respite care digital health tools and services that are more accessible, and thus more widely available, used, and effective. However, before proceeding to exploring the potential of digital health tools to address key challenges in respite care access, I will first discuss the specific respite care needs of families coping with advanced cancers and related palliative care needs. For this work, we defined this population as adults living with cancers staged 3 or 4, and/or receiving palliative care services (*Advanced cancer*, 2024).

2.1.2 Respite care for families with advanced cancers and palliative care needs

As populations age, cancer cases are rising worldwide (Brenner et al., 2024; Lambert et al., 2016). For adults living with advanced cancers, families are increasingly called upon to care for members living with advanced cancers (Rao et al., 2021; Thomas et al., 2020). Often, these family caregivers have promised their care-receivers that they will be able to die at home, but frequently, neither realizes the intensity of the skilled care required to enable death at home (Nysaeter et al., 2024; Robinson et al., 2017; Wolkowski & Carr, 2017). Such care includes providing psychosocial and bereavement support, providing transportation to appointments, managing feeding tubes and central lines, performing wound care, managing finances, providing hygiene care, cooking, and sanitizing the environment, among many other responsibilities (AR Castro et al., 2022; Lambert et al., 2016). A 2013 Statistics Canada report found that cancer caregiving is one of the top three most intensive forms of caregiving in Canada (Sinha, 2013). A 2015 report by the National Alliance for Caregiving in the United States found that family caregivers of persons with cancer were spending over 32 hours per week of caregiving over nearly 2 years, on average (Hunt et al., 2016). With similar aging and cancer diagnosis demographics, Quebec caregiving time-costs likely align with these reports.

As a result of these challenges for end-of-life care, and with insufficient palliative homecare supports, nearly half of Canadians die in-hospital rather than at home or in a community care setting (CIHI, 2023). Only 13% of Canadians presently die at home with formal palliative care supports, like specialized respite care (CIHI, 2023). A 2022 survey study of 150 palliative care stakeholders in Canada found that while some areas of palliative care services in Canada have improved since the implementation of the 2018 Canadian Palliative Care Framework and Action Plan, other service areas have faltered. In particular, improvements had been made in leveraging palliative care technologies, but few improvements had been made in family caregiving supports, with respondents reporting that quality of respite care and in-home palliative care supports had decreased since the COVID-19 pandemic began (Pesut et al., 2022).

Respite care access is one of the most cited unmet needs by family caregivers of those living with advanced illnesses like cancer (Rao et al., 2021; Thomas et al., 2020). Yet, respite care services can benefit both family caregivers and care-receivers with advanced cancers and other serious illnesses by offering short breaks and relief from these intensive family roles. There is compelling qualitative research that in-home respite care services can reduce hospitalizations and help to achieve families' goals of dying at home (Nysaeter et al., 2024; Rao et al., 2021; Robinson et al., 2017). However, the paradox of respite care being in-demand yet under-utilized may particularly apply to families coping with the challenges of advanced cancer care (Hunt et al., 2016). These challenges include: needing both increased flexibility and availability of in-home respite care, which is preferred by families with cancer; managing guilt by family caregivers for wanting time away from their dying care-receiver; and lacking trust in respite care providers' abilities to offer appropriate palliative respite care (Robinson et al., 2017; Thomas et al., 2020; Wolkowski & Carr, 2017). Cancer caregivers, in particular, are also known to under-utilize the support services that may be available to them (Hunt et al., 2016; Lambert et al., 2016). For these families, a palliative approach to respite care may be needed, where providers have palliative care training, are comfortable managing hygiene care for a person who is frail and in pain, and perhaps most importantly, have the interpersonal skills and training to meet families where they are at, and to offer accompaniment in their unique grieving processes (Rao et al., 2021; Wolkowski & Carr, 2017).

2.1.2.1 Quebec context for advanced cancers and palliative respite care needs

Quebec manifests many of the challenges for accessible respite care services that have been noted in the national and international respite care literature. In 2024, alone, Quebec is projected to have 63,000 cases of cancer, and 22,800 deaths (Brenner DR & L, 2024). With Quebec's aging population and cancer being the largest cause of mortality in the province, the need for appropriate respite care services is increasing for cancer caregiving families (Brenner et al., 2024; *Causes de décès*, 2024).

In 2020, the Quebec Cancer Society made a call for more in-home palliative care supports, including services like respite care to support family caregivers (*Ccs: Quebec*, 2020). Yet, as our environmental scan found, accessible and appropriate respite care services are frequently unavailable to Quebecers with palliative support needs (Chapter 5, Paper 3) (Castro, Lalonde-LeBlond, et al., 2024). Navigating the fragmented patchwork of public, non-profit, and for-profit services is a challenge for time-strapped clinicians and families who are already overwhelmed by caregiving responsibilities and coping with the imminent death of the person they are caring for (Castro, Lalonde-LeBlond, et al., 2024; Viens, Éthier, et al., 2024). Furthermore, with one of the oldest populations in Canada, and with the large geography and multi-lingual needs of Quebec families, comprehensive access to respite care services that can meet Quebec families' diverse needs is extremely difficult to achieve (Castro, Lalonde-LeBlond, et al., 2024). Quebec needs new tools to improve comprehensive access to respite care services across the province, especially for families with palliative care support needs.

2.2 The Potential of Smartphone Apps to Facilitate Respite Care Access

For respite care services to be more accessible, the services must be geographically available, provided by skilled and trained respite care staff, and offered with flexibility and adaptability for families' unpredictable caregiving trajectories (Castro, Lalonde-LeBlond, et al., 2024; Viens, Éthier, et al., 2024). This accessibility can be created in part by offering flexible scheduling and coordination, and by designing respite care coordination platforms that engender trust in the service and in providers' training, and that offer gentle nudges to access respite care (Castro et al., 2023).

Digital health tools like smartphone apps have increasingly powerful capacities to address several of these challenges for accessing respite care services. Smartphones offer: geolocation for immediately finding available providers and services; multimedia supports for sharing respite care information and provider training resources; and synchronous and asynchronous messaging for communication, scheduling, and auditing (Bining et al., 2022; Phongtankuel et al., 2018; Schurgin et al., 2021).

Designing such an app to help resolve the paradox of respite care was a key driver for my doctoral research. Chapter 6 (Paper 4 – scoping review) and Chapter 7 (Paper 5 – app store search) of this dissertation present our published knowledge syntheses that delve further into the current landscape of digital health tools for facilitating access to respite care services. Paper 4 is a scoping review of the academic literature of how information and communication technologies (ICTs), including apps, have been studied to date for supporting the provision of respite care services. Paper 5 is a systematic search of the Apple iOS and Android Google Play app stores for existing apps that coordinate respite care services.

2.2.1 Beyond apps: Other web-based respite care platforms

In addition to the apps identified in my scoping (Paper 4) and app store (Paper 5) knowledge syntheses, we also reviewed other web-based platforms, such as the popular American platform care.com, that focus more on website coordination of their services rather than on app-based coordination. These web-based platforms typically lack the advanced features and functionalities of a dedicated app, including ease of access, geolocation with estimated time of arrival for visits, and notification capabilities. Existing web-based platforms have been criticized for not guaranteeing appropriate background checks or specialized training, placing the burden of determining trustworthiness of the service on families (Grind, 2019). Furthermore, these platforms, like many respite care apps, typically group various types of caretaking services together, including pet care, babysitting, and home cleaning, without a specific focus on respite care for adults with functional dependencies (Ticona & Mateescu, 2018). When many services are grouped together, seeking out specific services like respite care can be difficult for families to do.

In contrast to these platforms, our iRespite app is designed to provide a more comprehensive and specialized respite care solution for families with advanced and palliative cancer support needs. We used the identified strengths and weaknesses of these apps and web-based respite coordination platforms to inform the design of iRespite.

Based on this literature review and our published knowledge syntheses (Chapters 6-7), there are very few apps for facilitating access to respite care, and to our knowledge, none have been designed with and for families coping with advanced cancers or palliative support needs. As will be discussed in Chapter 6 (Paper 4 – scoping review), this literature emphasized the importance of participatory design methods for developing respite care services and digital health tools, such as ICTs and apps, to ensure that these services and technologies effectively meet the needs of end-users. This emphasis on the value of participatory approaches to respite care ICT design validated our decision to conduct a user-centred design study – a methodology that I will describe in the next section.

2.3 Methodology: User-Centred, Formative Design

Participatory design methods align well with the paradigm of design science, which focuses on theorizing and designing novel artifacts to solve problems (Baskerville et al., 2018). Design science research is a paradigm of the "artificial sciences" within the pragmatist tradition, in contrast with research paradigms focused on the "natural sciences", such as physics, and the "human sciences", such as behavioral psychology (Baskerville et al., 2018; Hevner, 2007). Design science "invents or builds new, innovative artifacts for solving problems or achieving improvements . . . Such new and innovative artifacts create new reality, rather than explaining existing reality or helping to make sense of it" (p. 9) (Iivari & Venable, 2009).

A specific type of participatory design is user-centred design, sometimes called “human-centred design”, which is becoming a gold standard for digital health design research (Cornet et al., 2020; Risling & Risling, 2020). User-centered design is a broad research approach for constructing problem-solving artifacts with end-users (Farao et al., 2020; Risling & Risling, 2020; Still & Crane, 2017). Key principles of the user-centered design methodology include: (1) end-users are significantly involved throughout the entire design process, (2) empirical methods are used to evaluate the relevance of the artifact for addressing end-users’ needs, and (3) the artifact is iteratively refined (Cornet et al., 2020; Still & Crane, 2017).

There are two broad periods for designing an artifact: the *formative* design period, where the main goals, features, and content of the artifact are iteratively established, often through qualitative methods; and the *summative* design period, leading to artifact development and implementation, where the artifact undergoes more quantitative usability testing to refine the features and assess overall effectiveness in achieving the desired aims (Still & Crane, 2017). Formative design of a complex artifact like a digital health intervention is difficult. As (Rousseau et al., 2019) noted when interviewing researchers in complex health intervention design, “Design is more varied and more challenging than other intervention development actions” (p. 6). They also found that “the action of designing the intervention, that is generating ideas and making decisions about the content, format and delivery of the intervention, varied substantially, and challenges were more difficult to overcome" (p. 7) (Rousseau et al., 2019). These authors argue that it can be difficult to find explicit guidance for the design-stage of creating complex interventions, which I also found to be the case - until I discovered a detailed user-centred research framework from the discipline of Information Systems.

The Information Systems Research Framework (Hevner, 2007) is a methodological framework that outlines key design science research goals and activities for constructing rigorous and relevant ICT artifacts with end-users (Farao et al., 2020; Hevner, 2007). The framework focuses on integrating diverse data sources, such as literature reviews, expert advising, focus groups, and end-user testing, to build and test the artifact. This framework offers three explicit, iterative research cycles to achieve rigorous artifact design: (1) the Rigor Cycle, where relevant literature and kernel theories are consulted and synthesized; (2) the Design Cycle, where the artifact is iteratively designed and internally evaluated by the team, and (3) the Relevance Cycle, where end-user and stakeholder needs are clarified, and where the design is assessed by end-users for the relevance of the design towards addressing their needs. I opted to use this framework because it provides strong guidance on how to conduct rigorous research to design complex artifacts. It has also been successfully followed by other nursing and community health scholars for digital health research (Farao et al., 2020; Schnall et al., 2016).

Given the challenges of conducting rigorous formative design work, my doctoral research focused primarily on the formative design, i.e., designing a proof-of-concept of an app to facilitate access to respite care services. I focused on formative design to ensure that we first created a rigorous app design, before moving forward with future programming, summative testing, and implementation during my postdoctoral research.

3.0 Paper 1: Published Protocol of Planned Methods

3.1 Bridge 1

The first manuscript of this dissertation is my original protocol, published in 2021 prior to the commencement of data collection. As other scholars have noted, formative design research in healthcare is difficult to conduct, with various potential methods to choose from but few established guidelines (Cornet et al., 2020; O'Cathain et al., 2019b; Rousseau et al., 2019). Furthermore, the methods sections of most published research papers are typically concise, with only the major research steps reported. For these reasons, we believed that publishing a detailed protocol of our proof-of-concept research in nursing would be beneficial to other scholars seeking more detailed insights on formative digital health research processes. This protocol may be particularly useful for scholars aiming to design apps for health service coordination, as well as for scholars who are planning on using the Information Systems Research Framework (Hevner, 2007).

Given that our approach was iterative and user-centred, we noted in the published protocol that the proposed methods and aims might change once data collection began, depending on feedback from the Expert Council and other study participants. Since the publication of this protocol, significant changes mere made to the methods and aims of this dissertation. Firstly, during Phase 2 (low-fidelity sketching), I realized the design would benefit from further formative design research with a higher-fidelity proof-of-concept. My research team agreed, so we conducted an additional phase of interview-based formative design with the proof-of-concept in Phase 3, rather than moving on to usability testing with a clickable prototype[2]; summative usability testing

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[2] I use the term "proof-of-concept" to refer to lower-fidelity and higher-fidelity wireframes of a non-interactive artifact. I use "prototype" to refer to a higher fidelity, clickable version of the artifact. Other scholars and industry professionals may use these concepts interchangeably (e.g., O'Cathain, 2019b).

is what we had originally proposed in the published protocol, which would have necessitated a larger sample size than our formative research required. Secondly, after experiencing difficulties recruiting care-receivers who were actively receiving palliative care services, we expanded participant recruitment to adults living with advanced cancers. Thirdly, we used convenience rather than purposive sampling. Fourthly, based on participant feedback, we focused on designing the app for respite care providers who would have palliative care training, but who would not necessarily have to be nurses. These changes are further detailed in Chapter 8 (Paper 6 - iRespite formative design results), and in the Chapter 9 Discussion of this dissertation.

3.2 Paper 1 Manuscript

Cite as: 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.

(A. Castro et al., 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

Abstract

Background: Patients living with palliative-stage cancer frequently require intensive care from their family caregivers. Without adequate community support services, patients are at risk for inadequate care, and family caregivers are at risk for depression and poor health. For such families, in-home respite care can be invaluable, particularly when the services are flexible and staffed by trusted care providers, such as nurses. Other industries are using mobile applications ("apps") to make services more flexible. However, few apps have been developed to coordinate nurse-provided respite care services, and to our knowledge, none have been designed with families with cancer.

Objective: The aim of this study is to develop an mHealth app prototype for coordinating flexible and trusted in-home respite care services, provided by nurses to families coping with palliative-stage cancer in Québec, Canada.

Methods: This user-centered design research comprises the core component of the *iRespite Services iRépit* research program. For this study, we are recruiting 20 nurses, 15 adults with palliative-stage cancer, and 20 of their family caregivers, from two palliative oncology hospital departments, and one palliative home-care community partner. Overseen by an Expert Council, remote data collection will occur over three research phases guided by the iterative Information Systems Research Framework: Phase 1, brainstorming potential app solutions to challenging respite care scenarios, for better supporting the respite needs of both family caregivers and care recipients; Phase 2, evaluating low-fidelity proofs-of-concept for potential app designs; and Phase

3, usability testing of a high-fidelity interactive proof-of-concept that will then be programmed into an app prototype. Qualitative and quantitative data will be descriptively analyzed within each phase and triangulated to refine the app features.

Results: We anticipate that preliminary results will be available by Spring 2022.

Conclusions: An app prototype will be developed that has enough complimentary evidence to support future pilot testing in the community. Such an app could improve the delivery of community respite care services rendered to families with palliative-stage cancer in Québec, supporting death at home, which is where most patients and their families wish to be.

Keywords: Respite Care; Caregivers; Cancer; Neoplasms; User-Centered Design; Mobile Applications; Palliative Care; Home Care Services; Information Systems Research Framework; Hospice and Palliative Care Nursing

Introduction

Cancer is the leading cause of death in both Canada and Québec, with nearly 50% of Canadians developing the disease at some point in their lives (Brenner et al., 2020; *Quebec cancer foundation*, 2020). Cancer symptoms often result in patients relying heavily on the skilled assistance of their family caregivers to continue living in the community, where most palliative care patients want to be (*Ccs: Quebec*, 2020; *Fact sheet: Cancer in Canada*, 2018; Sinha, 2013). However, without adequate support services, patients are at higher risk for inadequate care and for costly hospital re-admissions if their care becomes impossible to manage at home (Adashek & Subbiah, 2020; Rao et al., 2021). Simultaneously, family caregivers encounter a high risk for negative role consequences, including sleep deprivation, depression, reduced immunity, and early-onset mortality (Adashek & Subbiah, 2020; Guerriere et al., 2016; Lambert et al., 2016). These risks are heightened during the palliative-stage of cancer, when complex symptoms management is prioritized over curative treatments (Adashek & Subbiah, 2020; Guerriere et al., 2016).

As cancer cases in Québec continue to rise (*Quebec cancer foundation*, 2020), in-home respite care can be a crucial support service for families (Rao et al., 2021; Thomas et al., 2020). Respite care services offer opportunities for caregivers and care recipients to experience short breaks from each other and their care-giving/care-receiving family roles, while another person provides care (Evans, 2013b; Miriam S Rose et al., 2015). Yet, based our preliminary research, including literature reviews and discussions with directors of palliative and respite care organizations, the current landscape of these services in Québec is fragmented, with services often being difficult to access (*Ccs: Quebec*, 2020). Most families accessing respite care services pay out-of-pocket, creating a potential affordability barrier (Alfano et al., 2019; *Respite care in Canada*, 2012). Furthermore, respite care services often have inflexible hours, and are typically staffed by homecare providers who lack clinical expertise (Barrett et al., 2009; Robinson et al., 2017; Smith et al., 2017b; Thomas et al., 2020). As a result of these barriers, respite care services are often underutilized, especially by families managing complex medical cases such as palliative-stage cancer (Robinson et al., 2017; Miriam S Rose et al., 2015).

Families coping with palliative-stage cancer require easily scheduled respite care services staffed by trusted providers (Barrett et al., 2009; Muliira et al., 2019; Robinson et al., 2017). Nurses are consistently ranked as the most respected and trusted profession by the public (Milton, 2017). With their extensive clinical and theoretical training, nurses may be best positioned to provide trusted respite care services to families coping with complex care conditions (Barrett et al., 2009; Muliira et al., 2019). Furthermore, these nursing services could be flexibly scheduled with opportunities to personalize the services received, by mobilizing the capabilities of mHealth applications ("apps") (Currin et al., 2019; Phongtankuel et al., 2018).

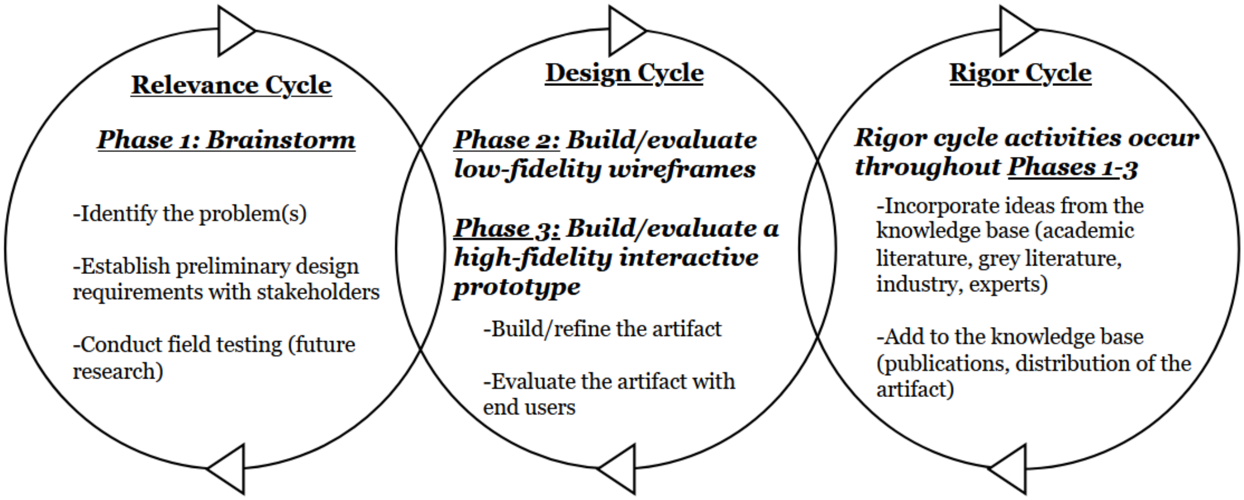
This context warrants the creation of a new mHealth app to optimize the flexible coordination of respite care services in Québec, beginning with nurse-provided services for palliative-stage cancer. Other service providers such as AirBnB and DoorDash are using apps to improve service coordination by facilitating communication and scheduling. However, we have not identified any apps in academia or industry that focus on providing respite care services to families coping with cancer. Moreover, we have only identified one app in the research literature for specifically coordinating nurse-provided respite care services to families with age-related chronic conditions (Currin et al., 2019). Therefore, the aim of this study is to develop an mHealth app prototype for coordinating flexible and trusted in-home respite care services, provided by nurses to families coping with palliative-stage cancer in Québec. This study has been awarded a

Rossy Cancer Network Care, Quality, and Innovation research fund grant (2020) to support the work described (Multimedia Appendix 1).

Study Design & Framework

Following ethical approval, a user-centered design study will be conducted over three phases to develop a rigorous and relevant app prototype (Fox et al., 2008; Norman & Draper, 1986; Schnall et al., 2016; Still & Crane, 2017). An Expert Council composed of the research team and five key informants will oversee the study. *Phase 1* will consist of brainstorming how an app might be used to address families' needs, given various respite care scenarios. *Phase 2* will involve wireframing several low-fidelity *proof-of-concept* app designs and prioritizing key features. *Phase 3* will consist of designing and testing the usability of a high-fidelity interactive proof-of-concept (i.e., the online design will be "clickable"), which will then be programmed into a functional app *prototype*. The cyclical Information Systems Research Framework (Hevner, 2007) has been adapted to inform each study phase (Figure 1). The iterative and integrative cycles of this framework consist of the: (1) relevance cycle, composed of research activities supporting end-user app refinement; (2) rigor cycle, where external knowledge and research is synthesized for informing the app design; and (3) design cycle, where the app is built into a functional prototype.

(Figure 3.2.1) Figure 1. An adaptation of the Information Systems Research Framework (*Hevner, 2007*), with its three methodological cycles, will guide the proposed study.



Objectives

The objectives are as follows:

(1) To explore participants' perspectives on the relevance of mHealth for the provision of nurse-provided respite care services.

(2) To design a rigorous and relevant proof-of-concept of a mHealth app for coordinating trusted and flexible respite care services, provided by nurses, to families coping with palliative-stage cancer.

(3) To conduct usability testing on the interactive proof-of-concept to support the development of a functional app prototype.

Description of the Potential App

The development of this app comprises the core component of the *iRespite Services iRépit* research program led by the manuscript authors. Depending on participants' needs identified throughout the study, the resulting app prototype could facilitate advanced and flexible scheduling for respite care with the same nurse-providers, or perhaps even offer on-demand scheduling. We predict that the final prototype will include features to support separate but integrated processes (i.e., "dashboards") focused on the needs of the two primary end-users of the app: family caregivers and nurses. The dashboard for family caregivers will likely allow caregivers to sign up and directly schedule nurse-provided respite care services, with opportunities to request a nurse with specific skills (e.g., experience caring for patients with a specific type of cancer) or payment option (e.g., nurses whose services might be reimbursed through insurance). The dashboard for nurses will likely allow the nurses to sign up, describe their skills and certifications, and indicate their availabilities to provide respite care. However, since this study will incorporate ongoing end-user participation, we anticipate that our current predictions of the prototype features will differ significantly from the final prototype design.

Methods

Sampling Methods

Target Sampling Networks

The targeted online sampling networks will comprise the patient, family, and nursing networks of two palliative oncology hospital departments, and one palliative home-care community partner, in Montreal, Québec.

Participant Eligibility

The recruited sample will be composed of: (1) family caregivers of adults living with palliative-stage cancer (“family caregivers”), (2) adults living with palliative-stage cancer (“care recipients”), (3) registered nurses (“nurses”), and (4) key informants.

Inclusion criteria for all participants will consist of adults (18 years or older) who live in Québec. *Family caregivers* must self-identify as a family caregiver providing in-person care to a person diagnosed with cancer who is: (a) receiving palliative care services or (b) known to the palliative care teams of the target sampling networks. Family caregivers may also be up to 6 months post-bereavement to a person diagnosed with cancer who had received palliative care services via the target sampling networks. *Care recipients* will be cancer patients who have a family caregiver providing them with regular in-person care. Care recipients will be either: (a) receiving palliative care services, or (b) known to the palliative care teams of the target sampling networks. *Registered nurses* will consist of nurses who are licensed in Québec and who have experience in providing home-care, palliative care, respite care, and/or oncology care. *Key informants* will be identified by the research team as having relevant knowledge and expertise related to the management and deployment of the overall project.

Exclusion criteria for all participants will be that they: (1) are not comfortable speaking and reading in English or French, (2) are unable to provide consent, or (3) do not have access to an Internet-connected device capable of video-conferencing.

Sample size

Sample sizes for Phases 1 and 2 focus groups and interviews

The participant numbers and research activities for each research phase are displayed in Multimedia Appendix 2.

Thirty participants (10 nurses, 10 family caregivers, and 10 care recipients) will be needed for the Phase 1 focus groups and individual interviews. These same participants will be invited to participate in Phase 2 focus groups and interviews. Focus groups for formative user-centered design research should be large enough to encourage brainstorming among diverse, representative target end-users, but these groups should be no larger than 12 participants (Still & Crane, 2017; Tremblay et al., 2010). Therefore, a total of 10 participants for each major type of focus group (nurse, family caregiver, and care recipient), further divided into English or French focus groups, should offer appropriate focus group sizes for the proposed research.

Sample sizes for Phase 3 usability testing

Phase 1 and 2 nurses and family caregivers will be invited to participate in Phase 3. An additional 5 nurses and 5 family caregivers will be recruited for individual usability testing to provide new perspectives on the interactive proof-of-concept (Schnall et al., 2016; Still & Crane, 2017), for a total of 15 nurses and 15 family caregivers participating in this phase. A sample size of 15 in each sample sub-group is estimated to identify at least 90% of usability problems in artifact design (Faulkner, 2003; Sauro & Lewis, 2016).

Expected recruitment for this study, accounting for attrition rates

Attrition rates for palliative-care studies, conducted over the course of several months to over one year, can range from 24% (Samuels et al., 2021) to 63% (Ahlner-Elmqvist et al., 2009). Flexible research strategies, video-conferencing, and in-home data collection can increase enrolment and reduce attrition in the palliative care population (Applebaum et al., 2012; Hanson et al., 2014; Hudson, 2003). Our research will be implementing these strategies of virtual and in-home data collection, which should improve participant enrolment and retention in our study.

We anticipate that family caregivers will have similar retention rates to those of care recipients, given how intertwined family caregiver and care recipient roles are (Hanson et al., 2014). Assuming a 50% attrition rate for each group of participants over the course of the study, we expect to recruit 15 care recipients, 20 family caregivers, and 20 nurses in total, to achieve the above sample sizes for each phase. With 5 key informants recruited for the Expert Council, the total sample size will be 60 participants recruited remotely across the study sites.

Recruitment

In the current context of COVID-19, this study has been adapted to recruit and collect data solely online. Purposive sampling will be used to recruit potential participants via the targeted nursing-, respite, and cancer-related networks (Palinkas, 2015; Still & Crane, 2017). Collaborators within these target networks will be requested to share the bilingual study brief with nurse employees in the networks, as well as with families receiving palliative care services, via the associated social networks and institutional apps of the target networks (i.e., the organizational social media accounts; email list-servs; workplace communications; intranets; institutional apps; and on-site television screens). The study brief will contain bilingual links to the study Qualtrics contact forms for interested family caregivers, care recipients, and nurses to follow up with the team. Key informants will be directly recruited via email by the doctoral candidate on this study.

Eligible recruits who follow up using the Qualtrics contact form, as well as key informants who indicate interest, will be contacted by a member of the research team to set up a videoconferencing appointment to further explain the study. Once they have received information about the study purpose and scope, informed consent will be sought by all participants through a Qualtrics e-consent form.

Participants will be purposively chosen based on a few demographic questions that will be included in the consent forms. Family caregivers and care recipients will be chosen to achieve sample diversity according to age (Romito et al., 2013), cancer typology (Yabroff & Kim, 2009), and gender (Morgan et al., 2016; Romito et al., 2013). These factors are known to affect individuals' cancer caregiving and care receiving experiences (Morgan et al., 2016; Romito et al., 2013; Yabroff & Kim, 2009), as well as their perspectives on mHealth supports (Lewis et al., 2016; Seiler et al., 2017). Nurses will be purposively recruited to ensure a diversity of relevant perspectives on palliative care, oncology nursing, respite care, and homecare services (Arnaert & Wainwright, 2009; Kiyanda et al., 2015).

Purposively chosen participants will be contacted by email, a mutually agreed upon focus group or individual interview date will be arranged, and a videoconferencing invitation will be sent. Once the target sample size and diversity have been achieved, any additional eligible recruits will be placed on a waitlist for future inclusion, should participant attrition of the original 30 participants from Phase 1 occur.

Each participant will be offered a $25 gift card for either Visa or Mastercard following each interview or focus group that they choose to participate in (Richards et al., 2018). A $500 stipend will be offered to each key informant at the end of the study, following their participation in the fourth Expert Council meeting and their ongoing advisement on the study. Key informants will be asked to provide a maximum of 15 hours of work over the course of the study (Richards et al., 2018).

Data Collection

Setting

Participant data collection will be conducted remotely using videoconferencing software. All Expert Council meetings, focus groups, individual interviews, and usability test sessions will be video-recorded using Microsoft Teams or Zoom built-in recording functionalities, to record participant interactions with the different app designs. Although we will encourage key informants and participants to keep their video-cameras on, they will be allowed to turn off their video-cameras if they choose to do so. All meetings will also be audio-recorded for back-up using a voice-recorder. Focus groups, individual interviews, and proof-of-concept usability testing sessions should last between 60 to 90 minutes. The interviewer (Phases 1 and 2) or test session guide (Phase 3) will be PhD candidate Castro and/or a member of the research team. Another member of the research team will record field notes during data collection, recording observations about what participants see, say, and do (Bernard, 2017; Still & Crane, 2017).

Phases 1-3: Rigor cycle 1 (ongoing)

Literature and app store reviews are presently ongoing and will continue throughout the three phases with the support of a librarian scientist. Google Scholar and Google Search Engine alerts have been set up to receive notifications of new, relevant data sources for further informing the design of the proof-of-concepts and the development of the functional app prototype.

Phase 1: Brainstorm mHealth solutions to respite care scenarios

Relevance cycle 1: Determine respite care problem scenarios and brainstorm together

During the first Expert Council meeting, the key informants will review the study materials prior to the recruitment of other participants. The review of the study materials by the key informants will help ensure that the proposed study is designed to meet the needs of end-users and other stakeholders. In this first meeting, the Expert Council will also determine 2-3 brief respite care video scenarios to be created using an animation software such as Doodly (*Doodly*, 2020). These videos will be discussed during the upcoming Phase 1 focus groups and interviews with nurses, family caregivers, and care recipients. Summary notes will be taken during all Expert Council meetings.

Next, 3-6 focus groups will be conducted in English and French with nurses (1-2 groups), family caregivers (1-2 groups), and care recipients (1-2 groups). Each participant will complete an online Qualtrics demographic survey prior to the meetings. Using semi-structured interview guides, the interviewer will ask participants about their experiences and interests in respite care, their thoughts on mHealth apps to potentially support palliative-stage family caregiving, and any service coordination apps they currently like or dislike and why. Examples of the key questions and instructions for participants in each phase are listed in Multimedia Appendix 3. The whiteboard, chat, and other key features of the videoconferencing software will be used to help illustrate key points arising from the discussion and promote online engagement. Following these initial discussions, the interviewer will share various potential respite care scenarios that palliative-stage oncology families might find themselves in. Participants will discuss if and how mHealth apps might be used to support the families in those situations.

Finally, follow-up semi-structured individual interviews will be conducted with a total of any 8-10 participants who agree to be individually interviewed, to gain a more in-depth understanding of participants' perspectives on mHealth, apps, and respite care (Lambert & Loiselle, 2008). These individual interview participants will be recruited from among participants who participated in the focus groups, or selected from eligible recruits who preferred to only participate in individual interviews.

Phase 2: Build and evaluate several low-fidelity wireframes

Design cycle 1a: Build several wireframes

The Expert Council will review the potential design features identified through the data collected and analyzed in Phase 1. This second Expert Council meeting will focus on achieving consensus as to which design features should be prioritized for the app design. A list of design feature requirements derived from the ongoing data collection, and the creation of a value versus feasibility matrix, will help guide these discussions (Gibbons, 2018). Potential design features will be categorized by Expert Council members as being perceived to be: (1) of high or low value to the end-users, and (2) of high or low feasibility to implement in practice. Features that are deemed completely unfeasible to implement and are perceived to be of very low-value to end-users will be excluded at this stage. All other features will be included, if these features do not prevent the inclusion of the highest priority features (i.e., high value, high feasibility).

Using Figma rapid prototyping software (*Figma: Wireframes*, 2020), the research team will construct several wireframes (i.e., low-fidelity / non-clickable proof-of-concepts) of potential app designs. These wireframes will be based on the Phase 1 rigor and relevance cycle data collected, and the Expert Council discussions prioritizing different design features. Creating different wireframes will help prevent premature anchoring of the final design, allowing for more diverse ideas to emerge in subsequent focus groups and interviews (Still & Crane, 2017).

At this time, a member of the research team will begin programming the back-end software needed to make the proof-of-concepts into a functional app prototype. This software programming will be updated to incorporate new design features identified throughout data collection.

Design cycle 1b: Evaluate several wireframes

Next, 3-6 semi-structured focus groups will be conducted using interview guides designed for Phase 2. At each focus group, the interviewer will screenshare the low-fidelity Figma wireframes of each dashboard. All focus groups will review the wireframes of the family caregiver dashboard. The nurse focus groups will also review the wireframes of the nurse dashboards. Participants will be asked to share detailed feedback on the different proof-of-concept wireframe design features and their perceptions of the potential usefulness of the wireframes. Participants will be asked which of the low-fidelity wireframe features should be prioritized for a future app prototype.

Semi-structured individual interviews will also be conducted with any 8-10 participants who agree to participate, to gain a deeper understanding of their perceptions of the wireframes. These individual interview participants will be recruited from among participants who participated in the focus groups, or from eligible recruits who preferred to only participate in individual interviews.

Phase 3: Build and evaluate an interactive proof-of-concept of the app, and develop a functional app prototype

Design cycle 2a: Build an interactive proof-of-concept for usability testing

The Expert Council will have a third meeting to discuss the ongoing data analyses and the preferred prototype features of the Phase 2 participants. Figma will be used to construct a high-fidelity interactive ("clickable") proof-of-concept (*Figma: Wireframes*, 2020), based on the prioritized design features from the Expert Council meeting. The interactive proof-of-concept will be combined with Maze usability testing software (Luchita, 2019), to create a URL to be shared with participants for online usability testing.

Design cycle 2b: Evaluate the usability of the proof-of-concept, and program the final prototype

Design cycle 2b will be used to quantitatively assess the usability of the high-fidelity, interactive proof-of-concept in individual test sessions using the Maze usability testing link with the two primary end-user groups: family caregivers and nurses. All new participants will be asked to fill out the Qualtrics demographic survey in advance prior to the meeting, after providing e-consent. Participants will be asked to share their screens, so their assessments of the proof-of-concept are video-recorded by the videoconferencing software. Family caregiver participants will be asked to assess the family caregiver dashboard, and nurse participants will be asked to assess both dashboards.

The Maze software will collect usability metrics for proof-of-concept effectiveness and efficiency. Effectiveness will be assessed based on: (1) success rate, i.e. the proportion of participants who successfully click through the proof-of-concept tasks; (2) the type of participant errors while navigating the different features of the proof-of-concept; and (3) the number of participant errors while navigating the proof-of-concept (*Iso 9241*, 2018; Luchita, 2019). Efficiency will be measured based on: (1) the time spent on specific steps while using the proof-of-concept dashboards; and (2) the total time taken for participants to use the proof-of-concept (*Iso 9241*, 2018; Luchita, 2019).

These data will be analyzed to further refine the interactive proof-of-concept using Figma software. *Refinement #1* will occur after 7 nurse test sessions and 7 family caregiver test sessions have been conducted. *Refinement #2* will occur after the final 8 nurse test sessions and 8 family caregiver test sessions have been conducted. The new recruits for Phase 3 will be purposively distributed to participate either before Refinement #1 or before Refinement #2, to achieve a roughly equal mix of new perspectives (i.e., new recruits for Phase 3) and old perspectives (i.e., participants from Phases 1 and/or 2) during Phase 3 data collection. Participants will also be distributed to achieve a roughly equal mix of perspectives from participants with varying levels of comfort with technology, based on participants' demographic questionnaire responses.

The fourth Expert Council meeting will: (1) review the findings from Phase 3, and (2) determine the final design features to prioritize for building into the functional app prototype being programmed in parallel, based on general consensus within the Expert Council.

During *Refinement #3***,** the interactive proof-of-concept design will be refined based on the Expert Council meeting decisions, and these features will be programmed into the functional app prototype.

Data Analyses

Data collection and analyses will occur simultaneously with ongoing discussion with members of the research team. Qualitative data sources will include focus group and individual interview transcriptions; observations and field notes taken during all Expert Council meetings and participant interviews and focus groups; rigor cycle literature review findings; and screenshots of the proof-of-concept. These data sources will be copied into Excel for qualitative content analysis to determine key design features for the app prototype (Elo & Kyngäs, 2008b; Still & Crane, 2017). Quantitative demographic survey data will be analyzed using descriptive statistics and displayed in a demographic data table, to offer a rich presentation of the characteristics of the participants who informed the app design. Descriptive statistics will also be used to analyze the Maze usability data for the interactive proof-of-concept. These data will help the Expert Council decide if more data needs to be collected to improve the proof-of-concept, prior to the final programming of the functional app prototype.

Ethical Considerations

The ethical review of this study is pending (McGill University Health Centre, #MP-37-2022-7986). There is minimal personal risk involved in participating in this study. In the event that family caregivers or care recipients become distressed, the note-taking member of the research team will ask the participant via a private chat box message if they would like to take a break from the meeting (Hudson, 2003). This research team member will also suggest that the participant follows up with their primary treating clinician at the study site (Hudson, 2003). We will have a list of available resources on-hand for cancer support recommended by the study sites.

Results

The estimated milestones include: (1) 4 months for study set up (e.g. ethical approval, hiring and training of personnel, and establishing the Expert Council key informants); (2) 3 months for Phase 1 recruitment, data collection and analysis; (3) 3 months for Phase 2 recruitment, data collection and analysis; (4) 3 months for Phase 3 recruitment, data collection and analysis; and (5) 2 months for final programming of a functional app prototype, and knowledge translation. We anticipate that preliminary results will be available by Spring 2022.

Discussion

We are proposing a new solution to eventually address a significant gap in access to care: access to trusted and flexible respite-care services, to ameliorate the current fragmented services rendered to families coping with palliative-stage cancer. To our knowledge, this is the first app being designed to coordinate nurse-provided respite care services to families coping with palliative-stage cancer. A few scholars (Currin et al., 2019) and industry leaders (*Ayd cares*, 2020; *Caremap*, 2018) are designing apps for coordinating other forms of respite care services, such as services staffed by non-clinician providers for families coping with age-related chronic health conditions. However, based on our ongoing literature and app store searches, an app for coordinating nurse-provided respite care services, designed with and for families coping with advanced cancers or other palliative needs, has not been developed thus far.

The proposed research is clinically important because palliative-oncology families require uniquely intensive and skilled respite care services, to allow their dying loved ones to remain at home (Kiyanda et al., 2015; Rao et al., 2021; Robinson et al., 2017). Respite care providers without nursing or palliative care training likely do not have these skills, limiting their ability to meet the respite care needs of families coping with palliative-stage cancer (Barrett et al., 2009; Rao et al., 2021). Without trusted, flexible, and accessible respite care services, achieving death at home can become an impossible endeavour (*Ccs: Quebec*, 2020; Robinson et al., 2017). However, an app for improving the coordination of respite care could have features that make this endeavour possible. Such features could include flexible scheduling options and choosing among diverse skillsets by the trusted nurse providers of care. These mHealth capabilities could improve the support services rendered to families wishing to support death at home, thus improving the quality of life of patients and their families.

The proposed research is also methodologically important, because our rigorous user-centered design study will help to ensure the sustainability of the proposed app-based respite care service, by focusing on the needs of end-users (Fox et al., 2008; Norman & Draper, 1986; Schnall et al., 2016; Still & Crane, 2017). This app will be collaboratively developed with our transdisciplinary research team of nurse scholars, computer scientists, institutional and community partners, and key informants. With a functional app prototype designed with end-users, additional grant applications will be submitted to support future pilot-testing and to assess further relevance of the prototype in the field (Hevner, 2007). While the initial findings will be contextualized to Québec, this innovative methodological approach may be transferable to other populations and settings. Future research could explore the potential of this respite care app to support families with other complex health conditions in other provinces, leading to improved coordination of respite care services across Canada - services that are centered on families' individualized respite care needs.

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Conflicts of Interest

None declared.

Abbreviations

App: smartphone application

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List of appendices for Paper 1

Multimedia Appendix 1. The following documents confirm the grant support and peer review process by the Rossy Cancer Network Care, Quality, and Innovation Research Fund (2020). View this Appendix 1 online: https://jmir.org/api/download?alt_name=resprot_v10i12e34652_app1.pdf&filename=49f64002c2f74f880cbedad07473eeb4.pdf&__hstc=178719527.d2b09ab44204cac92168ea0cb289fd47.1726065575847.1730819772875.1731337355084.6&__hssc=178719527.1.1731337355084&__hsfp=4044781704

Multimedia Appendix 2 (below). The research activities and participant numbers for each phase are displayed in tabular form.

Multimedia Appendix 3 (below). Key questions and instructions for participants during each research phase are listed below.

(Table 3.2.1) Multimedia Appendix 2

The research activities and participant numbers for each phase are displayed in tabular form.

Phase	**Cycle**	**Research Activities**	**Participants**
Phases 1-3: **Literature and app store reviews**	**Rigor Cycle 1**	-Academic literature reviews -Google Scholar and Google Search Engine alerts -App store searches	-Not applicable
Phase 1: **Brainstorm mHealth solutions to respite care scenarios**	**Relevance cycle 1: Brainstorming**	**-Expert Council meeting #1**	-5 key informants and research team
		-Focus groups (n=3-6), separate groups for each participant type (nurse, family caregiver, or care recipient) and language (English or French)	***-Nurse focus group(s):*** 10 nurses in total ***-Family caregiver focus group(s):*** 10 family caregivers in total ***-Care recipient focus group(s):*** 10 family caregivers in total
		-Individual interviews (n=8-10)	-8-10 participants in total from any of the focus groups who agree to participate, or any participants who prefer to solely participate in individual interviews
Phase 2: **Build and evaluate several low-fidelity wireframes**	**Design cycle 1a: Building**	**-Expert Council meeting #2**	-The same 5 key informants and research team
		-Rapid prototyping of several low-fidelity wireframes	-Not applicable
	Design cycle 1b: Evaluating	**-Focus groups (n=3-6),** separate groups for each participant type (nurse, family caregiver, or care recipient) and language (English or French)	***-Nurse focus group(s):*** 10 nurses, either from Phase 1 or new recruits ***-Family caregiver focus group(s):*** 10 family caregivers, either from Phase 1 or new recruits

			-Care recipient focus group(s): 10 care recipients, either from Phase 1 or new recruits
		-Individual interviews (n=8-10)	-8-10 participants in total from any of the focus groups who agree to participate, or any participants who prefer to solely participate in individual interviews
Phase 3: **Build and evaluate an interactive proof of concept, to be programmed into a functional app prototype**	**Design cycle 2a: Building**	**-Expert Council meeting #3**	-The same 5 key informants and research team
		-Rapid prototyping of a high-fidelity interactive app proof-of-concept	-Not applicable
	Design cycle 2b: Evaluating	**-Individual usability test sessions** of the high-fidelity interactive proof-of-concept (n=14 of the total 30 nurse and family caregiver participants for usability testing)	***Individual test sessions:*** -7 nurses, either from the previous phases or new recruits -7 family caregivers, either from the previous phases or new recruits
		-Refinement #1 of the interactive proof-of-concept	-Not applicable
		-Individual usability test sessions of the high-fidelity interactive proof-of-concept (n=16 of the total 30 participants for usability testing)	***Individual test sessions:*** -8 nurses, either from the previous phases or new recruits -8 family caregivers, either from the previous phases or new recruits
		-Refinement #2 of the interactive app proof-of-concept	-Not applicable
		-Expert Council meeting #4	-The same 5 key informants and research team
		-Refinement #3 of the interactive proof-of-concept, to be programmed into a functional app prototype.	-Not applicable

Multimedia Appendix 3

Key questions and instructions for participants during each research phase are listed below.

Phase 1: Brainstorming ways that a smartphone app could improve respite care services for families coping with palliative-stage cancer

Questions for family caregivers and adults living with cancer:

1) What are your thoughts on using in-home respite care services?
2) For families using respite care services, think back over your respite care experiences. What went well? What didn't go well?
3) For those of you who don't use respite care services, what homecare support services (if any) do you use instead?
4) We know from other studies that families with cancer often experience challenges trusting respite care agencies to provide appropriate care. What are your thoughts on the trustworthiness of respite care services available to families?
5) What are your thoughts on the flexibility of scheduling or coordinating respite care services for families?

Questions for nurses:

1) As nurses, what are your perspectives on in-home respite care for families coping with palliative stage cancer?
2) What are your thoughts on the trustworthiness of respite care services available to the families you care for?

3) What are your thoughts on scheduling or coordinating respite care services for the families you work with?

Questions for everyone: Using apps for coordination or scheduling different services:

1) What aspects of an app make you more comfortable using it? Which apps do you use most frequently?
2) What are your thoughts on using apps for scheduling or coordinating different services? What are your thoughts on using apps like DoorDash for food delivery, Uber for transportation, etc.?
3) What do you think about using apps for scheduling or coordinating different healthcare services?

For each respite care scenario video designed during Phase 1 with the Expert Council, we will ask participants:

1) How could an app be designed to improve this situation, especially for improving the delivery of respite care services?

Questions for everyone: Constructive feedback:

1) Please be our “devil’s advocate”: what do you foresee going wrong with an app for coordinating nurse-provided respite care?
2) What do you think is the most important thing for us to consider when designing an app-based respite care support service for families, staffed by nurses?

3) Is there anything else regarding in-home respite care, palliative care, and apps that you would like to discuss?

<u>Phase 2: Discussing the features of several possible wireframe designs for an app to improve respite care services for families coping with palliative-stage cancer</u>

Prior to the focus groups, there will be approximately 2-4 different low-fidelity wireframes designed for an app to coordinate respite care services by nurses to families coping with palliative-stage cancer. Family caregiver and care recipient focus groups will only review the family caregiver dashboard of each wireframe design. Nurse focus groups will review both the family caregiver and nurse dashboards of each wireframe design.

For each wireframe:

1) What do you like about the content of this design?
2) What do you dislike about the content of this design?
3) What app features would improve trust in the respite care service?
4) What app features would help create easier access to respite care services?

General questions:

1) Which of these designs would you most want to have turned into an actual app-based service?
2) Which app features absolutely must be in the final app design, for you to ultimately use the app?
3) Which features must not be in the final app design, for you to ultimately use the app?

4) What aspects of the service itself would make you more likely to use it?
5) Is there anything else regarding in-home respite care, palliative care, and apps that you would like to discuss?

Phase 3: Individual testing session guide for nurses and family caregivers

Family caregiver *participants will only test the family caregiver dashboard of the interactive app prototype.* ***Nurse*** *participants will first test their ability to click through the family caregiver dashboard, as if they were a family caregiver requesting respite care. Then, nurses will test their ability to click through the nurse dashboard.*

1) In the chat box, I've shared the link to the app design. Please click on it and let me know when it opens in your browser.

[Request screen sharing.]

2) Now, can you please begin sharing your computer screen with me, so that I can see the app design, too?

3) Please follow the instructions in the link to test out this design.

[Participant clicks through the interactive prototype on their screen. Usability data is recorded on success rate, types of errors while using the app, number of errors while using the prototype (compared to the primary click pathway established by the research team), and time taken to use the prototype.]

4.0 Paper 2: Concept Analysis of "Informal Caregiver"

4.1 Bridge 2

The next four papers in this dissertation (Chapters 4-7) address the Rigor Cycle objective of our adapted methodological framework: i.e., to synthesize relevant literature and knowledge on caregiving and respite care support needs, digital health design for respite care, and accessible service design, to inform the interview guides and proof-of-concept design of the app. These manuscripts are a continuation of the literature review overview reported in Chapter 2 of this dissertation.

Paper 2 is a concept analysis of the evolving meaning of the concept "informal caregiver" in academic nursing literature, outlining the attributes and consequences of this dyadic family role. Eight of the 48 papers (17%) focused on informal caregiving in the context of cancer care. This concept analysis emphasized the present challenges of intensive family caregiving and underscored the value of family-centered and accessible services, such as respite care, in supporting dyadic family caregiving roles. Thirteen of the 48 included papers (27%) called for flexible, accessible respite care services to prevent negative role consequences of caregiving and care-receiving. This finding provided justification for my research to make respite care services more accessible through rigorous app platform design. The papers also highlighted that to be truly accessible, support services for informal caregivers should be designed in partnership with both family caregivers and care-receivers, which supported our decision to partner with family caregivers, care-receivers, and nurses throughout our study.

In the discussion section of how the concept could evolve, we also discussed how with this concept analysis as a shared starting point for identifying informal caregivers, nurses may even be able to offer supports *before* informal caregivers identify themselves as caregivers. If informal caregivers do not identify with the role, they may fail to access supportive services that specifically target informal caregivers (Whitmore, 2022). Nurses can encourage family caregivers to self-identify as such, helping families to process these role transitions and subsequently connect them with earlier support services.

Relatedly, we also noted that caregivers often need to be made aware of and encouraged to use support services like respite care, as other scholars have found (Nysaeter et al., 2024). These findings supported our decision to include a chatbot in the final iRespite proof-of-concept, to remind and nudge families about respite care opportunities. It also served as an important reminder for future implementation, that for a respite care service to be approachable and for families to perceive a need for such support services, they will often need encouragement from their nurses and clinicians (Levesque et al., 2013; Whitmore, 2022). Therefore, we have partnered with nurses throughout this study, and I have plans to ensure that with future implementation, we collaborate with nurses from different organisations to raise awareness about respite care services and the iRespite platform, so that clinical nurses can share these resources with families in their care.

I began this research with a focus on the concept of “informal caregiver”. However, after immersing myself in this literature, I learned that some families and clinicians find the “informal” language to be inappropriate, and that there are synonyms and related terms like “family caregiver” that avoid potential negative connotations of the “informal” description. These readings helped me decide to use the term “family caregiver” rather than “informal caregiver” in my dissertation, unless I was specifically discussing findings from this concept analysis, to improve communication of my ideas with families and clinicians. Yet, *Advances in Nursing Science* also offered me the opportunity to write a blog post related to my journal publication. I used that blog post to explore the potential *strengths* of “informal” caregiving relationships, in contrast with present negative cultural connotations of the “informal” descriptor (Appendix 1) (Castro, 2023).

4.2 Paper 2 Manuscript

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(AR Castro et al., 2022)

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"Informal Caregiver" in Nursing: An Evolutionary Concept Analysis

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Author Contributions Statement:

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Abstract

The informal caregiver experience has surged as a research topic in healthcare, including in nursing. However, the “informal” language is controversial, lacking conceptual clarity. Without a common understanding of who an “informal caregiver” may be, nurses may fail to consistently identify informal caregivers requiring support. Therefore, a concept analysis of “informal caregiver” was conducted, based on a sample of 20% of relevant nursing literature. The analysis of the attributes, antecedents, consequences, and contexts associated with “informal caregiver” offers a foundational guide for the ongoing development of nurses’ understanding of the informal caregiver role.

KEYWORDS: Caregivers, Informal Caregivers, Nursing, Definition, Concept Analysis

Statement of Significance

What is known, or assumed to be true, about this topic

In recent decades, healthcare and nursing scholars have been studying the needs and experiences of supposed informal caregivers with mounting interest. Such research is of particular salience to nurses, as nurses spend significant time with families, partnering and caring for individual patients as well as their entire families. Despite the common use of the term "informal caregiver", the "informal" language is controversial, and the concept is loosely defined. Without a consistent understanding of who informal caregivers may be, nurses may fail to recognize informal caregivers who need support in their caregiving roles. This inadequate recognition may contribute to the invisibility of informal caregiving work and feelings of abandonment and distress experienced by many informal caregivers.

What this article adds

We conducted a concept analysis of the term "informal caregiver" to provide a more nuanced understanding of the concept. A sample of 20% of literature from 1986-2021 offered a starting point for a shared foundational understanding of "informal caregiver" in nursing. In these publications, we identified "role" as the main attribute of "informal caregiver", which was informal and dyadic. The concept antecedents consisted of a pre-existing relationship with a person requiring care for a functional dependency due to a health- or aging-related condition. Role consequences resulted in numerous responsibilities with health and social implications for the informal caregiver/care receiver dyad. These consequences were often experienced negatively when dyads did not have access to adequate community health and social supports. The findings direct nurses' attention towards critically analyzing their use of this concept. This analysis can help to identify the current limits of the concept and reveal unintentional omissions in its usage, enabling nurses to better identify and support informal caregivers and care receivers. To our knowledge, no other concept analysis of “informal caregiver” has been conducted, either in nursing or allied health literature. With a common understanding of how the concept is currently used and of how it might evolve, nurses may be better equipped to recognize and support informal caregivers in practice and research.

Introduction

Family-centered care, including care of patients' informal caregivers, is part of the nursing role. (*Rnao*, 2015) Furthermore, nurses are expected to ensure that patients receive continuity of care even after discharge, which in many instances depends on the abilities of patients' informal caregivers. (Van Durme et al., 2012) Over the past few decades, there has been a surge in research to better understand the needs and experiences of informal caregivers so that nurses and other clinicians can better support them. (Streck et al., 2020; Van Durme et al., 2012) Yet, issues in communication between families and healthcare workers may arise with the use of the concept of "informal caregiver".

Currently, there is debate in healthcare circles regarding the meaning of this concept and the appropriateness of using "informal" for describing patients' caregivers. (Stall et al., 2019; Sterling & Shaw, 2020) When a discipline does not share a deep understanding of a concept, the concept may be inconsistently applied by practitioners of the discipline, such as by different practitioners of nursing. Hence, the support needs of informal caregivers may be overlooked or inconsistently addressed if their roles do not match with the assumptions of nurses. (Nolan & Grant, 1989) For instance, given the gendered nature of caregiving and aging populations, nurses may assume that all informal caregivers are older adult women, ignoring those who may be male, younger, or unrelated to the patient. (Cascella Carbó & García-Orellán, 2020; Eriksson et al., 2013) The informal nature of the role could also lead nurses to assume that informal caregivers are simply family or friends visiting with patients, leading nurses to overlook informal caregivers' knowledge and contributions to patient care. (Nolan & Grant, 1989; Pereira & Rebelo Botelho, 2011) Failure to recognize informal caregivers and their contributions renders their work invisible and unsupported, contributing to caregiver feelings of abandonment by nurses and society. (Bove et al., 2016; Castro & Tsimicalis, 2020; Nolan & Grant, 1989; Pereira & Rebelo Botelho, 2011) Furthermore, in intervention research for informal caregivers, the concept is inconsistently defined and measured, limiting the external validity of the study conclusions. (Van Durme et al., 2012)

Agreement on the meaning of “informal caregiver” is essential to recognize and optimally support the work of informal caregivers, enhance rigour of informal caregiving studies, and advance empirical efforts to improve nursing-led assessments and interventions benefiting patients and their informal caregivers. (Van Durme et al., 2012) Therefore, a concept analysis of “informal caregiver” was conducted to offer a deeper understanding of: (1) how nursing has been using this concept, i.e., what was “the common manner of employing the concept” (Rodgers, 2000, p. 82(p82)) in the sampled nursing literature; and (2) how the concept may evolve in the future, generating implications for future applications of the concept in practice and research.

Methods

Design

This study was conducted using Rodgers’ evolutionary view of concept analyses. (Rodgers, 2000) Concept analyses are used to learn the essence of a concept, providing a more nuanced and well-defined understanding of what the concept means. (Rodgers, 2000) According to Rodgers, clusters of attributes, antecedents, consequences, and contextual factors give meaning to evolving concepts across time periods, professional disciplines, and social contexts. (Rodgers, 2000) As the informal caregiver concept has been increasingly used and studied over recent decades in the discipline of nursing, (Streck et al., 2020; Van Durme et al., 2012; Williams, 2003) this design was appropriate.

Search Strategy and Selection Criteria

The detailed search strategy and the inclusion and exclusion criteria used in this concept analysis are displayed in Tables 1 and 2. To ensure the data sampling population was highly specific to the nursing discipline, the search was restricted to CINAHL, the predominant nursing and allied health academic database. Search terms relating to “informal”, “caregiving”, and “definitions” or “reviews” in titles, abstracts, and subject headings were used to search the CINAHL database for relevant literature (Table 1). Moreover, references were excluded from the returned literature if they did not have Nurs* in the journal title. No search restrictions were placed for language, publication date, or peer review (Table 2). All references deemed eligible for inclusion were sorted by year. These references were subsequently selected to ensure 20% of the retrieved nursing literature was included over time by selecting every 5th record, as per Rodgers’ methodology. (Rodgers, 2000)

(Table 4.2.1) Table 1: CINAHL search strategy used to identify literature sampling population

Sub-Search Numbers	**Search Strategy**
S1	(MH “Caregivers”) AND [(MH “Scoping Review”) OR (MH “Concept Analysis”)]
S2	(TI “Informal”) AND (MH “Caregivers”)
S3	TI (“Informal” or “Lay” or “Volunteer”) N4 care* N4 (Concept* or Defin* or “Terminology” or “Analysis”)
S4	AB (“Informal” or “Lay” or “Volunteer”) N4 care* N4 (Concept* or Defin* or “Terminology” or “Analysis”)
Final search:	S1 OR S2 OR S3 OR S4

Note: In CINAHL, “MH” means that both major and minor CINAHL subject headings were searched. “TI” refers to a search for terms found in the reference “Title”. “AB” refers to a search for terms found in the “Abstract”. “Nx” is a proximity searching operator, with x representing the number of words allowed nearby. For instance, “N4” indicates the terms being searched will be within 4 words of each other. “S” refers to “the sub-searches” which were combined using the “OR” operator, generating the final search.

(Table 4.2.2) Table 2: Inclusion and exclusion criteria

	Inclusion Criteria	**Exclusion Criteria**
Article focus	The needs or experiences of informal caregivers were a focus of the publication, as indicated in the title or abstract	The needs or experiences of informal caregivers were only peripherally related to, or not relevant at all to, the purpose of the publication
Publication type	Literature reviews, theoretical papers, empirical studies, and commentaries longer than one page or more	Abstracts and commentaries less than 1 page, as we deemed these texts to be too short to offer a deep understanding of the use of the "informal caregiver" concept
Title	Published in an explicitly stated nursing discipline journal, with "Nurs*" in the journal title, where * represents variations on "Nurse" (E.g., nurse, nurses, nursing)	Published in a journal without "Nurs*" in the title
Percentage of the literature	20%	80%
Chronological Selection	Every 5th reference from the 236 references listed in chronological order	Removed every 1st, 2nd, 3rd, and 4th reference from the references listed in chronological order

Data Extraction and Analysis

Rodgers recommends that thematic analysis be delayed until the main data sources are collected, to avoid premature commitment to an analytical structure. (Rodgers, 2000) Therefore, all included manuscripts were first retrieved and read in their entirety for preliminary data immersion. (Rodgers, 2000) The texts were then analysed for any usage of the concept by any nurses featured in the literature: i.e., how nurse participants used the concept in study results; or how authors of these nursing manuscripts used the concept when discussing their results or related nursing and caregiving literature.

The full-text data from each manuscript pdf file (i.e., manuscript introductions, methods, results, conclusions, discussions, and any commentary data) were copied into Microsoft Excel. Each paragraph was pasted into its own cell, although paragraphs were sometimes split or duplicated if the text was relevant to multiple category labels. Each row of data was deductively coded if the data could fit under any of the data analysis categories suggested by Rodgers: attributes, antecedents, consequences, any other contextual factors, surrogate terms, and related concepts. (Rodgers, 2000) Data were categorized as "attributes" if the data discussed core defining features of the concept that occurred repeatedly. (Rodgers, 2000) "Antecedents" was used to categorize data discussing features or events that had to be present prior to the occurrence of the concept. (Rodgers, 2000) "Consequences" was used to label data describing incidents or events that happened after or due to the presence of the concept. (Rodgers, 2000) "Contextual factors" was used to label other recurring themes surrounding the use of the concept, such as temporal patterns, social contexts, and linguistic nuances. (Rodgers, 2000) "Surrogate terms" referred to words or phrases that were synonyms of the concept. (Rodgers, 2000) "Related terms" was used to categorize any words or phrases that were similar to the concept under study, but which differed by one of the attributes or defining features. (Rodgers, 2000) The category of "Other" was sometimes used as a placeholder for data that seemed relevant to defining the concept but required further reflection as to which Rodgerian category the data fit into best.

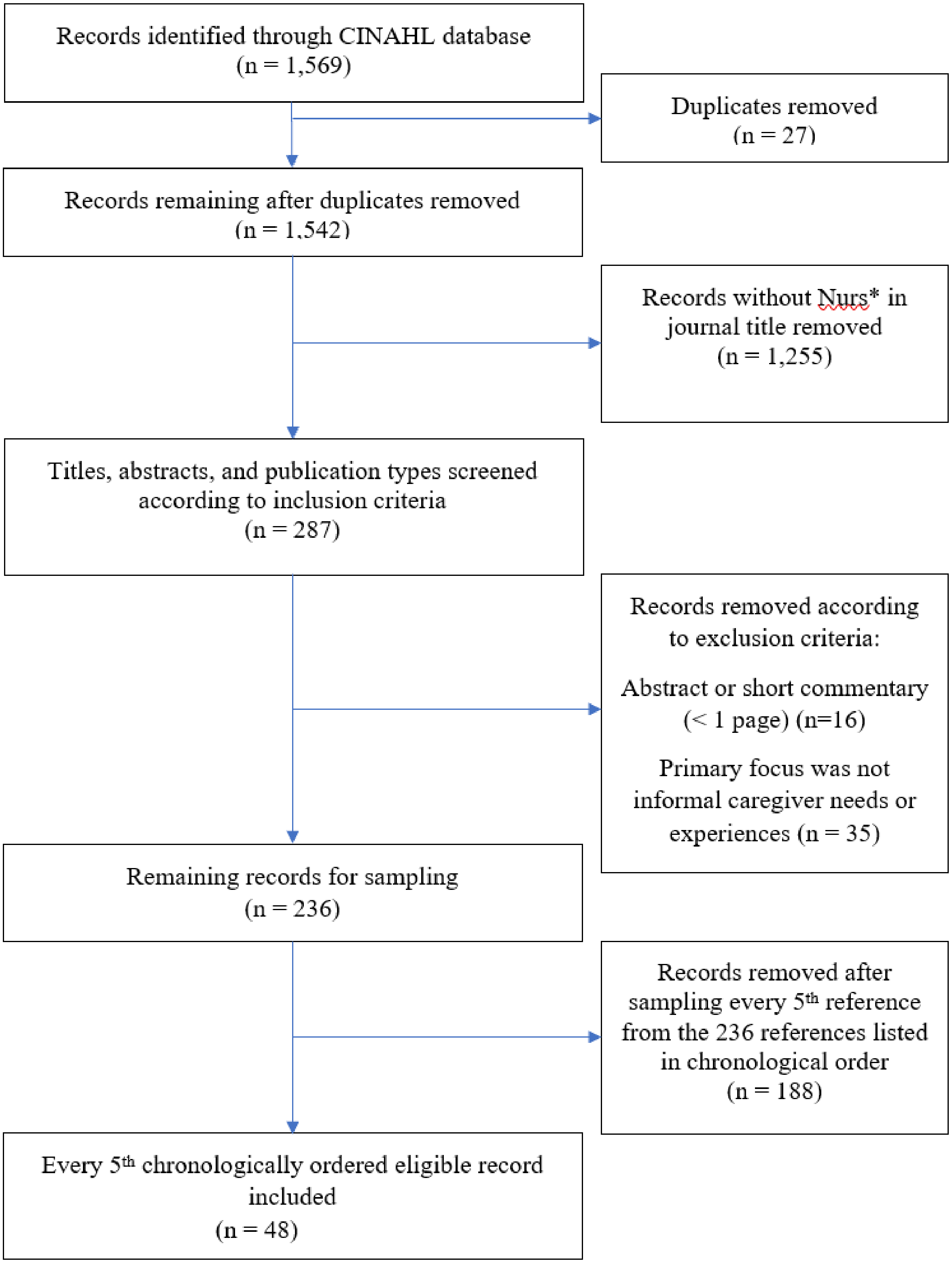
These categories of data were then clustered in Excel to identify labels for any sub-themes describing each main category. Next to each category, a few additional potential descriptors or details of the category were added that were referenced in the text data (e.g. "consequences - effects on caregiver - physical"). Similar ideas in the literature were grouped, re-organized, and re-labeled by row, until we had generated cohesive descriptors for each category. (Rodgers, 2000) Supplementary Digital Content 1 provides examples of the data analysis process, illustrating how data were re-organized to generate the final labels of the sub-themes.

Results

Search Results

The CINAHL search was conducted in July 2021 (Figure 1). 1,569 references were screened in total. After excluding 27 duplicates and 1,255 records published in journals that did not have “Nurs*” in the title, 287 titles and abstracts were screened. Abstracts and commentaries less than one page were excluded because these designs were deemed too short to explore nurses’ use of the concept. Furthermore, 35 manuscripts were excluded when the abstract indicated that informal caregiver needs or experiences were not the primary focus of the publication. Of 236 eligible publications, every 5th record was included resulting in 48 publications. This sample size surpasses the suggested minimum of 30 references for a Rodgerian concept analysis. (Rodgers, 2000) The earliest eligible manuscript was published in 1986. These manuscripts were written in 18 countries. The study designs included knowledge syntheses, such as integrative and systematic reviews (n=10); commentaries (n=2); mixed methods studies (n=4); quantitative studies (n=12); and qualitative studies (n=20). A summary of these 48 publications is displayed in Supplementary Digital Content 2, including the country of origin of the research or publication, the design of the study or manuscript, and the health condition(s) of the care receivers under discussion. What follows is a description of the constellation of conceptual features for “informal caregiver” that we identified in the nursing literature.

(Figure 4.2.1) Figure 1. Search results



Attributes of "informal caregiver"

"Role" was the essential attribute of the concept "informal caregiver". (Abiola Hazzan et al., 2015; Alves et al., 2021; "American nurses association position statement on informal caregiving," 1995; Araújo et al., 2018; Armstrong-Esther et al., 2005; Barber, 2007; Bove et al., 2016; Cascella Carbó & García-Orellán, 2020; Chamberlain et al., 2018; Eriksson et al., 2013; Evans et al., 2012; Gemmill et al., 2011; Goodman, 1986; Grant & Graven, 2018; Kirton et al., 2012; Künzler-Heule et al., 2016; Laitinen & Isola, 1996; May et al., 2001; Mishra et al., 2018; Nahm et al., 2010; Nolan & Grant, 1989; Pallangyo & Mayers, 2009; Pereira & Rebelo Botelho, 2011; Puig et al., 2015; Reynolds & Alonzo, 1998; Rosas-Santiago et al., 2017; Sales Graça et al., 2017; Sapountzi-Krepia et al., 2008; Schumacher et al., 2000; Spigelmyer & Schreiber, 2019; Van Durme et al., 2012; Williams, 2003; Wilson et al., 2009; Wrubel et al., 2001) This role was "dyadic": a person could not adopt the role of an informal caregiver, without another person being the receiver of their care. (Alves et al., 2021; Gemmill et al., 2011; Grant & Graven, 2018; Mishra et al., 2018; Nahm et al., 2010; Schumacher et al., 2000; Williams, 2003; Wilson et al., 2009) However, this dyadic role was rarely described as a caregiving "partnership" between the informal caregiver and care receiver. Informal caregivers were only referred to as "partners" with the care receivers if they were the romantic partners. (Bove et al., 2016; Eriksson et al., 2013; Kirton et al., 2012; Künzler-Heule et al., 2016; Pallangyo & Mayers, 2009; Reynolds & Alonzo, 1998; Wrubel et al., 2001) This role was also "informal", in the sense that caregivers were typically unpaid; (Eriksson et al., 2013; Gemmill et al., 2011; Grant & Graven, 2018; Pereira & Rebelo Botelho, 2011; Sapountzi-Krepia et al., 2008; Van Durme et al., 2012; Williams, 2003) they were usually untrained by structured or standardized training initiatives for homecare and nursing skills, instead learning complex caregiving tasks independently (Künzler-Heule et al., 2016; Laitinen, 1992; Nolan & Grant, 1989; Rosas-Santiago et al., 2017; Wilson et al., 2009); and there were no formal organizations coordinating the informal caregivers' responsibilities. (Cascella Carbó & García-Orellán, 2020; Chamberlain et al., 2018; Spigelmyer & Schreiber, 2019) This "informal" adjective was sometimes used to explicitly differentiate the unpaid work of informal caregivers, from the "formal" paid and trained work of other carers, such as nurses and personal support workers. (Cascella Carbó & García-Orellán, 2020; Chamberlain et al., 2018; Spigelmyer & Schreiber, 2019) In one instance, the term "informal caregiver" included an unpaid family caregiver, and a paid but untrained homecare aide. (Chiao et al., 2017) No other papers suggested payment for the informal caregiver role.

Antecedents of "informal caregiver"

Four antecedents of "informal caregiver" were identified: (1) a pre-existing relationship, (2) a person needing care, (3) functional dependencies, and (4) a health- or aging-related condition. The pre-existing relationship emphasized emotional ties (e.g., love or a desire to care), (Abiola Hazzan et al., 2015; Bove et al., 2016; Evans et al., 2012; Künzler-Heule et al., 2016; Mishra et al., 2018; Nahm et al., 2010; Pallangyo & Mayers, 2009; Reynolds & Alonzo, 1998) as well as social obligations (e.g., family ties, and cultural values of filial piety or duty). (Evans et al., 2012; Laitinen, 1992; Nolan & Grant, 1989; Reynolds & Alonzo, 1998; Tseh et al., 2005; Wrubel et al., 2001) The care receiver needed assistance with activities they could not perform independently, and that formal support services were not providing. (Nahm et al., 2010; Nolan & Grant, 1989; Sapountzi-Krepia et al., 2008) Care receivers lived with functional "dependencies" due to a health or aging-related condition, requiring physical, mental, and/or emotional assistance from caregivers to function in their daily lives. ("American nurses association position statement on informal caregiving," 1995; Araújo et al., 2018; Cascella Carbó

& García-Orellán, 2020; Goodman, 1986; Grant & Graven, 2018; Nahm et al., 2010; Nolan & Grant, 1989; Puig et al., 2015; Tseh et al., 2005; Williams, 2003)

Consequences of "informal caregiver"

Three major role consequences were identified. Firstly, there were numerous responsibilities fulfilled by informal caregivers. Secondly, these responsibilities led to various health sequelae for the caregiving dyad. Thirdly, without access to community health and social supports, these responsibilities and health sequelae often led to informal caregiver role strain and distress.

Enacting numerous responsibilities to fulfil the role

All publications listed responsibilities associated with the process of becoming an informal caregiver. These responsibilities included: providing nutrition, administering medication, managing feeding tubes and central lines, performing wound care, coordinating the household, providing hygiene care, offering emotional and spiritual supports, ensuring safety, communicating with healthcare teams, and financially supporting the household. These tasks could be very unpredictable, leading to derailed family schedules and unexpected stress. (Bove et al., 2016; Grant & Graven, 2018; Künzler-Heule et al., 2016; Pereira & Rebelo Botelho, 2011) Learning these responsibilities and their sustained enactment were at the heart of the ongoing process of becoming an informal caregiver. (Grant & Graven, 2018; Pereira & Rebelo Botelho, 2011; Puig et al., 2015; Reynolds & Alonzo, 1998; Schumacher et al., 2000; Williams, 2003) The final responsibilities of the role involved transitioning out of the role, usually in the context of death and bereavement, with the care receiver entering hospice care or dying. (Pallangyo & Mayers, 2009; Reynolds & Alonzo, 1998; Wilson et al., 2009; Wrubel et al., 2001)

Experiencing a myriad of health and social consequences due to the role

The informal caregiver role had a myriad of mental and physical health consequences. Informal caregivers frequently felt mentally distressed and uncertain about their role. (Araújo et al., 2018; Barber, 2007; Bove et al., 2016; Gemmill et al., 2011; Goodman, 1986; Hewison, 1994; Puig et al., 2015; Williams, 2003) They often suffered from physical exhaustion and lack of sleep. (Abiola Hazzan et al., 2015; Cascella Carbó & García-Orellán, 2020; Gemmill et al., 2011; Goodman, 1986; Nahm et al., 2010; Pallangyo & Mayers, 2009; Puig et al., 2015; Reynolds & Alonzo, 1998) Informal caregivers of people living with an infectious condition experienced additional mental distress due to fears of becoming ill themselves. (Pallangyo & Mayers, 2009; Reynolds & Alonzo, 1998; Wrubel et al., 2001) Some informal caregivers felt resentment, with accompanying feelings of guilt or stigma for resenting their caregiving role. (Eriksson et al., 2013; Goodman, 1986; Hewison, 1994; Nolan & Grant, 1989; Reynolds & Alonzo, 1998; Wrubel et al., 2001) If informal caregivers became overburdened or experienced burnout, care receivers were more at risk for neglect and elder abuse. (Tseh et al., 2005; Van Durme et al., 2012)

Dyads also experienced social consequences, particularly financial and relational. The presence of an informal caregiver reduced the likelihood the care receiver would need formal, publicly-subsidized services, such as hospitalization, home care, or long-term care. (Armstrong-Esther et al., 2005; Evans et al., 2012; Goodman, 1986; Laitinen, 1992; Laitinen & Isola, 1996; May et al., 2001; Sapountzi-Krepia et al., 2008; Williams, 2003) Hence, costs were spilled-over to the informal caregiver and care receiver, who incurred direct out-of-pocket costs (e.g., paying for homecare support, lost incomes), (Chiao et al., 2017; Gemmill et al., 2011; Goodman, 1986; Pallangyo & Mayers, 2009; Sapountzi-Krepia et al., 2008) and indirect costs (e.g., time costs and career challenges). (Abiola Hazzan et al., 2015; Evans et al., 2012; Goodman, 1986; Kirton et al., 2012) Some informal caregivers had limited time to address the needs of other family members, (Hewison, 1994; Nolan & Grant, 1989; Reynolds & Alonzo, 1998) and many caregivers experienced social isolation. (Bove et al., 2016; Cascella Carbó & García-Orellán, 2020; Goodman, 1986; Hewison, 1994; Künzler-Heule et al., 2016; Pereira & Rebelo Botelho, 2011; Puig et al., 2015; Reynolds & Alonzo, 1998; Tseh et al., 2005) The informal caregiver role sometimes generated feelings of self-sacrifice and identity-loss. (Bove et al., 2016; Eriksson et al., 2013; Hewison, 1994; Nahm et al., 2010; Nolan & Grant, 1989; Van Durme et al., 2012; Wilson et al., 2009) Caregivers and care receivers often grieved their past relationship and their previous hopes for their future together. (Araújo et al., 2018; Bove et al., 2016; Cascella Carbó & García-Orellán, 2020; Gemmill et al., 2011; Künzler-Heule et al., 2016; Pallangyo & Mayers, 2009; Pereira & Rebelo Botelho, 2011; Reynolds & Alonzo, 1998; Sales Graça et al., 2017; Wilson et al., 2009) However, over time and with appropriate supports, the dyads often found their relational bonds strengthened as they adjusted to their caregiving and care receiving roles. (Künzler-Heule et al., 2016; Mishra et al., 2018; Reynolds & Alonzo, 1998; Sales Graça et al., 2017)

Needing supports to prevent role-related distress

Most informal caregivers wanted to be their care receiver's informal caregiver, but they required support to thrive in this complex and often challenging role. (Bove et al., 2016; Evans et al., 2012; Gemmill et al., 2011; Nolan & Grant, 1989; Puig et al., 2015; Reynolds & Alonzo, 1998; Wilson et al., 2009) Every publication noted that without access to community health and social supports, informal caregivers were at increased risk of role strain and distress. Various supports were helpful including: education and training for informal caregivers on their care receiver's health trajectory, (Abiola Hazzan et al., 2015; Araújo et al., 2018; Armstrong-Esther et al., 2005; Barber, 2007; Grant & Graven, 2018; Künzler-Heule et al., 2016; Mishra et al., 2018; Rosas-Santiago et al., 2017) government subsidies and supplemental incomes for caregiving, (Abiola Hazzan et al., 2015; Armstrong-Esther et al., 2005; Hewison, 1994) family members and friends providing substitute caregiving work, (Grant & Graven, 2018) protected leaves of absence, (Armstrong-Esther et al., 2005) and accessible respite care services. (Abiola Hazzan et al., 2015; "American nurses association position statement on informal caregiving," 1995; Armstrong-Esther et al., 2005; Barber, 2007; Gemmill et al., 2011; Goodman, 1986; Grant & Graven, 2018; Hewison, 1994; Laitinen, 1992; Nolan & Grant, 1989; Pallangyo & Mayers, 2009; Puig et al., 2015; Wrubel et al., 2001) When informal caregivers and their care receivers had access to adequate social and healthcare supports, they often experienced joy, meaning, and personal growth from their dyadic roles. (Armstrong-Esther et al., 2005; Bove et al., 2016; Gemmill et al., 2011; Goodman, 1986; Mishra et al., 2018; Nahm et al., 2010; Pallangyo & Mayers, 2009; Puig et al., 2015; Reynolds & Alonzo, 1998; Williams, 2003; Wrubel et al., 2001)

Still, some authors noted that even when support services were available, these services might not have been used or requested by informal caregivers. (Armstrong-Esther et al., 2005; Eriksson et al., 2013) Caregivers sometimes downplayed their need for support, often due to feelings of guilt for wanting role support, (Bove et al., 2016; Chamberlain et al., 2018; Eriksson et al., 2013; Goodman, 1986) or to a lack of awareness of their eligibility for services. (Nahm et al., 2010) Furthermore, available support services were often inadequate or inaccessible to many families. (Cascella Carbó & García-Orellán, 2020; Goodman, 1986; Grant & Graven, 2018; Nahm et al., 2010) Authors noted that efforts to optimize accessibility required co-designing supports with families and tailoring services to their unique needs, so that services were not only available, but also accessible. (Gemmill et al., 2011; Goodman, 1986; Grant & Graven, 2018; Hewison, 1994; Künzler-Heule et al., 2016; Mishra et al., 2018; Nahm et al., 2010; Rosas-Santiago et al., 2017)

Contextual features of "informal caregiver"

Four major contextual features were identified in the literature: (1) the demographic representation of informal caregivers, (2) the language of "burden" and "costs", (3) nurses' complex and contradictory perceptions of informal caregivers, and (4) the healthcare and societal contexts of the publishing period (1986-2021).

The demographic representation of informal caregivers

The representation of "informal caregiver" was highly gendered. ("American nurses association position statement on informal caregiving," 1995; Cascella Carbó & García-Orellán, 2020; Eriksson et al., 2013; Gemmill et al., 2011; Goodman, 1986; Pallangyo & Mayers, 2009) Few studies had male caregivers equally represented or as the sampled majority. (Chamberlain et al., 2018; Mishra et al., 2018; Reynolds & Alonzo, 1998; Wrubel et al., 2001) Immediate family members were most commonly the informal caregiver; less common were extended family, neighbors, or friends. (Kirton et al., 2012; Pallangyo & Mayers, 2009; Reynolds & Alonzo, 1998) Informal caregivers were typically over 40 years old; informal caregivers under the age of 30 were rarely discussed. (Barber, 2007; Kirton et al., 2012)

The language of "burden" and "costs"

In the nursing literature, informal caregivers were frequently viewed as a low-cost solution to the rising costs of an aging population. Authors often introduced their collective works with explicit or implicit concerns of the costly healthcare resources needed to support aging populations. (Araújo et al., 2018; Armstrong-Esther et al., 2005; Cascella Carbó & García-

Orellán, 2020; Evans et al., 2012; Gemmill et al., 2011; Grant & Graven, 2018; Kirton et al., 2012; Nolan & Grant, 1989; Schumacher et al., 2000; Tseh et al., 2005; Williams, 2003) The "formality" and "training" language associated with the role alluded to the "costs of care" and political economic ideology in discussions of informal care. Finally, the persistent use of "burden" (Abiola Hazzan et al., 2015; Alves et al., 2021; Araújo et al., 2018; Chamberlain et al., 2018; Evans et al., 2012; Gemmill et al., 2011; Grant & Graven, 2018; Künzler-Heule et al., 2016; Puig et al., 2015; Reynolds & Alonzo, 1998; Sapountzi-Krepia et al., 2008; Spigelmyer & Schreiber, 2019) suggested informal caregivers were not receiving adequate supports. Informal caregivers and care receivers were left to "cope" with their roles, (Bove et al., 2016; Goodman, 1986; Mishra et al., 2018; Rosas-Santiago et al., 2017; Williams, 2003; Wrubel et al., 2001) without the supports that could help them find joy and growth in these roles.

Nurses' complex and contradictory perceptions of informal caregivers

Informal caregivers were perceived by nurses in complex and contradictory ways: as resources, as trainees, as experts, as annoyances, and as care receivers themselves. Authors of these publications noted that nurses, alongside their institutional employers, sometimes viewed informal caregivers as presumed additional resources for patient care, especially in healthcare systems facing limited budgets. ("American nurses association position statement on informal caregiving," 1995; Cascella Carbó & García-Orellán, 2020; Laitinen, 1992; Laitinen & Isola, 1996; May et al., 2001; Nolan & Grant, 1989; Sapountzi-Krepia et al., 2008) Simultaneously, the included nursing literature suggested training should be afforded to informal caregivers, particularly when informal caregivers desired this service. (Abiola Hazzan et al., 2015; "American nurses association position statement on informal caregiving," 1995; Araújo et al., 2018; Bove et al., 2016; Gemmill et al., 2011; Grant & Graven, 2018; Künzler-Heule et al., 2016; Laitinen & Isola, 1996; Mishra et al., 2018; Nahm et al., 2010; Nolan & Grant, 1989; Sales Graça et al., 2017) Acknowledging the expertise of informal caregivers, nurses sometimes advocated for informal caregivers to be viewed as essential care partners with the healthcare teams. (Bove et al., 2016; Gemmill et al., 2011; Künzler-Heule et al., 2016; May et al., 2001; Nolan & Grant, 1989; Sales Graça et al., 2017; Sapountzi-Krepia et al., 2008; Schumacher et al., 2000; Wilson et al., 2009; Wrubel et al., 2001) Yet, at times, nurses were said to perceive informal caregivers as annoyances to be avoided or prevented from integration within healthcare teams. (Grant & Graven, 2018; Laitinen & Isola, 1996; May et al., 2001; Nolan & Grant, 1989) Finally, some authors noted that informal caregivers could benefit from receiving supportive nursing care alongside their care receivers, due to the negative health and social consequences that often correspond with their unsupported caregiving role. ("American nurses association position statement on informal caregiving," 1995; Chamberlain et al., 2018; Eriksson et al., 2013; Goodman, 1986; Hewison, 1994; Künzler-Heule et al., 2016; Laitinen & Isola, 1996; Nolan & Grant, 1989; Pallangyo & Mayers, 2009; Pereira & Rebelo Botelho, 2011) As part of this care, nurses were advised to assess informal caregivers' perceptions of support services, regularly inform them of available services, and showcase the benefits of accessing such services. (Chamberlain et al., 2018; Grant & Graven, 2018; Hewison, 1994; Spigelmyer & Schreiber, 2019)

Healthcare and societal contextualities (1986-2021)

Nurses' understandings of the concept "informal caregiver" were embedded within the healthcare and societal contexts that nurses found themselves in when these manuscripts were published. The role has evolved as different conditions with different caregiving needs have emerged. From 1986 to 2021, HIV/AIDS and cancer became more chronic conditions, especially in higher income countries; populations were aging; and many healthcare services were being shifted to the community. The nursing literature forecasted society's increasing reliance on informal caregiver support with the continuing shift of healthcare from hospitals to the community. ("American nurses association position statement on informal caregiving," 1995; Armstrong-Esther et al., 2005; Cascella Carbó & García-Orellán, 2020; Goodman, 1986; Kirton et al., 2012; May et al., 2001; Pallangyo & Mayers, 2009; Pereira & Rebelo Botelho, 2011; Reynolds & Alonzo, 1998; Schumacher et al., 2000; Tseh et al., 2005; Wilson et al., 2009) Concerns of the informal caregivers of HIV/AIDS patients coincided with the aftermath of the initial panic surrounding the epidemic. With time, HIV/AIDS treatments extended lives and became more widely available, necessitating ongoing informal caregiving support. (Pallangyo & Mayers, 2009; Reynolds & Alonzo, 1998; Wrubel et al., 2001) Cancer, too, was a predominant health condition requiring informal caregiving support. (Gemmill et al., 2011; Mishra et al., 2018; Sapountzi-Krepia et al., 2008; Schumacher et al., 2000; Van Durme et al., 2012; Williams, 2003; Wilson et al., 2009) However, since cancer frequently develops in late adulthood, the cancer literature overlapped significantly with the majority of publications that investigated informal caregiving in aging populations (see Supplementary Digital Content 2 for a table listing the different health conditions reviewed).

Surrogate and related terms for "informal caregiver"

Surrogate terms for "informal caregiver" included "informal carer", (Barber, 2007; Chamberlain et al., 2018; Goodman, 1986; Hewison, 1994; Kirton et al., 2012; May et al., 2001; Nolan & Grant, 1989) "primary caregiver", (Abiola Hazzan et al., 2015; Laitinen, 1992; Laitinen & Isola, 1996; Rosas-Santiago et al., 2017) and "family caregiver". (Laitinen, 1992; Schumacher et al., 2000) Use of these surrogate terms was influenced by context; for example, "informal carer" was mostly used in the United Kingdom. (Barber, 2007; Goodman, 1986; Hewison, 1994; Kirton et al., 2012; May et al., 2001; Nolan & Grant, 1989) Related terms included "parent", "partner", and "spouse". Being a "parent" was similar to being an "informal caregiver" but specifically entailed parenting one's underage or adult children who lived with complex medical conditions. (Barber, 2007; Kirton et al., 2012; Reynolds & Alonzo, 1998; Rosas-Santiago et al., 2017; Sapountzi-Krepia et al., 2008) A romantic "partner" or a "spousal" role was related to but differed from an informal caregiver role. (Bove et al., 2016; Eriksson et al., 2013; Reynolds & Alonzo, 1998; Wilson et al., 2009) Without the antecedents of a health or aging condition causing functional dependencies for the care receiver, being a "parent", "partner", or a "spouse" did not have the same meaning as being an "informal caregiver". Only when all the antecedents were met were they considered "informal caregivers".

"Provider" was another term frequently noted in the literature. A few publications used the term "service providers", referring to the people and organizations that were paid to provide formal caregiving services. (Hewison, 1994; Nolan & Grant, 1989) Other "provider" terms included "formal care provider", (May et al., 2001) "care provider", (Abiola Hazzan et al., 2015) and "formal service provider" (Armstrong-Esther et al., 2005) to differentiate these formal caregivers from unpaid and untrained informal caregivers who "gave" their time, rather than "provided" their services for pay. However, a few organizations used "informal care provider" ("American nurses association position statement on informal caregiving," 1995; Reynolds & Alonzo, 1998; Tseh et al., 2005) or just "care provider" (Chiao et al., 2017) to refer to informal caregivers, making "provider" both a surrogate and related adjective, in this literature.

Discussion

We performed this concept analysis to provide a deeper understanding of what “informal caregiver” means in nursing, based on a selection of nursing literature on informal caregivers. With the current attributes, antecedents, and consequences identified for the concept, the discipline of nursing can have a common foundation for understanding what the concept currently entails in our discipline. With the contextual features identified, nurses can foresee how this concept may evolve in the future. In the following sections, we discuss how these results could be used by nurses to better identify and support informal caregivers, as well as how the findings can be used to evolve nursing’s understanding of the informal caregiver role towards more positive partnerships.

Applying this Analysis to Better Identify and Support Informal Caregivers

This concept analysis offers nurses a shared understanding of the attributes and antecedents of this concept, creating a starting point for nurses to more consistently identify those who are engaged in the role of informal caregiver, and to support them better. Furthermore, by recognizing that the current literature typically focuses on a certain demographic of “informal caregiver” (i.e., middle-aged and older women caring for aging parents or spouses), nurses will be equipped to question their personal assumptions about who they expect an informal caregiver to be. (Cascella Carbó & García-Orellán, 2020; Morgan et al., 2016) They may ask themselves questions like, “Am I subconsciously expecting middle-aged and older women to be more responsible for caregiving?”, “Am I ignoring other relations to the patient who may also need informal caregiving resources, such as male relations and young caregivers?”, and “Am I forgetting about the needs of caregivers of patients with conditions less represented in the literature, such as those with conditions unrelated to aging, cancer, or HIV/AIDS; or the parents of children living with disabilities?"

By evolving towards a broader understanding of the concept, nurses can better understand informal caregivers' diverse needs, and more consistently connect them with appropriate resources, such as informal caregiver training (Havyer et al., 2017) and respite care. (Rose et al., 2015a) With improved understanding of the informal caregiver role, nurses will be better equipped to support informal caregivers and care receivers in their roles. Still, while it is important that nurses work to support informal caregivers who want to be their loved ones' caregivers, it is important to recognize that not all informal caregivers willingly adopt this role. (Castro & Tsimicalis, 2020) Therefore, nurses should also be advocating for more inclusive structural supports to avoid forcing reluctant individuals into the informal caregiver role. ("American nurses association position statement on informal caregiving," 1995; Castro & Tsimicalis, 2020)

Nurses may even be able to offer supports *before* informal caregivers identify themselves as caregivers. It can take time for informal caregivers to self-identify as "informal caregivers". (Reynolds & Alonzo, 1998; Rose et al., 2015a) However, if informal caregivers do not identify with the role, they may fail to access supportive services that specifically target informal caregivers. (Rose et al., 2015a) Nurses may identify and help families process these role transitions and subsequently connect them with earlier support services. (Pereira & Rebelo Botelho, 2011) By assisting informal caregivers to access caregiving supports from the outset, nurses may prevent some of the burdens associated with the role and facilitate greater personal growth.

Evolving the Concept Towards Positive Partnerships

This concept analysis reveals that there is space for nurses' understanding of the concept to evolve towards a more positive understanding of the partnerships between informal caregivers, care receivers, and nurses. This finding aligns with another concept analysis on "family caregiver-receiver mutuality", where the nurse authors found that the establishment of a family caregiver-receiver dyad was an antecedent for mutuality to occur, and that positive consequences of mutuality in the dyad included increased trust and fulfillment in the caring relationship. (Streck et al., 2020) In our analysis, the informal caregiver role was not a partnership. Informal caregivers were mostly perceived to be providing care *to* care receivers in the dyad; reciprocity in care was rarely discussed. Nurses should encourage patients and other care receivers to identify ways in which they may be offering reciprocal care in the relationship too, for example, by providing emotional support to their informal caregivers. (Teunissen et al., 2018) When informal caregivers and care receivers are treated as mutually supportive partners in care, and when they view their roles as a two-way partnership, both informal caregivers and care receivers are more likely to thrive and experience fewer role burdens. (Lindahl et al., 2011; Streck et al., 2020; Teunissen et al., 2018)

This concept analysis also revealed that nurses often have conflicted perceptions of the informal caregiver role, preventing true partnership from being established between nurses and informal caregivers. These complex nurse-informal caregiver dynamics are well-documented. (Lindahl et al., 2011) Nurses often have reason to feel frustrated at work; when units are understaffed, and when distressed families are yelling at them, it can be exhausting for nurses to engage meaningfully with patients and informal caregivers. (Hartley et al., 2019) Ultimately, however, perceiving informal caregivers as anything other than care partners will be counter-productive to effective nursing work and patient care. (Lindahl et al., 2011) Thus, the nursing discipline has a decision to make: nurses can choose to keep adhering to conflicted and sometimes negative perceptions of informal caregivers, seeing them as either annoyances or resources to exploit; or, nurses can choose to focus on positive perceptions of informal caregivers. To evolve towards the latter understanding, nurses could more consistently recognize informal caregivers' role as experts on the healthcare team, while also acknowledging that informal caregivers may want additional training for their role, and that informal caregivers may need nursing care themselves.

Efforts to improve this nurse-informal caregiver partnership warrant a critique of the negative linguistic patterns of "burden", "informality", and "costs" noted in this concept analysis. Focusing on the "burden" of informal caregiving without addressing the underlying reasons for burden, such as lack of publicly funded and accessible support programs, does not support the caregiving dyad. Furthermore, linking "informal caregivers" with reduced budgets and cost-cutting measures may undermine efforts to encourage non-exploitative partnerships among informal caregivers, care receivers, and nurses.

Finally, it is important to remember that different groups of people understand concepts differently. (Rodgers, 2000) Some scholars and caregiving advocates have argued that the "informal" label may lead others to misconstrue the role as being casual, unskilled, and unessential. (Stall et al., 2019) In our analysis, the "informal" adjective was often used strategically by nurses to differentiate the complex and unpaid work of informal caregivers, from the work of formally trained and paid healthcare workers. (Cascella Carbó & García-Orellán, 2020; Chamberlain et al., 2018; Spigelmyer & Schreiber, 2019) Even when nurses viewed informal caregivers as annoyances, the concept itself was never used by nurses to imply that the role was undemanding or unnecessary. Still, none of the 48 publications critically analyzed the use of the “informal” adjective for informal caregivers. If nurses choose to use the language of “informal caregiver”, nurses should be prepared to defend this language choice, particularly if this concept is used in company with patients and their families.

Implications for Nursing Research

This concept analysis has additional implications for nursing research. Van Durme et al. (Van Durme et al., 2012) argued that many tools used to assess informal caregivers’ experiences and needs are being developed without a clear understanding of what is meant by “informal caregiver” in the context of each study. The goal of a Rodgerian concept analysis is to “serve as a heuristic by providing the clarity necessary to create a foundation for further inquiry and development” (Rodgers, 2000(p84)) of knowledge relevant to the concept. Our analysis can provide an initial foundation for building better nursing measurement tools, policies, and interventions to support informal caregivers, by offering nurses a shared understanding of the current use of “informal caregiver”, and by directing attention towards evolutionary opportunities for the concept.

Limitations and Future Considerations

Although our sample included nursing literature from 18 countries, 24 of the 48 publications originated from the United Kingdom and the United States. There was little discussion in these manuscripts on the effects of specific cultural traditions or socioeconomic status on the informal caregiver role. The sampled literature likely did not contain enough variation in the health conditions of care receivers to offer strong conclusions regarding potential differences between the meaning of “informal caregiver” for one type of health condition versus another. Future research to develop this concept should also more explicitly acknowledge the needs of informal caregivers who are male, who are younger, and/or who are caring for children living with complex medical conditions. Although restricting our literature sampling population to journal titles with “Nurs*” was useful for improving the specificity of the sampled literature, the restriction likely undercut the depth of nursing-focused literature on informal caregivers, such as journals that focus on topics relevant to nursing and caregiving but that do not have “Nurs*” in the title. Future analyses of this evolving concept may wish: to include a broader sampling population of literature, focus the sample on more specific contexts of informal caregiving, or move towards a transdisciplinary understanding of the concept.

Conclusion

This concept analysis can act as a foundational guide for ongoing development of nurses’ understanding of the concept “informal caregiver”. This study offers the nursing discipline a starting point to better identify and understand the needs of informal caregivers, so that nurses may improve their capacities to support informal caregivers. Thus, this analysis helps to create a foundation for the structurally and conceptually sound development of knowledge, policies, and interventions necessary to support informal caregivers in the future.

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Legend for Supplementary Digital Content

Supplementary Digital Content 1 (below): Table illustrating the organization of data into categories and labels.

Supplementary Digital Content 2: Table providing further details for the 48 included publications (.pdf). See online: https://cdn-links.lww.com/permalink/ans/a/ans_2022_05_10_castro_2232_sdc2.pdf

(Table 4.2.3) Supplementary Digital Content 1: Table illustrating the organization of data into categories and labels

Raw Data (Source)	Rodgerian Categories	Preliminary Labels	Final Labels
"Owing to the multitude of caring roles, environments and contexts, those who are informal carers have a multitude of needs. However, many informal carers have many common needs, including: the carers' own physical, emotional and psychological health which can often be poor". (Barber, 2007(p769))	Attributes	Caregiver is a "role"	Attribute - role
	Attributes	The role is "informal"	Attribute – role is informal
	Consequences	Caregivers need help	Needing supports to prevent role-related distress
	Consequences	Physical, psychological, and emotionoal consequences	Experiencing a myriad of health and social consequences due to the role
	Surrogate and related terms	Surrogate – "informal carer"	Surrogate terms
"The caregiving situation allows them to experience and learn more about each other as they spend more time together overcoming the new life challenge, such as hip fracture. This is an important positive aspect of caregiving that has significant implications in practice. For instance, interventions maximizing this psycho-social dynamic within the dyad, such as caregiver educations to help care recipients adhere to therapy plans, could be effective approaches". (Nahm et al., 2010(p260))	Attributes	"Dyadic" relationship	Attribute – role is dyadic
	Consequences	Consequences – social – old relationship changing	Experiencing a myriad of health and social consequences due to the role
	Consequences	Consequences – needing supports so can experience growth through the relationship changes	Needing supports to prevent role-related distress
	Contextual features	Caregivers should receive education, training – nursing perspective	Nurses' complex and contradictory perceptions of informal caregivers
"The primary caregivers in this study were other relatives (72%), such as daughter-in-law, sister, niece or grandchild, all of whom were women. Participation of relatives in the care of elderly	Contextual features	Demographics of caregivers – women, relatives	The demographic representation of informal caregivers
	Antecedents	Family to provide care	A pre-existing relationship

patients in the hospitals was limited. Family members or other significant others most often gave emotional support (26% every day), otherwise they helped their elderly relative to exercise (8% every day), dress/ undress (4% every day) and stand up/get into bed (4% every day) (Table 1)". (Laitinen, 1992(p1235))	Antecedents	Elderly needing care	A person needing care
	Antecedents	Elderly needing care	A health- or aging-related condition
	Consequences	Caregiving responsibilities – emotional support, physical support	Enacting numerous responsibilities to fulfil the role
	Surrogate and related terms	Surrogate – "primary caregiver"	Surrogate terms
"The study took place in the Chinook Health Region in south-western Alberta.The population was non-randomly selected from 736 home care clients aged 75 years and over. The participants had a classification of between 3 and 9 (moderate-to-high dependency) based on the Home Care Client Classification (HCCC)". (Armstrong-Esther et al., 2005(p285))	Antecedents	"Dependency"	Functional dependency
	Antecedents	Older adults needing care	A health- or aging-related condition
"Furthermore, the majority of the participants answered that usually nurses or physicians suggest one of the relatives stay at the patient's bedside even after visiting hours or hire a private paid patient's helper. This is quite concerning and implies that the hospital staff considers the contribution of the family or of the privately paid patient's helper necessary for the patients' care". (Sapountzi-Krepia et al., 2008(p1292))	Contextual features	Viewing caregivers as healthcare resources	Nurses' complex and contradictory perceptions of informal caregivers
"Role of hired help: Caregivers also noted that the [Caregiver Burden Scale] and the [Clinical Nurse Specialist Performance Appraisal instrument] do not	Consequences	Families need respite care services to improve care provided	Needing supports to prevent role-related distress

address the role of hired help or other care providers that families often pay to provide temporary reprieve for the regular caregiver. Hired help like those available through respite care provide temporary relief for the regular family caregiver to pursue other activities (for example, training or relationships with other caregivers) that may ultimately help improve the level or quality of care provided to the care recipient". (Abiola Hazzan et al., 2015(p6))	Contextual features	Caregivers may benefit from training	Nurses' complex and contradictory perceptions of informal caregivers
	Consequences	Social consequences - other relationships affected by caring roles	Experiencing a myriad of health and social consequences due to the role

References for Supplementary Digital Content 1

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5.0 Paper 3: Environmental Scan of Quebec Palliative Respite Services

5.1 Bridge 3

Paper 3 for this dissertation was conducted in shared first authorship, with McGill University Master's in Nursing-Direct Entry student, Gabrielle Lalonde-LeBlond, who graduated in May 2024, and who I co-supervised with Dr. Tsimicalis for Gabrielle's Master's work. Ms. Lalonde-LeBlond gave her permission for this co-first authored publication to be published in my dissertation. Ms. Lalonde-LeBlond's degree was for a course-based Master's, so she did not present this work in a final thesis.

For this paper, we conducted a novel digital environmental scan across the Google search engine and two Canadian healthcare databases. This environmental scan mapped respite care agencies in Quebec that specifically offered in-home respite care services to families facing advanced and palliative illnesses, including cancer. Out of 401 screened services, 52 in-home respite care services catering to palliative populations were identified, compiled, and analyzed. These services varied in terms of assistance types, providers, fees, and geographic coverage.

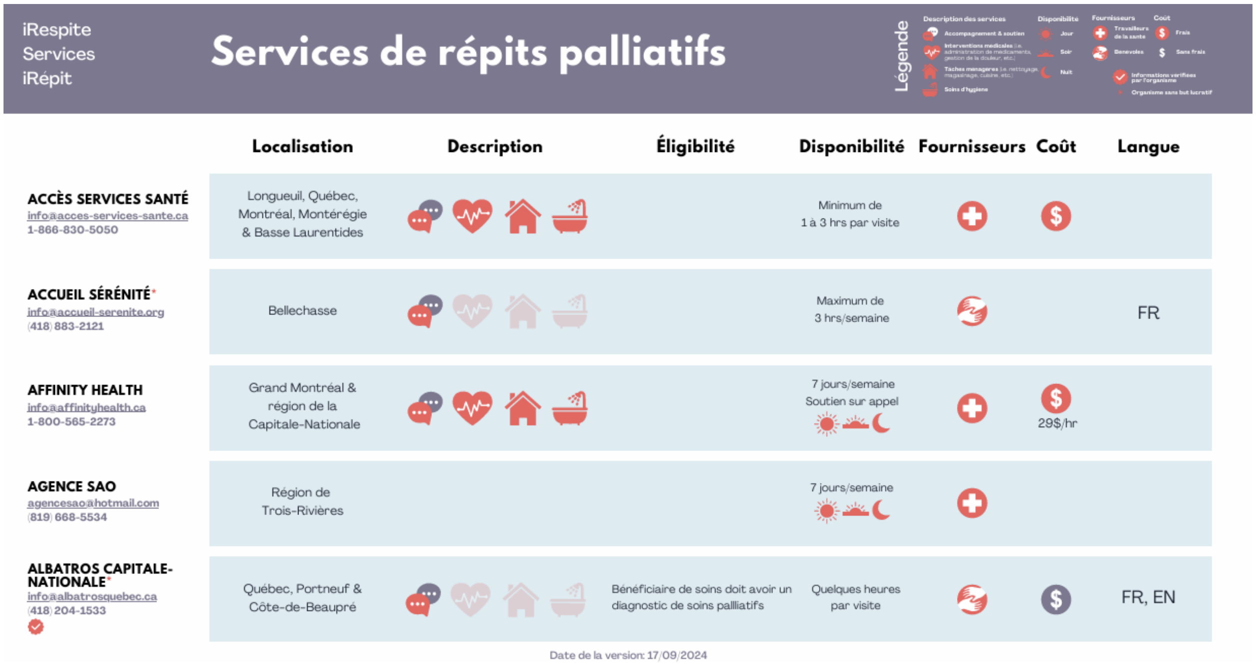
These results contributed in several ways to the overall aim of this dissertation for designing the iRespite proof-of-concept for coordinating respite care services. This scan underscored the challenges that families and clinicians face in navigating formal respite care services. It particularly revealed a challenge of access in terms of lack of available agencies in many regions of Quebec, creating opportunities for self-contracting respite care providers. An Expert Council member noted that in rural regions of Quebec, informally coordinated respite care services like Quebec's "chèque emploi-service" cash-for-care program, where local community and health centres (CLSCs) can pay for families' friends to provide respite care, are often in even higher demand than in cities (*Chèque emploi*, 2022). They explained that this higher demand is because in rural regions there are frequently no formal agencies available

This environmental scan resulted in an academic mapping of 52 agencies. Post-publication, we also developed a user-friendly, printable .pdf tool outlining these agencies in Figure 5.1.1 below. An interactive prototype of this tool is available on my website: https://aimeecastro.com/irespite-services-irepit/irespite-agency-navigator/. This tool is being developed into an app module of an agencies navigator, to be embedded into the iRespite app proof-of-concept. By providing both, digital and printable versions of this palliative respite care agencies navigation tool, we aimed to ensure that this tool is available across digital divides (Singh & Chobotaru, 2022). We have already shared this tool at conferences and with over 25 direct care clinicians. The Canadian Centre for Caregiving Excellence has shared the tool on their website (*Caregiver resources*, 2024).

(Figure 5.1.1) User-friendly .pdf and searchable palliative respite care agencies navigator

Link to pdf: https://aimeecastro.com/wp-content/uploads/2024/09/2024.09.17_User-FriendlyTool_GLL.pdf

Screenshot of the first .pdf page in French:



iRespite
Services
iRépit

Services de répits palliatifs

Légende

Description des services	Disponibilité	Fournisseurs	Coût
💬 **Accompagnement & soutien**	☀ **Jour**	✚ **Travailleurs de la santé**	$ **Frais**
❤ **Interventions médicales** (i.e. administration de médicaments, gestion de la douleur, etc.)	🌅 **Soir**	🤝 **Bénévoles**	$ **Sans frais**
🏠 **Tâches ménagères** (i.e. nettoyage, magasinage, cuisine, etc.)	☾ **Nuit**		
🛁 **Soins d'hygiène**			

✓ **Informations vérifiées par l'organisme**
* **Organisme sans but lucratif**

	Localisation	Description	Éligibilité	Disponibilité	Fournisseurs	Coût	Langue
ACCÈS SERVICES SANTÉ info@acces-services-sante.ca 1-866-830-5050	Longueuil, Québec, Montréal, Montérégie & Basse Laurentides	💬 ❤ 🏠 🛁		Minimum de 1 à 3 hrs par visite	✚	$	
ACCUEIL SÉRÉNITÉ* info@accueil-serenite.org (418) 883-2121	Bellechasse	💬		Maximum de 3 hrs/semaine	🤝		FR
AFFINITY HEALTH info@affinityhealth.ca 1-800-565-2273	Grand Montréal & région de la Capitale-Nationale	💬 ❤ 🏠 🛁		7 jours/semaine Soutien sur appel ☀ 🌅 ☾	✚	$ 29$/hr	
AGENCE SAO agencesao@hotmail.com (819) 668-5534	Région de Trois-Rivières			7 jours/semaine ☀ 🌅 ☾	✚		
ALBATROS CAPITALE-NATIONALE* info@albatrosquebec.ca (418) 204-1533 ✓	Québec, Portneuf & Côte-de-Beaupré	💬	Bénéficiaire de soins doit avoir un diagnostic de soins palliatifs	Quelques heures par visite	🤝	$	FR, EN

Date de la version: 17/09/2024

QR code and link to searchable navigator prototype:

Prototype: iRespite Agency Navigator – Aimee Castro

5.2 Paper 3 Manuscript

Cite as: *Castro, A., *Lalonde-LeBlond, G., Freitas, Z., Arnaert, A., Bitzas, V., Kildea, J., Moffatt, K., Phillips, D., Wiseblatt, L., Hall, A.J., Després, V., & Tsimicalis, A. (2024). In-Home Respite Care Services Available to Families with Palliative Care Needs in Quebec: Novel Digital Environmental Scan. *JMIR Nursing*, *7*, e53078.

(Castro, Lalonde-LeBlond, et al., 2024)

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A Novel Digital Environmental Scan of In-Home Respite Care Services Available to Families with Palliative Care Needs in Quebec

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Abstract

Background: Caregiving dyads in palliative care are confronted with complex care needs. Respite care services can be highly beneficial in alleviating the caregiving burden, supporting survivorship and dying at home. Yet, respite care services are difficult to locate and access in the province of Quebec, Canada, particularly when navigating ubiquitous sources of online health information of varying quality.

Objective: This project aimed to (1) compile a list of at-home palliative respite care services in Quebec, Canada; (2) describe key accessibility features for each respite care service; (3) identify accessibility gaps and opportunities; and (4) describe a novel method for conducting environmental scans using internet search engines, internet-based community health databases, and member checking.

Methods: A novel environmental scan methodology using 2 internet-based targeted databases and 1 internet search engine was conducted. Results were screened, and data were extracted, descriptively analyzed, and geographically schematized.

Results: A total of 401 services were screened, and 52 at-home respite care services specific to palliative populations were identified, compiled, and analyzed. These respite care services were characterized by various types of assistance, providers, fees, and serviced geographical regions. Accessibility, through the lens of service amenability, availability, eligibility, and compatibility was explored. The data revealed important barriers to accessing respite care services, such as a lack of readily available information on service characteristics, limited availability, and a time-consuming, technical search process for potential respite care users and clinicians to identify appropriate services.

Conclusions: Both methodological and contextual knowledge have been gained through this environmental scan. Few methodologies for conducting internet-based environmental scans have been clearly articulated, so we applied several learnings from other scans and devised a methodology for conducting an environmental scan using the mixed methods of internet search engines, internet-based community health databases, and member checking. We have carefully reported our methods, so that others conducting community health environmental scans may replicate our process. Furthermore, through this scan, we identified assorted respite care services and pinpointed needs in the provision of these services. The findings highlighted that more easily accessible and centralized information about respite care services is needed in Quebec. The data will enable the creation of a user-friendly tool to share with community support services across Quebec and ultimately help alleviate the added burden caregivers and clinicians face when looking for respite care services in fragmented and complex digital spaces.

Keywords: respite care; palliative care; caregiving; environmental scan; digital methodology; accessibility

Introduction

Overview

Palliative caregiving is a particularly intensive form of caregiving. Respite care is one of the essential services helping to support informal caregivers (ie, generally individuals with a preexisting relationship to the care recipient, with no additional training, and contributing unpaid work), and care recipients, particularly those in the palliative stage of care. (AR Castro et al., 2022) The goal of respite care is to provide short-term relief to informal caregivers and care recipients, from their dyadic care-giving and care-receiving relationship, by allowing both parties to spend time away from each other, interact with others, and perform activities that they enjoy or need to do. (Dunbrack, 2003; Evans, 2013a; Smith et al., 2017a) During respite, another person acts as the care recipient's temporary caregiver. (Evans, 2013a; Smith et al., 2017a) Respite can be accessed via a variety of service provisions (eg, palliative care, hospice day centers, and home care), offered in different settings (at home, in a facility, in the hospital, and in the community) and provided by an array of health care personnel to individuals coping with disabilities or illnesses. (Dunbrack, 2003; Evans, 2013a; Ingleton et al., 2003; Whitmore, 2017)

For dyads in a palliative stage of care, respite care often contributes to supporting death in the home setting, which most patients prefer, all the while improving both parties' psychosocial well-being and quality of life. (Evans, 2013a; Fenton, 2020; Gomes et al., 2013; Ingleton et al., 2003; Rao et al., 2021) Additionally, these services are linked to decreased hospital admissions, health care costs, and the use of aggressive care at the end-of-life. (*C. D. Howe institute*, 2021; Rao et al., 2021) In fact, dyads coping with terminal illnesses and needing palliative care support are increasingly requesting respite care services in Canada. (*C. D. Howe institute*, 2021; Canadian Healthcare Association, 2012; Dunbrack, 2003) Despite these benefits, there seems to be no clear, comprehensive, and easily accessible information on overall or specific resources offered in Quebec.

In Canada, and particularly in Quebec, the provision of respite care falls outside the Canadian Health Act, which governs health care provision across Canada. As a result, a patchwork of services, funded through a variety of public, private-for-profit, and private nonprofit initiatives, is offered to nearly 1.5 million informal caregivers and care recipients in Quebec. (Institut de la statistique du Québec, 2022b) Government guides direct caregivers to their local CISSS (integrated health and social services centers) and CIUSSS (integrated university health and social services centers) for details on respite care services as opposed to specific agencies. (*Guide to programs*, 2017) Additionally, some nonprofit organizations offer web portals for searching respite care services within their target population, such as Portail Répit for caregivers of children living with disabilities. The lack of a seamless respite care access pathway results in a lengthy, multistep process to access services—a process that can be overwhelming for exhausted palliative care dyads, and time-consuming for nurses, who typically oversee respite care service coordination and home care service provision.

Difficulties encountered while searching, locating, and accessing respite care impose an additional, undesirable burden on informal caregivers seeking respite. (Canadian Healthcare Association, 2012; Revenu Québec, 2021) Even with internet access at home, nearly a quarter of Canadians, particularly those most likely to resort to at-home health care services, have very limited internet use and digital skills. (Cai et al., 2017; Statistics Canada, 2021; Wavrock et al., 2021) Consequently, individuals with varying levels of digital literacy (ie, the ability to successfully use and navigate the internet and the associated apps or devices), are stranded to identify a search strategy by themselves. (Wavrock et al., 2021) The paucity of relevant information and difficulties in finding available services specific to individual needs may render respite care services inaccessible. (Doig et al., 2009; Fenton, 2020; Phillipson et al., 2014; Quinn et al., 2021; Rao et al., 2021) Considering the overall preference for death at home, and challenges associated with palliative caregiving, addressing access to information and support services, such as respite care, is essential to ensure all parties are supported through this phase of care.

Objectives

This environmental scan study aimed to identify and describe the characteristics of in-home respite care services currently available to caregiving dyads with palliative care needs in the French-speaking province of Quebec, by (1) mapping a current list of in-home palliative respite care services available to adults in Quebec; (2) describing and analyzing key offerings and accessibility features for each service; (3) identifying gaps and opportunities to increase accessibility and usage of these services; and (4) describing a methodology for conducting environmental scans using various internet-based sources and member checking.

Methods

Overview

Environmental scans methodologically support the systematic collection and analysis of information and services available within a specific environment, for addressing the needs of a specific population. While no standard approach exists, this design often relies on searching beyond the academically published literature to identify all currently available programs. (Charlton et al., 2019; Charlton et al., 2021; Choo, 2001; Hatch & Pearson, 1998; Rowel et al., 2005) Environmental scan strategies consist of combining sources of information consolidated from grey literature, internet search engines, and stakeholder consultations to identify all up-to-date and accessible services of a specific type available in a given geographic region. (Rowel et al., 2005) This project implemented a novel environmental scan methodology to compile existing respite care services for individuals with palliative care needs in Quebec.

The novel and iterative strategy we developed consisted of (1) conducting a comprehensive search of internet-based respite and health care databases and internet search engines, (2) identifying and screening results for eligibility, (3) extracting and compiling the data, (4) seeking expert consultations, (5) analyzing the data, and (6) synthesizing the results into a coherent report on respite care services in Quebec. The general framework for scoping reviews by Peters et al (Peters et al., 2020b), was taken into consideration, as were the methods used by related environmental scans, which tended to use analog paper sources and grey literature, rather than digital and internet-based resources. (Charlton et al., 2019; Wurz et al., 2019)

Eligibility Criteria

The eligibility of respite care services was determined through a 2-step process. First, for respite care services to be considered eligible for this environmental scan (1) respite care services had to be offered in Quebec, (2) these services had to be coordinated by an official organization, (3) respite care services had to be offered in-person, and (4) these services had to be offered as a stand-alone service. Home support services that did not specifically mention the concept of respite were excluded, along with Google Ads. Remote respite care services (eg, video camera "nanny cams") and informal respite care provided by family, friends, or self-employed individuals were not considered, as well as services only available when participating in the organization's broader activities. (AR Castro et al., 2022)

Second, eligible respite care services were further screened to identify a subgroup of services that (1) were offered in the family's home and (2) indicated that services were either destined for a population in palliative care or at the end of life or that specialized services for persons in palliative care or at the end of life were offered in conjunction with general respite care.

Internet-Based Search of Respite Care Services

Respite care services were identified by (1) searching internet-based respite and health care databases and (2) searching the most commonly used internet search engine. The search strategies and methodology were created in collaboration with an expert librarian and reviewed by consulting coauthors to ensure that the keywords used were most appropriate for the Quebec context. Examples of keywords used in these search strategies included “respite care,” “short-term care,” and “home caregiving” (see Textbox 1 for the full list of keywords)

(Textbox 5.2.1): Textbox 1. Keywords related to the main research question and concept of respite care; keywords were translated from English to French by a bilingual member of the research team, with the corroborating assistance of DeepL Translator (DeepL SE). (Linguee)

English keywords

- Respite care
- Respite
- Short-term care
- Short term care
- Sitting service
- Adult day-care
- Adult day care
- Adult daycare
- Day respite facility
- Hospice at home
- Home hospice
- Hospice day centre
- Palliative day centre
- Home-based palliative care
- Home care
- Homecare
- Home caregiving
- Caregiving help
- Help for caregivers

French keywords

- Soins de répit
- Service de répit
- Répit
- Soins de relève
- Service de relève
- Relève
- Soins à court terme
- Soins de courte durée
- Service de garde
- Soins de jour pour adulte
- Établissement de répit de jour
- Centre de répit de jour
- Maison de répit de jour
- Centre de jour de soins palliatifs
- Centre de jour palliatif
- Soins palliatifs à domicile
- Soins à domicile
- Assistance à domicile
- Aide pour proches aidants
- Aide pour aidants
- Aide aux aidants
- Aide aux proches aidants

Step 1: Searching Internet-Based Respite and Health Care Databases

Overview

A bilingual, French and English, search was conducted using web resource databases intended for caregivers and patients and that are relevant to the subject of caregiving support and respite care in Quebec—the Canadian Cancer Society Community Services Locator and the resource directory for L'Appui Proche Aidants, an organization supporting informal caregiving in Quebec. (Canadian Cancer Society, 2021; L'Appui proche aidants) Our search strategy slightly differed from 1 database to the next due to their unique search functionalities.

Canadian Cancer Society Community Services Locator

This database was searched using the keywords found in Textbox 1, with Quebec, Canada, listed as the location. No specific search parameters or limitations were applied, and the results were sorted by relevance.

L'Appui Resource Directory

This database was searched using the "Search by Service" function along with selecting the subcategory listed in the database filters of "respite care services offered in the home." This directory does not allow for a province-wide search. Thus, the most populated postal codes for each of Quebec's 18 health regions were used to facilitate the search for services across Quebec. (*Msss qc*, 2022; *Statcan*, 2016) The results were automatically sorted from closest to farthest away from the postal code.

Step 2: Searching an Internet Search Engine

Google, the most popular search engine option in Canada, was used on a private browsing window to further identify respite care services. (Statcounter GlobalStats, 2021) The following search permutation (see Textbox 2) was selected based on its ability to return a high number of relevant results.

(Textbox 5.2.2) Textbox 2. Search permutation for Google search; "Keyword" was replaced by each keyword listed in Textbox 1. Quebec, Montreal, Sherbrooke, Trois-Riviere, Chicoutimi, Saint-Jerome, and Saint-Jean-sur-Richelieu were selected due to being populous regions in the province of Quebec.

For English keywords: "Keyword" AND ("palliative" OR "hospice" OR "dying" OR "end-of-life") AND (Quebec OR Montreal OR Sherbrooke OR Trois-Rivieres OR Chicoutimi OR Saint-Jerome OR Saint-Jean-sur-Richelieu)
For French keywords: "Keyword" AND ("palliatif" OR "mourant" OR "mourir" OR "fin de vie") AND (Québec OR Montréal OR Sherbrooke OR Trois-Rivières OR Chicoutimi OR Saint-Jérôme OR Saint-Jean-sur-Richelieu)

Before conducting each search, Google settings were adjusted to deactivate results personalization based on prior activity, location, and stored data. Such adjustments reduce the probability of previous search activities by the researcher, or their location, affecting the results of the search. (Monton et al., 2019) Google alerts for once-a-month returns were also created for the keyword combinations to identify new results after the initial search period.

Step 3: Screening

Based on preliminary searches, the 2 caregiving support databases, and particularly the 1 internet search engine, yielded a large number of results. In order to screen a feasible number of relevant results, we reviewed the first 100 results for each search, which accounts for the first 10 pages of results on Google with default settings. (Donnelly & Thompson, 2015; Godin et al., 2015) In general, users interact most with first page results, with few visiting or clicking the following pages' results. (BackLinko, 2022) Therefore, our approach goes beyond the typical use of internet search engines.

Duplicates were removed, and each returned result's home page was previewed for eligibility. Search results that did not meet the eligibility criteria, such as information sheets that shared caregiving support information but not respite care contact information, news articles or general reports on respite care, were not included. When eligibility was unclear, the team discussed the service to determine if the result should be included.

Step 4: Data Collection

Once screened, each eligible respite care organization's website was saved and reviewed to extract information on the service eligibility criteria, service features, geographic availability, targeted demographics, costs, and language of the respite care service. (Whitmore, 2017) Similar variables have been identified and used in previous research. (Dunbrack, 2003; Légaré et al., 2012; Rosa Fortin et al., 2014; Wurz et al., 2019) To foster a consistent approach, the data collection was done independently by 1 researcher. If any discrepancies arose, issues were discussed and resolved with the research team.

Step 5: Conducting Expert Consultations

Preliminary search strategy findings with a current list of services were sent to a group of 5 stakeholders (experts) comprising community members involved in respite care coordination and research. For review and feedback, experts were asked to verify our list of respite care services. They were also invited to direct us to any other respite care services in Quebec and identify any other essential feature required to describe the respite care services. (Légaré et al., 2012) Stakeholders and identified organizations were also asked to provide feedback on the final paper and results.

Step 6: Data Analyses

Qualitative deductive content analysis was used to descriptively analyze and interpret the data using a predetermined coding framework consisting of the following categories: service features, length of services, setting, care provider, region, costs, language, eligibility criteria, and user profile. (Elo & Kyngäs, 2008a) A geographical map of the services by region was created using graphic design software.

A framework defining “access” to health care was also identified post hoc as part of our iterative data analyses for further analyzing the data related to “accessibility”. (Norris & Aiken, 2006) Norris and Aiken (Norris & Aiken, 2006) conceptualized access to health care as characterized by (1) the family’s amenability to receive services (ie, the client’s readiness and knowledge of service and contextual factors), (2) the services’ availability (including location and hours of operation), (3) the eligibility of the client to access such services (including costs), and (4) the compatibility between the service and individual needs. This framework helped contextualize and structure our analysis of the findings, whereby each predetermined coding category was matched to 1 of the 4 components of health care accessibility.

Results

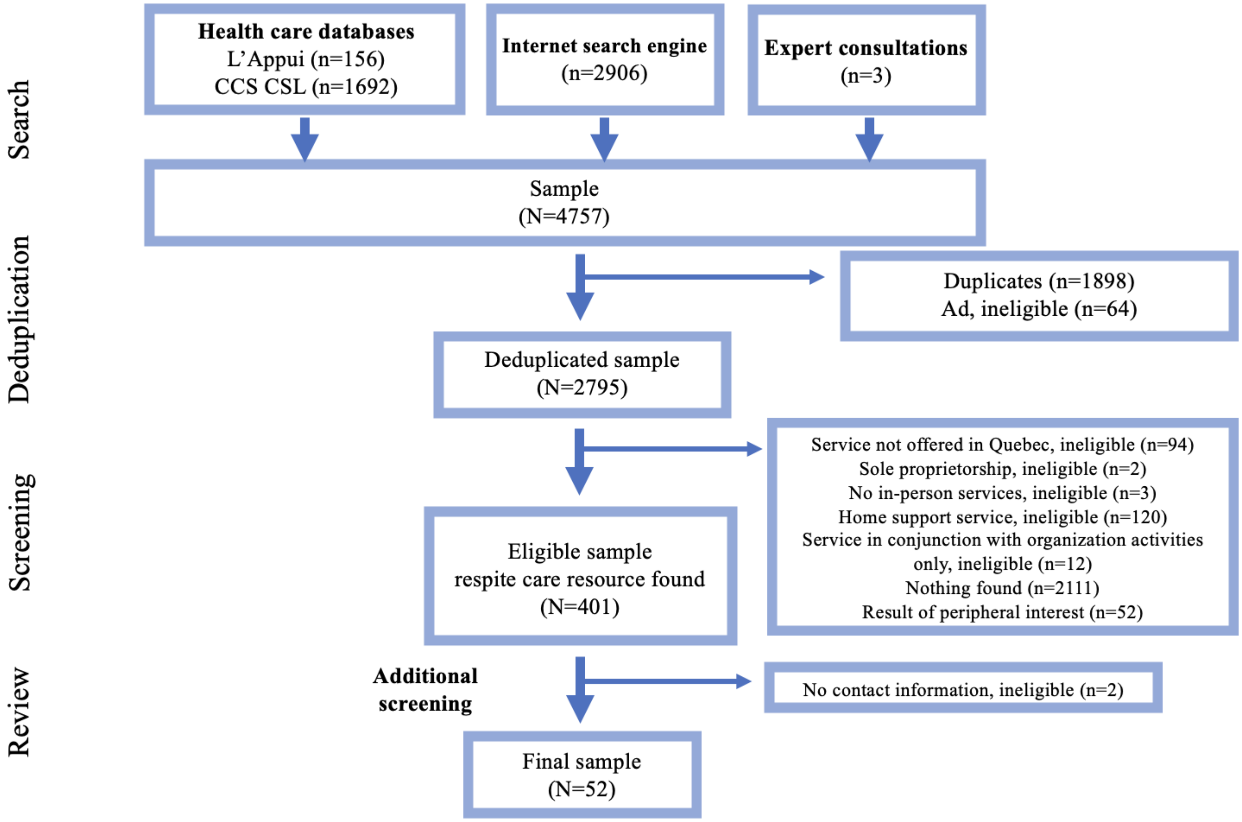
Overview

We used descriptions of the services along with specific service features, according to Norris and Aiken's (Norris & Aiken, 2006) framework of personal access to health care, to determine the overall accessibility of the respite care services identified—amenability, availability, eligibility, and compatibility.

Amenability

A total of 100 searches were conducted, including 41 on the Canadian Cancer Society Community Services Locator, 18 on the L'Appui Resource Directory, and 41 on Google (including monthly search alerts) producing a total of 4757 search results. Of these results, 401 results corresponded to respite care services, 52 of which were included in our analyses as they offered in-home respite care targeted to individuals with palliative care needs. The remainder of services were offered in a designated location (eg, a hospice or care home) and targeted to other key populations (eg, children with chronic disabilities). The most common reasons for exclusion were that respite care services were offered outside the province of Quebec (n=94), that home support services did not mention respite (n=120), and overwhelmingly, that no services specific to the concept of respite care were found on the website (n=2111). A total of 2 services were ultimately excluded due to providing no contact information. In some cases, these identified websites corresponded to an unrelated database, caregiving resource, news article, miscellaneous service, or obituary. Figure 1 summarizes the results obtained through data collection and screening.

(Figure 5.2.1): **Figure 1.** Flowchart of respite care data collection strategy, adapted from Moher et al’s model. (Moher et al., 2009)



Google was the most successful database for the identification of relevant respite care services. In fact, 40 eligible services (40/52, 75.5%) were discovered through Google, 26 of which (26/40, 65%) were exclusive to this search engine and were not found in the Canadian Cancer Society Community Services Locator or L’Appui databases. The Canadian Cancer Society Community Services Locator enabled the identification of 23 eligible services (8 exclusively), while the L’Appui Resource Directory identified 7 eligible services (1 exclusively). The expert consultations uncovered 3 services, 1 of which is currently in development, as well as others already identified through the other search strategies. An overview of each respite care service's characteristics is explored in the following sections and summarized in Multimedia Appendix 1.

Description of the Variety of Respite Care Services Offerings

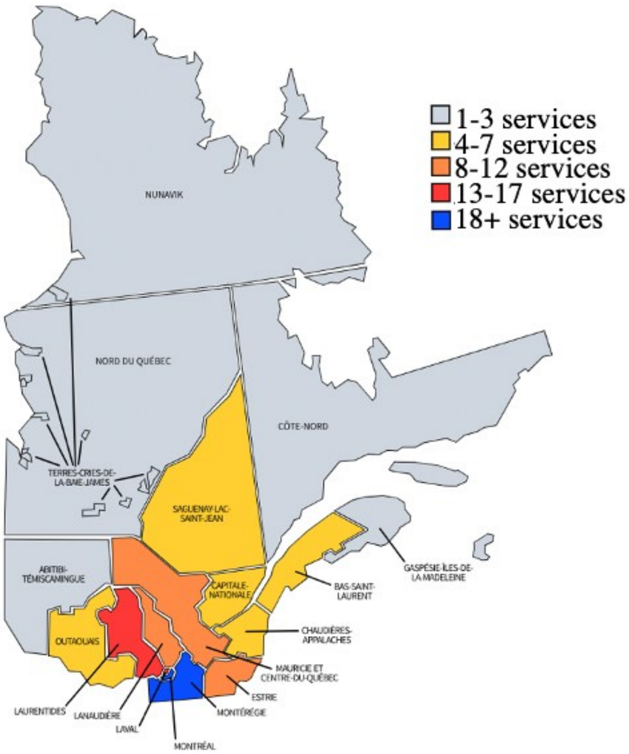
The specific respite care offerings were characterized by a variety of activities and types of care for both the caregiver and the care recipient. All of these activities occurred in the context of a respite care visit, that is, this visit consisted of another person coming to the home to provide care for the care recipient so that the informal caregiver could leave the premises if they so desired. The most common respite care activities offered were accompaniment (36/52, 69.2%), assistance with daily activities (29/52, 55.8%), personal care (19/52, 36.5%), and specialized care (17/52, 32.7%). In many cases, the organizations offered several types of specialized care, like palliative and cancer care. A total of 7 (13.5%) organizations specifically mentioned that they provided symptom and pain management as part of their respite care services. A total of 2 (3.8%) organizations listed restricted activities that they could not offer during the respite period (ie, medication administration and hygiene care). All organizations focused on assisting the care recipient. A total of 9 (17.3%) organizations also included some type of support for informal caregivers while on respite; for example, 1 organization had a rest lounge available for caregivers that the caregivers could visit while the respite care provider went to the care recipient's home.

Availability, Including Flexibility

Respite care services were found primarily across Eastern Quebec, as can be observed in Figure 2. Only 1 service was identified in the regions of Abitibi-Témiscamingue, Nord-du-Québec, Nunavik and Terres-Cries-de-la-Baie-James. The greatest concentration of services was found in Greater Montreal, a densely populated metropolitan area comprised of the health regions of

Montreal and Laval, as well as parts of Lanaudière, Laurentides, and Montérégie. (Institut de la statistique du Québec, 2022c)

(Figure 5.2.2) **Figure 2.** Locations of respite care services across Quebec Health Regions. The map was adapted from Qualifications Quebec and the Ministry of Health and Social Services. (*Msss carte,* 2016; Qualifications Québec) Some services are offered in more than 1 region.



Agencies valued service flexibility. Many organizations emphasized individualized care for the unique situation of the family and explicitly specified that both planned and unplanned (emergency or on call) services were available (10/52, 19.2%). Some services had a designated telephone line for questions and service requests, available at all times (3/52, 5.8%). Furthermore, the majority of services report a 7-days-a-week (28/52, 53.8%), 24-hours-a-day (22/52, 42.3%) availability, for periods of a few hours (31/52, 59.6%), and at a frequency of once or twice a week

(3/52, 5.8%). Some services explicitly advertised overnight respite services (9/52, 17.3%) and for lengths of over 24 hours (8/52, 15.4%). More flexibility with the number of hours and timing of the service was seen in some exceptional situations. A total of 4 (7.7%) organizations stated that overnight services were available for patients at the end of life. That said, it is unclear how quickly families can access respite care services identified in the sample due to delays between a request and service provision (14/52, 26.9%) due to requirements for initial consultations or waitlists.

Eligibility

The care recipient target population for the identified respite care services consisted of persons in palliative care, at the end of life, persons with specific diagnoses like cancer, older adults, and persons affected by a loss of autonomy. Caregivers and loved ones were also targeted by the services, with some services citing specific eligibility requirements such as being a care recipient at the end-of-life, in palliative care, with a cancer diagnosis, or residing in a specific region. However, many organizations did not disclose their eligibility criteria (24/52, 46.1%).

A total of 20 (38.5%) respite care services were free of cost for the users, while 27 (51.9%) had associated fees. Often, these fees were not defined or openly available on the organization's website (23/27, 85.2%), thus, requiring families to contact the respite care organization for more information. The disclosed fees ranged from CAD $15 (US $11.08) per day to CAD $32 (US $23.63) per hour, with the bottom range much lower than Quebec's minimum hourly wage of CAD $15.25 (US $11.26). (Commission des normes, 2023)

Compatibility

Of the 52 services identified, 29 (55.8%) were offered by organizations classified as nonprofits as per Quebec's Enterprise Register. (Registraire des entreprises Québec) Respite care services often involved either volunteers (17/52, 32.7%); a team of multidisciplinary health professionals including patient care attendants and nurses (21/52, 40.4%); or a combination of volunteers and health care providers (4/52, 7.7%). Volunteer-provided services were most frequently free and accompaniment-based, whereas, health care professional-provided services generally consisted of nursing-oriented care with associated fees. Nonetheless, staff, including volunteers, often had additional training for a specific clientele (23/52, 44.2%; eg, volunteers trained in end-of-life care). Agencies emphasized caregiver consistency and finding a good match between the caregiving dyad and staff.

A total of 29 (55.8%) organizations had a unilingual website (French or English) and 20 (38.5%) organizations had a bilingual website (French and English). The identified services' websites often did not specify which languages were available for the provision of care (18/52, 34.6%), although some organizations specified language—some services were available only in 1 language (French, 9/52, 17.3%); others were bilingual (English and French, 17/52, 32.7%); or in 3 or more languages (8/52, 15.4%). Additionally, the websites of these services were not always available in the languages offered.

Member-Checking Feedback From Organizations

An email was sent to respite organizations to confirm the findings of our research. A total of 15 (28.8%) organizations provided feedback on the results and validation for our project. Most frequently, organizations added additional information to what was provided on their website. For example, many organizations clarified the nature of activities performed during the respite period (5/15, 33.3%), the languages of services (6/15, 40%), or the availability and length of services (3/14, 21.4%). In some cases, the information gathered from the website was inaccurate and further clarified by the organization. For example, 1 organization provided fees that differed from that of their website.

Discussion

Overview

Respite care services should strive for high quality and safety. Norris and Aiken's (Norris & Aiken, 2006) framework of personal access to health care was identified post hoc and seemed to match our themes nicely. We analyzed the results based on how these services fit into this framework of accessibility. We will use the following section to discuss the gaps affecting amenability, variety of types of services, limited availability of services, eligibility and provider impacts, as well as the limitations, strengths of our research, and opportunities for future research.

Amenability: Gaps Affecting the Amenability of Respite Care Services

The need for advanced digital health literacy skills, incomplete information and language barriers are some of the key gaps affecting the amenability of respite care services that were identified as part of this environmental scan.

A significant time investment and high digital literacy skills were required to carefully create search strategies, sift through thousands of results, and retrieve a relatively small selection of respite care services relevant to palliative care families in Quebec. Even a sophisticated user may not have the mindset required to go through a tedious search process given the demanding nature of caregiving in the palliative care context. Caregivers or clinicians may not be familiar with internet search strategies or be in a position to dedicate time and energy to the search and identification process for respite care services. Thus, the intensive search and screening process constitutes an important accessibility barrier, needing to be addressed as part of best practice guidelines, and perhaps alleviated with the use of collaboratively developed digital tools (eg, chatbot) or care navigators. (Castro et al., 2023; Doig et al., 2009; Edgar & Uhl, 2011; Fenton, 2020)

Incomplete access to information was one of the most significant challenges encountered in this project. Many of the identified respite care organizations' websites did not share critical information on their services, such as the fees, eligibility criteria, or availability. In some cases, this missing information could be obtained by reaching out to the organization directly. However, many organizations did not respond to our request for feedback. Incomplete information on respite care services is a deterrent to access, often resulting in caregivers having unanswered questions and unclear expectations. (Skilbeck et al., 2005) In other words, caregivers may find it difficult to gauge if the respite care service is relevant to their unique situation, if they are eligible and what procedure they should follow to access the service. Clinicians may also find it difficult to know what services are available in the community, where to link or refer their clients and what the request procedure looks like. This challenge may be accentuated when respite care organizations' websites are only available in 1 language, as was seen in our sample. With this in mind, respite care organizations may wish to make information about their services more widely available online and continue to incorporate clinician, caregiver, and care recipient feedback, so that their services can become more widely accessible, available, and family-centered. (Edgar & Uhl, 2011; Evans, 2013a)

Types of Services: Complex Variety of Respite Care Service Offerings

Respite care services take on many formats and should aim to address a variety of individualized needs. (Edgar & Uhl, 2011; Harding & Higginson, 2003; Ingleton et al., 2003; Whitmore, 2017; Wolkowski et al., 2010) Frequently cited priorities for end-of-life care at home include physical (eg, symptom management) and psychosocial care (eg, interpersonal connection), which nurses are often best equipped to provide. (Cai et al., 2017; Evans, 2013a; Hagan et al., 2018; Ingleton et al., 2003; Skilbeck et al., 2005; Ventura et al., 2014; Wolkowski et al., 2010)

Service offerings aimed at caregivers, like rest lounges or psychological care, may help to alleviate the caregiver burden in targeted ways so that they can be better equipped to cope and care for their loved one. (Gomes et al., 2013; Harding & Higginson, 2003)

Our sample of 52 respite care services offers an array of respite care services and reflects the various priorities of families in a palliative stage of care. This data contradict the common criticism of respite care, that it is too often focused solely on caregiver needs and burdens while ignoring the care recipient's needs. (Evans, 2013a) These findings also suggest that services have the potential to address a wide range of needs and provide caregivers with greater flexibility to choose how they want to spend their time while on respite. (Dunbrack, 2003) However, the variety in respite care service descriptions may make it difficult for users and clinicians to compare and contrast options in their community, and perhaps select what they need. Systematic reporting of basic services across all service providers, such as an easy-to-search database that is regularly updated, is needed to determine the best types of service provision. Organizations should also troubleshoot how to deliver effective services within a low-cost model, in an effort to improve at-home respite care across Quebec regions.

Availability: Limited and Sparse Availability of Services

Rural and Indigenous communities are often faced with service provisions not meeting the needs and preferences of families, nor supporting death at home. (Harding & Higginson, 2003; Quinn et al., 2021) Our research identified a lack of in-person services in Western and Northern Quebec, areas representing approximately 2.2% of Québec's population (estimated population of 195,409 in 2022) and 2.5% of Quebec's deaths every year (1719 deaths in 2021). (Institut de la statistique du Québec, 2022a, 2022c) These findings accentuate the scarcity of resources described in the literature. (*Exploring successful models of respite care for first nations communities in*

Quebec 2007) Therefore, to enable more caregiving dyads to benefit from adapted respite care, infrastructure, targeted funding, and service options need to be expanded, particularly in rural and Indigenous communities of Quebec. Inclusivity, community leadership, and family-centered approaches should take the forefront in these efforts. (*Exploring successful models of respite care for first nations communities in Quebec* 2007)

Best practice guidelines for the provision of respite care stipulate that flexibility in service provision is a key criterion to ensure that the ever-changing needs of the caregiver and care recipient are being met, that a continuum of care is maintained, that the diversity of the clientele is respected and that caregiving dyads can make the most of the respite period. (Doig et al., 2009; Edgar & Uhl, 2011; Ingleton et al., 2003; Whitmore, 2017) In Quebec, the length of the 52 identified services' availability and frequency were diverse. Flexible services, such as those available 24 hours a day and 7 days a week, for a longer period of time (hours to days) or with "on-call" availability, may enable the caregiving dyad to engage in a greater selection of activities (eg, sleeping, running errands, and social interactions), as opposed to respite care services limited to a specific time of the day. The services' flexibility also potentially impacts how quickly caregivers can access respite care when an urgent or unplanned need arises, to ensure the care recipient is still being cared for. Given the results' significant range of availabilities, we can conclude that some services are as flexible as current guidelines suggest. These results point to a larger issue of gaps and barriers affecting the accessibility and usage of respite care services.

Eligibility: Eligibility Requirements Limiting Access to Respite Care Services

The respite care clientele is diverse. (Canadian Healthcare Association, 2012) Hence, eligibility requirements have the potential to restrict access to families most likely to use such home-based nursing services, such as users with less financial resources or those who speak minority languages. (Cai et al., 2017; Dunbrack, 2003; Fenton, 2020; Quinn et al., 2021) Services without specific eligibility criteria or free of charge may be more appealing to a greater population of families in need of respite. The organizations specifically mentioning eligibility criteria may help to ensure the population of a given region has access to services in their community, or that the respite care services meet the needs of that specific population (ie, services tailored to people at the end-of-life). However, the respite care services that were most flexible, were also generally fee-based. Consequently, financial barriers may limit access to such services for families who need them most.

Compatibility: Provider Impact on the Compatibility of Respite Care Services

The therapeutic relationship between the caregiver, care recipient, and respite care provider is essential in achieving satisfaction with a respite care service and is tightly linked with caregiver well-being. (Corrado, 2018; Doig et al., 2009; Fenton, 2020; Rao et al., 2021; Whitmore, 2017) Several organizations highlighted caregiver consistency in their description of services, which may play an important role in the development of a collaborative and trusting relationship. Thus, these results may prompt organization leaders to consider diversifying multidisciplinary teams, provide further training and aim for greater care provider consistency in an effort to achieve high-quality respite care service provision.

As suggested within best practice guidelines for respite care, service providers must be equipped with the skills, training, and experience to provide safe and high-quality care. (Corrado, 2018; Doig et al., 2009; Edgar & Uhl, 2011; Whitmore, 2017) Volunteers are great resources for respite care service provision but may be limited in the offerings they are allowed to provide. (Candy et al., 2015; Edgar & Uhl, 2011; Rao et al., 2021) This may explain why many identified volunteer-provided respite care services in our sample were oriented around accompaniment, a service that may be more personalized and adaptable to a client's unique psychosocial needs. (Chinn, 2023) Volunteer limitations may also provide context for the restrictions in service provision, a potential deterrent for families, depending on their care requirements. (Whitmore, 2017) On the other hand, health care providers have the benefit of training and experience with structured, specialized interventions corresponding to the common requests of caregivers, the needs of the care recipient, and the specialized nature of palliative care in general. (Chinn, 2023; Hagan et al., 2018; Skilbeck et al., 2005; Wolkowski et al., 2010) Nurses, in particular, are heavily involved in clinical, coordination, and leadership positions associated with palliative care and home care services due to the holistic nature of their role and therapeutic relationship with families. (Schroeder & Lorenz, 2018; Sekse et al., 2018) In our sample of services, health care professional-provided services were often centered on physical care, symptom management, and other nursing interventions. Collaborations between health care professionals and volunteers, as seen in the sample, potentially contribute to providing cost-effective and family-centered respite care, while overcoming challenges associated with limited health care resources. (Sekse et al., 2018) Similarly, additional training, showcased by some agencies, may further clarify the roles and responsibilities of the care provider while enabling them to provide high-quality care specifically targeted to individuals with cancer, at the end-of-life or in palliative care, for example. (Edgar & Uhl, 2011) This centralized information about respite care providers may encourage involvement in local respite care organization activities, for example, by creating a network of respite care providers and collaborative training opportunities.

Limitations and Strengths

Limitations to this research include the availability of information on the internet, the use of specific languages (ie, only English and French), limited data collection (ie, restricting to 3 search databases or engines, and 100 results per return), and the impact of digital algorithms. This analysis represents only the information available on the internet and feedback from a limited number of organizations, which may slightly differ from actual respite care service features or currently available services. Many excluded services highlighted the provision of home care services without specifically mentioning a respite component. Therefore, relevant services that provide respite care without explicitly advertising these services may have been excluded. However, "respite care" is the term most commonly found in the literature and that caregivers are most likely to use when seeking a break from their dyadic informal caregiving roles. (Evans, 2013a; Rao et al., 2021) Future research could examine subsets of this project's ineligible services (ie, home care services and respite care services outside the home) in an effort to better understand the breadth of community health care services available to informal caregivers and care recipients. Additionally, due to resource constraints, not every postal code could be searched in the L'Appui Resource Directory, and only the first 100 results for each search were screened. This cut-off point was chosen in other grey literature searches and justified by the amount of traffic received by results on the first page of Google compared to any additional pages. (Chitika, 2013; Donnelly & Thompson, 2015; Godin et al., 2015) Nonetheless, there is still the possibility that some less popular or poorly advertised respite care services may have been missed in the search process. Similarly, Google algorithms may have played a role in the display and order of search results despite taking precautions to disable such alterations. However, we believe our multimethod approach helps to overcome these limitations.

All things considered, the environmental scan methodology devised for this project was successful at identifying diverse at-home palliative respite care services across the province of Quebec and synthesizing service features. (Graham et al., 2008; Rowel et al., 2005) Novel methodologies used in the project, such as combining search engines and internet-based community health databases, using postal codes to search for services, as well as seeking expert feedback via member-checking, may be useful for other researchers attempting to comprehensively map other types of services while reducing bias. (Arksey & O'Malley, 2005) There is also a potential to further expand our search strategy by including other tools (eg, Google Maps and artificial intelligence chatbots), strategies we have attempted but ultimately abandoned due to the lack of existing methodologies and the current functioning of these tools not showcasing relevant results.

Opportunities for Future Research

Caregivers are often challenged by overwhelming amounts of information when seeking health care services on the internet, hence, a coordinated database is an important unmet caregiving need. (Doig et al., 2009; Fenton, 2020; Ingleton et al., 2003; Ventura et al., 2014) Therefore, concise and complete records of respite care services are warranted to (1) improve families' knowledge of the services available in their community and how to access them, (2) to improve clinicians' ability to share and refer clients to such services, and (3) to promote the expansion of existing services and development of complementary resources. (Castro et al., 2023) Best practice guidelines and digital databases should be updated, further developed, and validated by users and organizations, to reflect health care service search and identification challenges. For example, key filters like type of respite care provider, fees, service offerings, and eligibility criteria, could be included as part of a digital database. Moreover, the methodology and findings may be of interest to referring clinicians and policymakers responsible for planning future needs as Canada moves away from institutional care, toward holistic community care.

Conclusions

Comprehensively identifying available respite care services is essential for assessing the overall availability of respite services, as well as identifying potential barriers that individuals and clinicians face when seeking out these services. (Edgar & Uhl, 2011; Smith et al., 2017a) The findings of this project emphasize that the identification, navigation, and access to such services likely remain challenging for individuals in need of respite and clinicians looking to refer their patients. These results stress the need for a centralized searchable database to render accessible information on respite care services available in communities across Québec. The proposed methodology, consisting of combining several data sources, may guide researchers in conducting other community health service environmental scans.

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Conflicts of Interest

Coauthor AJH is a nurse manager of one of the palliative home-care organizations that was also identified through the search.

Abbreviations

CISSS: integrated health and social services centers

CIUSSS: integrated university health and social services centers

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Multimedia Appendix 1

List of N = 52 Quebec respite care services offered at home to families with palliative care needs identified via Google, in the Canadian Cancer Society Community Services Locator or the L'Appui Resource Directory.

View online:

https://jmir.org/api/download?alt_name=nursing_v7i1e53078_app1.docx&filename=a61073ddc7612ad14ac2dd3c69d0f8a6.docx

6.0 Paper 4: Scoping Review of Respite Care Technologies

6.1 Bridge 4

Paper 4 is a scoping review conducted across 6 academic literature databases, which identified 15 unique programs worldwide that explored the potential of ICTs to support the provision of respite care services. This review determined that ICTs can play an important role in facilitating access to respite care by:

(1) enabling the sharing of relevant respite care information with families and providers,

(2) helping to recruit and train respite care providers, and

(3) flexibly coordinating respite care services.

The findings emphasized that when developing ICTs for respite care, it is essential to prioritize trustworthiness of the service delivery, of the service providers, and of the ICT platform. The findings also drew attention to the benefits of involving families and community care stakeholders in participatory design processes.

This scoping review contributed to my overall dissertation in several ways. First, the findings confirmed the burgeoning interest in, and opportunities for, rigorously designing ICTs like apps in partnership with families, so that these ICTs can better support access to respite care services for families. Second, this review revealed that only one other smartphone app prototype had been designed by academics for facilitating access to respite care services; this app was designed by computer science graduate students in the United States, but to our knowledge, it has not yet been launched and implemented (Currin et al., 2019). This finding underscores the novelty of my empirical iRespite proof-of-concept research. Third, the findings highlighted internal design considerations; such as the value of participatory methods, and designing features to improve trust and flexibility in respite services; which we have incorporated throughout the design process.

Fourth, the findings brought attention to implementation factors that are external to the ICT design, such as families' readiness for respite care and marketing of the ICT. These internal and external factors will be planned for in the design and launch of iRespite, to help ensure that it is accessibly designed and sustainability implemented in the future.

6.2 Paper 4 Manuscript

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(Castro et al., 2023)

Information and Communication Technologies to support the provision of respite care services: A scoping review

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Abstract

Background: Respite care is one of the most frequently requested support services by family caregivers. Yet, too often, respite care services are inaccessible, due in part to families' lack of knowledge regarding available services and to a lack of service flexibility. Information and communication technologies (ICTs) may help to improve the flexibility of services available and families' knowledge of such services. However, an understanding of the usage of ICTs and research in this area is lacking.

Objective: The objective of this study was to provide a comprehensive overview of the academic literature on ICTs for supporting the provision of respite care services.

Methods: A scoping review study was conducted. Six library databases were systematically searched for relevant literature. Key data were extracted into a summary chart. Text and quantitative data were coded using descriptive qualitative content analysis techniques, and the results were collated and summarized into a comprehensive narrative.

Results: 23 articles describing 15 unique ICT programs exploring the potential of ICTs to support respite care services met the inclusion criteria. ICTs supported the provision of respite care by facilitating: information-sharing with families and providers, recruiting and training respite care providers, and coordinating services. Key design considerations for developing respite care ICTs were trustworthiness and participatory design methods. Implementation considerations included designing for complementarity with existing services, assessing the appropriate timing for introducing the ICT-based services, and ensuring adequate promotion strategies to raise awareness about the services.

Conclusions: There is limited but promising research on the potential of ICTs to support the provision of respite care services. Further research should be conducted to advance the results of this review, ultimately aiming to build ICTs that can improve the quality of, and access to, respite care services.

Key words: Caregivers; Respite Care; Short Break Care; eHealth; mHealth; Home Care Services; Health Services Accessibility

Introduction

Respite care is one of the most frequently requested support services by family caregivers and is typically provided in-person by a home care nurse or healthcare aide (Buscemi et al., 2010b; Rose et al., 2015b; Whitmore & Snethen, 2018). Respite care services are meant to help provide caregivers with short breaks from their caregiving responsibilities, so they may sustain their caregiving roles (Whitmore & Snethen, 2018). These breaks also offer care-receivers opportunities to socialize with new people and to access additional healthcare services via new care providers in their homes (Whitmore & Snethen, 2018).

Unfortunately, respite care services are often under-utilized, largely due to a lack of service flexibility and accessibility among respite care services capable of addressing different families' unique needs (Robinson et al., 2017; Rose et al., 2015b; Shaw et al., 2009). Families may also lack information regarding the resources available to support them (Phillipson et al., 2019; Zwaanswijk et al., 2013). Family caregivers suggest that easier, more flexible access to respite care services would help support their caregiving work and alleviate feelings of burden (Buscemi et al., 2010b; Rose et al., 2015b).

Information and communication technologies (ICTs) have unique capabilities for supporting the flexible and efficient provision of community and homecare services like respite care (Lindberg et al., 2013). ICTs are tools that can be used to coordinate activities immediately over a distance, and to facilitate the provision of flexible services (Lindberg et al., 2013). Different forms of ICTs exist, such as personal computers, smartphones, and telephone systems (*Ict*, 2020). The unique capabilities of ICTs could be used to make respite care services more flexible and accessible, by making it easier to coordinate care, share information about local respite care services, and/or provide continuing education to train more respite care providers (A. Castro et al., 2021; Hanson et al., 1999; Neef et al., 1991).

A review of existing literature on technologies for supporting respite care services could be used to guide future research on developing ICTs to facilitate the provision of respite care services. Furthermore, a review can be particularly helpful for providing an overview of recommendations and trends from across multiple smaller research projects on ICTs for supporting respite care, when such recommendations and trends are not obvious in any single one of the smaller, context-specific studies. To our knowledge, no review has been conducted on respite care ICTs. Therefore, the aim of this scoping review was to provide a comprehensive overview of academic literature on ICTs for supporting the provision of respite care services.

Methods

A scoping review study was appropriate for our purposes, as this method allows researchers "to assess and understand the extent of the knowledge in an emerging field" (p. 2121) (Peters et al., 2020b). This study was conducted by adhering to the following key procedural steps for scoping review studies, as per the most recent JBI Manual for Evidence Synthesis (Peters et al., 2020a):

Defining and Aligning the Objective/s and Question/s

The primary research question was: (1) What uses of ICTs have been studied in the academic literature for supporting the provision of in-person respite care services?

As per the JBI scoping review methodology, this question includes the following PCC (participant, context, concept) elements of a scoping review question: Participant (stakeholders of respite care services, including family caregivers, patients, managers, and software engineers), Context (respite care services), and Concept (ICTs) (Peters et al., 2020a).

Related sub-questions that we identified after iterative analyses were: (a) What design factors should research teams consider when developing ICTs for respite care? and (b) What implementation factors should research teams consider when developing ICTs for respite care, in order to support the uptake of ICTs?

Developing and Aligning the Inclusion Criteria with the Question/s

The above research questions and PCC elements were used to identify our final inclusion criteria, as listed in Table 1.

(Table 6.2.1) Table 1. The inclusion and exclusion screening criteria are listed below.

	Inclusion criteria	**Exclusion criteria**
Concept / Phenomenon of interest		
	ICTs primarily supporting the provision of in-person respite care	Respite care that was not an in-person service (e.g., if a robot or a video game were to be used to monitor or distract the care-receiver temporarily) ICTs were primarily used for different purposes than respite care support (e.g., telemedicine appointments with general practitioners, general social media networks for caregivers to share their experiences)
Participants and/or target end-users of the ICTs		
	All participants and/or target end-users of the ICTs where care-receivers had a medical or an aging concern	General parenting support services (e.g., babysitting coordination) Respite as a service for people experiencing homelessness
Context		
	The context for ICTs to support the provision of respite care services located in the community (e.g., in-home care, adult day-care centers, or short-term stays in long-term care institutions) Respite care had to be "in-person", i.e., another person would be physically present to provide care, allowing the caregiver to safely remove themselves from the care-receiver's environment	Virtual presence (e.g., in-home robotic tele-monitoring) Hospital-based care
Research design		
	All literature retrieved from academic library databases: empirical studies,	Full text was unavailable

	editorials, commentaries, letters, abstracts, dissertations, perspectives, reviews, and study protocols	Study protocols without preliminary data were excluded
Languages included		
	English, French, and Chinese	Articles written in other languages would have been excluded However, no articles were excluded due to language because all retrieved sources were written in one of these three languages

Describing the Planned Approach

We did not submit a protocol for this scoping review for publication (Peters et al., 2020a). However, Appendix 1 displays our PRISMA extension for scoping reviews checklist (Tricco et al., 2018), summarizing our commitments to the scoping review methodology (Peters et al., 2020a; Peters et al., 2020b).

Searching for the Evidence

A preliminary search strategy was: (1) reviewed by a research librarian (Peters et al., 2020a; Peters et al., 2020b); (2) applied to MEDLINE (via OVID) and the Cumulative Index of Nursing and Allied Health (CINAHL) Plus (via Ebscohost); and (3) refined and applied to MEDLINE and CINAHL, in addition to another four library databases: Embase Classic (1947-Present) (via OVID), APA PsycINFO (1987-Present) (via OVID), Scopus (via Elsevier), and Web of Science Core Collection (via Clarivate). A search strategy example for MEDLINE is outlined in Appendix 2. The final comprehensive search was conducted in January 2022.

The reference lists of included publications and excluded ineligible literature reviews on respite care or technology for caregivers were also screened. Included publications were entered into Google Scholar to screen their “cited by” connections for inclusion. The Research Gate and

Google Scholar profiles of first and last authors were screened for references relevant to the research questions. The authors of respite care ICT programs established since 2010 were emailed seeking further information or updates on the projects that might not have been published yet (Peters et al., 2020b).

Selecting the Evidence

EndNote software was used to manage the search and remove duplicate entries (Bramer et al., 2016). Rayyan literature management software was used to independently screen all titles and abstracts, followed by reviewing the full-texts of selected articles by two authors based on the inclusion criteria (Peters et al., 2020a). The screening process was iterative and at least two reviewers (AC and LOB or AP) discussed any challenges they encountered, refining the selection strategy as needed with input from co-authors.

Data Extraction

One reviewer (AC) was responsible for charting data into an Excel workbook. Data items included: year of publication, author, manuscript type, stated objectives, country, participant data, health condition necessitating caregiving, setting details, ICTs discussed (i.e., intervention type), and other key results specific to our research questions (Peters et al., 2020a). Another reviewer (QC) independently extracted data from five manuscripts to verify the preliminary extraction process (Peters et al., 2020a).

Analysis of the Evidence

Descriptive qualitative content analysis techniques were used to code and re-label data into categories that addressed the research questions (Peters et al., 2020a; Peters et al., 2020b). The full-text data from each manuscript (i.e., introductions, methods, results, discussions, and/or any commentary data) were copied into Microsoft Excel. Each row of data was open-coded to offer a brief summary of the main ideas for each data cell and to gain familiarity with the data. By re-reading, comparing, and contrasting these open codes, we were able to generate a list of initial codes relevant to ICT uses, design, and implementation. The data were then re-labelled in a new Excel column according to these initial codes. Using the "sort" function in Excel, similar ideas were grouped and re-grouped in an iterative process as the codebook was refined to build new categories that we identified in the grouped data.

Presentation of the Results and Summarizing the Evidence

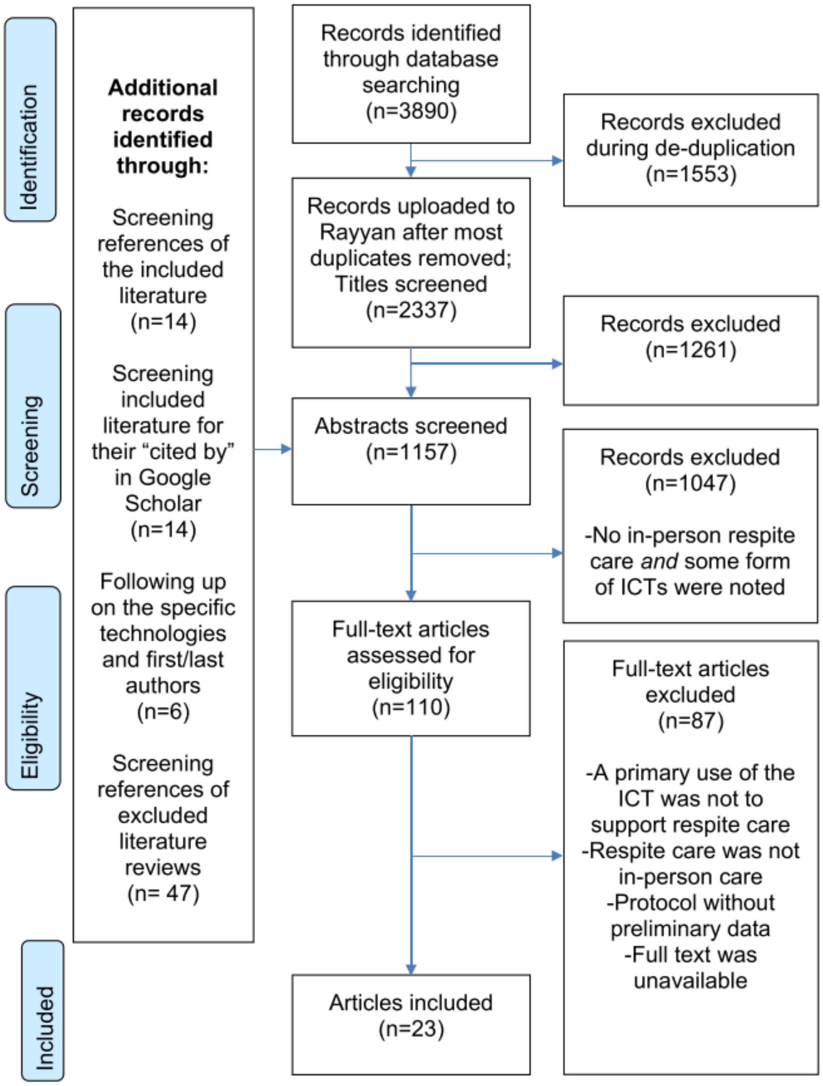
We have presented the results using both, a table summarizing the extracted data and key results (Appendix 3), and a text-based narrative of our results addressing the primary and secondary research questions in "a descriptive format that aligns with the objective/s and scope of the review" (p. 422) (Peters et al., 2020a). Appendix 4 provides examples of raw data extracted from the publications that exemplify the key ideas addressing our research questions.

Results

Search Results

Refer to Figure 1 for the results of the screening process. Of the 3,890 records screened, 23 met the inclusion criteria. All articles were published in English between 1990 and 2021.

(Figure 6.2.1) Figure 1. This flow chart outlines the results of the screening process.



Study and Sample Characteristics

Fifteen unique ICT research programs for exploring the uses of ICTs to support the provision of respite care services were described across the 23 papers (Appendix 3). Sixteen of the articles were empirical studies, including 6 qualitative (Abarca et al., 2018; Campos-Romero et al., 2020; Currin et al., 2019; Hanson et al., 1999; L. McSwiggan et al., 2017; Min et al., 2020a), 6 quantitative (Batata et al., 2017; Batata et al., 2018; Neef et al., 1991; Ozawa & Morrowhowell, 1993; Phillipson et al., 2019; Pierse et al., 2020), and 4 mixed methods (Chou et al., 2011; Foley, 2002; Hanson et al., 2000; Yang, 2009) studies. Seven other articles provided project commentaries and overviews, or brief literature reviews (Chou et al., 2008; Cole, 2008; De Soysa et al., 2010; Looman & Deimling, 1993; Looman et al., 1990; Petrovic, 2013; Ryan et al., 2008).

Collectively, the 16 empirical studies included 2,698 participants, although 74% (n=2,000) of the total participants were derived from one survey study (Batata et al., 2018). Participant types were typically family caregivers, healthcare providers, or healthcare stakeholders. Gender was only indicated in 6 studies, with women representing 76% (n=128) of these studies' total participants (n=168). Age was indicated in 7 studies, with a range of 21 to 92 years old, although most participants were middle-aged or older.

Additional details specific to program location, caregiving conditions necessitating respite care, and respite care settings discussed, are listed in Table 2.

(Table 6.2.2) Table 2. The fifteen programs' geographic locations, caregiving conditions, and respite care settings, are listed below.

	Detailed criteria	**Programs and papers**
Geographic locations		
	North America (United States, only) n = 5 programs	Program 1 (Looman & Deimling, 1993; Looman et al., 1990) Program 2 (Neef et al., 1991) Program 3 (Ozawa & Morrowhowell, 1993) Program 9 (Petrovic, 2013) Program 14 (Currin et al., 2019; Min et al., 2020a)
	Europe n = 7 programs	Program 4 (Hanson et al., 1999; Hanson et al., 2000) Program 5 (Foley, 2002) Program 6 (Cole, 2008) Program 7 (De Soysa et al., 2010; Ryan et al., 2008) Program 10 (L. McSwiggan et al., 2017) Program 11 (Batata et al., 2017; Batata et al., 2018) Program 15 (Pierse et al., 2020)
	South America (Chile, only) n = 1 program	Program 12 (Abarca et al., 2018; Campos-Romero et al., 2020)
	Australia n = 1 program	Program 13 (Phillipson et al., 2019)
	Asia (Taiwan, only) n = 1 program	Program 8 (Chou et al., 2008; Chou et al., 2011; Yang, 2009)

Caregiving populations		
	Older adults with chronic illnesses n = 8 programs	Program 1 (Looman & Deimling, 1993; Looman et al., 1990) Program 3 (Ozawa & Morrowhowell, 1993) Program 4 (Hanson et al., 1999; Hanson et al., 2000) Program 7 (De Soysa et al., 2010; Ryan et al., 2008) Program 12 (Abarca et al., 2018; Campos-Romero et al., 2020) Program 13 (Phillipson et al., 2019) Program 14 (Currin et al., 2019; Min et al., 2020a) Program 15 (Pierse et al., 2020)
	General chronic conditions, age unspecified n = 1 program	Program 11 (Batata et al., 2017; Batata et al., 2018)
	Children living with developmental disabilities n = 6 programs	Program 2 (Neef et al., 1991) Program 5 (Foley, 2002) Program 6 (Cole, 2008) Program 8 (Chou et al., 2008; Chou et al., 2011; Yang, 2009) Program 9 (Petrovic, 2013) Program 10 (L. McSwiggan et al., 2017)

Respite care setting		
	In-home respite care n = 10 programs	Program 1 (Looman & Deimling, 1993; Looman et al., 1990) Program 3 (Ozawa & Morrowhowell, 1993) Program 4 (Hanson et al., 1999; Hanson et al., 2000) Program 5 (Foley, 2002) Program 9 (Petrovic, 2013) Program 10 (L. McSwiggan et al., 2017) Program 11 (Batata et al., 2017; Batata et al., 2018) Program 12 (Abarca et al., 2018; Campos-Romero et al., 2020) Program 13 (Phillipson et al., 2019) Program 14 (Currin et al., 2019; Min et al., 2020a)
	Respite day-care access n = 7 programs	Program 1 (Looman & Deimling, 1993; Looman et al., 1990) Program 4 (Hanson et al., 1999; Hanson et al., 2000) Program 5 (Foley, 2002) Program 9 (Petrovic, 2013) Program 10 (L. McSwiggan et al., 2017) Program 13 (Phillipson et al., 2019)

		Program 15 (Pierse et al., 2020)
	Short-term stay planning n = 4 programs	Program 9 (Petrovic, 2013) Program 10 (L. McSwiggan et al., 2017) Program 11 (Batata et al., 2017; Batata et al., 2018) Program 13 (Phillipson et al., 2019)

Uses of Respite Care ICTs: Information-Sharing, Recruiting and Training, and Coordinating Care

ICTs were explored for the following uses in respite care services: (1) facilitating information-sharing with families and care providers, (2) offering recruitment and training resources for respite care providers, and (3) coordinating respite care services. Most programs focused on one of these three uses of ICTs for respite care, although one publication explored ICTs for both information-sharing and coordination (L. McSwiggan et al., 2017). Appendix 3 describes key findings for these ICT uses in more detail.

ICTs for sharing information about respite care services

In four of the programs (n=5 publications), the use of text and video information about local respite care services was explored for supporting information-sharing with families and respite care providers (Hanson et al., 1999; Hanson et al., 2000; L. McSwiggan et al., 2017; Petrovic, 2013; Phillipson et al., 2019). ICTs for information-sharing included using televisions and remote controls to share modules about "Getting a Break" (Hanson et al., 1999; Hanson et al., 2000); and using websites (L. McSwiggan et al., 2017; Petrovic, 2013; Phillipson et al., 2019), social media (Petrovic, 2013), or telephone helplines (Phillipson et al., 2019) to learn more about local respite care services. However, two papers noted that for information on respite care services, families often relied on recommendations from their friends or clinicians, more than they relied on ICTs like the Internet (L. McSwiggan et al., 2017; Phillipson et al., 2019).

ICTs for recruiting and training respite care providers

Three programs (n=4 publications) used ICTs to support respite care provider recruitment and training (Cole, 2008; De Soysa et al., 2010; Neef et al., 1991; Ryan et al., 2008). One commentary briefly described the value of DVD materials for recruiting providers to serve ethnically diverse families (Cole, 2008). Another research program studied the effectiveness of using a video-based training program to teach respite care skills to volunteers (Neef et al., 1991). This program reported a mean improvement in the percentage of total correct responses on respite care skills questions after videotape training as between 35.5% and 47.6%, depending on the size of the training group (Neef et al., 1991). Two publications described the creation of a CD and DVD training program to teach respite care students and staff how to provide high quality respite care services (De Soysa et al., 2010; Ryan et al., 2008).

ICTs for coordinating respite care services

Nine programs (n=15 publications) studied the uses of ICTs for facilitating respite coordination (Abarca et al., 2018; Batata et al., 2017; Batata et al., 2018; Campos-Romero et al., 2020; Chou et al., 2008; Chou et al., 2011; Currin et al., 2019; Foley, 2002; Looman & Deimling, 1993; Looman et al., 1990; L. McSwiggan et al., 2017; Min et al., 2020a; Ozawa & Morrowhowell, 1993; Pierse et al., 2020; Yang, 2009). Authors noted that mobile devices, with features such as texting, location-based tracking, and mobile payment options, could improve the accessibility and flexibility of services by making communication and scheduling between families, respite care managers, and respite care providers easier (Chou et al., 2008; Chou et al., 2011; Currin et al., 2019; L. McSwiggan et al., 2017; Min et al., 2020a; Petrovic, 2013; Yang, 2009).

Other programs explored the potential for ICTs to make service planning more efficient. For instance, information-sharing via inter-agency databases could improve service efficiency by ensuring that agencies have up-to-date information on service usage, in order to efficiently allocate their agencies' resources (Looman & Deimling, 1993; Looman et al., 1990; Ozawa & Morrowhowell, 1993). Furthermore, several publications argued that ICTs; such as computerized databases, geographic information systems (GIS), and machine learning techniques; are often better at synthesizing large amounts of data than humans are. Authors suggested that these big data syntheses could be used for epidemiological studies and to predict and plan for community health initiatives, such as planning for different communities' respite care needs (Batata et al., 2017; Batata et al., 2018; Foley, 2002; Looman et al., 1990; Pierse et al., 2020).

Design Considerations: Designing for Trust by Using Participatory Design Methods

Two key design considerations were noted across the research programs: the importance of designing for trust in the respite care services and their ICT platforms; and the importance of using participatory design methods for developing these ICTs.

Designing for trust in the providers, services, and ICT platforms

These ICT programs emphasized that for a respite care ICT to be useful, end-users had to trust in: (1) the providers delivering the respite care, (2) the service being facilitated by the platform, and (3) the ICT platform itself.

Trust in the competencies of the providers

End-users had to believe that respite care providers being coordinated through a respite care ICT platform were competent and safe. Trust in the providers could be facilitated by sharing providers' training experiences or institutional affiliations through the coordination platform (Abarca et al., 2018; Campos-Romero et al., 2020).

Authors also emphasized that the ICTs should provide basic background information about the respite care service provider and the family receiving care, such as their care preferences and routines (Abarca et al., 2018; Campos-Romero et al., 2020; Chou et al., 2011; Currin et al., 2019; Min et al., 2020a; Yang, 2009). Easier communication with respite care agencies and providers using mobile devices and texting could further increase trust in the reliability and safety of respite care providers (Abarca et al., 2018; Chou et al., 2011; Currin et al., 2019; Min et al., 2020a; Yang, 2009). One program accomplished this through a quick check-in communication feature to facilitate communication between the family caregiver and respite care provider (Currin et al., 2019). This program also recommended using elements of social matching (based on families' and providers' skills, preferences, and demographic features) to match the family with a suitable respite care provider (Min et al., 2020a). Another program used the geo-location capabilities of ICTs to facilitate matching local and available respite care volunteers with families nearby in need of immediate respite care (Chien et al., 2011; Chou et al., 2008). Other recommended features to engender trust in the programs' respite care providers included: background checks of respite care providers, training in community care ethics, and training in the fundamental skills of providing personal care (Abarca et al., 2018; Campos-Romero et al., 2020; Chou et al., 2008; Chou et al., 2011; Ozawa & Morrowhowell, 1993).

Trust in the reliability of the service

End-users needed to trust that suitable respite care services could be scheduled easily and reliably through the ICT platforms (Abarca et al., 2018; Currin et al., 2019; De Soysa et al., 2010; Phillipson et al., 2019). ICT features to support such scheduling included embedding the following features within the ICT platforms: scheduling assistants, respite care to-do lists (with task prioritization highlighted), lists of care-receivers' personal habits and family requirements for respite care services, and medical case files (Chou et al., 2008; Chou et al., 2011; Currin et al., 2019; Yang, 2009). Features to enable calendar sharing, easy scheduling, and estimated arrival times also supported trust by helping to enhance the reliability of the service (Chou et al., 2008; Currin et al., 2019). Additionally, a few programs recommended embedding a log feature to record respite care visit details and any additional notes or concerns for the family or future care providers to be aware of, in order to facilitate continuity of care (Chou et al., 2008; Min et al., 2020a).

Trust in the data privacy standards and usability of the platform

Finally, end-users had to trust in the data privacy standards and usability of the platform. End-users needed to trust that their employees' and/or families' data recorded through the platform would remain protected, private and confidential (Abarca et al., 2018; Chou et al., 2008; Chou et al., 2011; Currin et al., 2019; Foley, 2002; Looman et al., 1990; Yang, 2009). Features to engender trust in ICT platforms included log-in modules that tracked where the sign-in occurred, and information-exchange portals monitored by program administrators (Chou et al., 2008; Chou et al., 2011; Min et al., 2020a; Yang, 2009). Two research programs suggested that for synthesizing large data sets of clients in order to plan services across respite care agencies, the patient/family data must first be de-identified (Foley, 2002; Looman et al., 1990). End-users also needed to trust that the platform would be useful and easy to use. For instance, one program added the option to leave voice recording notes as feedback, which was perceived as an easier input method than expecting users to type in notes (Chien et al., 2011). To facilitate ease-of-use, the included programs particularly advocated the use of participatory design methods to build platforms that end-users would trust.

Using participatory design methods to build usable and trusted platforms

The importance of designing ICTs with and for the end-users (i.e., family caregivers, patients/care-receivers, and/or healthcare managers), was either stated explicitly in the articles, or implicitly in the methods by including end-users from the study onset (Abarca et al., 2018; Chou et al., 2008; Currin et al., 2019; De Soysa et al., 2010; Foley, 2002; Hanson et al., 1999; Looman & Deimling, 1993; Looman et al., 1990; Ryan et al., 2008; Yang, 2009). A user-centered approach was explicitly used in two of the research programs (Currin et al., 2019; Hanson et al., 1999; Hanson et al., 2000). Iterative testing with end-users was implemented by at least two programs, to ensure that ICT platforms met end-users' needs (Hanson et al., 1999; Hanson et al., 2000; Looman & Deimling, 1993; Looman et al., 1990).

A participatory approach was also evident in the designers' considerations of the users' comfort and ease with the technologies. Familiarity with the technology corresponded with end-users' willingness to use a new ICT for supporting respite care services (Abarca et al., 2018; Hanson et al., 2000; L. McSwiggan et al., 2017). One program suggested that older adults and family caregivers would be willing to use ICTs that they perceive to be helpful to them, such as television sets, remote controls, and telephone technologies to provide information and support on local respite care services (Hanson et al., 2000). Similarly, (Foley, 2002) concluded that in order for GIS to be beneficial to healthcare planners, the planners must have a basic knowledge of GIS capabilities. Authors suggested that if ICTs are developed using tools that are less familiar to the end-users, then developers should expect to spend additional time and resources in order to appropriately and efficiently train these service users (Foley, 2002; Looman & Deimling, 1993; Looman et al., 1990).

However, although user-centered design and partnerships were emphasized, only 1 of the publications discussed participation by patients (Hanson et al., 2000); most of the 15 ICT programs focused on family caregivers, respite care providers, and respite care managers as the end-users.

Implementation Considerations for Respite Care ICTs

In addition to offering ICT design considerations, the 15 programs also offered considerations for successfully implementing the ICT platforms once they were developed. Specifically, the programs highlighted the importance of complementarity, timing, and promotion of respite care ICTs, to support ICT uptake.

Considering complementarity of the ICTs with existing services

Authors and participants noted that the ICTs being implemented should be designed to complement existing in-person respite care services, rather than to replace these services (Abarca et al., 2018; Foley, 2002; Hanson et al., 1999; L. McSwiggan et al., 2017; Min et al., 2020a; Neef et al., 1991; Phillipson et al., 2019). Several publications suggested that ICTs should facilitate, not replace, in-person contact with healthcare providers (Abarca et al., 2018; L. McSwiggan et al., 2017; Phillipson et al., 2019). Similarly, (Abarca et al., 2018) and (Campos-Romero et al., 2020) noted that initial face-to-face meetings between volunteer respite care providers and families might be needed, before these end-users would be comfortable using the ICT to further coordinate respite care.

Considering timing and family readiness for implementing the ICTs

Timing was an important factor in family caregivers' willingness to use ICTs for respite care information and services (Hanson et al., 2000; L. McSwiggan et al., 2017; Phillipson et al., 2019). (L. McSwiggan et al., 2017) and (Hanson et al., 2000) highlighted that the success of ICTs for accessing respite care depended on the caregiver's stage of caregiving. For instance, at the early crisis stage of accepting the need for respite care, most caregivers relied on their social networks; they did not typically use ICTs or the Internet to find respite care information (L. McSwiggan et al., 2017). As they became more settled into their roles, caregivers also became more open to using ICTs (L. McSwiggan et al., 2017). Therefore, ICT developers must not only create the tool, but also assess when end-users, such as respite care managers or families themselves, are most likely to be amenable to adopting the ICTs into their routines.

Considering promotion strategies to raise awareness for respite care and the ICTs

Efficient promotion of novel services was also essential for addressing families' needs for respite care and to diminish the burden of navigating ICT-based services (L. McSwiggan et al., 2017; Phillipson et al., 2019). Authors shared that when accessing respite care, caregivers often felt guilty or conflicted about needing these services, causing them to delay their search until a crisis occurred (De Soysa et al., 2010; Hanson et al., 2000; L. McSwiggan et al., 2017; Min et al., 2020a; Phillipson et al., 2019; Ryan et al., 2008). Once caregivers finally sought respite care, some found that adequate, flexible assistance was often difficult to find or unavailable (De Soysa et al., 2010; L. McSwiggan et al., 2017). (Phillipson et al., 2019) concluded that launching a new ICT service was insufficient for supporting family caregivers and care-receivers; frequent promotional strategies by the respite care services and primary healthcare providers are necessary when new ICTs are developed, in order to raise awareness of these respite care ICTs among families and care providers (Phillipson et al., 2019). Such promotional strategies should include: developers sharing the ICT links or platforms with families and healthcare providers; clinicians reminding families at regular primary care check-ups that respite care services are available in their region; and clinicians reminding families that respite care services can improve both caregiver and patient well-being (L. McSwiggan et al., 2017; Phillipson et al., 2019). These strategies for promoting novel respite care services should be implemented as early in the caregiving journey as possible, so that families are made aware of resources before a crisis occurs (Min et al., 2020a; Phillipson et al., 2019).

Discussion

This scoping review analyzed 23 articles exploring how ICTs can support the provision of respite care services, providing a foundational map of the literature on respite care ICTs. The following discussion will compare our results to findings in related literature on ICTs for supporting other community health services. We will also discuss implications for future healthcare strategies and research on respite care ICTs.

ICT Uses in Related Caregiving Services

Our scoping review found that ICTs can be used to support information-sharing about local respite care services with families and care providers, helping to raise awareness of existing services. Similarly, a cross-sectional questionnaire study of ICT-mediated support for family caregivers in the paid workforce found that 76.8% of caregivers reported that access to information via the Internet about family caregiving support services was very valuable to them (Andersson et al., 2019). Another scoping review on ICT and non-ICT supports for employed family caregivers also found that ICTs can be used to support information-sharing on caregiver supports like respite (Spann et al., 2022). Therefore, our results add to the growing body of knowledge that ICTs may be particularly beneficial for supporting family caregivers by making information on respite care services more accessible.

ICTs can also support the building of caregiving skills, by offering more flexible and remote training structures than in-person training allows for. For example, ICTs such as e-learning platforms and text messaging have been found to be useful modalities for offering healthcare provider training in palliative care skills and supporting knowledge retention (Finucane et al., 2021). Thus, our results showing that ICTs can be used for respite care skills training align with previous work in this area.

Finally, our review found that a common use of ICTs was for facilitating respite care coordination. Other researchers have also argued that ICTs can be used to support family caregiving by facilitating the coordination of caregiving support services (Schurgin et al., 2021; Spann et al., 2022). Coordination support for homecare nursing included easily text messaging or calling members of the care team, as well as storing information on the care-receiver's healthcare status and caregiving support needs. This information could then be accessed digitally by new healthcare providers using secure ICT platforms (Spann et al., 2022). (Spann et al., 2022) did not mention the coordination of respite care directly in this context, but their results likely transfer to the coordination of respite care services, which are a specific type of homecare service. Furthermore, (Andersson et al., 2019)'s study of ICT- and non-ICT-mediated caregiver supports found that family caregivers valued having assistance with planning and care coordination; yet 79.4% (n=102) of respondents did not receive such support from their care teams. Combined, our review and these other studies highlight the potential benefits of using ICTs to share information, provide training, and coordinate services to better support family caregiving.

Design and Implementation Considerations for Related ICTs and Services

Design considerations for respite care ICTs identified in this study emphasized the need for trust, as well as the need for participatory design methods. Without trust in the respite care services, providers, and ICT platforms, family caregivers will not use the available resources (Phillipson et al., 2014; Robinson et al., 2017; Schurgin et al., 2021). In a recent scoping review on the challenges of using ICTs to support family caregiving, (Hassan, 2020) concluded that facilitating trust in the ICT was an important factor for successful ICT deployment. Trust in an ICT platform could be facilitated in a variety of ways, such as by working with end-users and medical experts to co-design the ICTs, by teaching these end-users how to assess the quality of healthcare ICTs, and by integrating the ICTs with complementary non-digital interactions (e.g., face-to-face meetings) (Hassan, 2020). Furthermore, without participatory design methods, ICTs may be designed that do not actually meet the needs of family caregivers, healthcare workers, and care-receivers; and/or that are not easy and efficient for these end-users to use (Hassan, 2020; Lindberg et al., 2013). Thus, the conclusions of our scoping review on the importance of designing for trust with end-users, and of using participatory design methods when designing respite care ICTs, are corroborated by external literature on ICTs for supporting caregiving.

Our review also found that if ICT developers did not plan for successful implementation within the existing healthcare context, well-designed ICTs might also not be taken up. Authors warned that ICT implementation was likely to fail for three reasons: (1) the ICT did not complement existing services, (2) it was not introduced to families at the appropriate time(s), and (3) it was inadequately promoted to existing services and families. Three other reviews on ICTs to support family caregiving also concluded that ICTs should complement, not replace, face-to-face services, because families often feel that they uniquely benefit from face-to-face interactions with caregiving peers and healthcare teams (Hassan, 2020; Lindberg et al., 2013; Spann et al., 2022). Furthermore, respite care supports, including ICT-based respite care tools, must be frequently promoted to family caregivers for early uptake, so that families have respite care resources in place prior to caregiving crises (Rose et al., 2015b; Spann et al., 2022). In order for ICTs to support these healthcare services, they must also be implemented with strategies to raise awareness of these programs among clinicians, families, and other stakeholders (Hassan, 2020).

These design and implementation findings also speak to the importance of clinical-academic partnerships in ICT development for respite care (Q. Chen et al., 2022). Clinicians know that family caregivers and patients need more flexible and efficient respite care services (Buscemi et al., 2010b; Rose et al., 2015b). Nurse clinicians can inform the design of complementary and useful ICT supports, which these clinicians can then promote with families and colleagues in their practices (Q. Chen et al., 2022; Hassan, 2020). Furthermore, clinicians are best placed to assess timing and promotion of services that might help families. Clinicians should regularly update their knowledge of existing respite ICTs for families, frequently assess families' readiness for such services, and regularly promote these services (Spann et al., 2022; Whitmore & Snethen, 2018).

Future Research Opportunities for Respite Care ICTs

There is limited but promising research on ICTs in respite care, as evidenced by the inclusion of only 23 articles despite our expansive search. Several of the articles touched on the same ICT respite care programs as other articles, with only 15 unique programs discussed. The studies often had small sample sizes and no control groups, as they were focused on ICT design and brainstorming with participants, rather than on conducting rigorous evaluations of the effects of ICT programs on respite care service outcomes. Such outcomes could include effects on caregiver and patient quality of life, service efficiency, or cost effectiveness. Future research should not only describe the potential of ICTs to support respite care services, but also evaluate the effectiveness of these programs in doing so.

Furthermore, ICTs have the potential to synthesize massive amounts of data. Yet, little work has been done to date to explore the potential of computerized data science tools (e.g., GIS, machine learning) to facilitate the accessibly and delivery of respite care services using large healthcare datasets. Other technology evidence gaps in the academic literature included limited discussions of the potential of social media to support respite care information-sharing, training, and coordination; and little discussion of the use of ICTs for remote notification reminders of existing services. Given the importance that family caregivers placed on learning about respite care services from their peers and clinicians identified in our review (L. McSwiggan et al., 2017; Phillipson et al., 2019), social media platforms may be important sources of peer-to-peer learning about caregiving support services (Finucane et al., 2021). Additionally, there was no discussion of ICT use for reminding families of available respite care services, such as using app notifications to remind families about the importance of beginning respite care services early in the caregiving role, or to notify families of new respite services in their regions. Future research should build on these works to rigorously design and test the feasibility of smartphone applications for improving direct respite care coordination.

Finally, the participant demographics were relatively homogenous: the average age of included participants was often over 50 years old and mostly focused on ICT support services to caregivers of aging adults. ICTs should be explored for their potential to support other specialized forms of respite care services, such as supporting families coping with cancer diagnoses, or families of younger adults with severe mental health challenges. Future research should consider the different perspectives of younger caregivers and care-receivers and who will be using ICT-facilitated caregiving support services for many years to come (Campos-Romero et al., 2020; AR Castro et al., 2022; Metzing et al., 2020). Furthermore, only one program discussed care-receivers as the participants or end-users. For respite care ICT research to be truly user-centered in the designs and implementations, the perspectives of patients and care-receivers should be included, as well (Cornet et al., 2020; De Vito Dabbs et al., 2009; Hassan, 2020; Schurgin et al., 2021).

Strengths and Limitations

This review adhered to the most recent JBI scoping review methodology (Peters et al., 2020a), and it was conducted across six library databases, allowing for a broad search and inclusion of relevant articles. Due to time and resource constraints, and several iterations of the protocol, we did not submit a protocol for this scoping review for publication (Peters et al., 2020a). However, we did submit a PRISMA checklist to support the rigor of our methods (Appendix 1).

The original search was conducted in October 2019, and fully updated across the 6 databases in January 2022, making the comprehensive search for this review just over 1 year old. The January 2022 search only returned 1 new manuscript. In February 2023, an abbreviated search was conducted across MEDLINE (via OVID), and limited to publications since January 1st 2022, using the following subject headings and search terms: (exp respite care/ OR respite.tw,kf) AND (exp technology/ OR (info* and communication* technolog*).tw,kf OR digital health.tw,kf). In MEDLINE, this search retrieved 4 references, none of which met the inclusion criteria. We conducted a similar search across CINAHL, and none of the retrieved references were eligible. Given these results and the limited resources of our team, we decided it would not be beneficial to re-update the entire search.

The focus of this review on the academic literature means that the results of the included articles are evidence-based, reducing some of the risks of translating the conclusions of this review to clinical settings. However, by only searching academic databases, we may have missed uncatalogued but relevant grey literature (such as policy documents, or existing respite care smartphone applications). A forthcoming app store search study by our research team will help to address the latter limitation (A Castro et al., 2022). Finally, by keeping the search focused on the concept of “respite”, we may have missed literature that included respite but that was categorized under broader concepts, such as “palliative care” or “home care”. However, other systematic reviews on ICTs for palliative care (Finucane et al., 2021; Ostherr et al., 2016) and ICTs for home care (X. Chen et al., 2022; Lindberg et al., 2013) have previously been conducted, offering complementary knowledge syntheses to this scoping review.

Conclusions

This scoping review study adds to the bodies of academic literature on respite care services and ICTs by being the first study to offer an overview of the intersection of these two areas. This review establishes that there is limited but promising research on the potential uses of ICTs to support the provision of in-person respite care, by facilitating information-sharing, coordination, and training. However, for such ICTs to be successfully launched, they must be co-designed to engender trust, and they should be implemented with consideration for contextual concerns like complementarity, timing, and promotion. Additional research should be conducted to advance these conclusions and build ICTs for services that are designed with and for families needing respite care services, alongside the respite care organizations that serve these families. Patients and family caregivers want more flexible, trusted, and efficient respite care services; further research in this area should develop respite care ICTs to fulfill these needs.

Author contributions

Design: AC, LOB, AQV, AA, AT. Data collection: AC, LOB, QC, AP. Analyses: AC, LOB, AA, AP. Discussion and preparation of the manuscript: All authors contributed to writing the manuscript, finalizing the discussion points, and/or approving the final submission.

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Conflicts of Interest

None declared.

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List of Appendices and Abbreviations

Multimedia Appendices Legend

Appendix 1: PRISMA-ScR: Checklist for scoping reviews. View online: https://jmir.org/api/download?alt_name=nursing_v6i1e44750_app1.docx&filename=ccd22050bbcff22ee1a3b752a81aa534.docx

Appendix 2 (below): The search strategy for one library database, MEDLINE.

Appendix 3: Summary chart of the 15 programs described in the 23 publications. View online: https://jmir.org/api/download?alt_name=nursing_v6i1e44750_app3.docx&filename=30079e2be7d95ddcaeb14d60b40ec9c6.docx

Appendix 4 (below): Examples of raw data coded into categories addressing the research questions.

Abbreviations

CINAHL: Cumulative Index of Nursing and Allied Health

GIS: geographic information system

ICTs: information and communication technologies

(Table 6.2.3) Appendix 2: The search strategy for one library database, MEDLINE

Search number and topic	**Search termsa**
Search 1: **Subject headings (/), title words (.tw), and keywords (.kf) related to ICTs**	**Subject headings:** exp computers, handheld/ OR exp mobile applications/ OR exp telemedicine/ OR exp cell phone/ OR exp smartphone/ OR exp computer systems/ OR exp information technology/ OR exp internet/ OR exp telephone/ OR exp technology/ OR exp information system/ OR exp text messaging/ OR exp computers/ OR exp telecommunications/ OR exp information science/ OR exp robotics/ OR exp social media/ OR exp virtual reality/ **Title words and keywords:** OR smartphone*.tw,kf OR smart-phone*.tw,kf OR smart phone*.tw,kf OR mobile-app*.tw,kf OR mobile app*.tw,kf OR mhealth.tw,kf OR m-health.tw,kf OR telemedicine.tw,kf OR tele-medicine.tw,kf OR telehealth.tw,kf OR tele-health.tw,kf OR cellphone*.tw,kf OR cell-phone*.tw,kf OR cell* phone*.tw,kf OR mobile phone*.tw,kf OR ehealth.tw,kf OR e-health.tw,kf OR text* messag*.tw,kf OR mobile health.tw,kf OR apps.tw,kf OR handheld computer*.tw,kf OR hand-held computer*.tw,kf OR hand held computer*.tw,kf OR short messag* service*.tw,kf OR sms.tw,kf OR personal digital assistant*.tw,kf OR electronic health service*.tw,kf OR mobile devic*.tw,kf OR smart devic*.tw,kf OR texting.tw,kf OR info* technolog*.tw,kf OR communication* technolog*.tw,kf OR "info* communication* technolog*".tw,kf OR "info* and communication* technolog*".tw,kf OR ICTs.tw,kf OR internet.tw,kf OR telephone*.tw,kf OR tele-phone*.tw,kf OR phone*.tw,kf OR technolog*.tw,kf OR info* system*.tw,kf OR ((mobile or cell or smart) adj1 (phone* or app* or health or device*)).tw,kf OR ((info* or communication) adj1 (technolog* or system*)).tw,kf OR computer*.tw,kf OR digital tech*.tw,kf OR tele-communicat*.tw,kf OR telecommunicat*.tw,kf OR informatics.tw,kf OR wearable*.tw,kf OR smart-watch*.tw,kf OR smartwatch*.tw,kf OR smart watch*.tw,kf OR smart cloth*.tw,kf OR smart-cloth*.tw,kf OR robot*.tw,kf OR tele-rehab*.tw,kf or telerehab*.tw,kf OR remote consult*.tw,kf OR social media.tw,kf OR social network*.tw,kf OR website*.tw,kf OR virtual realit*.tw,kf
Search 2: **Subject headings (/), title words (.tw), and keywords (.kf)**	**Subject headings:** exp respite care/ **Title words and keywords:**

related to respite care	OR respite.tw,kf OR (respite adj2 care*).tw,kf OR (care* adj2 break*).tw,kf OR (care* adj2 relief).tw,kf OR (short-term adj1 care*).tw,kf OR (short term adj1 care*).tw,kf OR sitting service*.tw,kf OR adult day-care*.tw,kf OR adult daycare*.tw,kf OR adult day care*.tw,kf OR ((respite or relief or short-term or break*) adj2 care*).tw,kf
Search 3: **Combining Search 1 and Search 2 using the "AND" operator**	[Search 1] AND [Search 2]

Note: "exp" meant the subject heading was exploded to include sub-subject headings. MEDLINE uses * to search for concatenations of a term. For instance, "mobile app*.tw,kf" will search for any concatenations of this phrase among title word and keyword terms, such as "mobile applications" and "mobile apps." MEDLINE "adjN" is used to search for words that are adjacent to each other by N terms.

(Table 6.2.4) Appendix 4: Examples of raw data coded into categories addressing the research questions

Major and minor categories	**Example**
Uses of Respite Care ICTs: Information-sharing, Recruiting and Training, and Coordinating Care	
ICTs for sharing information about respite care services	"Use of information and communication technologies to promote information-sharing with respite services would benefit from further exploration." (L. McSwiggan et al., 2017) (p. 1404)
ICTs for recruiting and training respite care providers	"The savings in trainer time and cost that accrue through the use of packaged videotape instructional programs could be used to provide remedial training in individualized areas of need. Only 15 to 45 min of remedial training were required for any of the participants to reach criteria. (This does not include, however, the 30- to 60 min simulation probes used to assess performance.)" (Neef et al., 1991) (p. 484)
ICTs for coordinating respite care services	"According to the results of this study, potential volunteers are willing to use ICT to establish communication with caregivers and to ensure respite is achieved." (Campos-Romero et al., 2020) (p. 8)
Design Considerations: Designing for Trust by Using Participatory Design Methods	
Designing for trust in the providers, service, and ICT platforms	**Providers:** "One [professional respite care provider] observed the importance of being able to communicate both face-to-face and electronically during the early phase of the relationship-building process. She has utilized a smartphone app to chat, send messages, and share memos with [primary family] caregivers. *P12 (respite professional caregiver): 'We want to make sure we have good relationships with families, and so it's all about building trust. You don't start off that way when people start coming into our program. It gets built over time. ... Sometimes people will tell you more in the chat or text message function rather than in person.'"*

	(Min et al., 2020b) (p. 853) **Service:** "Having shared information with services about the type of respite care that would best suit their needs, carers were disappointed and frustrated when their expectations of accessible and equitable services could not be accommodated. Those living in rural locations, in particular, found that they had little choice in terms of location and types of respite care available to them." (L. McSwiggan et al., 2017)(p. 1407) **ICT platform:** "Since this system guarantees the security of location information and it also verifies user credentials, mobile users can ubiquitously access MSNSM system through Transmission Con-trol Protocol/Internet Protocol and Hypertext Transfer Protocol (HTTP)." (Chou et al., 2011) (p. 587)
Using participatory design methods to build a usable and trusted platform	"Collaboration has once again been a central feature in the development of the CD-ROM, based on the good communication that exists between the three main groups involved. This was necessary to help plan and co-ordinate the complex arrangements required for filming, finalising student tasks and preparing families for the arrival of film and production teams. Preparatory work with people with dementia and families was essential for the implications of their involvement to be fully understood, including the fact that their experiences would help shape the content of the documentary material. Academic and practice partners worked together in establishing a consent process for people with dementia involved in the filming." (Ryan et al., 2008) (p. 35)
Implementation Considerations for Respite Care ICTs	
Considering complementarity of the ICTs with existing services	"Many of the respondents at the workshops were generally positive about the potential of GIS as a complementary planning tool and could see its enhanced value when set against legislative and policy demands on them as purchasers and providers. They were particularly interested in the ability to present data at a number of aggregated levels simultaneously and the capability of querying the

	GIS to aid the planning of service provision by different age groups." (Foley, 2002) (p. 92-93)
Considering timing and family readiness for implementing the ICTs	"They document the feelings of anxiety and guilt that are frequently experienced by family carers, and recommend due sensitivity on the part of professional carers to acknowledge the complex emotions involved. . . . Thus, with regard to the 'Planning ahead' programme, appropriate timing according to the individual and his/her family carer is an important consideration." (Hanson et al., 2000) (p. 718)
Considering promotion strategies for respite care and the ICTs	"To better serve carers of people with dementia, this study highlights the need for promotional strategies using a wide variety of channels to provide respite service information. Greater promotion of new 'gateway' services, especially telephone helplines for respite information are also needed. Given the strong preference for interpersonal sources of information, the My Aged Care helpline could consider offering a named personal contact or 'case worker' whom carers of people with dementia can liaise with for follow up, rather than navigating their way through the Gateway system each time they call." (Phillipson et al., 2019) (p. 6)

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7.0 Paper 5: Systematic Search of Respite Care Apps

7.1 Bridge 5

Paper 5 reports our systematic search of respite care apps available on the Apple iOS and Android Google Play app stores. Using a keyword search informed by our scoping review (Paper 4), we identified 40 respite care smartphone apps across the two platforms worldwide, with eight apps available on both platforms making for 32 unique apps. One quarter of the apps (8/32, 25%) were based in Canada, suggesting burgeoning interest and expertise in this area of respite care entrepreneurship in Canada.

Our analyses identified patterns of design for respite care apps, such as the “filter pick” design and offering “training opportunities” to end-users, both of which we incorporated into the iRespite proof-of-concept. Our analyses also revealed key weaknesses of existing apps, including a lack of available respite care providers, limited marketing and awareness of the apps, and a lack of focus on coordinating care for families with advanced cancers or palliative care needs. By learning from these weaknesses and incorporating beneficial features from existing apps, our iRespite proof-of-concept research aimed to create a comprehensive and effective respite care app that meets the unique needs of families with advanced and palliative cancer care requirements.

7.2 Paper 5 Manuscript

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(Castro, Londono Velez, et al., 2024)

A Systematic Search of Publicly Available mHealth Apps for Respite Care Coordination

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Abstract

Respite care is frequently requested by family caregivers. Yet, accessible services remain underutilized due to challenges in scheduling and coordination. mHealth applications ("apps") have the potential to resolve these challenges. However, little research has been conducted to map and assess currently available apps for respite care coordination. Therefore, a systematic search was conducted across the Apple iOS and the Google Play stores. Using the Mobile App Rating Scale and the Enlight tool, this study reviewed, appraised, and characterized 40 apps that facilitate the provision of in-person respite care services for supporting family caregiving.

The results found that while respite care apps can create and sustain a market for respite care, they often underutilize their potential to deliver respite care, due in part to poor advertisement of their own functions. In keeping with previous literature, the scarcity and limited accessibility of respite care providers on these platforms was seen to hinder their practical usage. This study is among the first of its kind to provide both subjective and objective summaries of respite care app features and functions. As such, it may offer insights to future app developers and care providers, serving as a benchmark for future mHealth coordination app development.

Keywords: caregivers, eHealth, health services accessibility, home care services, mHealth, short break care, mHealth appraisal

Introduction

At some point in their lives, half of Canadians will provide unpaid care to a family member or friend with a chronic incapacitating illness, or age-related need (Sinha, 2013). These family caregivers will provide various forms of support (e.g., assistance with transportation, personal care, housekeeping, and/or care coordination) on a non-professional basis to promote the recovery and quality of life of the individual receiving care (AR Castro et al., 2022). These acts of caregiving amount to exceptional contributions to society and the healthcare system, totaling to an estimated of $25-$72 billion unpaid work per year in Canada (*Change foundation*, 2019; Barylak, 2016). However, too often, family caregivers exhaust themselves in their duties, and experience burn out when they do not have adequate support (Denham et al., 2020; Oliva-Moreno et al., 2018).

Distress among caregivers has been associated with negative effects on mental and physical health, and even life expectancy, highlighting the importance of addressing the need for improved family caregiving support (*Change foundation*, 2019). Different interventions exist to prevent caregivers from feeling overburdened. Of these interventions, respite care remains one of the most frequently requested by family caregivers (Buscemi et al., 2010a; Miriam S. Rose et al., 2015). Respite care is a healthcare model that permits community nurses or healthcare aides to visit the homes of family caregivers and take over their caregiving acts, temporarily relieving the caregiver and care recipient of their family caregiving duties and roles (Edelstein et al., 2017; Evans, 2013b). Current primary healthcare recommendations urge caregivers to use respite care services when needed (Swartz & Collins, 2019). However, these services are often underutilized because family caregivers are unaware of them; and, even when accessed, these services lack the flexibility and coordination abilities to adequately accommodate the needs of patients and families (Robinson et al., 2017; Rose et al., 2015a).

Information and communication technologies ("ICTs"), such as mobile health (mHealth) applications ("apps"), have emerged as a means to render respite care services accessible by delivering flexible support to family caregivers (Castro et al., 2023). These apps have the potential to ameliorate remote communication and care coordination among healthcare providers, family caregivers, and care recipients (Gagnon et al., 2012; Sala-González et al., 2021). Current evidence demonstrates a strong interest by family caregivers in adopting mHealth solutions, especially when these are supported by empirical evidence (Lau et al., 2021; Phongtankuel et al., 2018). Improving apps with desired key features such as portability, GPS location, and instant messaging may help to better coordinate respite care services; however, the extent and form in which these desired features are integrated into such apps remains unknown. Moreover, the overall quality and functionality of these apps have yet to be rigorously assessed using mHealth app assessment tools (A. R. Castro et al., 2021). Hence, the aim of this systematic search was to review, compare, appraise and characterize all publicly accessible mobile apps facilitating the provision of in-person respite care services for family caregivers. Doing so could help prospective respite care recipients understand their current respite care app options and create a launchpad that future mHealth app developers and researchers can refer to for information on the evidence-informed features and qualities of other apps in this industry.

Methodology

Study Design

A systematic "hybrid" design proposed by (Lau et al., 2021) was used to guide the app store searches, synthesize the results, and analyze the data. This design suggests that a traditional search of academic library databases can be conducted and used to inform a further systematic app store review, in order to produce a complete picture of current publicly available apps for respite care across both the academic and industry domains.

Apple and Android App Store Search Strategies

As recommended by the hybrid mHealth search methodology (Lau et al., 2021), the search terms of a recent scoping review of the academic literature on respite technologies were used to inform the search strategy (Castro et al., 2023). In addition, the expertise of an academic librarian was used to help devise, pilot test, and finalize the search list of English and French keywords included in the search. This final list is available in Table 1.

(Table 7.2.1) Table 1: Table of Keywords for App Search

Concept	English Keywords	French Keywords
(1) Respite Care	Respite care	*Soins de relève*
	Respite	*Soins de répit*
	Respite care on demand	*Soins infirmiers de relève*
	Respite on demand	*Services de relève*
	Care on demand	*Services de répit*
	Relief care	*Soins sur demande*
	Relief care service	*Soins de répit sur demande*
	Community care	*Soins communautaires*
	Short break care	*Soins de repos*
	Short term care	*Service de soins de repos*
	Short-break care	*Soins à court terme*
	Short-term care	*Soins de courte durée*
	Sitting service	*Service de garde*
	Home care	*Soins de jour pour adulte*
	Homecare	*Soins à la maison*
	Home-care	*Soins infirmiers à domicile*
	Home care nursing	*Soins à domicile*
	Homecare nursing	*Soins palliatifs à domicile*
	Home-care nursing	*Centre de répit de jour*
	Home-based palliative care	*Maison de répit de jour*
	Hospice at home	*Centre de jour palliatif*
	Home hospice	*Assistance à domicile*
	Hospice day center	*Aide pour aidants*
	Palliative day center	*Aide aux aidants*
	Adult day care	*Centre de jour de soins palliatif*
	Adult daycare	

	Day respite facilities Help for caregivers	*Garderie pour adultes* *Établissement de répit de jour* *Aide aux proches aidants* *Aide pour proches aidants*
(2) Caregiver	Caregivers Caregiving Carers Care providers Caregiving help Caregiver help	*Proche aidant* *Aidant naturel* *Personne aidante* *Aides pour proche aidants* *Aidants*

The search for publicly available apps was conducted on two platforms and their corresponding app stores: the Google Play Store via an Android operating system, and the Apple App Store via the Apple iOS operating system. These two app stores were selected as they represent the largest market share of apps (Anthony, 2021). Each app store was searched independently by a few members of the research team. Cookies were cleared prior to searching to avoid inadvertent bias (Donnelly & Thompson, 2015). The search was conducted for Android from April 2022-October 2022 and for iPhone from January 2022-October 2022 using the latest software versions available. To increase reproducibility of this study's search, the keywords by language (French and English) for both app store searches were recorded (Table 1), and screenshots and screen recordings for each search result were kept. The screenshots provided a record of the first 100 apps that appear from each keyword search and were kept in folders using a dating system to keep track of progress.

Appendix 1 provides a more detailed overview of the 7 steps for screening and selecting (Steps 1-5), and analyzing (Steps 6-7) the respite care apps.

App Screening and Selection (Steps 1-5)

The app screening and selection process was divided into 5 steps. *Step 1* entailed recording the device type (iPhone or Android), device owner, platform, software version, and search date. *Step 2* involved extracting the first 100 results of each keyword search into Excel spreadsheets to facilitate name sorting. *Step 3* entailed the removal of duplicate apps present in the same app store. Duplicates across the two app stores were further screened in case features varied between the two operating systems. *Step 4* involved selecting apps based on title and description and independently assessing the apps for inclusion by two reviewers (initial screening). *Step 5* entailed downloading the selected apps to further assess eligibility based on app features (secondary screening).

Most necessarily, included apps had to provide users with the ability to schedule in-person respite care services. These services had to afford the family caregiver the freedom to leave the care recipient attended by the respite service provider for a predetermined number of hours, such as by offering "accompaniment"; by this criterion, many home care activities like wound care or grocery shopping as the sole home care tasks requested would not qualify as respite care. Ambiguous apps that disputedly met the criteria were flagged, cross-checked, and discussed by the reviewers until consensus was reached.

Data Extraction and Synthesis (Steps 6-7)

Data from the final selection of apps were extracted from the apps and their own official websites and sorted into an Excel spreadsheet to produce a descriptive summary of the apps. Extracted data included: purpose of the app; demographic data such as country of app origin, app language(s), target user healthcare condition or group, specific app layout and functions, type of respite care provided; as well as marketing aspects such as price of the app and user comments, if available, and any other information necessary for the quality appraisal.

Quality Appraisal Methods: MARS and Enlight Criteria

Two complementary digital health appraisal tools were used to analyze the final selection of respite care apps: the Mobile App Rating Scale (MARS) (Stoyanov et al., 2015) and the Enlight tool (Baumel et al., 2017).

The MARS tool presents a quick, reliable, and multidimensional method to appraise mHealth apps. The MARS tool has 23 items, each rated on a 5-point scale (1-Inadequate, 2-Poor, 3-Acceptable, 4-Good, 5-Excellent). The first 19 items assess four objective app quality ratings sections: section *A – Engagement* (entertainment, interest, customisation, interactivity, target group); section *B – Functionality* (performance, ease of use, navigation, gestural design); section *C – Aesthetics* (layout, graphics, visual appeal); and section *D – Information Quality* (accuracy of app description, goals, quality of the information, quantity of information, visual information, credibility of the developer, evidence base/testing). The items in each of the sections are averaged to give a "*Mean Section Score*" out of 5 points. The Mean Section Scores are themselves then averaged to give an overall "*App Quality Mean Score*" out of 5 points.

The final fifth section E of the MARS (items 20 through 23) provides the "*App Subjective Quality Score*". This score is independent from the previous objective assessment sections, because it provides questions directed towards the evaluator in a separate section of the MARS (e.g., Would you recommend this app to people who might benefit from it?). The items in this section are also each scored out of a possible 5 points, and then averaged to get the "App Subjective Quality Score".

While many items from the MARS tools help assess critical elements of an mHealth app, there are no items that appraise the privacy, transparency, and security of user information. These domains were therefore analyzed using the criteria set by the Enlight tool's Privacy Explanation, and Basic Security checklists (Bining et al., 2022). These checklists encompass multiple criteria which are rated either as "Yes", "Not Applicable", or "No or can't tell". A point for every criterion *not* met is given, making the best score possible for the Privacy Explanation checklist a 0/8 and a 0/4 for the Basic Security checklist. This interpretation entails: 0/8 meets user Privacy Explanation checklist requirements, and 0/4 indicates user data is reasonably secured for the Basic Security checklist.

To test inter-researcher variability in scoring, a blind second-analysis of three Apple apps, and three Android apps was conducted by another researcher. There were no discrepancies greater than one point noted for any score in any of the MARS or Enlight sections assessed for any of the apps. The complete MARS and Enlight scores for all apps can be found in Appendices 2 and 3.

Data Analyses

The data were analyzed both quantitatively and qualitatively in Excel by three researchers using descriptive content analysis techniques (Elo & Kyngäs, 2008b). Visual data in the form of tables and clusters were generated from the information gathered by the MARS and Enlight tools to outline trends in the quantitative data. Qualitative features were analyzed and grouped into themes to facilitate comparison across the apps.

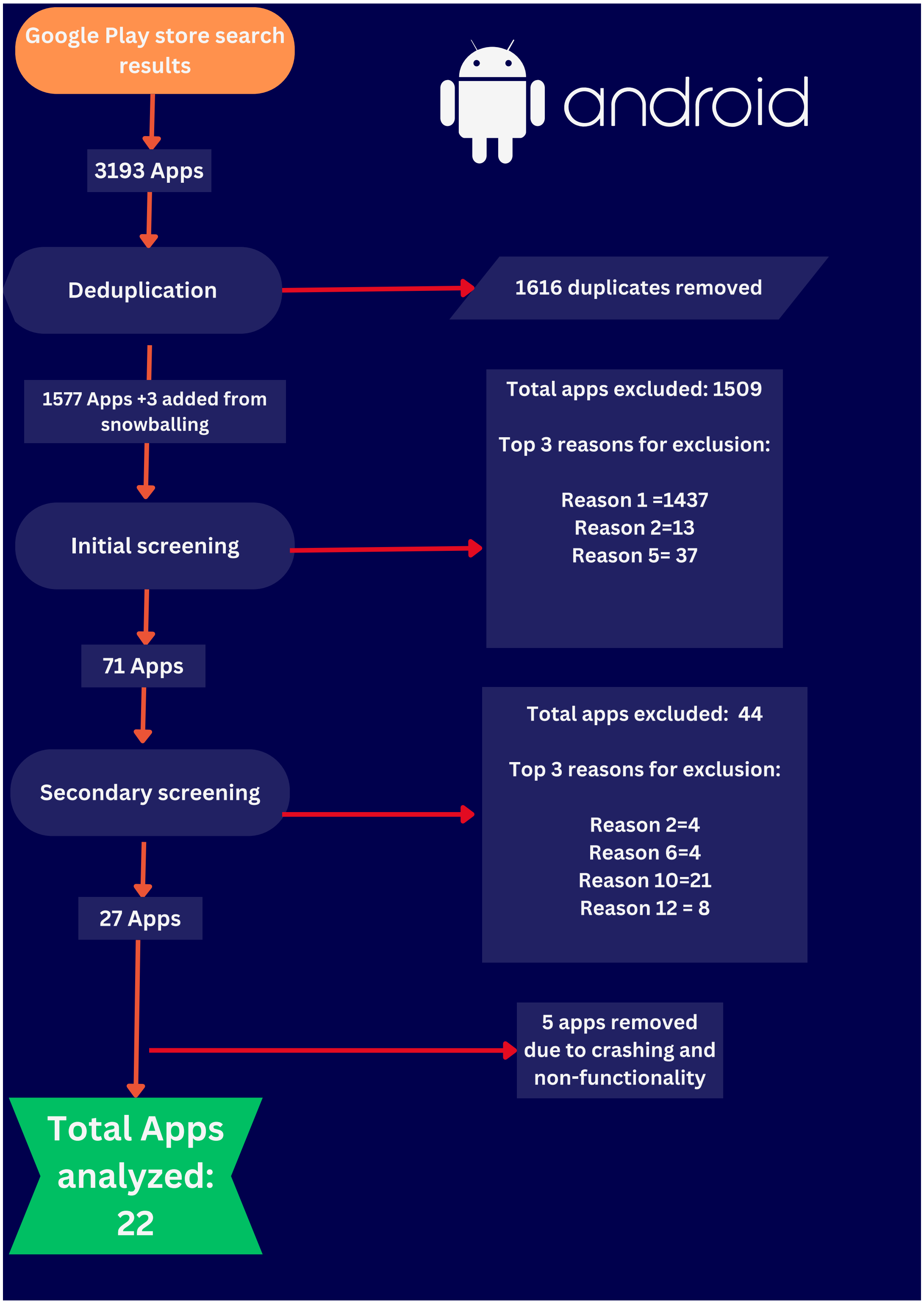
Results

Screening Results

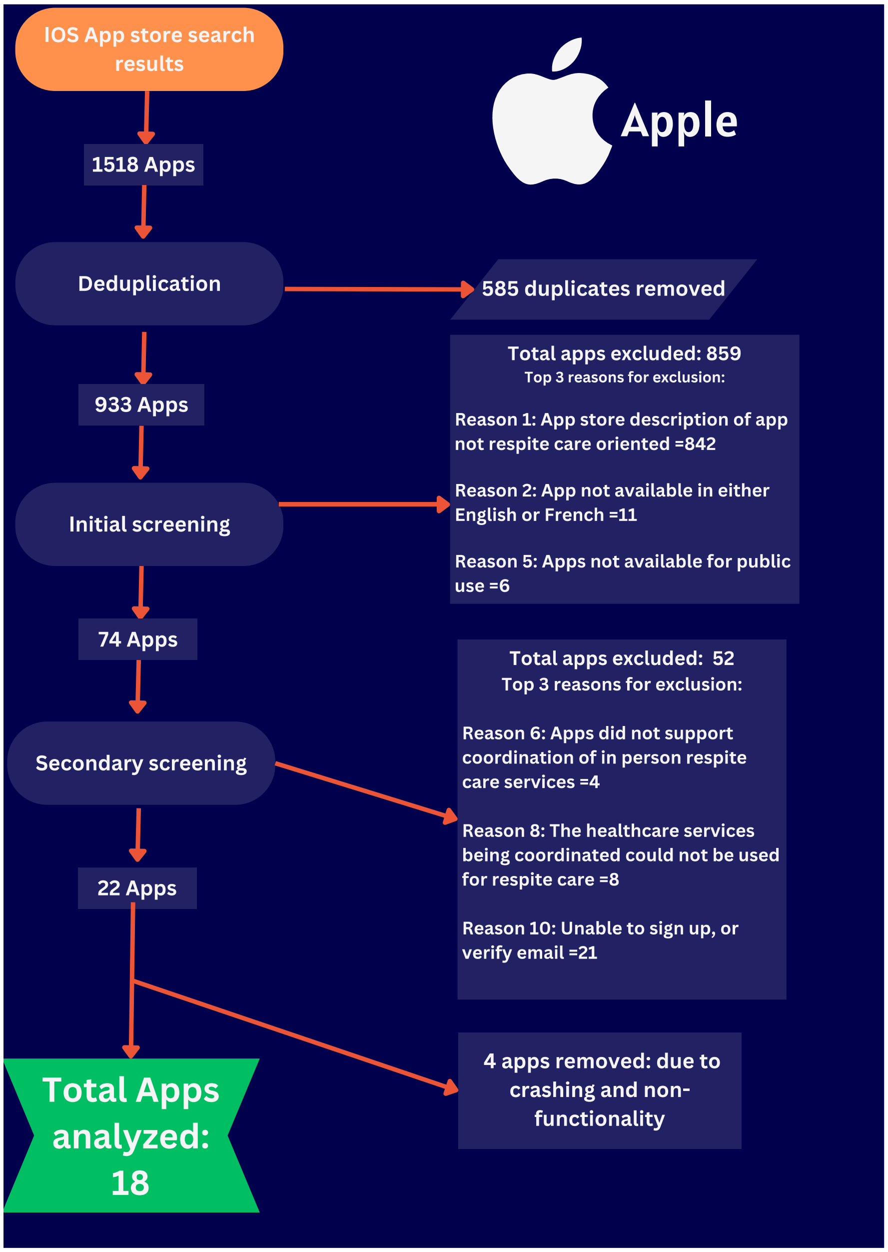
In total, 4,711 apps were screened (3,193 from the Android store, and 1,518 from the Apple iOS store). 2,510 (1577 from Android and 933 from iOS) apps remained after deduplication. 3 apps were added through snowball sampling after the deduplication process for a total of 2513 apps. From there, apps underwent two additional rounds of screening, each with their own set of exclusion criteria. Ultimately, 18 apps from the Apple store (Appendix 2) and 22 apps from the Google Play store (Appendix 3) met the inclusion criteria for download, data extraction, and analyses, for a combined total of 40 respite care apps analyzed. Eight of the apps had Apple-Android interoperability, however these apps were still counted separately in case there were differences in the design across the two stores.

See Figures 1 and 2 for flow charts outlining the stages of app inclusion criteria. See Appendix 1 for detailed reasons for app inclusion and exclusion. The most common reason for exclusion was Reason 1 (i.e., the brief app description in the returned results did not give indications of being respite care oriented. Specifically, there were no indications that the app would be used to coordinate some form of in-person support that would allow the family caregiver to leave the home.)

(Figure 7.2.1) Figure 1: Android Google Play Apps Screening Flow Chart



(Figure 7.2.2) Figure 2: Apple Apps Screening Flow Chart



Total apps excluded: 859
Top 3 reasons for exclusion:

Reason 1: App store description of app not respite care oriented =842

Reason 2: App not available in either English or French =11

Reason 5: Apps not available for public use =6

Total apps excluded: 52
Top 3 reasons for exclusion:

Reason 6: Apps did not support coordination of in person respite care services =4

Reason 8: The healthcare services being coordinated could not be used for respite care =8

Reason 10: Unable to sign up, or verify email =21

4 apps removed: due to crashing and non-functionality

Of the final list of apps assessed as being able to provide respite care services, only 7 apps explicitly advertised “respite care” or related terms, such as “short break care” or “accompaniment” as an official service. The remaining 33 apps were nonetheless included because their services could function as respite care, in that they provided users with the ability to coordinate in-home care services to a care recipient for a selectable number of hours where the home care services that could be provided did not require supervision by a family caregiver; such respite care activities included psychosocial support, accompaniment, and overnight care for sleep. Therefore, while not explicitly using the term “respite care” in their ads or services, these apps could be used for coordinating respite care services.

The most highly represented countries by number of operating respite care apps were Canada with 11 apps, the United States with 10 apps, and Singapore with 6 apps. The number of app users could not be reliably determined from the app stores or apps themselves, so these statistics were not recorded. Of the 40 apps, only 2 apps had more than 10 reviews online; these apps were Carelinx (Android) with 1,160 reviews giving a mean of 4/5 stars, and Curam (Android) with 286 reviews giving a mean of 4.3/5 stars.

Most apps had multiple target populations: 21 apps mentioned senior/elder care as an option, 19 apps mentioned services to all ages and populations, 8 apps explicitly mentioned serving populations with chronic illnesses or disabilities, and 3 apps mentioned care for children. Only one app (Ianacare) had “Primary caregiver” as a target population.

Below, we share the key quantitative appraisal and thematic results for these respite care app analyses.

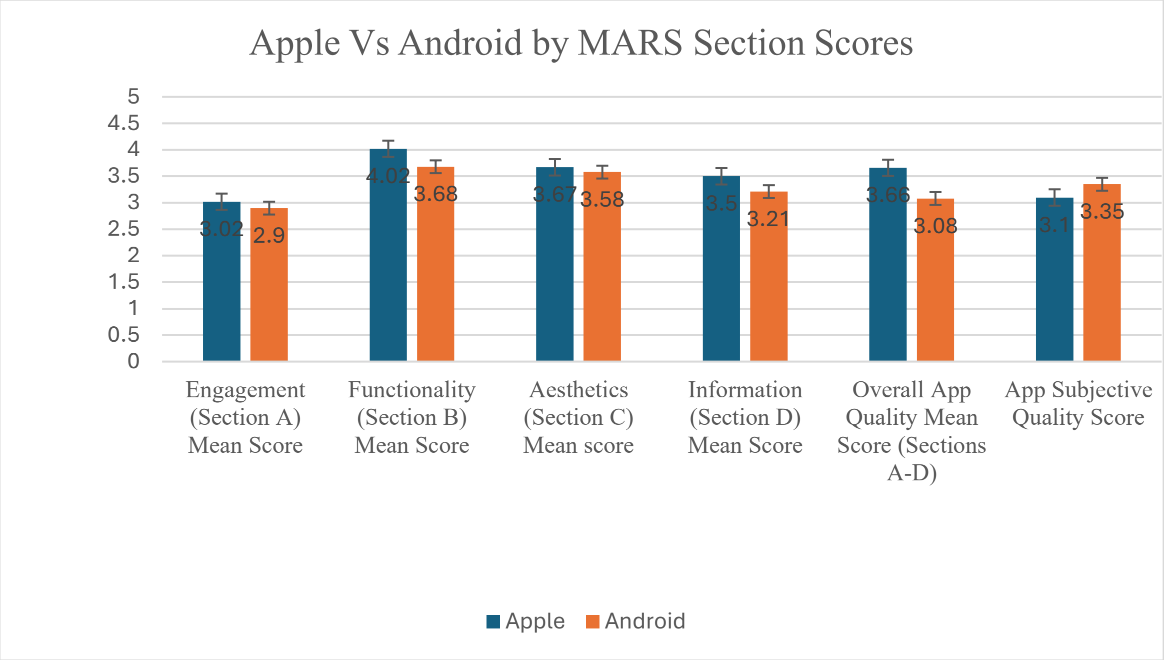
MARS Quality Appraisal

The following is a summary of the findings gathered with the MARS scores, the complete tables can be found in Appendices 2 and 3.

The app "Quality Mean Score" section of the MARS indicated the apps were on average between "acceptable" and "good" (Stoyanov et al.), with an average quality mean score across the 40 apps of 3.33. Apple apps scored higher on average (mean = 3.66, SD 0.53) than Android apps did (mean=3.08, SD= 0.54). For overall MARS Quality Mean Score, the United Arab Emirates-based Dardoc (4.7) and the United States-based Carelinx (4.5) scored highest overall, averaging across sections A-D. The Canada-based Vytality at Home app scored highest for mean quality subjective score (4.5/5).

As shown in Figure 3, Apple apps outperformed Android apps in every section except perceived (subjective) score, which was slightly worse for Apple apps. Amongst all sections (A to D), Functionality Mean Score (Section B) was the only criterion showing a major difference in app store app performance between Apple (mean=4.02) and Android (mean=3.68) apps. See Figure 3 for a complete visual comparison of the Apple and Android MARS sections.

(Figure 7.2.3) Figure 3: Apple iOS Versus Android App MARS Quality



Enlight Appraisal: Privacy and Security Checklists

The following is a summary of the findings of the Enlight checklist, the complete tables can be found in Appendices 2 and 3.

Both Android and Apple apps performed well on average in the Enlight privacy checklist (Apple =2.29/8, Android = 2.3/8), but poorly in the security checklist (Apple = 2.18/4, Android = 2.56/4).

Privacy

For both Android and Apple, the privacy criterion least met by all apps was question (Q.) 5: "Does system explicitly tunnel users through terms of use before program utilization." For Apple, 11/18 apps did not meet the criterion, and for Android 20/22 apps did not meet this criterion.

The best scoring point for Apple apps on the privacy checklist was Q.1: “Terms of use informs users of data journey in detail and sources of exposure.” 16/18 apps met this criterion. For Android, the best scoring point was Q.8: “The system warns users about providing private identifiable information”; 20/22 apps met this criterion.

The worst performing apps in the Enlight Privacy checklist were *Respite Now* (Apple) and *Good Homecare* (Android) scoring 7/8 points and one N/A each. Both apps did have a Terms of Service page, and a Privacy Policy page, though neither met any of the criteria outlined by the Enlight Privacy checklist. The terms of service on the *Respite Now* website did not appear to make any reference to the online aspects of data privacy such as measures for data protection, how or where personal data will be stored, whether information will be encrypted, or whether personal identifiable information will be kept secured.

The best performing app in the Enlight Privacy checklist was *Damava.* Present on both the Android and Apple stores, it scored 0/8. *Damav*a describes which data the users are consenting to have collected when they agree to the Terms of Service and Privacy Policy, how the data is used, how the data cannot be used (with examples like: your email address will not be shared with third parties), and how all personal identifiable information will be removed before data sharing with third party. These, as well as all other points in the Enlight Privacy checklist, were met.

Security

For the security checklist scores, both Apple and Android apps scored lowest on Q3: “Is there documentation of data exposure through monitoring of login activities on platform servers and data.” 14/18 Apple apps did not meet this criterion, and 20/22 Android apps did not meet this criterion.

The best scoring point on the security checklist for both was Q.1: "Is there encryption protection and de-identification of data as well as device password protection." 14/18 Apple apps met this criterion; 14/22 Android apps met this criterion.

App Themes

While objective tools like the MARS and Enlight are necessary to provide results against a comparable and referable set of criteria, they do not explain how or what functions the various apps have been created with to be able to successfully provide their respite care services. The following section describes the respite care apps' operational features and categorizes in terms of themes.

App layouts, Care Package and Filter Pick

The apps assessed came in two general layouts for which we coined the names "Care Package" and "Filter Pick".

Care package apps

"Care Package" apps had simple layouts: the respite care recipient or family caregiver could sign up by creating a personal account, and then pick from a short list of predetermined services ("Care Packages") with assigned hourly rates or monthly/contractual rates. These "Care Packages" did not disclose any information (e.g., profile) about the care provider hired for the service before the booking process commenced, nor did these apps include a filter for specific needs of the family caregiver or care recipient.

Filter pick apps

For "Filter Pick" apps, after signing in, users were given the opportunity to "get care", "search care providers", or "find nearby care providers", whereupon they were presented with a listing of care providers, who could be sorted through using a filter (i.e., a “Filter Pick”). Filter options could be laid out in terms of the specific tasks needed by the prospective family seeking care (e.g., hygiene care or PEG tube feeding); or by respite care provider credentials, hourly charge, or certifications/licensures. After setting filters on care providers, users (i.e., family caregivers or care recipients) could click on the care provider’s profile and request to schedule care. The next page was typically a fillable form with instructions on how to schedule care, and which additional services would be needed on the day of care as part of the respite care (e.g., solely accompaniment/companionship, hygiene care, cooking, etc.). Once the request for a care provider and their services had been submitted, family end-users could contact the selected care provider, or they could be asked to pay in advance, depending on the app.

End-User Profiles and Scheduling

Family profiles

Besides creating an account for family caregivers to login, some apps, like *Respite Now, Carer,* and *Carers* required the creation of at least one care recipient profile. Profile information varied per app, but the most common categories included: name, age, sex, medical conditions, medical needs (e.g., help with ambulation, feeding assistance) of the care recipient, and preferences for incoming respite care providers (e.g., must be male, must be an RN, etc.). Once completed, the profile would be saved within the app and any care sought thereafter could be directed to a specific care recipient profile.

Care provider profiles

Each “Filter Pick” app presented varying degrees of information about the care providers listed from the search. After setting filtering options, “Filter Pick” apps had two main pages to navigate: (1) the list of care providers and (2) the provider's personal information. The first page would be a list of care provider profile names with pictures, which the care recipient could scroll down and click on to reach the second page. This second page allowed users to view individual care provider profiles more closely and review additional information. The type of information found at each stage of the search is summarized in Table 2 below.

(Table 7.2.2) Table 2: Care provider profile contents in Filter Pick apps

	Description	**Elements included**
1st page	Lists of care providers	• Full Name • Picture (headshot) • Rate ($/hour) • Age and sex • Profession (personal support worker, nurse, physician) • Rating (stars out of 5)
2nd page	Individual care provider profile	• Personal Blurb - experience (how long they have been working) • Services offered (accompaniment, light housekeeping, feeding, bathing, bed transfers, etc.) • Certifications (driver's license, CPR, counseling, IV certification) • Availabilities (per day of the week) • Willingness to take on a part-time or full-time schedule • Languages spoken • Reviews (beyond the available 5 stars to give, one could provide an anonymous written review) • Highest level of education (high school diploma, bachelors, etc.)

Theme: Reliability and Safety of the Respite Care Coordination Service

For most of the apps, care provider performance, reliability, and safety could not be assessed because app hiring policies and certification standards were difficult to identify and not always available. Hiring information and criteria were not centralized, but instead were fragmented across the app websites, terms and conditions, and in-app information blurbs. Nonetheless, useful qualitative data on the apps' care coordination reliability were gathered after thorough review of each app's filter capabilities, and a scan of the resulting care providers.

The most unreliable aspect of apps' care coordination functions was the availabilities (or lack thereof) of care providers, based on user location. Some apps internally kept a maximum distance limit, and those often returned "0 care providers in your area". Those that did not have a maximum distance limit, or those that allowed users to pick a maximum commute, returned care providers thousands of miles away. Furthermore, the apps did not give clear indications as to providers' willingness to commute. See Table 3 below for the different methods of location filtering that the apps provided.

(Table 7.2.3) Table 3: Location filtering functions

Type of location filtering	**Description**
Method 1: Modifiable maximum distance (with GPS)	• App would use the end-user's GPS location and determine if there were listed care providers within a certain distance of the end-user • If none, the app would return: "There are no available care providers in your area." • By default, the app had a maximum kilometer distance radius, which could be shortened
Methods 2: "Filter Pick" style choice (with GPS)	• Allowed the user to set a "Maximum Radius" to filter out care providers based on their maximum desired distance of travel
Method 3: Unmodifiable maximum distance (without GPS)	• The app had a fixed, unchangeable maximum radius • Based on the user's location that was inputted, the app would then decide on its own if there were any care providers in the area

	• No information available on how the app decided max distance
Method 4: Live map (with GPS)	• GPS map with real-time locations of listed care provider
Method 5: No location filtering function	• App did not ask for location and did not have a distance filtering capability • Profiles had to be manually viewed for the location of the care provider

Another aspect of reliability was that of the quality of the respite care provider profiles on the apps. Most in-app care providers' profiles did not have any client reviews despite the availability of the common "Leave a Rating" function, and profiles gave no other indications that they were providing the services they claimed to be capable of.

Training Opportunities for Care Providers and Caregivers

Of the 40 assessed apps, four provided training options for its staff or clientele. *Nurse on Call* and *Respite Now* sent emails with links to Zoom invitations in which they offered app demos to its users and to prospective care recipients. *Respite Now* went one step further and offered care provider training, sending monthly emails, such as: "Strategies virtual training: Here you will learn some strategies on how to effectively support individuals with Fetal Alcohol Spectrum Disorder." The app *Carer* advertised eight training modules tailored to the caregiver-recipient dyad lasting two hours each, which could take place in the dyad's home with an instructor (e.g., Stoma Care, Caring for Dementia Patients, etc.). The app *Carelinx* also provided online educational care classes for families via a company website called CareAcademy. These classes consisted of asynchronous modules that one could complete at one's pace on any device. All the apps providing training were from the Apple store; the Android versions of *Carelinx* and *Carer* did not provide links to their training modules.

Initial Home Visits by Care Providers

Before providing care to new users, two apps (*Vitality* and *Homage*) required that their employees perform environmental scans of care recipients' homes and care environments. *Vytality* specified that patient care requirements would be determined by their assessment findings made during the preliminary visit. For *Homage*, although the visit was stated to be "optional but highly recommended", the company would not allow new users to progress to order care without agreeing to the preliminary visit.

Discussion

To develop an app that provides family caregivers with useful tools, the search, dissection, and appraisal of existing apps needed to be completed. The following discussion analyses the above findings and explores the implications of the MARS Quality Mean Scores, the apps' performances on the Enlight checklists, noted issues regarding respite care accessibility and the inadequate marketing of respite care services. Throughout this discussion, we compare the results of this app store search with the companion academic scoping review (Castro et al., 2023) completed as part of the chosen hybrid methodology (Lau et al., 2021). We finish with a discussion of this study's strengths and limitations, and of the future opportunities for research in the areas of respite care and home care app development

MARS Quality Mean Score Comparisons

The overall app Quality Mean Score from the MARS for the 40 tested apps was 3.33, translating into an average app score between the MARS scale's "acceptable" and "adequate" marks. This finding is consistent with other app store reviews that evaluated the average MARS mean scores for other mHealth apps. In a study of 23 mHealth apps, (Kim et al., 2018) reported an average mean score of 3.23 for apps that mapped out drug interactions, while another study of 17 apps for informal caregivers of people with dementia conducted by (Werner et al., 2022). calculated an average mean score of 3.08. (Richardson et al., 2019) also attributed a mean score of 3.37 in a study of 18 mHealth apps for parents of children in intensive neonatal care units. The proximity in Quality Mean Scores between this study's findings and others' work indicates that respite care app development is at a similar level to that of other mHealth app services.

Enlight Privacy and Security Checklists

Lack of security was apparent among the apps assessed. Our companion scoping review of academic studies of respite care information and communication technologies also noted the importance of end-user trust in the data privacy standards and usability of the respite care platform (Castro et al., 2023). Lack of security in the assessed apps could be problematic for some consumers, as many people wish to know their risk of data exposure before downloading an app (Madden et al., 2013). Security information relayed by apps' terms of service and privacy policies varied, and these data were frequently scattered across various documents (e.g., terms of service vs privacy policy) or locations (e.g., the accompanying website for the app vs the app itself). Poor accessibility to security and privacy information could make it more difficult for users to relieve their security concerns. Poor privacy standards could be a serious barrier to respite app use, as existing literature suggests that privacy concerns have a strong influence over willingness to provide personal information. This is especially true for sensitive data, as privacy concerns over health information have been shown to negatively impact the use of mHealth app interventions, and could even prevent individuals from obtaining other healthcare services (Nurgalieva et al., 2020; Wu et al., 2012). A solution proposed by Albrecht and colleagues to this could come in the form of an “App synopsis” produced by the manufacturer (Albrecht et al., 2015). This synopsis would yield a structured and highly legible document that can “aid users in evaluating whether an app meets their needs and can be used in a safe manner, even if they are not familiar with performing such evaluations” (Albrecht et al., 2015).

Respite Care Accessibility and a Limited Supply of Providers

The issues of limited care provider supply and accessibility are common topics of discussion within respite care literature (Cooke et al., 2020) and were once again demonstrated in this study. “Filter Pick” apps that internally kept a maximum distance limit, or those that allowed to filter by distance, often returned “0 care providers in your area”. Furthermore, very few apps made it clear which locations had care providers available and which locations did not. To avoid respite care recipients and family caregivers from wasting their time, it is important that respite care coordination apps make it swiftly clear to their users when their app does not have the personnel to provide care services in the user’s area.

Care provider results often mapped to residences in large USA cities, possibly suggesting a larger concentrations of respite care providers in urban areas. Access to respite care services in rural areas has been described as a challenge in other respite care studies (Cooke et al., 2020). The results of this app store search once again show that care provider accessibility is highly dependent on region, and that at this stage, a large subset of the population cannot reliably use apps to command respite care to their homes. By marketing such apps to schools of nursing, homecare training programs, and employment agencies, respite care app development teams could potentially build their supply of respite care providers on the apps (Winston et al., 2023). Furthermore, by partnering with existing institutions, home care support agencies, and community health organizations, these apps may also be perceived as being more trustworthy due to their established affiliations.

Inadequate Marketing of "Respite Care" Services

Of the 40 respite care apps identified through our search strategy, only 7 apps explicitly advertised "respite care" as a core service; the others described services that can count as "respite care" but did not use this term, or related terms such as "short break care". Our results suggest that care coordination apps are failing to advertise respite care as part of their services, despite being capable of coordinating such services. These results align with our complementary scoping review of respite care ICTs, where adequate promotion and marketing of technologies to support respite care services was emphasized (Castro et al., 2023). Building a well-designed technology is insufficient for successfully facilitating respite care services; families and providers must be aware of these novel avenues for coordinating respite care, if these platforms are to be used. Participatory design methods with families, respite care providers, and homecare agencies may help to ensure the successful implementation of respite care apps (Castro et al., 2023).

Failing to adequately promote the "respite care" service nature of these apps can be seen as a missed opportunity for apps, respite care providers, and family caregivers who could mutually benefit from this service. After all, respite care services remain underutilized, due partly to too few, and too inflexible respite care options (Cooke et al., 2020). However, this study suggests that the problem goes beyond just the lack of options, as poor advertising of respite care services may be limiting the pool of visible apps. Developers of apps with care models that allow for users to specify a type of medical service, and book a healthcare professional for a selectable number of hours to fulfill this service independently, and have the capacity to provide respite care (i.e., where the family caregiver can leave the care recipient alone with the trusted care provider), and should advertise it and include “respite care” or “short break care” explicitly as a service option in their app.

Limitations

There were several limitations to this systematic app store search. The most notable limitation was the absence of an actual coordination of respite care events by members of the research team. This app store search had the aim of determining the state and quality of respite care apps, not the quality of the caregivers hired by the apps to provide services. As a result, we did not assess the caregiving services beyond the point of digital contact with respite care workers. Knowing how an app behaves after payment, and knowing how its features provide communication, location, and timing information in a safe and reliable way to connect users to care providers, is essential for fully comprehending the user experience and the limitations of current respite care coordination apps.

Another constraint lies with the assessment tools. Previous studies of mHealth app systematic searches have highlighted that both the MARS and Enlight tools complementarily evaluate certain aspects of mHealth apps (Dogtiev, 2021). However, these complementarities are not exhaustive (Belen Sotillos et al., 2021). Even with the combination of the MARS and Enlight tools, to our knowledge, there is no validated tool available to assess app scalability, interoperability, or the care provider certification and competency verification policies for mHealth apps coordinating community services. In this respect, the two tools are not comprehensive in their ability to analyse app features specific for supporting the coordination of in person healthcare services.

Future Opportunities for Research

It will be important for future researchers to find a method of assessing apps beyond the point of care provider contact or payment prompt, as data beyond this point is essential to capturing the full user experience, and synthesizing a comprehensive view of respite care apps. Furthermore, similarly to other respite care studies, this app store search has found that accessibility to respite care remains a problem. Many studies have also found that existing respite care services are often in-demand yet underutilized due to issues such as scheduling flexibility and trust, pointing to a disconnect between the chains of supply and demand of respite care (Robinson et al., 2017; Rose et al., 2015a). Based on these findings, the next steps for respite care software developers and respite care organizations should be to conduct research into how respite care apps can break down the barriers to accessibility, weave together the chains of supply and demand, and increase recruitment and engagement of respite care providers in respite care apps across various communities.

Conclusion

This systematic search for respite care coordination apps revealed that many apps are capable of creating and sustaining a market for respite care, but are not realising the potential of their platforms to deliver respite care -- due in part to a lack of supply of respite care providers or connections with existing agencies. Furthermore, these apps often fail to explicitly advertise respite care in their app store descriptions. In agreement with other respite care related research, this study again highlighted how the short supply and poor accessibility to app-going care providers negatively affects the practical use of these apps and keeps them severely limited by user location.

Strengths of our study included the rigour of the methodology, the size of our app sample, and the descriptive explanations of respite care apps' functions and layouts. Our methodology followed a hybrid approach, which searched the app store using key words suggested from the results of a traditional systematic search of academic library databases for research on respite care technologies conducted by (Castro et al., 2023). This search strategy ensured that the greatest number of words relating specifically to respite care, both in English and French, would be used to scour the app stores for relevant respite care applications. Our search was also conducted over two app stores, further increasing the breadth of our sample, and allowing for a more thorough examination of the mHealth respite care app market.

This respite care app store search is among the first of its kind in that it provides objective and descriptive summaries of respite care apps' features and functions. Our study provides respite care app developers and service providers with a comprehensive summary of what other respite care app creators have done to automatize and simplify the process of coordinating respite care. This study can serve as a benchmark that future developers of mHealth coordination technologies can use to guide the development of similar respite care and home care coordination apps.

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Conflicts of Interest

None declared.

Author contributions

ARC and AT designed the study. JLV, TN, and AP collected the data. JLV, TN, AP, ARC, and AG analyzed the data. All authors contributed to writing the manuscript, finalizing the discussion points, and/or approving the final submission.

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List of appendices for Paper 5

Appendix 1 (below): Detailed steps of search, selection, and data extraction process.

Appendix 2: 18 Apple iOS app store applications analyzed. View online:

https://cjni.net/journal/wp-content/uploads/2024/05/Castro-Appendix-2.pdf

Appendix 3: 22 android Google Play store applications analyzed. View online:

https://cjni.net/journal/wp-content/uploads/2024/05/Castro-Appendix-3.pdf

(Table 7.2.4) Appendix 1: Detailed steps of search, selection, and data extraction process.

	Step 1: Identify mobile devices and App Store used for search	
	1) Mobile Phone: iPhone XR Owner's Initials: J.V. Operating System: iOS iOS Version:16.4 Last updated on: 27/03/2023 2) Mobile Phone: iPhone XR Owner's Initials: A.P. Operating System: iOS iOS Version: 15.5 Last updates on: 16/05/2022 For J.V. & A.P.: Related App Store: Apple App Store Location: Montreal QC Canada	1) Mobile Phone: Samsung Galaxy S9 Owner's Initials: T.N. Operating System: Android Google Play Store Version: 29.0.14-21 [0] [PR] 423376132 Last updated on: 26/01/2022 2) Mobile Phone: Samsung Galaxy S8 Owner's Initials: A.P. Operating System: Android Google Play Store Version: 32.5.16-21 [0] [PR] 476484547 Last updated on: 28/11/2022 For T.N. & A.P.: Related App Store: Google Play Store Location: Montreal QC Canada
	Step 2: Perform search with predetermined set of keywords	
	For each of the above devices, personalized recommendations were turned off such that the app store was not affected by cookies. For the Android device this additionally included clearing cache and data in settings. Within a shared folder entitled "yyyy.mm.dd_Search Results and Screening" on Microsoft Teams, two subfolders respectively named "Phase 1: Search and Selection" and "Phase 2: Screening" were created. Within the "Phase 1: Search and Selection" subfolder, there were two Excel files. One titled "Keywords - Apple" (for the Apple Store search) and "Keywords - Android" (for the Google Play Store search). Within each Excel file on the first sheet, Row 1 comprised of 70 columns (one for each keyword in English, and one for each keyword in French). The columns were titled: [keyword]_ [search date]. Row 2 was reserved to indicate the number of results for each respective keyword.	

	Each column, starting from Row 3, listed the app names generated by the keyword, up to the first 100 results. (One cell per app name). For each keyword search, a Word document was created entitled: [keyword]_[yyyy.mm.dd (search date)]. Screenshots scrolling through the top 100 apps returned by each keyword search were taken and saved, in order, in this document. These documents were saved in a subfolder entitled: "Keywords – [Apple/Android] – Word documents for auditing" within the Phase 1 folder. These documents served for auditing purposes of the apps that were returned on the day we searched.
	Step 3: Remove duplicates
	The first Excel sheet of keywords created for Step 2 was copied onto a second sheet in the same Excel file (i.e., either the Apple or the Android excel sheet). The rows and columns were re-organized to search for any duplications that were removed (i.e., an app that was returned more than once within the same store, by the various keyword searches). Duplicates of the exact same app returned were deleted from this copied sheet, with duplicates coming from later keywords in Table 1 being removed. Note that if an app had an iOS and an Android version, or had a basic and deluxe version, all versions were saved as separate items, and sub-analyzed together as a group, noting differences between platforms and versions. The de-duplicated results were saved in new Excel sheets entitled "yyyy.mm.dd_De-duplicated results-[Apple/Android]-preliminary screening-[screener's name]" also within the phase 1 folder. Copies were created for each screener: J.V. (Apple), T.N. (Android), and A.P. (Apple & Android).
	Step 4: Initial screening using inclusion and exclusion criteria, based on app descriptions in the Apple and Google Play stores.
	Apps were rejected based **on exclusion criteria** at this stage for the following reasons: **Reason 1:** The brief app description in the returned results did not give indications of being respite care-oriented, given in-store description. Specifically, there were no indications that the app would be used to coordinate some form of caregiving support by another person (i.e., not just a personal records document for the care recipient or family caregiver), such as coordinating volunteers, secondary family caregivers, home care aides, or nurses. [In this case, the cell with the app name was flagged **pink** in the Excel sheet, "yyyy.mm.dd_De-duplicated results-[Apple/Android]-preliminary screening-[screener's name]". **Reason 2:** The app was in a language that was neither English or French. [In this case, the cell containing app name was flagged **orange**]

	Reason 3: The app had not been updated in the past 5 years. [In this case, the cell containing app name was flagged **brown**] **Reason 4:** The app needed reviewing by another member of the team, and was reviewed. Exclusion due to reason 4 occurred if both reviewers agreed that ultimately the app did not meet the inclusion criteria. [In this case, the cell containing app name was flagged **yellow**]. **Reason 5:** The apps were used internally by agencies and employees and were not intended for public use [In this case, the cell containing the app name was flagged **blue**] All apps that passed the above exclusion criteria were labeled in **green** and subjected to further tests. Once both screeners completed their results, they traded documents, and discussed and cross-checked any ambiguous apps that disputedly met the inclusion criteria until consensus was achieved. The apps accepted to proceed at this preliminary stage continued to Step 5 for download on a mobile device and detailed screening.
	Step 5: Detailed screening using inclusion and exclusion criteria
	Reviewers J.V., T.N, and A.P. independently downloaded apps that had passed the first stage of screening from the Apple App Store and Google Play Store respectively. These apps were then subjected to further screening according to the eligibility criteria. Within Teams, the folder "Phase 2 screening", a subfolder was titled "[Apple/Android] Preliminary results step 5" containing Word documents titled: "[App name]-Version[x]-updated [time ago]". No additional screening notes were taken on these Word documents. Instead, (JV) created separate Excel sheets entitled: "Results Step 5 [Android/Apple]" with their decisions for each app, and the specific reason number from "further exclusion criteria" noted with details. **Further exclusion criteria:** At this step, apps were rejected for the following reasons: **Reason 6:** App interventions were virtual and did not support the coordination of in-person respite care services (e.g., an app solely providing information about local caregiving supports, but not offering contact information or coordination of the actual care, were excluded)

Reason 7: App was not targeted towards the family caregiver, but more towards the care recipient.

Reason 8: The care services being coordinated were unambiguously not for respite care (e.g., the app was coordinating nursing services for wound care, but the visits were short and the family caregiver would not be able to leave the home.)

Reason 9: App needed further reviewing by another team member, who determined exclusion.

Reason 10: Unable to sign up, unable to download, or unable to verify email

In the same fashion as the first round of screening, once the second round of screening was completed, J.V. J.T. A.P reviewed each other’s screening sheets to note any inclusion/exclusion discrepancies. A discussion between the research group members took place to resolve any disagreements about including or excluding an app.

Reason 11: App meant for care coordination among friends and family (No outsourcing of help, no ability to order care to home).

Reason 12: App crashes, unable to download, non-functional.

Reason 13: App no longer available/ could not be found on app store.

Step 6: Data extraction

The Apps remaining after step 6 underwent data extraction by J.V., T.N., and A.P. All data at this stage was stored in an Excel file within a new subfolder entitled “Data Extraction step 6” within a greater “Data Extraction and Analysis” folder at the same level as the Search Results and Screening folder.

The following data for each app was copied into each app’s Sheet as text descriptions:

1) App Name
2) App Developer (search app name on Google and verify if the developer has a website)
3) Country of Origin
4) App Language(s)
5) Purpose of App
6) Target healthcare condition
7) Type of respite care provider (e.g., unpaid family/friend, nurse, personal support worker, volunteer...)
8) Cost of App
9) App store rating, if any
10) Reviewer comments (top 15 most recent) will be recorded, and recurring critiques and

appraisals were noted and compared across apps

11) MARS tool (Stoyanov et al., 2015):
  a. Engagement mean score; based on (Entertainment, Interest, Customization, Interactivity, Target group)
  b. Functionality mean score; based on (Performance, Ease of use, Navigation, Gestural design)
  c. Aesthetics mean score; based on (App layout, Graphics, visual appeal)
  d. Information mean score; based on (Accuracy of app description, Goal setting, Quality of information, Quantity of information, Visual information, App credibility, Evidence base)
  e. App quality mean score (ABCD mean)
  f. Subjective quality score

12) Enlight checklist (Baumel et al., 2017):
  a. Privacy and explanation (transparency) checklist score
  b. Basic security checklist score

13) Any other notes relevant to the purpose of the study

14) Extra screenshots and or videos necessary for the detailed extraction during step 6 including the graded MARS and Enlight tools were saved in folders titled "[app name]-step6proofs" within "Data extraction step 6"

Step 7: Data synthesis

A new Excel sheet entitled "yyyy.mm.dd_App Data Synthesis" was created.

Separate sheets were used to group and synthesize related data across the apps, from the separate Sheets created in Step 6.

Descriptive content analysis (Elo & Kyngäs, 2008b) of the included apps was conducted to facilitate comparisons in qualitative data of app features and themes.

8.0 Paper 6: iRespite Design

8.1 Bridge 6

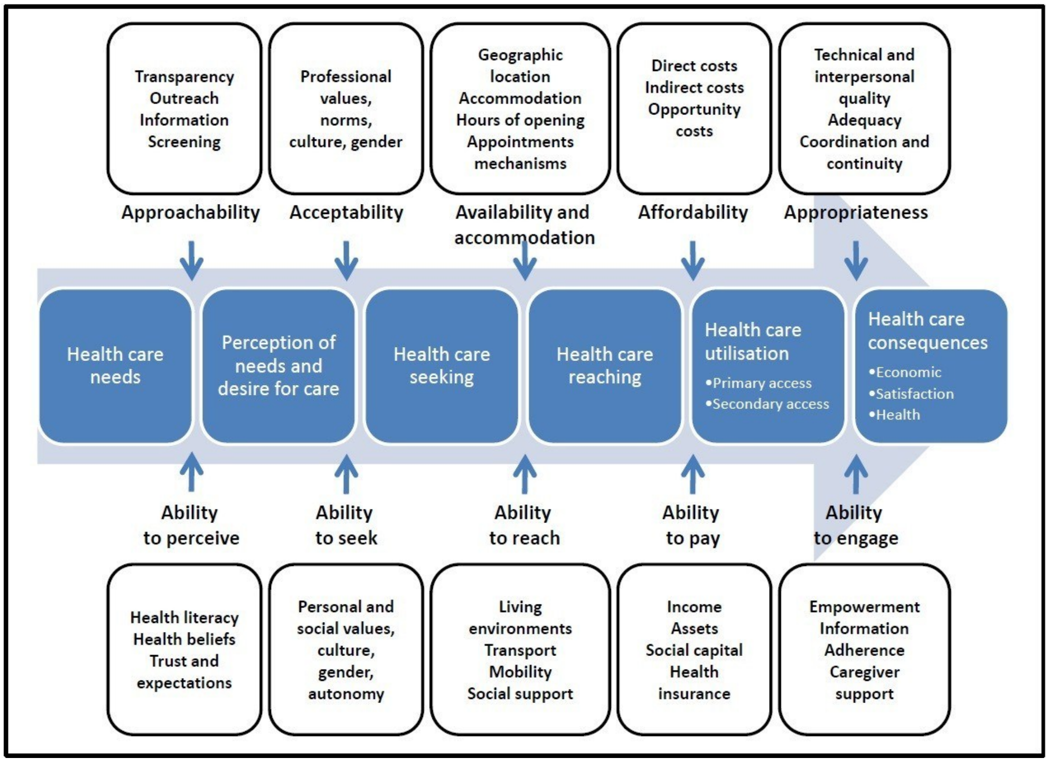
The final manuscript of this dissertation presents the results for the formative design of the iRespite proof-of-concept. Empirical data were gathered from 3 Expert Council meetings and 26 individual interviews and focus groups with 21 participants (9 nurses, 9 family caregivers, 3 care-receivers). The proof-of-concept was primarily designed to facilitate direct respite care coordination, in an Uber-for-respite model, between families seeking respite care and self-contracting respite care providers with palliative care training. However, as our iterative user-centred design research evolved, based on Expert Council and participant feedback, we began to incorporate other features beyond direct respite coordination to facilitate broader access to respite care services. Therefore, in addition to direct service coordination features, the final design also integrates: (1) a chatbot for synchronous and asynchronous support via notifications and messaging; (2) an interactive database of palliative respite care agencies in Quebec, based on the environmental scan work from Paper 3 and presented previously in Figure 2.1.61; and (3) additional training and education resources for both families and respite care providers. Participants found the final proof-of-concept design to be acceptable and appropriate for addressing their perceived respite care access and support needs, although they had some concerns about feasible implementation.

8.1.1 Circling the concept of "access": Applying a comprehensive framework

Throughout the protocol development (Paper 1), the knowledge syntheses (Papers 2-5), and the preliminary design of the app proof-of-concept (Paper 6, below), we found ourselves circling key ideas around *access* to respite care services. For Paper 3 (environmental scan), we used an early concept analysis of four attributes of access to healthcare, to analyze our environmental scan results (Norris & Aiken, 2006). We also found ourselves delving into the notion of access in Paper 4 (scoping review), in terms of appropriateness and trust in the services provided. Across our knowledge syntheses, additional factors kept arising, like the need for flexibility in care coordination, and the importance of reminders to make families aware of and perceive the need for respite care early on in the caregiving trajectory (AR Castro et al., 2022; Castro, Londono Velez, et al., 2024; Castro et al., 2023). However, we did not initially have a comprehensive framework that could fully capture nuanced aspects of "access" like trust and ability to perceive a need.

It was not until we were finalizing the iRespite proof-of-concept design that I identified (Levesque et al., 2013)'s seminal framework on "patient-centred access to health care," which is based on a literature review of previous models of accessibility. This framework describes five key dimensions of accessible services, with an additional five corresponding "abilities to" access. This framework provided a comprehensive lens through which we could assess how the design features we had created for iRespite address many nuanced factors of access. These factors included both supply-side dimensions of access to services (i.e., approachability, acceptability, availability, affordability, and appropriateness of the service), and demand-side abilities of patients and families (i.e., to perceive, seek, reach, pay, and engage with health services like respite care). Figure 8.1.1 provides an overview of this conceptual framework on patient-centred access to health care, copied under its Open Access Creative Commons Attribution License.

(Figure 8.1.1) From (Levesque et al., 2013): A conceptual framework of access to health care



While the app proof-of-concept was able to address many of (Levesque et al., 2013)'s dimensions, such as approachability, acceptability, and the ability to reach and engage with services, our empirical research also revealed the limitations of a technology-based solution for achieving comprehensive access to a complex health care service. Aspects like availability of providers, affordability, and willingness to pay for care are deeply rooted in sociopolitical factors that cannot be solely addressed by a rigorously designed app. Our post-hoc application of this access lens aligned with key findings of Paper 4 (scoping review) for implementation considerations, as well as Paper 5 (app store search) regarding availability of providers; this alignment is further described in the Chapter 9 Discussion of this dissertation. Applying this lens underscored the importance of considering the broader context of access when developing and implementing healthcare innovations like iRespite.

8.2 Paper 6 Manuscript

To be submitted to: Journal of Medical Internet Research

iRespite Services iRépit: Formative design of an app proof-of-concept to accessibly coordinate respite care services for families with advanced cancers

Authorship

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Abstract

Introduction: Respite care services provide temporary relief of role responsibilities for families coping with advanced cancers. These services offer numerous benefits for both the caregiver and care-receiver. However, existing respite care services can be difficult to access, with inflexible scheduling and concerns about the ability of service providers to deliver appropriate care. Therefore, the aim of this research was to rigorously design a bilingual proof-of-concept of an app called iRespite Services iRépit ("iRespite") that families and nurses perceive to be relevant for facilitating access to in-home respite care services for families coping with advanced and palliative cancers in Quebec, Canada.

Methods: Guided by the Information Systems Research Framework, a three-phase, user-centered design study was conducted and overseen by an Expert Council. Data were collected through virtual individual interviews and focus groups with family caregivers of adults with advanced cancers, adult care-receivers living with advanced cancers, and registered nurses. Interview guides were informed by literature reviews and Expert Council guidance. Phase 1 began with conducting knowledge syntheses, followed by brainstorming respite care needs and potential app features with participants. Phase 2 entailed sketching and discussing low-fidelity wireframe features. Phase 3 entailed refining a higher-fidelity proof-of-concept. Data analysis consisted of descriptive statistics and qualitative content analyses of interview data to prioritize and refine app goals and features, ultimately towards the design of a proof-of-concept of an app-based platform that could optimize access to respite care services.

Results: Data were gathered from 3 Expert Council meetings with n=5 key informants, and from 26 interviews and focus groups involving n=21 participants (9 nurses, 9 family caregivers, and 3 care-receivers) over 2 years (2022-2024). The proof-of-concept was designed to: (1) facilitate direct respite care coordination between families and self-contracting respite care providers who have palliative care training, through the CareNOW and CareMATCH modules, (2) use a chatbot for support and engagement, and (3) share information on relevant resources, including training links and a database of palliative respite care agencies in Quebec. Participants considered the app design to be highly acceptable and appropriate, although they had some concerns for feasibility of launching the app. The app design addressed 10 key factors identified in a seminal framework for facilitating access to a health care service, although some factors, such as affordability and availability, could not be solely addressed by the rigorously designed app, alone.

Conclusion: The user-centered iRespite proof-of-concept has potential to improve access to respite care for families with advanced and palliative cancers in Quebec. While the app addresses key accessibility factors, broader policy changes regarding service affordability and availability will be crucial for its long-term success and sustainability. Future research will focus on usability, feasibility, and pilot testing of iRespite in Quebec.

Key words: access to health care, advanced cancers, caregiving, co-design, digital health, mHealth, palliative care, respite care, short break care

Introduction

Respite care is a critical support service for families coping with advanced cancers (Rao et al., 2021; Thomas et al., 2020). When accessible, in-home respite care services benefit both family caregivers and care-receivers by providing reprieves from their intensive family caregiving and care-receiving roles, time for themselves, and access to additional social supports (Rao et al., 2021).

The need for respite care is particularly high during the advanced stages of cancer care (*Advanced cancer*, 2024; Rao et al., 2021; Robinson et al., 2017; Thomas et al., 2020). For this research, we defined advanced cancers as cancers staged 3 or 4, or where families are receiving palliative care services to focus on symptoms management, rather than curative treatments (*Advanced cancer*, 2024). With cancer consistently ranking as a top three cause of mortality and rising among aging populations in Canada, including in Quebec, the respite care needs of families with advanced cancers are increasing simultaneously (Brenner et al., 2024; Brenner DR & L, 2024; Pesut et al., 2022). Accessible caregiving support services like respite care are needed to reduce the costs of dying in-hospital and to allow families to remain at home, in their preferred place, for as long as possible (Barrett et al., 2009; Rao et al., 2021; Robinson et al., 2017).

Despite the benefits associated with respite care, current services are often inaccessible, particularly due to the limited flexibility and availability of services, and familes' perceptions of varying quality in respite care providers' skillsets (Robinson et al., 2017; Thomas et al., 2020). Key logistical barriers in accessing current respite care services include inflexible scheduling systems (e.g., synchronous phone calls, voice mails, and pre-visit assessments) (Castro et al., 2023; Phongtankuel et al., 2018; Robinson et al., 2017; Schurgin et al., 2021), with limited options for affordable last-minute and overnight care (Leocadie et al., 2018; Rao et al., 2021; Robinson et al., 2017; Wolkowski & Carr, 2017). Furthermore, respite care services are rarely guaranteed by publicly funded healthcare systems, causing families to rely on a mix of public, non-profit, and for-profit services (Castro, Lalonde-LeBlond, et al., 2024; Viens, Éthier, et al., 2024). Navigating this patchwork of services requires time, reading comprehension skills, and computer literacy, creating additional barriers to access (Castro, Lalonde-LeBlond, et al., 2024; Levesque et al., 2013). As a result of these barriers, many respite services often go unused, particularly for families coping with terminal illnesses, such as advanced cancers (Robinson et al., 2017; Rose et al., 2015a).

Smartphone applications ("apps") offer an innovative way to improve the accessibility of navigating and coordinating homecare services like respite care (Currin et al., 2019; Phongtankuel et al., 2018). Smartphones provide geolocation capabilities that allow users to quickly find and access available service providers. They also offer multimedia features that support the sharing of information about respite care services and provider training resources, and they can enable notifications and asynchronous messaging to facilitate scheduling and communication (Castro et al., 2023; Phongtankuel et al., 2018; Schurgin et al., 2021). Other sectors already use the ubiquity and technical capabilities of smartphones to optimize scheduling, communication, and appropriate matching between client and provider needs (e.g., Uber, TaskRabbit). However, systematic searches and reviews of the literature (Castro et al., 2023) and the iOS and Android app stores (Castro, Londono Velez, et al., 2024) revealed a notable gap in the delivery of respite care services: while there has been limited but increasing interest in app-based platforms for respite care coordination, to our knowledge, there is no appropriate app for coordinating respite care services for families with advanced cancers or terminal illnesses.

Objective

The original purpose of this iRespite Services iRépit ("iRespite") doctoral research was to rigorously design a proof-of-concept of an app that families and nurses perceive to be relevant for directly coordinating respite care services for families coping with advanced cancers, like an Uber-for-respite model. However, with feedback from our Expert Council and key informants, the purpose of the app design expanded beyond focusing narrowly on flexible service coordination with trained providers, to leveraging smartphone capabilities to facilitate access to respite care services beyond just direct scheduling. Therefore, the final participatory objective of this research was to rigorously design a bilingual proof-of-concept of an app that family caregivers, care-receivers, and nurses perceive to be relevant for broadly facilitating access to in-home respite care services for families coping with advanced cancers in Quebec.

Methods

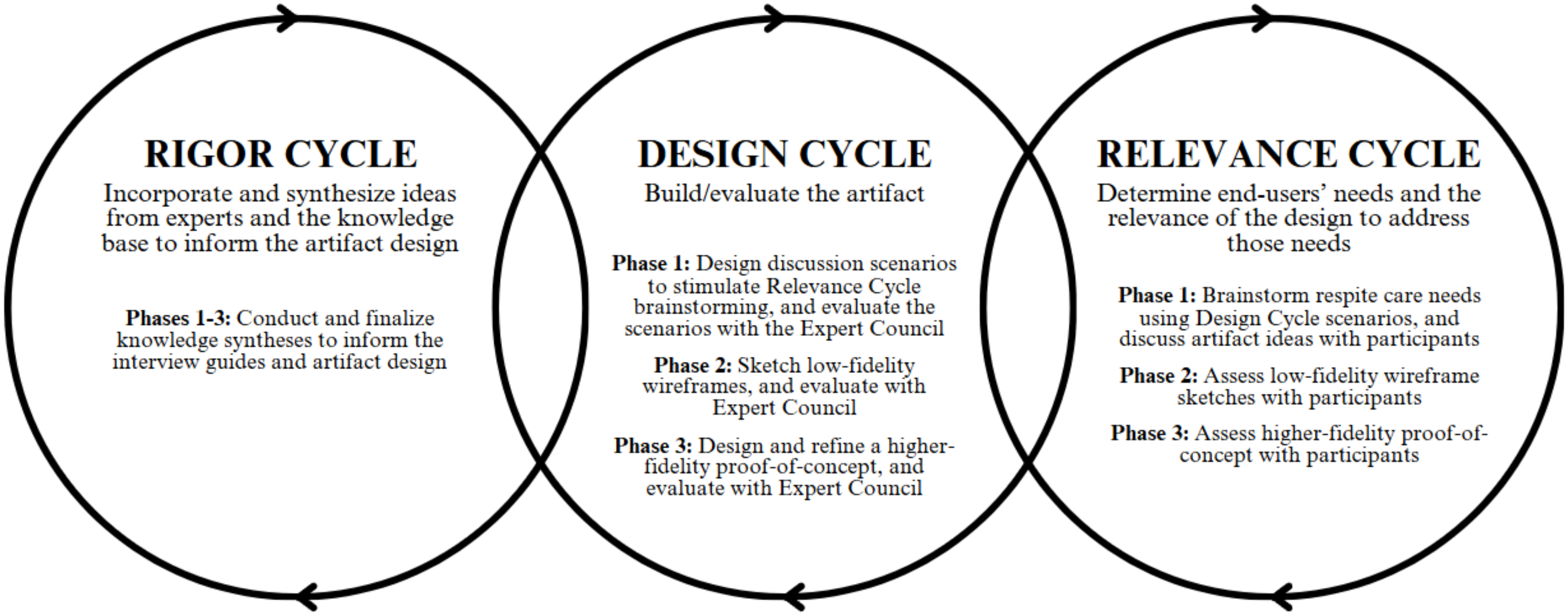
Study design: Formative, user-centred design

This proof-of-concept research was formative design research, which is suitable for the early stages of designing complex healthcare interventions with end-users (Cornet et al., 2020; Still & Crane, 2017). Formative research differs from summative design research, which focuses on later usability and efficacy testing of higher-fidelity prototypes (Still & Crane, 2017). The goal of formative research is to ensure that the intervention is rigorously designed and meets end-users' needs, before committing to more detailed refinement, testing, expansion, and implementation.

The methodological approach to conduct this formative proof-of-concept research was user-centered design, guided by an adapted version of Hevner's Information Systems Research Framework (Hevner, 2007; Risling & Risling, 2020). This methodological framework outlines the research process for the participatory design of technological artifacts, like apps, with key end-users. In this framework, iterative research cycle activities that address concerns of “rigor”, “relevance”, and “design” are integrated to ultimately construct the new artifact (Hevner, 2007). Rigor Cycle activities entail comprehensive knowledge syntheses to inform the design and content of a problem-solving artifact. Design Cycle activities iteratively test the artifact with internal team evaluation and refinement of the artifact. Relevance Cycle activities entail participant design input, to ensure that the purpose and design features of the artifact address participants’ needs.

We adapted this framework to conduct the study over three distinct research phases within the methodological framework: (1) brainstorming respite care needs and potential app features using video scenarios, (2) sketching low-fidelity wireframe features, and (3) refining a higher-fidelity proof-of-concept. The three phases with their associated research activities are situated within each of the three Framework Cycles (Figure 1). The figure was revised to the version below after our original study protocol was published (A. Castro et al., 2021).

(Figure 8.2.1) Figure 1: Adapted methodological framework with embedded research cycles and phases



Settings and recruitment

Following ethical approval (McGill University Health Centre IRB # MP-37-2022-7986), this user-centered design study was conducted virtually using Zoom and Microsoft Teams videoconferencing software, over a two-year period (March 2022-July 2024). Participants were recruited through two university-affiliated hospitals, the virtual professional networks of our research team, and a non-profit palliative care organization based in Montreal, Quebec. Collaborators within these target networks shared the bilingual study brief with nurse colleagues and families, via their associated online social networks and email listservs of the target networks.

Participants

Two sets of relevant stakeholders were recruited: key informants and study participants. Key informants were purposively recruited for our Expert Council based on our research team's knowledge of their expertise. Convenience sampling was used to recruit study participants for the Relevance Cycle individual interviews and focus groups. Participants were eligible if they were: (1) adult *family caregivers* of adults living with advanced cancers or bereaved caregivers up to 10 years, (2) adult *care-receivers* living with advanced Stage 3 or 4 cancers, or receiving palliative care services (*Advanced cancer*, 2024), and (3) registered *nurses* with palliative, oncology, and/or homecare experience. All participants had to be living or providing care in Quebec, Canada, and be comfortable speaking and reading in English or French. All key informants and study participants provided informed consent prior to data collection, with consent being an ongoing discussion.

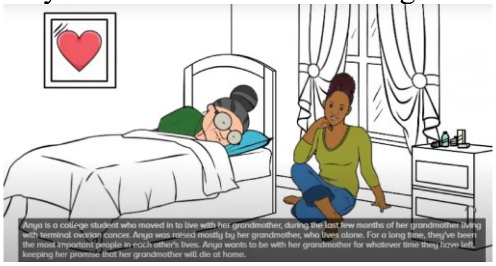
Data collection

The Expert Council was convened prior to each of the three research phases, to oversee the study design, direction, and ongoing analyses.

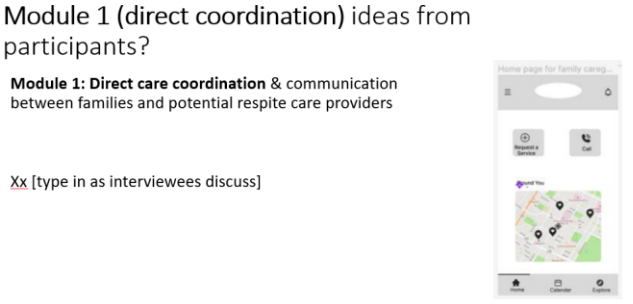
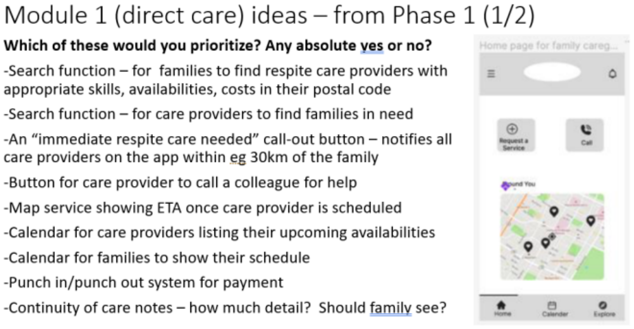
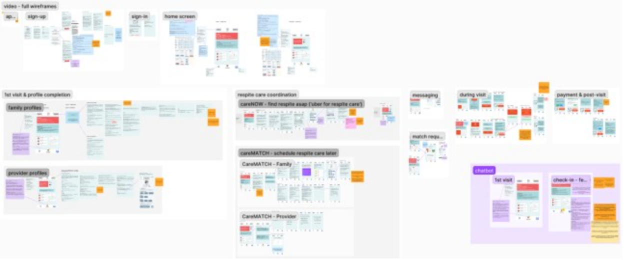
Data collection work for Phase 1 brainstorming began with the commencement of the "Rigor Cycle" research activities of the methodological framework. The Rigor Cycle consisted of iteratively conducting knowledge syntheses of academic literature and data that were relevant for informing the artifact design (Hevner, 2007). The four resulting knowledge syntheses were a concept analysis of "informal caregiver", an environmental scan of palliative respite care agencies in Quebec, a scoping review of respite technologies, and an app store search of existing respite care apps (AR Castro et al., 2022; Castro, Lalonde-LeBlond, et al., 2024; Castro, Londono Velez, et al., 2024; Castro et al., 2023). These syntheses confirmed that no appropriate apps appeared to be available worldwide that have been designed specifically to support the complex respite care needs and service navigation challenges faced by families with advanced and palliative cancers.

Beyond the Rigor Cycle knowledge syntheses, each research phase also consisted of Relevance Cycle and Design Cycle activities. For each phase, a series of Relevance Cycle interviews (individual or focus group) were conducted, lasting 90-120 minutes each, to explore participants' perspectives on respite care needs and on the iterative proof-of-concept design. Semi-structured interview guides were informed by the Rigor Cycle activities and facilitated the online interviews, with supporting material such as video scenarios, wireframes, and chatbox discussions, to further explore the interview topics. To avoid the "deference effect" during interviews, where participants may struggle to give critical feedback, we included "devil's advocate" questions in every interview, encouraging participants to share any potential problems with our project (Albert & Tullis, 2013; Bernard, 2017). Table 1 provides a further overview of the research activities and data collection tools used for each phase.

(Table 8.2.1) Table 1: Research activities and data collection tools

Research Phase	**Research Activities**	**Key Data Collection Tools**
Phase 1: Brainstorming respite care needs and potential app features	Commencement of Rigor Cycle knowledge syntheses Expert Council meeting #1 Individual interviews with video scenarios	Commencement of knowledge syntheses, resulting in 4 publications: (1) A concept analysis of the meaning and needs of "informal caregiver", including the need for respite care (AR Castro et al., 2022) (2) An environmental scan of palliative respite care agencies in Quebec (Castro, Lalonde-LeBlond, et al., 2024) (3) A scoping review of technologies for respite care (Castro et al., 2023) (4) A systematic search of respite care coordination apps on the Apple iOS and Android Google Play stores (Castro, Londono Velez, et al., 2024) Interview guide – Phase 1 (French / English) Three video scenarios for Phase 1 brainstorming were created: (1) Anya - a young caregiver to her grandmother; Anya needs a break and overnight care  Anya is a college student who moved in to live with her grandmother, during the last few months of her grandmother living with terminal ovarian cancer. Anya was raised mostly by her grandmother, who lives alone. For a long time, they've been the most important people in each other's lives. Anya wants to be with her grandmother for whatever time they have left, keeping her promise that her grandmother will die at home. English URL: https://youtu.be/T6yiCPHzK0c French URL: https://youtu.be/sLAsd_bZ8xg

		(2) Jade - a sandwiched caregiver between her father with cancer and her son who broke his leg  One evening while she's with her father, Jade's husband calls. Their son has broken his tibia and is going in for surgery soon. Jade needs to get to the hospital, but homecare isn't answering the phone after hours, and Jade's brother is at work on a nursing shift. No one else knows how to manage her father's recurring hallucinations, his mouth sores, or his urinary catheter. Jade doesn't have time to train someone in all of this; she needs someone who understands palliative home care, and she needs them right away. Because her son needs her, but her father does too...and she'd never forgive herself if something happened while she left him alone. English URL: https://youtu.be/wW0EYl3NDKY French URL: https://youtu.be/QNFGaI6Dr1Q (3) Pablo - whose husband with cancer is fairly stable at home, except he needs help with his pain medications, and Pablo cannot afford to keep taking time off work to be with him  Pablo and Ray have been together for 10 years. 3 years ago, Ray was diagnosed with a brain tumor. At that time, they had just taken out a mortgage for their first home, and they'd adopted their young son. Now, the oncologist estimates that Ray has about 4 months left to live. English URL: https://youtu.be/t0sMR3DxzLs French URL: https://youtu.be/2a9s0Geq-qI
Phase 2: Sketching potential low-fidelity wireframes	Expert Council meeting #2 Group or individual interviews, as participants preferred	List of potential app features from Phase 1 analyses, and preliminary PowerPoint sketches, to be discussed and prioritized with the Expert Council Interview guide, Phase 2 (French / English) Examples of our low-fidelity wireframe sketches using PowerPoint software:

		 Module 1 (direct coordination) ideas from participants? **Module 1: Direct care coordination** & communication between families and potential respite care providers Xx [type in as interviewees discuss]  Module 1 (direct care) ideas – from Phase 1 (1/2) **Which of these would you prioritize? Any absolute yes or no?** -Search function – for families to find respite care providers with appropriate skills, availabilities, costs in their postal code -Search function – for care providers to find families in need -An "immediate respite care needed" call-out button – notifies all care providers on the app within eg 30km of the family -Button for care provider to call a colleague for help -Map service showing ETA once care provider is scheduled -Calendar for care providers listing their upcoming availabilities -Calendar for families to show their schedule -Punch in/punch out system for payment -Continuity of care notes – how much detail? Should family see?
Phase 3: Refining a higher-fidelity proof-of-concept	Expert Council meeting #3 Group or individual interviews, as participants preferred	Design iteration #1: higher fidelity proof-of-concept was designed with Figma whiteboarding software to share with the Expert Council (*Figma: Wireframes*, 2020) Design iteration #2: a higher fidelity proof-of-concept was re-designed post-Council to share with study participants. This iteration is zoomed out to provide an overview of all the features:  A 26 minute video of the English-language version of the proof-of-concept shared with Phase 3 participants is available on YouTube: https://youtu.be/AqLlHOPQ6QY.

		A bilingual French proof-of-concept was also created. Interview guide, Phase 3 (French / English): Interview questions were discussed either following or during the proof-of-concept video, as participants preferred. These interview questions were embedded into orange text boxes that overlaid the proof-of-concept design. An anonymous post-interview survey was sent to Phase 3 participants for their perceptions on the acceptability, appropriateness, and feasibility of the proof-of-concept, and for their open-ended feedback (Weiner et al., 2017)

Data analyses

Data sources across the Rigor, Relevance, and Design Cycles of the three research phases included literature reviews and knowledge syntheses, Expert Council notes, participant interview transcripts, handwritten field notes, fieldnotes posted as digital sticky-notes on top of the Figma proof-of-concepts, chatbox messages, interview summary notes, design notes, and screen recordings. Following each phase, these diverse data sources were analyzed and integrated throughout the study to iteratively refine the design features of the app proof-of-concept prior to the next research phase. Interview data were recorded and transcribed verbatim. Transcribed interviews, fieldnotes, summary notes, and chatbox messages were imported into Excel and synthesized at the end of each data collection phase using content analysis techniques, with the unit of analysis being paragraphs or groups of sentences with shared meaning (Elo & Kyngäs, 2008b). Descriptive statistics were used to describe the sample demographic and anonymous survey data, and to count app feature requests over the course of the interviews, to assist in prioritizing potential app features alongside Expert Council guidance (Still & Crane, 2017).

In Phase 1, based on preliminary Rigor Cycle literature reviews, an initial deductive codebook was created (Elo & Kyngäs, 2008b) (Table 2). Phase 1 data sources were analyzed in Excel using these deductive categories in the first column beside the transcript, and a second column to open-code the data further to inductively refine the categories and incorporate additional details related to respite care needs and app design. These Phase 1 data were used to produce a large list of potential app features, which was discussed during Expert Council meeting #2, to prioritize app features to be discussed during the Phase 2 interviews with the low-fidelity wireframe sketches. Non-app feature data, such as descriptions of participants' previous respite care experiences, were used to identify external factors that might affect acceptability and future implementation of iRespite.

(Table 8.2.2) Table 2: Preliminary deductive categories for Phase 1

Category	**Examples of the category**
(1) Respite care experiences of advanced cancer families	-Prior experiences of using (families) or providing (nurses) respite care services -Barriers to accessing respite care -Costs of respite care -Features to engender trust in respite care, particularly when coping with advanced cancers
(2) Implementation considerations for respite care services	-Marketing the service -Financing the service
(3) Service considerations	-Trust in the service -Training of providers
(4) App features *This was the key category for this design research, and as such, it also had a separate column in Excel for coding relevant data	-Security features -Scheduling options -Aesthetics -Usability -Any app capabilities or content to be included

(5) Other	-A placeholder for data that seemed important but did not fit a preliminary deductive category

Phase 2 data analyses involved first deductively coding the data broadly using the Table 1 categories, followed by open-coding and inductively coding the transcripts and fieldnotes (Elo & Kyngäs, 2008b). The 279 sub-categories generated from inductive coding were re-grouped into 135 sub-categories that addressed 10 main categories for the design and future implementation of iRespite: (1) respite care needs and experiences, (2) the need for participatory design in services and tools, (3) experiences using digital health tools like apps, (4) trust in the service, app, and providers, (5) content of end-user profiles, (6) direct respite care coordination via CareNOW and CareMATCH, (7) a respite care agencies database or navigator, (8) a chatbot, (9) education and training for end-users, and (10) other iRespite app design features,

In Phase 3, these categories were used to guide the design of a higher-fidelity proof-of-concept in Figma's wireframing software to first present in Expert Council meeting #3 (*Figma: Wireframes*, 2020). The design was further refined based on the Expert Council's feedback, prior to Phase 3 participant interviews (Table 1). During Phase 3, the proof-of-concept was discussed in detail with the participants. The guiding question for this final phase of our formative research was: *Is there anything missing, or are there any major red flags that you see with this overall design for an app, to make respite care more accessible, flexible, and trusted to families?* Data collection was terminated when two research team members (AC and GLL) analyzed the interview, video, and survey data, and determined that formative design was finished: no new major design features or content changes were being identified through Phase 3 data collection, and overall, participants found the design to be acceptable for facilitating access to respite care services.

Post-hoc theoretical framework for contextualizing iRespite design decisions in terms of access

Levesque et al. (2013)'s seminal conceptual framework on the meaning of "patient-centred access to health care services" was identified post-hoc after Phase 3 data collection to further contextualize our design decisions in terms of key dimensions of accessible health services. The access framework includes supply-side (i.e., service design) dimensions for access, and demand-side factors (i.e., patients' and families' "abilities to" interact with the service) that correspond with each service dimension. The five over-arching dimensions of access to services are: acceptability, appropriateness, availability, affordability, and approachability. Five corresponding abilities of families to access these services are their abilities to: perceive, seek, reach, pay for, and engage with the services.

Changes from our published protocol

Further data collection and analyses details are reported in our published protocol (A. R. Castro et al., 2021). Notable changes from the protocol that occurred after Expert Council consultation and participant feedback included: (1) no longer requiring that respite care services coordinated through the app be provided by nurses, but rather by providers with palliative care training, (2) a focus on formative early design research, rather than summative usability testing, which was the final phase of the original protocol, (3) convenience sampling for formative research, rather than purposive sampling, and (4) the use of (Levesque et al., 2013)'s framework to assess the final iRespite proof-of-concept design in terms of access.

Results

Sample characteristics

Prior to data collection, n=5 key informants were recruited for the Expert Council to provide continued guidance on the study: a palliative homecare nurse manager, a user-experience

(UX) computer scientist with caregiving experience, a palliative caregiver/advocate, a palliative care physician, and a social worker with expertise in supporting families through aging and dying. Additionally, n=21 study participants were recruited: 9 nurses (abbreviation N), 9 family caregivers (CG), and 3 care-receivers (CR). All but one of the caregiver participants (CG-09) were bereaved and no longer caregiving for an adult with cancer. CG-09 and CR-03 were the only family dyad. Several caregivers had cared for multiple cancer care-receivers. One of the caregiver participants, CG-03, was also a nurse and a breast cancer patient in remission; she participated in Phases 1 and 3, and offered a key perspective on all three roles, although we focused on her family caregiving role. Another caregiver from Phase 2, CG-05, had recently been diagnosed with cancer herself. Lung, brain, and breast cancer were the most common diagnoses. Two of the nine caregivers, and zero of the care-receivers, had used respite care services. Of the care-receivers, one was enthusiastic about respite care, one was ambivalent, and one was hesitant to use respite care with strangers; but none were antagonistic towards respite care services, generally. Participants self-reported race and cultural heritages, with several participants reporting multiple identities. Further sample sociodemographic details are listed in Table 3.

(Table 8.2.3) Table 3: Sample characteristics

	Registered Nurse n = 9	Caregiver n = 9	Care-receiver n = 3
Gender			
Woman	8	8	2
Man	1	1	1
Non-binary			
Age range			
18-24 years old			
25-34 years old	2		
35-44 years old	3	2	1
45-54 years old	3	2	
55-64 years old	1	3	1
65-74 years old			
75 years or older		2	1
Race and/or cultural heritage (self-reported)			
Canadian	3	3	1
French Canadian	1	1	1
Caucasian	5		
European	3	4	1
Indigenous			1
African		1	
Arab		1	
Muslim	1	1	
Catholic	1		
Not specified			
Location			
Montreal	7	8	2
Mauricie			1
Estrie		1	
Lanaudière	1		
Saguenay-Lac-Saint-Jean	1		
Caregiving living arrangement	N/A		
Living in the same household		5	2
Not living in the same household		4	1
Comfort with apps			(Not asked)
Very comfortable	6	4	
Somewhat comfortable	1	3	
Neutral		1	
Somewhat uncomfortable	1	1	
Very uncomfortable	1		
Education			
Elementary school (some or completed)			1
Completed secondary / high school degree		1	
Completed CEGEP	2	2	
Completed university or college	3	3	1
Postgraduate education	4	3	1
Use of respite care services	(Not asked)		
Yes		2	
No		7	3

Between Spring 2022 and Spring 2024, a total of 3 Expert Council meetings and 26 interviews (individual or focus group) were conducted over the three research phases (Table 4). Each interview lasted 90-120 minutes each. Nine of the 21 participants participated in more than one phase, with some of the earlier participants invited to re-interview in Phases 2 and 3 due to the rich data they provided in Phase 1 interviews. New participants were also recruited for Phases 2 and 3 to offer additional perspectives on the formative app design. Over 45 hours of interview data were recorded, with more than 10,000 lines of transcribed text, field notes, and chatbox messaging copied and analyzed in Excel to identify respite care needs and refine the iRespite app design over the three phases.

(Table 8.2.4) Table 4: Participants per research phase and research activities

Research phase	**Design and Relevance Cycle research activities**	**Participants**
Phase 1: Brainstorming respite care needs with video scenarios, and discussing potential app features	Design Cycle: Expert Council meeting #1 Relevance Cycle: 14 individual interviews	5 Expert Council key informants 9 nurses 3 caregivers, 1 of whom was also a palliative care nurse 2 care-receivers
Phase 2: Sketching potential low-fidelity wireframes	Design Cycle: Expert Council meeting #2 Relevance Cycle: 2 focus groups with nurses 2 individual nurse interviews 2 individual caregiver interviews	5 Expert Council key informants 7 nurses from Phase 1 2 new caregivers
Phase 3: Refining the higher-fidelity proof-of-concept	Design Cycle: Expert Council meeting #3 Relevance Cycle: 1 group interview – caregiver/ care-receiver dyad 4 individual caregiver interviews 1 individual care-receiver interview	5 Expert Council key informants 4 new caregivers 1 new care-receiver 1 original caregiver from Phase 1, who was also a palliative nurse 1 original care-receiver from Phase 1

Description of iRespite

The bilingual iRespite app proof-of-concept was collaboratively designed for accessibly coordinating respite care services for families coping with advanced cancers in Quebec, Canada. We defined "features" as both, technical functionalities of the app, such as scheduling respite visits; as well as service design elements for using the app, such as requirements for service providers to upload proof of palliative care training. The iRespite proof-of-concept includes similar functionalities to other service-coordinating apps, such as a welcome screen (Figure 2), a sign-up page, separate home screens for families receiving care (Figure 3) and contractors providing the respite care (Figure 4), followed by creation of end-user profiles, scheduling, and payment.

(Figure 8.2.2) Figure 2: Welcome screen

For palliative oncology families in Quebec, Canada:

Find your trusted care provider.
Take a break, FOR each other.

(Figure 8.2.3) Figure 3: Family – home page

CareNOW
Do you need respite **CareNOW**?
Contact a palliative respite care provider directly.
Send a call-out for care NOW.
Find respite care provider contractors available near you!

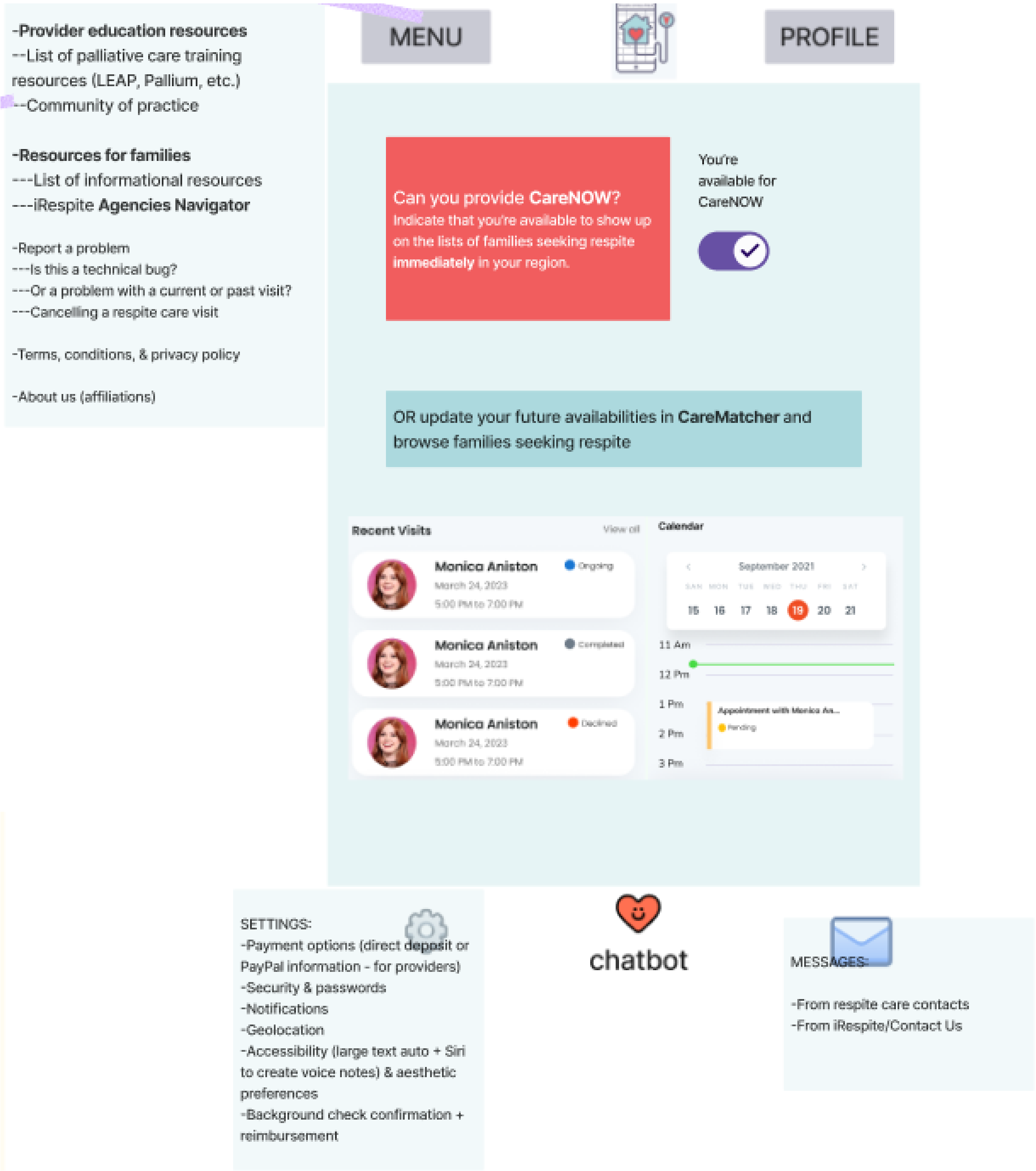
CareMATCH
OR are you looking to schedule for the FUTURE?
Use **CareMatcher** by:
(1) filtering & reviewing providers and their general availabilities, or
(2) posting a respite care opportunity on the job board

SETTINGS:
-Payment options (paypal or credit card on file - for families - could scan in card)
-Security & passwords
-Notifications
-Geolocation
-Accessibility (large text auto + Siri to create voice notes) & aesthetic preferences
-Account sharing + consent with patient

MESSAGES:

-From previous respite care contacts
-From iRespite/Contact Us

(Figure 8.2.4) Figure 4: Providers – home page



-Provider education resources
--List of palliative care training resources (LEAP, Pallium, etc.)
--Community of practice

-Resources for families
---List of informational resources
---iRespite **Agencies Navigator**

-Report a problem
---Is this a technical bug?
---Or a problem with a current or past visit?
---Cancelling a respite care visit

-Terms, conditions, & privacy policy

-About us (affiliations)

Can you provide **CareNOW**?
Indicate that you're available to show up on the lists of families seeking respite **immediately** in your region.

You're available for CareNOW

OR update your future availabilities in **CareMatcher** and browse families seeking respite

Monica Aniston ● Ongoing
March 24, 2023
5:00 PM to 7:00 PM

Monica Aniston ● Completed
March 24, 2023
5:00 PM to 7:00 PM

Monica Aniston ● Declined
March 24, 2023
5:00 PM to 7:00 PM

Appointment with Monica An...
● Pending

SETTINGS:
-Payment options (direct deposit or PayPal information - for providers)
-Security & passwords
-Notifications
-Geolocation
-Accessibility (large text auto + Siri to create voice notes) & aesthetic preferences
-Background check confirmation + reimbursement

MESSAGES:
-From respite care contacts
-From iRespite/Contact Us

Three main features of the iRespite proof-of-concept

As the iterative research progressed, the formative design focus widened from facilitating the direct coordination of respite care services, to including features for information sharing and nudging engagement. In the final iteration, three major functionalities of the app were included to facilitate the coordination of, and ultimately access to, respite care. The first functionality was the *direct care coordination* of respite care services, providing a platform for a self-organizing marketplace between families seeking respite care, and self-contracting respite care providers with palliative training and background checks. This direct coordination could occur through the CareNOW feature, for immediate and urgent respite care coordination within 24 hours, or through the CareMATCH feature for future scheduling of respite care. The second functionality was the integration of a *chatbot for behavioral nudging,* encouraging users to engage with the app and use respite care services. The third functionality was *information-sharing* of respite care resources tailored for families and providers. Such resources included educational and training opportunities for respite care providers (Figure 5); and a searchable database and navigator of existing organizations in Quebec that offer palliative respite care services (Figure 6). This navigator is based on the respite care agencies environmental scan research we previously conducted (Castro, 2024; Castro, Lalonde-LeBlond, et al., 2024).

See Appendix 1 for further design details for each screen of the iRespite proof-of-concept.

(Figure 8.2.5) Figure 5: Providers – links to palliative and respite care training resources

TRAINING RESOURCES FOR PROVIDERS

Palliative care is a particularly sensitive time for families. We need providers who understand how to meet the families where they are at, to never push one's own values on the family, to be excellent listeners, to read the patient's body language, and to accompany them through this journey. These are complex skills that can be learned through training:

LEAP - PALLIUM online certificates
→ Free intro course on palliative approaches: https://www.pallium.ca/taking-ownership/
→ $50 PSW course: https://www.pallium.ca/course/leap-personal-support-worker/?enroll=enroll
→ Fee family carers/friends course: https://www.pallium.ca/course/leap-carers/?enroll=enroll

CHPCA PACE PSW program: https://www.chpca.ca/news/pace-for-psw/

Pallium mobile app and pocketbook: https://www.pallium.ca/mobile-app-pocketbook/

Pallium ECHO training sessions: https://www.echopalliative.com/national-sessions/

Palli-Science (Universite de Montreal) trainings and courses - including Canadian Nurses Association: https://palli-science.com/formations-pour-les-professionnels-de-la-sante

Albatros Quebec - virtual palliative care respite training - online and in-person

McGill Council on Palliative Care Volunteer Training Program: https://www.mcgill.ca/council-on-palliative-care/article/palliative-care-mcgill-volunteer-training-program

Palliacco training (synchronous): https://www.palliacco.org/en/get-involved/

https://registreformationsspfv.com/ - RQSPAL recommendation (fr)

Saint Elizabeth (SE) Healthcare certificates:
--Hospice and palliative care certificate: https://onlinetraining.saintelizabeth.com/
--Palliative/End-of-life care in Indigenous communities: https://fnim.sehc.com/professional-learning/palliative-end-of-life-care-in-indigenous-communities/

ARCH volunteer respite manual

Victoria Hospice training programs: https://victoriahospice.org/how-we-can-help/education-and-research/professional-education/

DeSouza Institute palliative care courses: https://www.desouzainstitute.com/palliative-care-courses/

Safety for providers - what to bring (charged phone, battery pack, enable geolocation for iRespite)

Canadian Virtual Hospice training videos

Non-palliative: https://www.caregivercare.ca/foundational-course

McMaster University Caregiving Essentials Micro-Credits: https://continuing.mcmaster.ca/programs/health-social-services/caregiving-essentials/

University of Alberta & Sharon Anderson: Caregivercare.ca

https://www.respitecourse.ca/

(Figure 8.2.6) Figure 6: Families – additional links for families, including the agencies navigator

-Montreal: Maison Saint Raphael day hospice

-Montreal: ABOVAS - "Assistance de benevole de l'ouest volunteer assistance services"

-Information on cheque emploie, for paying friends to be care providers

-Information on Oxili Quebec, for additional training in using cheque emploie

-Bereavement resources:
--McGill University - CaregiverGrief.com (Eng/Fr): https://caregivergrief.com/mission/
--MyGrief.ca: https://mygrief.ca/
--20 ways to mark a loved one's death when you can't attend a funeral - CreatingCeremony
--The Artists' Grief Deck

MENU

-FAQs
---Guide: How to use this app
---Insurance & employment (CNESST)
---Self-contracting model for respite care providers + background checks

-Resources for families:
---List of informational resources
---iRespite **Agencies Navigator**

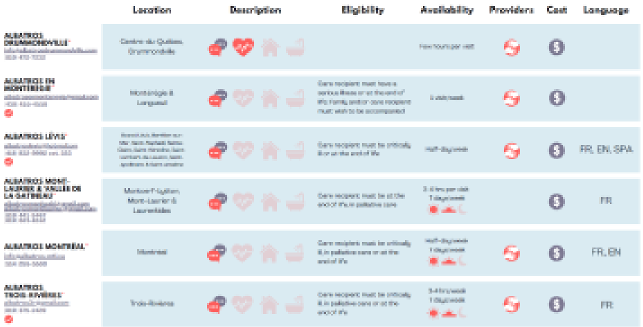
-Report a problem
---Is this a technical bug?
---Or a problem with a current or past visit?
---Cancelling a respite care visit
---Emergency? Call 911

-Terms, conditions & privacy policy

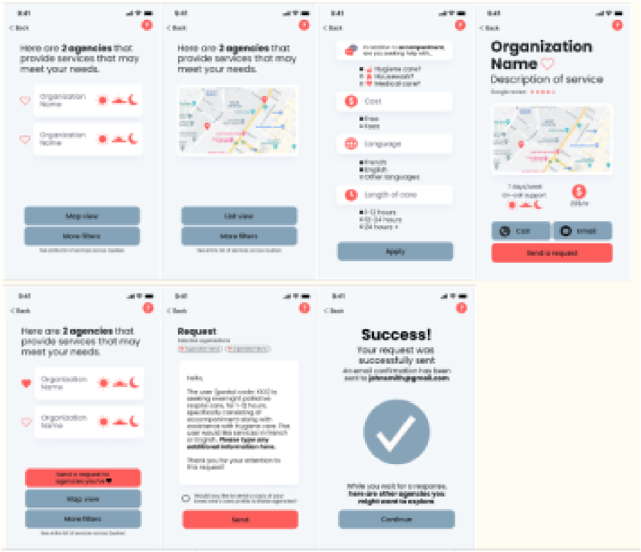
-About us (affiliation)

AGENCIES NAVIGATOR: find an agency, and contact them outside the app

https://aimeecastro.com/irespite-services-irepit/irespite-agency-navigator/



	Location	Description	Eligibility	Availability	Providers	Cost	Language
ALBATROS DRUMMONDVILLE	Centre-du-Québec, Drummondville			[illegible]		$	
ALBATROS EN MONTÉRÉGIE	Montérégie & Longueuil		[illegible]	[illegible]		$	
ALBATROS LÉVIS	[illegible]		[illegible]	[illegible]		$	FR, EN, SPA
ALBATROS MONT-LAURIER & VALLÉE DE LA GATINEAU	[illegible]		[illegible]	[illegible]		$	FR
ALBATROS MONTRÉAL	Montréal		[illegible]	[illegible]		$	FR, EN
ALBATROS TROIS-RIVIÈRES	Trois-Rivières		[illegible]	[illegible]		$	FR



CANCELLATION TERMS FOR CAREMATCH:

Reminder: Accepted matches can be cancelled up to 12 hours before the appointment.
After 12 hours:
If **families** cancel, they will be charged 50% of the appointment amount, which will go to the provider.
If **providers** cancel, they will be deducted 50% of the appointment amount, which will be credited towards the family's account.

...

Features specific to advanced and palliative cancer needs

Most of the included app features could be used by other apps that are designed to facilitate access to a homecare service. However, features that may be more specific to families seeking respite care while coping with advanced and palliative cancers included the following:

(1) Respite care providers aiming to offer their services through CareNOW and CareMATCH would have to provide proof of palliative care training, especially with psychosocial training for accompanying families through their grieving processes. Providers would also have to provide proof of a background check with the vulnerable sector, which could be reimbursed through iRespite once a visit was coordinated.

(2) Participants shared that while CareNOW and CareMATCH would be helpful for flexible and personalized respite care scheduling, they also wanted a database of existing respite care agencies that currently support palliative care families; for this reason, in Phase 2 we began researching the respite care agencies navigator module for the app. We included lists of additional resources for families to learn about and discuss respite care and caregiving during cancer, and a list of palliative care training resources (e.g., Pallium-LEAP (*Pallium-leap,* 2024), Albatros Quebec (*Formations en accompagnement palliatif,* 2024)) for provider continuing education (Figure 5).

(3) Family profile creation and respite care visit requests included questions related to the advanced cancer experience, including the care-receiver's pain and nausea status and how to relieve such symptoms for this particular care-receiver.

(4) Participants noted that the advanced cancer trajectory for adults can proceed rapidly, so while the chatbot should not send notifications every day (to avoid annoying families), it should still check in ever 5-7 days to remind families of the services on the app, before families forget

about the app, or they enter a crisis and are less able to benefit from respite. Furthermore, participants shared that if families indicate that they are experiencing higher stress levels to the chatbot, then it should be pro-active in checking in with them more frequently and offering concrete additional resources for support, such as connecting them with immediate respite care through CareNOW, or sharing the agencies navigator or other family resources.

Design features of iRespite that support access to respite care services

Next, we will use (Levesque et al., 2013)'s framework on access to health services to describe the relevance of specific iRespite features for facilitating access to respite care for families coping with advanced and palliative cancers.

Acceptability of the design and ability to seek out the services on the app

An ***acceptable*** design for respite care meets the needs of key end-users, which include family caregivers, care-receivers, and respite care providers (Hevner, 2007; Levesque et al., 2013). All participants agreed that the iRespite design was acceptable for the coordination of, and access to, respite services for families dealing with advanced cancers. The majority of participants agreed on the importance of respite care access, even if they had not personally used such services themselves. Families with strong social supports (e.g., large families living nearby), or those coping with a rapid end-of-life cancer trajectory, typically did not feel the need for respite care. They shared that they likely would not have used iRespite for direct respite care coordination, but they were interested in how the chatbot could provide emotional support and point them to other relevant family caregiving resources. However, participants shared that families with few local social supports, particularly in rural areas, often experienced a desperate need for respite but had few options. After viewing the Phase 1 video scenarios, a participant who had cared for two different relatives with advanced cancer shared, *"I really hope that this app comes into full* *function, because there have been many moments in my life where I've been stuck with these issues" (CG-05).* Another caregiver noted: "*I want to reiterate that I think this service app is an excellent idea. People absolutely need this service. Caregivers need partners and buddies they feel they can turn to, who they feel are qualified and won't be burdened by spending time with their loved ones." (CG-07).*

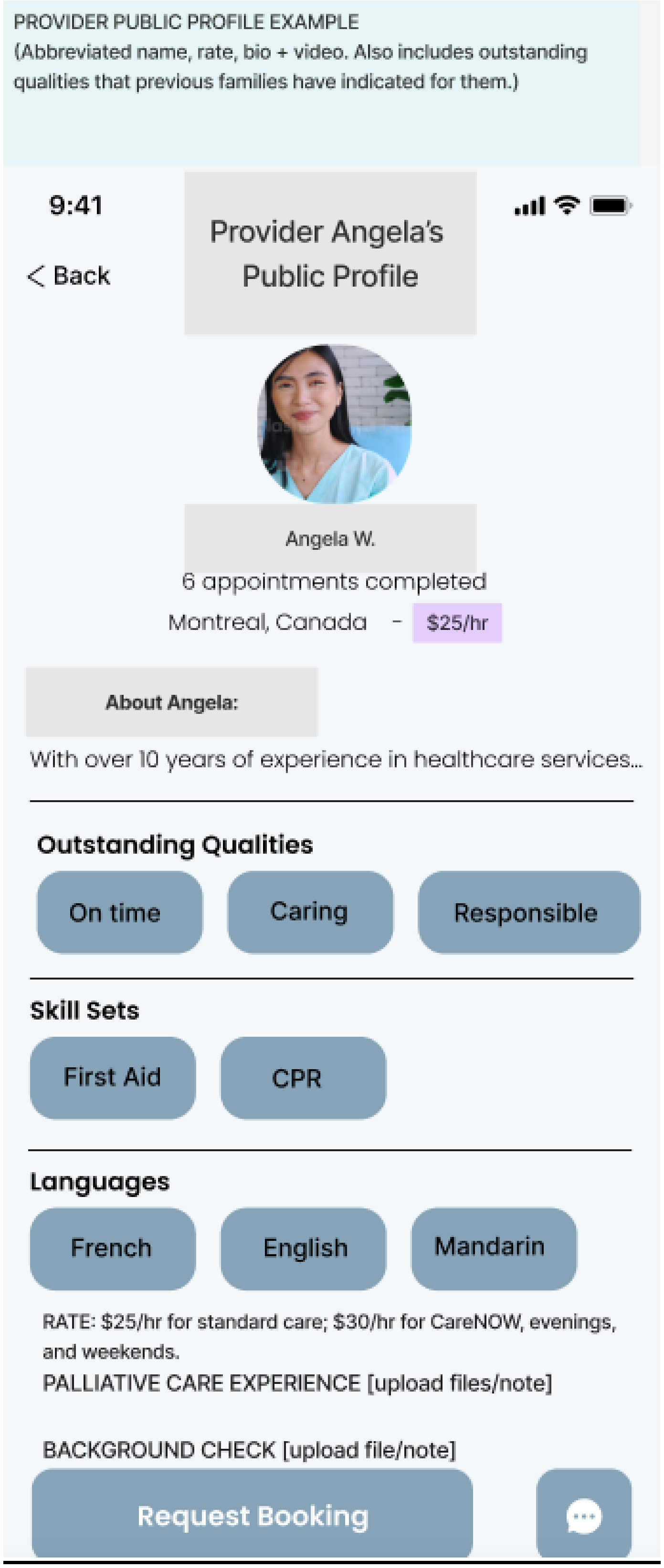
Complementary to the need for a service to be acceptable, is for service users to have the ***ability to seek out*** the service; that is, they must have the appropriate knowledge and resources to find existing respite care services. iRespite features to support families' abilities to seek out respite care relied primarily on families' access to Internet-connected smartphones, which all families had, in order to download the app and match with providers. The proof-of-concept also included a chatbot to regularly check in with families and providers, informing them how to use the app, and encouraging them to seek out respite through CareNOW and CareMATCH. Once fully programmed, the chatbot could send notifications every 5-7 days, reminding families of the benefits of respite care to reduce feelings of guilt, and prompting engagement with available resources. Chatbot notification settings could be modified by end-users. By the end of Phase 3 refinement, participants shared their positive feedback in interviews and optional survey responses, confirming that the iRespite proof-of-concept was an acceptable and appropriate design for improving access to respite care services for families with advanced cancers.

Appropriateness and ability to engage with the service: Trust and engagement

An ***appropriate*** respite care platform must ensure good coordination of respite care services, allowing families to match with service providers who are self-contracting through the platform. Furthermore, these respite providers must have the necessary technical and interpersonal skills to provide personalized and appropriate respite care for the families they match with.

Key themes from our research that aligned with aspects of the “appropriateness” dimension of access were the need for trust in: (1) the security of the platform, (2) the reliability of the service coordination, and (3) the appropriateness of the matches between the end-users, i.e., between families’ unique needs and providers’ competencies (Castro et al., 2023). Examples of iRespite proof-of-concept features to engender trust in the security of the iRespite app were secure log-in and payment options, and clearly explained terms and conditions. Examples of the proof-of-concept features to engender trust in the reliability of the coordinated services included providing estimated times of arrival, and in having an “on call” button for support with an iRespite manager. Examples of app service features to engender trust in the providers’ competencies included having detailed public profiles (Figure 7), with proofs of palliative care training and vulnerable sector background checks.

(Figure 8.2.7) Figure 7: Public profile of a self-contracting respite care provider



PROVIDER PUBLIC PROFILE EXAMPLE
(Abbreviated name, rate, bio + video. Also includes outstanding qualities that previous families have indicated for them.)

Provider Angela's Public Profile

Angela W.
6 appointments completed
Montreal, Canada - $25/hr

About Angela:

With over 10 years of experience in healthcare services...

Outstanding Qualities

Skill Sets

Languages

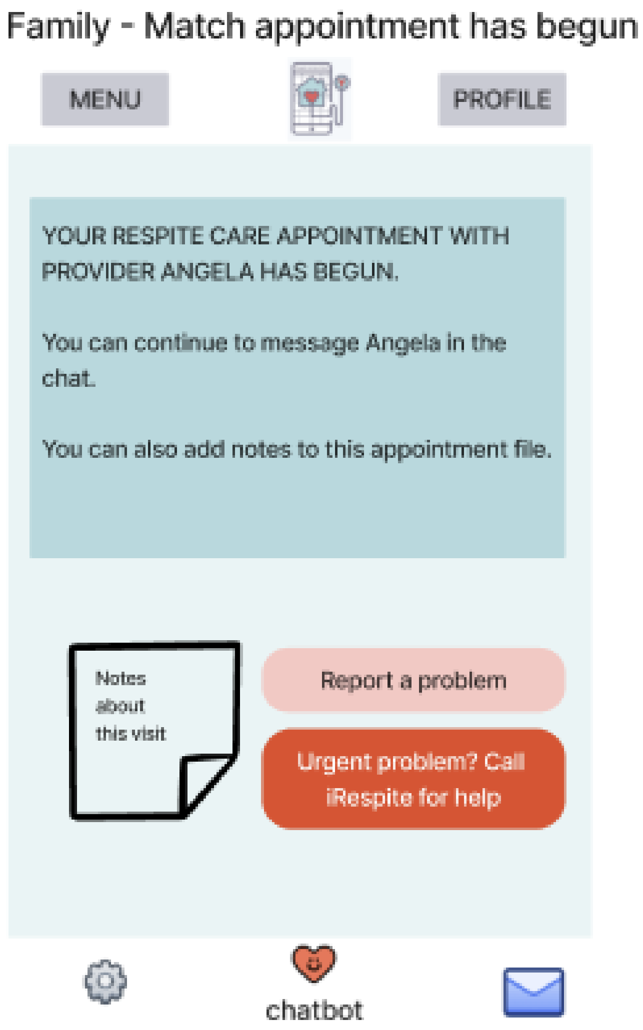
RATE: $25/hr for standard care; $30/hr for CareNOW, evenings, and weekends.
PALLIATIVE CARE EXPERIENCE [upload files/note]

BACKGROUND CHECK [upload file/note]

Given the Expert Council's and participants' advice in Phases 1 and 2 that the respite care provider did not have to be a nurse or clinician, but did have to have palliative care training, we were careful to indicate in the CareNOW and CareMATCH modules the following reminder to families: "Currently our providers offer accompaniment (company and psychosocial support) and hygiene care support. They CANNOT complete protected nursing tasks such as medication preparation or administration, or physical assessments." This transparency was highlighted by nurses as an important feature, to help families manage expectations of iRespite services, so that they were not expecting more from providers than the provider or platform actually offered. Appendix 2 further describes design decisions for iRespite that help address these areas of trust in the app platform, service, and providers.

An appropriate service is also one that families and providers have the ***ability to engage*** with and choose to do so — i.e., to coordinate a respite care visit, conduct the visit, and terminate the visit. iRespite features to support engagement with the app-based respite care services included the iRespite chatbot offering reminders to engage with the app, and the CareNOW and CareMATCH features to seek and filter matches between families and providers, to coordinate a match, and to terminate a visit. The screen for conducting and terminating a visit, from the family's point of view, is shared in Figure 8.

(Figure 8.2.8) Figure 8: Family view – screen during a respite care visit



YOUR RESPITE CARE APPOINTMENT WITH PROVIDER ANGELA HAS BEGUN.

You can continue to message Angela in the chat.

You can also add notes to this appointment file.

Approachability and ability to perceive a need: understandability, awareness, and partnership

The design of iRespite needed to be ***approachable***, in that the platform and services were appealing and appeared easy to begin engaging with. This entailed designing for both simplicity and comprehensiveness, which are seemingly conflicting ideals. Users wanted fast, easy sign-up and direct respite care coordination. As one caregiver explained, *"People have very short attention spans these days... Like, you only have like, 2 minutes to yourself. OK. Or maybe not even that.*

And you're looking for help now" (CG-09). However, while participants wanted simplicity, they also desired additional options and detailed profiles. To address these needs for both simplicity and comprehensiveness, we focused on enhancing understandability of the different app features, rather than reducing the number of features. We ensured that the app store description of the app will explicitly market the app as a platform for respite care for adults with advanced cancers in Quebec, so that in the future, when families search for “respite” in the app store, iRespite will be returned. We separated sign-up from detailed profile creation, allowing users to sign up quickly but then add more personal information later, such as answering optional questions and including pertinent family documents. Recognizing the potential for distress, a chatbot was integrated to guide users in how to use the app and to encourage respite care use. We also created a database of palliative respite agencies in Quebec to help families easily find additional respite care services outside of the app (Castro, 2024; Castro, Lalonde-LeBlond, et al., 2024).

Furthermore, an approachable service is one for which families are ***able to perceive*** that the service could improve their entire families’ health. This perception could be encouraged by addressing families’ lack of awareness of services, feelings of guilt, and partnership with care-receivers. Families had to both, be aware of available respite care services and their benefits, and also be encouraged to overcome feelings of guilt for wanting to use respite care services. For families, "ability to perceive" also meant recognizing the need for breaks from caregiving and care-receiving. Participants shared that this ability to perceive could be encouraged by nurses and clinicians encouraging the use of respite care services and sharing available community services. As a care-receiver with Stage 4 breast cancer stated, *“We [husband and herself] would have needed breaks in the past, for sure.” (CR-01).* However, while this nudging could come from clinicians, participants also agreed that this nudging could come from a chatbot on an app, using appropriately timed app notifications that end-users could customize for timing.

An approachable service is also one that is perceived to be based on family partnership and is beneficial to both family caregivers and care-receivers. As a nurse shared: *"[iRespite is] an opportunity for the patient who has the illness to be able to stand up and say, OK, this is what kind of care I need or I would like you to have this proper care or I wanna help find the caregivers*" (N-08). The iRespite proof-of-concept included educational resources and chatbot nudges to help family caregivers and care-receivers discuss the value of respite care and provide families with information on seeking services. Care-receivers must sign a consent form for respite services, and they can access the app and visit notes through the family account on their phone. Families are encouraged to fill out the "family profiles" and the "requirements for this visit" together, noting how the care-receiver is feeling that day. Families are also encouraged to have the app open on care-receivers' phones during visits, so they can message for help and add notes to the visit, too.

Availability and ability to reach services: Availability, flexibility, and transportation

True service access depends on the geographic ***availability*** of respite care services where families live. Yet, Quebec has a patchy network of respite care agencies able to support palliative care families. Hence, participants stressed the importance of being transparent about where iRespite CareNOW and CareMATCH services were actually available, by providing a list of regions with available providers in the app store description; this way, families do not sign up only to find that no providers are ever available in their region. Participants were also somewhat skeptical about future provider availability on the app, noting that without a supply of appropriate respite care providers, a well-designed app could not truly coordinate respite care. Still, they agreed that unique iRespite design features could enhance provider recruitment. To address provider availability and recruitment challenges, the app design includes: (1) a list of regions with available providers in the app store description; (2) CareNOW notifications for off-duty providers who opt-in, alerting them to urgent requests in their area; (3) flexibility for providers to set their own hours and rates (above $25/hour); and (4) opportunities for providers to engage in a secure community of practice with other providers via the app, to avoid isolation and burnout. Additionally, a nurse-caregiver participant suggested leveraging nursing school affiliations to recruit healthcare students for part-time respite care, which could further improve provider availability. Potential design features to support recruitment in this way have not yet been incorporated into this formative proof-of-concept, but these ideas will be explored in future pilot testing of a programmed prototype.

Truly available respite services need to be flexible and accommodating of families' schedules. Participants believed that an app could make respite care coordination simpler and more flexible. As one caregiver shared, *"if there was an app offered like this one that I could've used for them [respite care providers] to come in . . . it would've been simpler. He [care-receiver] would have also spent so much more time at home" (CG-05).* Features like CareNOW notifications and provider flexibility in scheduling hours help facilitate flexible services. Families liked having both CareNOW and CareMATCH options (Figure 9), as even if they could not find an immediate provider on CareNOW, knowing that they could schedule in advance gave them "hope" that future respite would be available to them soon. Other design choices for flexible coordination included family options to search or post jobs, cancellation terms that were considered reasonable by families and nurses, and optional detailed appointment questions to help coordinate more personalized respite visits.

(Figure 8.2.9) Figure 9: Family view of the “CareNOW” respite care coordination flow

CareNOW

Do you need respite **CareNOW**?

Contact a palliative respite care provider directly.

Send a call-out for care NOW.

Find respite care provider contractors available near you!

CareMATCH

OR are you looking to schedule for the FUTURE?

Use **CareMATCH** by:

(1) filtering & reviewing providers and their general availabilities, or

(2) posting a respite care opportunity on the job board

pg 1/7

Use the CareNOW feature if you’re in a crisis and need a respite care provider as soon as possible, for a minimum of 3 hours of care.

This feature lists providers who have enabled CareNOW requests and are currently available within 50km to provide care.

This is NOT a nursing service; it’s respite care. If your family is having a medical emergency, call your primary care provider or 911.

Would you like to proceed with CareNOW?
Or would you like to go back to schedule care for a future time, using CareMatcher?

←Back Get CareNOW⟶

pg 2/7

Note that you must have filled out at least one patient profile for your family in order to request care, and that the patient or their power of attorney must have signed the consent form.

Which patient are you seeking care for?
[drop-down based on profile]

Please confirm the postal code where you need a respite care provider ___
[this should match the patient profile’s location; if it doesn’t, the app will flag an error.]

Proceed to the next page to fill in key requirements for this visit.

You’re almost there!

Next ⟶

pg 3/7

What are your family’s REQUIREMENTS for THIS VISIT? (You can message the provider later to request any optional services.)
[copy from a previous match]
OR fill in again:

__Transportation: Does the patient need a provider with a car to transport them to an appointment within 20km?
-Language(s) spoken by provider?
-Gender of the provider?
-Tasks/skillset required, in addition to accompaniment/supervision (drop-down):
__Is hygiene care also needed?
__Is light housekeeping also needed?

Other key notes for this visit _______________________

If the patient starts to appear medically distressed, what should the provider do? Check only those that apply.
__Call the family caregiver, then: be present.
__Administer CPR
__Call 911
___Call a key medical contact listed in profile
Reminder: currently our providers offer accompaniment (company/psychosocial support) and potentially hygiene care support. They CANNOT complete restricted nursing or medical tasks such as medication preparation or administration, wound care, or physical assessments.

pg 4/7

As providers confirm their current availability, their profiles will show up for you to request a match with them. Keep your phone nearby for messages. A green dot means they are online now.

Notifying more providers of your request....

While you wait, our other respite care coordination feature - CareMATCH - lists providers who have indicated their previous availabilities at this time, but who aren’t currently online. Click their profile below to view their certifications and skillsets, and message them to see if they are still available to provide care.

[Click for more from CareMATCH]

Participants noted that ***"ability to reach"*** respite services is a particular challenge in rural areas, where there may not be any local respite care organizations. Some participants felt rural families might actually benefit more from iRespite than urban families would. Through the CareNOW and CareMATCH options, rural providers and families could develop their own coordination networks within the app, without needing a formal agency presence in their region.

Transportation was also identified as an important aspect of "ability to reach" services. Participants shared that transportation to medical appointments often served as a form of respite care, especially in rural regions where these appointments could involve long drives from home. To address this idea of transportation-as-respite, we included iRespite options for families to indicate if they need providers who have a valid drivers license and vehicle access to provide transportation as part of their respite care.

Affordability and ability to pay: Fair prices and willingness to pay

An accessible health care service is one that is ***affordable*** enough for families to be willing and able to pay for the services. Participants shared that the affordability of respite care services often depended on subsidies from governments or non-profits, as few families could pay the full private costs over the long-term. Maintaining cost transparency, by clearly displaying service pricing in the app store description of iRespite, was emphasized as an important design element.

Participants agreed with setting a minimum hourly rate of $25 for at least three hours of care, to ensure fair pay for providers and limit low-wage competition. Still, participants acknowledged that affordability remains a significant barrier, particularly for families who have experienced income losses due to time off work for treatments or caregiving responsibilities. Participants cautioned that for impoverished or rural families, $25/hour may still be inaccessible.

However, they noted a willingness to pay for emergency or crisis respite care like CareNOW, even when regular ongoing respite care may be unaffordable.

The iRespite app design incorporated features to facilitate families' technical ***abilities to pay***. Other payment support features included a payment-by-credit card system integrated directly into the app, allowing for seamless transactions and auditing. Providers also had the flexibility to set higher rates, especially for evening, weekend, and urgent CareNOW requests. By Phase 3 of this research, several families who previously said they would not pay for regular respite care indicated they would be willing to pay $25/hour for a minimum of 3 hours.

Discussion

A user-centred design study was conducted to create a proof-of-concept of an app that could broadly facilitate access to in-home respite care services for families coping with advanced cancers in Quebec. This research was conducted to address noted challenges in accessing respite care services, especially problems in navigating fragmented homecare services, and flexibly coordinating services with appropriately trained respite care providers for families coping with advanced cancers and palliative care needs (Castro, Lalonde-LeBlond, et al., 2024; Robinson et al., 2017; Thomas et al., 2020). Overall, our iRespite proof-of-concept was perceived to be acceptable and appropriate by nurse, family caregiver, and care-receiver participants coping with advanced cancers, and addressed their needs for accessibly coordinating respite care services that are more flexible and staffed by trained providers.

Our iRespite design decisions strongly aligned with the dimensions of access for acceptability, appropriateness, and approachability; as well as with some dimensions of availability, and affordability (Levesque et al., 2013). By Phase 3, the overall design of the proof-of-concept was deemed acceptable by participants for facilitating access to respite care services, with no major changes to the app goals or features being suggested. The design was considered appropriate for supporting trust in the respite care service, in the platform, and in the matching between families and providers. The design was also considered acceptable and appropriate for supporting engagement with the respite care app through chatbot nudging. The design of both the app and the respite services to be coordinated through the app were made more approachable by (1) focusing on understandability of the app features, (2) raising awareness of respite care services, and (3) building the platform in partnership with nurses, family caregivers, and care-receivers. Availability and ability to reach respite care services were partially addressed through the app design through (1) asynchronous and synchronous coordination features; (2) features to attract respite care providers, such as higher pay and flexible scheduling; (3) transparency in regional availability of iRespite providers; and (4) considering transportation to be a form of respite care. Affordability and ability to pay were addressed in part by discussing families' willingness to pay for respite care, particularly when immediate care or emergency respite was needed; and by discussing their perceptions on setting the minimum rate at $25/hour, as recommended by national caregiving guidelines (Canadian Centre for Caregiving Excellence, 2024).

However, other aspects of availability/ability to reach, affordability/ability to pay, and approachability/ability to perceive a need, could not be addressed by a rigorously designed technology like iRespite, alone. Such dimensions could affect the future feasibility of the app, and these dimensions need policy, research, and practice advancements on respite care, to truly make respite care services accessible according to all of (Levesque et al., 2013)'s dimensions of access. Therefore, this discussion section will focus on the opportunities revealed by this iRespite research program for policy making, practice, and research for these dimensions of access.

Availability: Future iRespite features and policy considerations

The lack of flexible respite care services for families with advanced cancer needs in Quebec was a key driver for designing this respite care app. With the widespread use of smartphones across Canada (Government of Canada SC, 2020), including for cancer caregiving supports, we saw that these tools offer opportunities to facilitate flexible access to respite care (Bining et al., 2022; Castro et al., 2023; Heynsbergh et al., 2019; Phongtankuel et al., 2018; Thomas et al., 2020). We believed that the ubiquity and capacities of smartphones could be leveraged to improve access to trusted and flexible respite care services, by making it easier for families and respite care providers to achieve appropriate matches in scheduling (through simple synchronous and asynchronous coordination features), as well as matches in trusted skillset (through sign-up requirements for provider palliative training, and detailed profiles that share families' specific needs and providers' unique qualifications).

However, as this research has revealed, rigorously-designed digital health interventions alone cannot solve all issues of availability or ability to reach; social and political support are crucial. While most Canadian families use smartphones, some do not, making complementary services and clinician involvement essential (Castro et al., 2023; Government of Canada SC, 2020). Future features of iRespite should include cross-platform capabilities, including a website-based corresponding platform, to reach users with Internet access but without smartphones. Furthermore, despite recent government efforts to increase high-speed Internet access, high-speed Internet and cellular data connections remain unreliable or unavailable in many rural and remote areas (Sui & Facca, 2020; Superina et al., 2022). Even with a good connection, complementary respite care services that are not coordinated through digital platforms will continue to be needed, especially for older adults who may be less comfortable with digital tools (Castro et al., 2023; L. C. McSwiggan et al., 2017).

Moreover, even with future features to improve the availability of services in terms of flexible scheduling, platforms like iRespite cannot single-handedly overcome a lack of available providers. Our previous app store search highlighted the lack of available providers on existing respite care apps (Castro, Londono Velez, et al., 2024). The recruitment and retention of respite care providers is an ongoing challenge, particularly in rural regions with few incentives or respite care agencies to hire them (Campbell-Enns et al., 2023; Castro, Lalonde-LeBlond, et al., 2024; Viens, Éthier, et al., 2024). Government and clinical programs to encourage students in health professional programs to provide respite care, as suggested by our participants, may be one incentive, including integrating iRespite into for-credit community health placements (McGrane et al., 2021; Sarasija, 2021; Winston et al., 2023). Incentives for paid training and self-contracting opportunities as respite care providers could also be offered (Viens, Éthier, et al., 2024). Partnering with existing cash-for-care programs that pay for friends and family members to provide respite care, like the chèque-emploie-service program in Quebec, could also facilitate recruitment of respite care providers (*Chèque emploi*, 2022). Other research on cash-for-care programs have found that these programs can particularly benefit rural and remote regions, as was suggested by our participants (Kelly et al., 2021).

Affordability: Future iRespite features and policy considerations

Future app features could include information on access to subsidies or financial assistance for respite care, such as integrating information on government programs or allowing families to indicate their need for subsidized care. Other features of iRespite to further improve affordable access could involve vouchers or donation-seeking, unpaid volunteer-provided respite care coordination, advertisement revenues (without selling private user data), and flexible payment plans (Abarca et al., 2018; Viens, Éthier, et al., 2024).

Even with additional app service features, affordability of respite care services is largely influenced by government subsidies, taxation or charitable donations (Levesque et al., 2013; Whitmore, 2022). While our participants were willing to pay a fair price for respite care that is aligned with national standards, concerns about out-of-pocket costs remained (Canadian Centre for Caregiving Excellence, 2024). Cancer caregiving costs can quickly escalate (Tsimicalis et al., 2020). At the same time, fair compensation for homecare and respite providers is essential for a reliable and competent workforce of available providers (Afzal et al., 2018; Canadian Centre for Caregiving Excellence, 2024; Viens, Éthier, et al., 2024). The participatory design process of iRespite rendered these service affordability issues more visible, highlighting the need for advocacy by clinicians and voters for affordable services, fair wages, and caregiver stipends; as well as leveraging existing supports and tax breaks (AR Castro et al., 2022; Viens, Éthier, et al., 2024).

Approachability: Future iRespite features and practice considerations

This research has implications for nursing practice in terms of approachable design for making respite services and their digital platforms more accessible. An “approachable” respite care service is one that nurses and families recognize as a service that exists, and that could easily support families’ needs (Levesque et al., 2013). User-centred design processes, like the methods we used, can help to co-design such services and digital platforms with nurses, to make them more appealing and approachable to nurses. Respite care services and platforms can also be made approachable, in part, by marketing their services appropriately, ensuring that clinicians are aware of these services to be shared with families in their care (Castro, Londono Velez, et al., 2024; Castro et al., 2023).

Only two of the nine caregivers in our study had actually used respite care services. Some had heard of respite care but could not find appropriate services for their families' linguistic needs, and others had never been told about respite care services by their clinical team. Our nurse participants stressed that respite care is vital for families managing advanced cancers, but that early encouragement for families to perceive a need and be familiar with respite care services before a crisis occurs is essential. These findings support previous research on the need for family education and encouragement by nurses to find and use respite care services. As other respite care scholars have noted, such encouragement helps caregivers overcome guilt and helps care-receivers recognize the benefits of and engage with respite care (Leocadie et al., 2018). Our scoping review (Castro et al., 2023) emphasized the importance of raising awareness about available services through broad advertising and trusted clinical connections. Current resources that clinicians can share to make respite care services more approachable to families include our iRespite Care Agencies Navigator, based on our team's environmental scan of palliative respite services in Quebec (Castro, Lalonde-LeBlond, et al., 2024), which will eventually be available both on the app and a website[3]. The iRespite app, once launched, will be a future resource.

Our previous concept analysis research also noted that for families to be able to access caregiving support services, they have to self-identify as caregivers, and that nurses may help families self-identify and transition into the family caregiver role (AR Castro et al., 2022). These findings align with a recent "value of respite" model created by the ARCH national respite care

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[3] https://aimeecastro.com/irespite-services-irepit/irespite-agency-navigator/ Castro, A. (2024). *Prototype: Irespite agency navigator*. aimeecastro.com. https://aimeecastro.com/irespite-services-irepit/irespite-agency-navigator/

association in the United States, where their researchers highlighted that for respite care services to be accessible, family caregivers must first self-identify as family caregivers before they can perceive a need to access respite care (Whitmore, 2022). Together, these findings highlight the benefits of making respite care services more approachable by having tools like the iRespite chatbot to nudge families' engagement with respite care; and by having clinicians be made aware of these services, and having clinicians help families to self-identify as caregivers who could benefit from respite care services.

Research implications

This proof-of-concept work has research implications for both, the continuation of the iRespite research program towards refinement and implementation, as well as for how future scholars might use this research.

This manuscript details the formative research for the iRespite proof-of-concept, emphasizing its main features of direct care coordination, information sharing, and chatbot nudging. The next phase of this research will focus on summative design testing and implementation. First author Castro will be conducting quantitative usability testing with families and respite care providers, co-designing a pilot test for a strategic launch in Quebec, and conducting a pilot test for families and respite care providers to coordinate respite care visits. This future work will incorporate more purposive sampling to include further diverse perspectives based on gender, racialization, and geography, to help ensure the design meets the diverse needs of families across Quebec.

Beyond the iRespite research team, this work presents opportunities for future scholars of digital health design for access to health services. Our design choices, like incorporating training resources and sharing information, may be useful for teams creating similar care coordination apps.

Other digital health platform designers may find our detailed protocol (A. R. Castro et al., 2021) and these results useful for applying two rigorous academic frameworks – one methodological, the other theoretical - to guide their own work for rigorously designing digital health tools for facilitating access to health services.

Strengths of this research

The highly cited methodological framework, the Information Systems Research Framework, offered strong guidelines for ensuring that this design research was being conducted in a rigorous manner. Guided by the Rigor Cycle research activities, we immersed ourselves in relevant caregiving, respite care, and informatics academic and grey literature, to learn from prior experts in these fields. As part of the Rigor Cycle fulfillment, we contributed to these bodies of literature by both conducting four relevant knowledge syntheses, and using those results to ensure that iRespite was evidence-informed (AR Castro et al., 2022; Castro, Lalonde-LeBlond, et al., 2024; Castro, Londono Velez, et al., 2024; Castro et al., 2023).

Dependability of the methods and analyses was also supported by the application of credible methodological and theoretical frameworks, and of our integration of diverse data sources to inform the proof-of-concept design. To our knowledge, only one other research team has used (Levesque et al., 2013)'s access framework while studying respite care service design, in a subsection of their scoping review on research for making respite care for older adults more flexible (Viens, Éthier, et al., 2024). We used the (Levesque et al., 2013) framework post-hoc to analyze the full proof-of-concept design. While it could have been helpful to be aware of this useful framework at the beginning of this doctoral work to directly inform the search strategies and interview guides, the use of the access framework post-hoc provided an opportunity to validate the ability of the Information Systems Research Framework methodology to create a rigorous design in terms of addressing factors of access. Post-hoc analysis validated this rigor, since with the emphasis of the Information Systems Research Framework on integrating diverse perspectives iteratively, the final iRespite proof-of-concept design managed to capture many of the key factors defined by (Levesque et al., 2013) for access to services, even without actually having the conceptual framework on-hand to guide the design. Post-hoc analysis also provided an opportunity to recognize which dimensions of access a rigorously designed digital health platform can help address. In particular, a rigorously designed app can address barriers to: (1) acceptability of the design and service, through participatory methods; (2) appropriateness and ability to engage, through features that engender trust; (3) approachability and ability to perceive a need, through co-design of approachable features, partnership, and nudging encouragement from a chatbot; and (4) partial availability and affordability factors, through flexible scheduling and payment options.

The Relevance Cycle activities helped ensure that the final research product, the iRespite proof-of-concept, was designed to truly address challenges faced by the end-users. As we shared with the Expert Council and participants during every interview: we did not want to build something that would not ultimately be helpful for addressing families' respite care support needs. The relevance of this research began with the personal experiences of our research team. I conceived of this project based on my experiences as a family caregiver, homecare worker, and nurse. My supervisors and research team, who also have lived experiences in family caregiving and palliative oncology care, helped me to refine the research questions. We then brought these questions to a transdisciplinary Expert Council of 5 key informants from homecare nursing, palliative medicine, social work, UX design, and caregiving advocacy, for further discussion and to ensure the value of the project to addressing advanced cancer families' respite care needs.

Finally, 21 potential end-users, i.e., nurses, family caregivers, and care-receivers, iteratively discussed the goals and features of the proof-of-concept over three research phases, ultimately towards ensuring that the final proof-of-concept was relevant for addressing many of families' respite care needs. This is a large sample size for formative digital health research, and thus adds to the rigor of the study in bringing in diverse perspectives on the final formative design, as data saturation was achieved by Phase 3 with our assessment of no major changes being recommended to the proof-of-concept design (Caine, 2016; Cornet et al., 2020).

Limitations of this research

We recruited only three care-receivers who were currently living with advanced cancers or receiving palliative care. Two of the caregiver participants were also being treated for cancer, but they did not have advanced cancers. This result of a small sample of advanced cancer care-receivers was unsurprising, as it is a known challenge in palliative care research to recruit patients living with advanced cancers and other palliative illnesses. This challenge is not necessarily because patients are disinterested in the research topic, but because they are over-taxed, and may have limited abilities to participate due in part to fatigue and end-of-life cognition challenges, as well as conflicting family priorities as they near end-of-life (Hanson et al., 2014; Kars et al., 2015). This small sample of care-receivers somewhat limits our data on acceptability and approachability, as care-receivers and family caregivers may disagree on the need or desire for homecare services like respite (Backhouse et al., 2022; L'Appui, 2024). However, we partially addressed this issue of limited care-receiver perspectives by including nurses and family caregivers as proxies for care-receivers' respite care needs, as suggested by other user-centered design scholars in digital health for cancer care (Islind et al., 2023).

We did not directly recruit current non-nurse respite care providers, as the study began with a focus on nurse providers as potentially being the most trusted respite care providers for advanced cancer care (A. Castro et al., 2021). However, several nurses in this study had prior experiences as homecare aides, providing valuable insights into provider recruitment and training.

Additionally, most participants were recruited from Montreal, with a sample predominantly of White-presenting women with higher education levels. While we initially aimed for purposive sampling according to factors such as gender and cancer typology (A. R. Castro et al., 2021), we were unable to purposively sample as diversely as we would have liked to due to time and resource limitations, resulting in more of a convenience sample of family caregivers and care-receivers with advanced cancers. Relatedly, self-selection is a potential bias when recruiting by online research flyers (Khazaal et al., 2014). We selected participants from those who reached out to us for more study information through our online recruitment form. Therefore, our recruitment strategy was biased towards those who had an Internet connection and were likely to be strongly interested in caregiving app design research conducted through virtual interviews. Still, for formative design research, convenience sampling is frequently considered appropriate to keep the iterative design process moving forward (Still & Crane, 2017).

Conclusions

We have rigorously integrated diverse data sources to develop a formative proof-of-concept of an app aimed at improving the coordination of and access to respite care services, which are often needed but inaccessible during critical times. To our knowledge, iRespite is the first user-centered app designed for families managing advanced cancers or terminal illness conditions, to coordinate both immediate and recurring respite care, and to connect end-users with complementary resources. It is also one of only a few respite care coordination platforms to have been conducted through academic research (Castro et al., 2023; Currin et al., 2019; Viens, Carrier, et al., 2024). The design addresses multiple access barriers, aligning with Levesque et al. (2013)'s access factors, and holds promise for improving respite care access in Quebec. The theoretical and methodological innovations arising from this work could eventually improve access to respite care services for other populations.

With further usability, feasibility, and pilot testing with respite care collaborators in Quebec, we aim to optimize respite care coordination, reduce fragmentation, and enhance respite care service quality. Leveraging smartphone technological capabilities, our team is working with nurses, families, and other end-users to develop a new app-based respite care service. If successfully launched, iRespite could facilitate better coordination of in-home respite care, helping families stay at home as long as possible, reducing institutional costs of hospitalization at end of life, and improving family well-being.

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List of appendices and abbreviations for Paper 6

Multimedia Appendices Legend

Appendix 1 (below): Screen descriptions of the iRespite proof-of-concept

Appendix 2 (below): Design features for trust in iRespite

Abbreviations

App: Smartphone application

CG: Caregiver participant

CR: Care-receiver participant

iRespite: iRespite Services iRépit

N: Nurse participant

UX: User experience

(Table 8.2.5) Appendix 1: Screen descriptions of the iRespite proof-of-concept

Proof-of-concept screen names	**Key design details**
App store screen	-Describes the need for respite care -Lists the geographic regions where current iRespite providers have signed up to provide services -Presents transparent pricing, with a minimum of $25/hr for 3 hours of care -Lists affiliations of our research team
Welcome screen and sign-up	-Sign up: -Role selection (family or provider) -First 3 letters of postal code where care is to be provided -For families: relationship to the care-receiver and care-receiver consent form -For providers: proof of background check, proof of palliative care training, links to potential resources for further training -Sign in security – multiple options: standard password, face identification, email one-time-code, etc., as the user chooses
Home screen for families seeking providers	-CareNOW link -CareMATCH link -Profile creation/editing -Menu to additional resources for families -Calendar of upcoming respite care appointments -Chatbot
Additional resources for families	-iRespite Agencies Navigator (Castro, 2024; Castro, Lalonde-LeBlond, et al., 2024): easy-to-navigate, searchable database, filterable according to family needs (e.g., location, services provided, eligibility, availability/hours per visit, type of provider, and costs). -List of additional resources for families to learn about and discuss respite care and caregiving during cancer -Information on self-contracting employment legislation in Quebec (*Cnesst: Individual who employs a domestic worker*, 2024).

Home screen for respite care providers	-Toggle on/off to be available immediately for CareNOW -Link to update CareMATCH schedule of availabilities -Link to CareMATCH to search family listings for respite care providers -List of palliative care training resources for provider continuing education, such as Pallium Canada's LEAP training and Quebec's Albatros training (*Formations en accompagnement palliatif*, 2024; *Pallium-leap*, 2024) -Information on self-contracting employment legislation in Quebec (*Cnesst: Individual who employs a domestic worker*, 2024)
Profile completion page for families	-Additional family caregiver and care-receiver information -Provides additional details regarding their family's needs to facilitate an appropriate provider match: language, gender, allergies, any history of cognitive impairments or dementia, mobility assistance, pets or smoking in the house, pain status, nausea status, shortness of breath and how to treat, key emergency contact(s), care-receiver's personality and likes/dislikes -Any other relevant information (open text) -Option to link family accounts (e.g., for sandwiched caregiving or multiple caregivers) -Preview both public (shorter) and private (matched) profiles
Profile completion page for providers	-Additional information about the respite care provider: language, gender, valid driver's license, access to a car, caregiving skills (accompaniment, glucose monitoring, suctioning, driving, etc.) -Certifications – eg. CPR, non-violent crisis intervention training -Optional verified profiles (e.g.., LinkedIn) -Optional "about me" video -Choice of hourly rates above $25/hr -Uploaded evidence of palliative care training and vulnerable sector background checks

Chatbot	-The chatbot will provide an initial overview of the app, as well as nudge families and care providers to engage with the app, via check-in questions every 5-7 days, and reminders about the value of respite care to both caregivers and care-receivers
CareNOW respite care coordinator to find a provider immediately	-Similar to the uber/on-demand service model, consisting of direct care coordination through an "immediate respite care needed" call button available in iRespite (CareNOW) -Further details on what is needed specifically for the CareNOW visit being scheduled -Includes reminders regarding self-contracting in Quebec: If an individual works for the same family for over 420 hours over a period of 1 year (12 months), or 30 hours a week over a period of 7 consecutive weeks, then the provider becomes an employee of the family with related obligations and benefits (*Cnesst: Individual who employs a domestic worker*, 2024).
CareMATCH respite care coordinator	-Similar to CareNOW, but can schedule respite for the future and connect with previous providers for continuity of care -Longer optional form to add in care details, compared to the faster form for CareNOW -Additional optional information, such as a brief rating of the care-receiver's mental wellness and mood for this visit
A messaging and match-request page, to coordinate visits in either CareNOW or CareMATCH	-Standard messaging platform
Home screen during a respite care visit	-Visit notes for continuity of care (including transcriptions of anything the care-receiver said that would be meaningful for the family caregiver to know) -Calling for help (in an emergency) -Reporting a problem - technical or otherwise
Payment page	-Standard payment page
Visit termination page	-Standard visit termination page

	-For families: option to leave any positive reviews/skills for the provider to share on their profile -For providers: a chatbot nudge to use the secure community of practice and to debrief with iRespite colleagues

(Table 8.2.6) Appendix 2: Design features for trust in iRespite

Category for trust	**Details**
Platform Security	- Secure log-in options - Commitment to not sell user data - Option for families and providers to use either avatars or real photos for their public profiles; however, once messaging begins or a match occurs, both families and providers must include a real photo - Secure payments and money transfers - Clearly explain terms and conditions - A plan to work with cybersecurity and legal experts when the back-end of the app is created
Service Reliability	- Clearly identifying on the app store page, which regions of Quebec that iRespite currently has service providers registered in - Estimated times of arrival - Transparent timelines for cancelling up to 12 hours prior to a CareMATCH appointment. After 12 hours, if families cancel, they will be charged 50% of the appointment amount, which will go to the provider. - Transparent costs and fees per visit - Continuity of care via both private and shared visit notes - Direct-messaging options between potential providers and families - Option for direct contact / emergency call button with an iRespite nurse manager for urgent issues, for both family and provider - De-identified SMS text messaging in case wifi/data is unavailable – but with in-app messaging prioritized, to avoid sharing phone numbers at first contact
Appropriate matching of families and providers	For families to trust providers, app features included: - Proof of palliative care training (e.g., Pallium-Canada) - Vulnerable sector background check - Links and chatbot nudging to training resources for respite care providers to continue their palliative care training - Detailed public and private (only matched families can view) profiles of provider skillsets - Optional detailed requirements by families for each visit when filtering potential matches between families and providers -A button to call for additional help on the home screen during a visit - Optional positive ratings/ “outstanding qualities” featured on providers’ profiles, but not negative ratings or global quantitative ratings, due to the sensitive, emotional, and highly specific nature of respite care visits

	For providers to trust families, app features included: -Detailed family profiles -Visit notes for continuity of care -A button to call for additional help on the homescreen during a visit

9.0 Discussion of this Dissertation

This dissertation is divided into eight sections: (1) establishing how I accomplished the objectives of this dissertation, (2-4) discussing my theoretical, methodological, and empirical contributions, (5) describing the relevance this research to the discipline of Nursing, (6) sharing potential next steps for this research program, (7) justifying the rigor of this dissertation, and (8) discussing the limitations of this work.

9.1 Accomplishing the Objectives of this Dissertation

The three objectives for this dissertation were guided by the research Cycles of the Information Systems Research Framework: the Rigor, Relevance and Design Cycles (Hevner, 2007). The dissertation objectives were: (1) To synthesize knowledge on caregiving and respite care support needs, digital health design for respite care, and accessible service design, to inform the interview guides and proof-of-concept design. (2) To explore how best to design an app that is relevant for addressing families' respite care needs, particularly in terms of access. (3) To sketch and refine across the research phases, a proof-of-concept design of an app that could, once fully programmed, facilitate access to respite care services for families coping with advanced cancers in Quebec. With the six manuscripts included in this dissertation, I have accomplished these objectives.

Objective 1: Synthesizing relevant literature and knowledge via the Rigor Cycle

For Objective 1, Papers 2-5 present knowledge syntheses on informal caregiving support, digital health design for respite care, and palliative respite care access, to inform the iRespite proof-of-concept. Paper 2 (concept analysis) offered a new understanding of the "informal caregiver" role, highlighting the importance of community support services like respite care to avoid negative role consequences for both caregivers and care-receivers. Paper 2 also underscored the need to adopt participatory design methods when designing caregiving support services. These insights informed the design of iRespite, incorporating features to mutually support both family caregivers and care-receivers. Paper 3 (environmental scan) revealed challenges in navigating and accessing respite care services in Quebec, especially for palliative care needs. These results guided interview questions and informed the design of the app features for navigating existing palliative respite care agencies, which led to the creation of a searchable database of respite care services that will be embedded into the future iRespite app (Figure 5.1.1 in Chapter 5 of this dissertation). Paper 4 (scoping review) found that existing respite care technologies in the academic literature focused on training, information sharing, and service coordination. Key design strategies from Paper 4 included building trust, using participatory methods, and ensuring complementarity with existing caregiving services, all of which we implemented in our decisions for the proof-of-concept. Paper 5 (app store search) confirmed the need for a specialized respite care app, as existing apps lacked features for appropriately coordinating care for families with advanced cancer or palliative needs. Together, these four papers synthesized relevant knowledge areas to comprehensively inform the design of the iRespite proof-of-concept, addressing the objective of the Rigor Cycle activities.

Objective 2: Exploring respite care needs and app potential via the Relevance Cycle

The Relevance Cycle activities sought to explore the respite care needs of participants and key end users coping with advanced cancers, and to understand how a relevant app might be designed to better address their needs, particularly in terms of respite care access. Papers 1 and 6 outlined the key methods and results for meeting this objective. We conducted an iterative user-centred design study with 5 key informants, 9 nurses, 9 family caregivers, and 3 care-receivers. With Expert Council and participant feedback, we pivoted away from my initial idea of an app focused on nurse-provided respite care services. Instead, we focused on requiring that respite care providers who wanted to self-contract through the CareNOW and CareMATCH features of the app would have to upload proof of appropriate palliative care training before any respite care visits could be made; we offered providers links to continuing education resources to obtain this palliative care training. Participants further directed us towards expanding the app beyond creating a marketplace platform for direct respite care coordination, to incorporating an easy to navigate database of existing respite care agencies that could meet families' palliative respite needs. None of the coordination apps identified in Paper 5 included tools to identify agencies or other supports external to the app. The Expert Council and participants also helped us explore how a chatbot could be designed to engage families in accessing respite care services through CareNOW, CareMATCH, or the agencies navigator module. By the end of Phase 3, the Expert Council and participants deemed these iRespite design features to be relevant for appropriately addressing common respite care challenges.

Objective 3: Designing a proof-of-concept via the Design Cycle

The Design Cycle objective was to produce an evidence-informed artifact, specifically, a proof-of-concept of an app for facilitating access to respite care services for families with advanced and palliative cancers in Quebec. Paper 6 establishes that we met this objective, particularly through the screenshots and the YouTube video[4] of the higher-fidelity proof-of-concept. This formative proof-of-concept is currently being coded by engineering students into a higher fidelity, interactive prototype, which will undergo usability testing and pilot testing in my postdoctoral research.

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[4] As noted in Paper 6, a video of the Phase 3 formative proof-of-concept design is shared on YouTube: https://www.youtube.com/watch?v=AqLlHOPQ6QY

In summary, the above section establishes how with my research team, I addressed the three objectives for the Rigor, Relevance, and Design Cycles of this dissertation. In the following sections, I will discuss how my dissertation makes original contributions to knowledge through these results.

9.2 Theoretical Contributions

This dissertation offers theoretical contributions on how to design ICTs and respite care services that are guided by concepts of partnership and access.

9.2.1 Designing for partnership in respite care services and ICT design

The concept analysis (Paper 2) advanced our conceptual understanding of "informal caregiver" and how this concept should be evolved further towards a role of more dyadic partnership with care-receivers. My concept analysis found that current nursing discussions of family caregivers and care-receivers are dyadic, but they lack an emphasis on mutuality and partnership. This finding aligns with (Wolkowski & Carr, 2017)'s work on the need for partnership in palliative respite care services, arguing that "the needs of the care[giver] cannot be looked at in isolation from the needs of the service user and vice versa" (pg. 177). This research also aligns with the recent call by the Quebec caregiving observatory for more research and services that support collaborative partnerships between family caregivers and care-receivers (Girard-Marcil, 2023).

The scoping review (Paper 4) revealed that few care-receivers are ever included in studies on ICTs for respite care. This insight on the need for partnership with care-receivers in the design of respite care services led my team to work hard to recruit a few care-receiver participants, to create a collaborative design that valued the perspectives of care-receivers. Originally, we planned to recruit a care-receiver with advanced cancer as a key informant, but our Expert Council felt that doing so would be asking too much of a care-receiver. When palliative care-receiver recruitment proved difficult, we also explicitly asked nurse and family caregivers to answer as proxies for care-receiver concerns (Islind et al., 2023).

As part of our Relevance Cycles research (Paper 6), we aimed to understand care-receivers' perspectives on respite, and to incorporate features for their respite care needs into the app. Such proof-of-concept features included creating a care-receiver consent form, and nudging families to fill out their family profiles and care matching needs together. The "family profile" app design allows care-receivers to have the app opened on their phones during a respite care visit, so they can also use the app to access supports and share their visit experiences in the visit notes. Hence, findings of Papers 2, 4, and 6, all offered a unique contribution to theoretical knowledge by applying a lens of partnership, particularly with care-receivers, to respite care service and ICT design.

9.2.2 Advancing a framework on access for respite care service and ICT design

This dissertation advances an influential public health framework on "patient-centred access to health care services" by showing how the framework can be applied towards rigorously designing or evaluating an ICT to facilitate access to homecare services like respite care (Cu et al., 2021; Levesque et al., 2013).

After scanning the Google Scholar "cited by" functions for Levesque's framework, I found that none of the "cited by" scholars used this framework to comprehensively inform or evaluate the design of a specific ICT for facilitating access to homecare services[5] (Martín-Martín et al., 2018). Furthermore, I identified only one paper that had used (Levesque et al., 2013)'s access

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[5] To confirm this novel application, I used the Google Scholar "cited by" function of the over 3,400 texts that cite Levesque et al (2013), to screen the titles and abstracts of the 260 cited by texts that also included the words "homecare" or "home care" or "respite".

framework to study respite care access. This recent paper consisted of a scoping review to explore the concept of designing flexible respite care services, and they innovatively applied the framework to a sub-section of the results discussing how flexible respite care could be delivered (Viens, Éthier, et al., 2024). However, like many papers that use this access framework, only the first five supply-side dimensions of access were incorporated, without explicitly exploring demand-side factors (i.e., "ability to…") that also affect families' access to services (Cu et al., 2021). In contrast, I applied both the supply and demand side factors to analyze the results.

(2013)'s comprehensive framework on access was helpful to our iRespite proof-of-concept research for providing a post-hoc theoretical explanation of how the different features of iRespite address key factors in accessing respite care services. By using a participatory design process, we helped to ensure that the final proof-of-concept was acceptable and appropriate. We also leveraged the technical capabilities of smartphones for facilitating flexible coordination, which is a key factor in the availability dimension of access.

This access framework also explained which factors of access even a rigorously designed app-based service platform might struggle to address, such as the affordability of services and the general availability of providers. These aspects of access need social and government support, in addition to a well-designed platform, to ensure overall accessibility of the services being supported by the app. Therefore, my work offers unique theoretical contributions by applying a highly-cited conceptual framework on healthcare access, towards providing a comprehensive description of factors on the supply and demand sides that affect access to respite care service delivery and accessible respite care ICT design.

9.3 Methodological Contributions

Key methodological contributions of this research are that it exemplifies the benefits of participatory user-centred design and transdisciplinary approaches for designing accessible health services. This research also offers an exemplar for using integrative methods to rigorously design a digital platform for accessible homecare coordination, including respite care services.

9.3.1 Applying participatory and transdisciplinary methods to respite care access

9.3.1.1 Complex health interventions need participatory and transdisciplinary design methods

Healthcare services like respite care are complex interventions, with many interacting factors to be addressed to successfully deliver and sustain the services (Levesque et al., 2013; O'Cathain et al., 2019a; Wolkowski & Carr, 2017). Participatory approaches like user-centred design are becoming a gold standard for researching and designing both complex health interventions and digital health tools (Cornet et al., 2020; O'Cathain et al., 2019a; Risling & Risling, 2020). Such approaches are considered to better integrate key stakeholders' and end-users' needs throughout design and implementation than non-participatory methods do (Cornet et al., 2020; Risling & Risling, 2020). If end-users' needs are not incorporated into a service, they will likely consider the service to be irrelevant to their needs and thus will choose not to engage with it, making the service ultimately inaccessible to the people the service was meant to serve. Our concept analysis (Paper 2) and scoping review of respite care ICTs (Paper 4) both underscored the need for partnership with end-users via participatory design when developing and implementing respite care interventions, so that the designed services and ICTs truly address families' needs. Through this work, we contributed to the literature on the value of participatory approaches when designing and implementing respite care services and ICTs to support those services (Papers 1, 2, 4, 6).

Moreover, our research team and Expert Council were transdisciplinary, which by its nature aligns well with participatory approaches (Rigolot, 2020). My thesis committee included nursing professor supervisors, as well as thesis committee members from digital health and oncology (Dr. John Kildea), and from age-tech and information studies (Dr. Karyn Moffatt). I also had a transdisciplinary Expert Council of a palliative homecare nurse manager, a palliative physician, a social worker, a caregiver advocate, and a UX designer. This Council helped us to make key research decisions, including: (1) expanding initial recruitment to families coping with advanced cancer, rather than only those receiving palliative care services; and (2) pivoting away from the original protocol requirement of designing an app for coordinating nurse-provided respite care, to coordinating palliative-trained providers.

Additionally, we had 21 participants from family caregiving roles, care-receiving roles, and nursing roles across homecare, palliative care, and oncology. I also mentored 15 undergraduate and graduate students on work related to this project from across the departments of nursing, oncology, information studies, and software engineering. By integrating diverse yet relevant perspectives throughout the design process, the iRespite intervention is more likely to be acceptable and feasible to implement, thus helping to ensure its accessibility and sustainability (O'Cathain et al., 2019a; Risling & Risling, 2020).

9.3.1.2 iRespite improved because of participatory, user-centred design

A benefit of the iterative user-centred approach is that it explicitly offers opportunities to pivot, when preliminary findings in the research process conflict with what the target end-users and key informants share as the research progresses. This dissertation reveals how the proposed research changed direction based on Expert Council and participant feedback. For example, based on early literature reviews, I identified some research suggesting that for complex family caregiving like advanced cancer and palliative care, nurses might be most trusted by families to provide this respite care (Barrett et al., 2009). I also hypothesized that flexible, on-demand respite care for urgent situations would be the most needed service (Rao et al., 2021; Thomas et al., 2020). For these reasons, the published protocol (Paper 1) focused on nurse-provided, on-demand respite care.

However, by the end of Phase 1 data collection, participants and the Expert Council had convinced me that to engender trust in the respite care providers on the platform, the providers did not have to be nurses; rather, providers – whether they were nurses or not – had to be familiar with palliative approaches to care, such as pain management and psychosocial strategies for managing grief. They also shared that while some families do desperately need emergency, on-demand care like “uber for respite” (e.g., CareNOW), others may simply want encouragement to connect with existing respite care services – hence, our inclusion of a chatbot and the agencies navigator.

9.3.2 Advancing integrative methods for complex digital health service design

This research further contributes methodologically by showing how to creatively integrate diverse methods and methodologies together, towards achieving the common aim of informing a rigorous digital health design.

Integrative methods in research combine diverse sources of data holistically, not so much to validate or confirm other findings - as triangulation does for mixed methods research - but rather, to build a holistic understanding of the phenomenon under study using whichever methods are relevant (Tonon, 2019). The iRespite proof-of-concept design research provides an example of integrating diverse data sources, including knowledge syntheses, key informant meetings, individual interviews, focus groups, and survey findings. These data sources were collected via diverse bilingual data collection tools such as literature reviews, environmental scans, interview guides, chatbox messages and reactions, caregiving video scenarios, wireframe sketches, surveys, and proof-of-concept videos, all towards richly informing the iRespite app design.

Furthermore, this proof-of-concept research establishes how to integrate a methodological framework and conceptual framework from different disciplines together. Few of the ICTs identified in the scoping review (Paper 4) or the app store search (Paper 5) explicitly used either a methodology or a conceptual framework. My research demonstrates the value of integrating *both* types of frameworks to design a respite care ICT. To our knowledge, and based on the "cited by" functions in Web of Science and Google Scholar, this is the first research program to combine the Information Systems Research Framework (Hevner, 2007), with (Levesque et al., 2013)'s comprehensive public health framework on access. By combining these highly-cited frameworks from two different disciplines, this iRespite research offers an original exemplar of how to integrate key frameworks towards designing a rigorous digital health platform for facilitating access to a community health service.

Furthermore, not only did the app proof-of-concept design (Paper 6) use integrative methods, the four knowledge syntheses that informed the iRespite design also used integrative methodologies. With the environmental scan (Paper 3), we created an innovative digital search methodology for combining systematic Internet search engine searches with healthcare database searches, geographical mapping, and key informant feedback. We used those results to produce a printable .pdf (Figure 5.1.1 in Chapter 5 of this dissertation) and a searchable agencies navigator of respite care organizations in Quebec that serve families in palliative care. With the app store search (Paper 5), we used an integrative search methodology to combine the search strategy used in the academic literature scoping review (Paper 4) with the search strategy for the app stores (Paper 5) (Lau et al., 2021). This integrative app research methodology is designed to holistically map the app landscape across both academia and industry (Lau et al., 2021), which we did through Papers 4 and 5. The Information Systems Research Framework is explicitly integrative with its Rigor, Relevance and Design Cycle research activities informing each other (Hevner, 2007) (Paper 1, Paper 6). Finally, (Levesque et al., 2013)'s patient-centred access to health care framework is integrative in its consideration of both service design accessibility and families' unique capacities to access services, resulting in a framework of 10 integrated factors, beginning with "approachability/ability to perceive" and ending with "appropriateness/ability to engage" (Paper 6) (Levesque et al., 2013). Thus, this dissertation research has conducted innovative methodological research by integrating numerous research methodologies in a complementary manner towards ultimately accomplishing the same objective of designing the iRespite proof-of-concept. Future digital health and health service design scholars may benefit from applying this combination of integrative methodologies to rigorously design other digital health tools to facilitate access to complex health services.

9.4 Empirical Contributions

9.4.1 Empirical artifact: The iRespite proof-of-concept

My main empirical contribution was to lead the user-centered participatory design of an app proof-of-concept for facilitating access to respite care services for families coping with advanced cancers in Quebec. This iRespite proof-of-concept was rigorously informed by systematic reviews of the literature (AR Castro et al., 2022; Castro et al., 2023), and mapping of existing palliative respite care agencies (Castro, Lalonde-LeBlond, et al., 2024) and respite care apps (Castro, Londono Velez, et al., 2024), over iterative interview design cycles with families and nurses. Based on these knowledge syntheses, few scholars have studied the potential of apps or web-platforms to facilitate access to respite care services, and none of those ICTs had been designed with families coping with advanced cancer or palliative care needs. Furthermore, none of the Paper 5 apps appeared to include features beyond flexible coordination that could also increase access, such as chatbot features for encouraging engagement and assessing readiness for respite care, or an agencies navigator to share availabilities of other regional respite care services.

The design of the iRespite proof of concept addressed some of the previous criticisms of workers' rights and on-demand work. One such criticism was that platforms too often rely on quantitative provider five-star ratings, which can be biased against the providers (Ticona & Mateescu, 2018). We considered including ratings for both providers and families, but with feedback from our Expert Council that echoed research by (Ticona & Mateescu, 2018), we pivoted towards allowing the option of qualitative positive comments, but no quantitative ratings. Another criticism is minimal guidance given to families and providers on pay requirements and minimum wages (Ticona & Mateescu, 2018). For this reason, we set the minimum allowed hourly rate at $25/hour, for a minimum of 3 hours of care, which is well above minimum wage in Quebec and based on recommendations from a national caregiving strategy (Canadian Centre for Caregiving Excellence, 2024; Commission des normes, 2023). We also included information in the app regarding the legalities of self-contracting homecare services in Quebec (*Cnesst: Individual who employs a domestic worker*, 2024).

Overall, this user-centred iRespite proof-of-concept has been deemed acceptable and appropriate by the target end-users, and it is now ready for higher-fidelity programming followed by usability, feasibility, and pilot testing. Through the design of this iRespite artifact, I have contributed original empirical knowledge on digital health participatory design for respite care coordination.

9.4.2 Advancing cancer and palliative research in respite care and digital health

While two of the six manuscripts were based specifically on Quebec data (Paper 3 – environmental scan; Paper 6 – iRespite design), these findings are likely transferable to other populations, across Canada and internationally, that are similarly coping with increased respite care support needs due to increasing cancer incidence, aging populations, and fragmented homecare services across large geographies (Brenner et al., 2024; Rao et al., 2021; Whitmore, 2022).

My research directly addresses calls for more research to support cancer family caregivers through homecare innovations. In 2020, a stakeholder workshop consisting of a series of small and large focus groups with 15 cancer family caregivers in the United States identified the caregivers' research priorities. These cancer caregivers emphasized the need for studies on navigating the healthcare system and on improving caregiver health and well-being (Thomas et al., 2020). A key finding from this workshop noted the need for more accessible respite care services:

> Longer-term caregivers or those providing more intense care reported being desperate for respite care to allow them personal time to attend to their own needs, including when such care is needed with short notice. Several caregivers expended a great deal of time searching, often without success, for available and affordable respite care. (p. 6) (Thomas et al., 2020)

Similarly, a 2019 international Delphi study with 103 clinicians, 63 researchers, 61 caregivers, and 22 managers aimed to establish cancer caregiver research priorities (Lambert et al., 2019). This Delphi study found home care interventions to be a top consensus priority – interventions that should include respite care services (Lambert et al., 2019). My iRespite work also aligns with two of six key calls from the recent white paper by nursing professors and the ARCH National Respite Network in the United States, to invest specifically in research on "systems change that improves respite access" as well as "improved respite provider competence" (p. 5) (Whitmore, 2022).

Furthermore, cancer and palliative care families and scholars have specifically called for more research on ICTs to support the delivery of homecare services like respite care. A systematic review found that ICT-based interventions are acceptable and usable to cancer family caregivers, and that more research should be conducted to develop supportive ICTs for these families (Heynsbergh et al., 2018). The international Delphi study on priorities for caregiver research in cancer care reported calls from researchers and managers to explore how technologies can support the delivery of caregiver interventions (Lambert et al., 2019). In 2016, the American National Cancer Institute and National Institute of Nursing Research published a call for cancer research priorities to focus on developing interventions that support family caregivers and care-receivers, including maximizing the potential of digital health technologies to support cancer family caregivers (Kent et al., 2016). My dissertation addresses these nurse and caregiver-led research calls by supporting family navigation of and access to flexible and trusted in-home respite care services for cancer caregiving families, particularly through the iRespite CareNOW and CareMATCH functions (Paper 6, iRespite design), and the agency navigator (Figure 5.1.1; Paper 3 – environmental scan).

Other literature has confirmed the need for flexible in-home respite care services by trusted and competent providers for families with palliative care support needs (Rao et al., 2021; Wolkowski & Carr, 2017). However, this research did not specify what trusted palliative respite care could look like, and research on the specific respite care service needs of palliative care families is limited. My dissertation offers a new perspective on what accessible respite care services could look like for advanced and palliative cancer families, particularly if they were coordinated through a user-centred digital health platform. Paper 2 (concept analysis) highlighted that flexible and accessible respite care is a needed support to prevent negative role consequences for informal caregiving. Paper 3 (environmental scan) highlighted the navigation challenges of palliative respite care, particularly with limited availability of formal respite care agencies in rural and northern regions. Paper 2 (concept analysis) and Paper 4 (scoping review) both demonstrated the need for families to receive encouragement to overcome barriers like guilt for considering respite care. Paper 5 (app store search) also identified availability challenges in respite care delivery, with a focus on the lack of available respite care providers on the apps.

This dissertation used the above ideas to advance knowledge on palliative respite care by confirming the importance of accessible respite care services for families with advanced and palliative cancers, especially for families with limited social support and/or long-term cancer care needs (Paper 6). Moreover, our participants reaffirmed the need for more trusted respite care services, with trained providers in palliative care. This decision aligns with (Wolkowski & Carr, 2017)'s doctoral nursing research calling for more empathic, palliative approaches for delivering respite care services.

The iRespite proof-of-concept design used these accessibility findings related to flexible scheduling, available agencies, and available and appropriately trained providers, to elucidate what accessible in-home palliative respite care service delivery could look like, through unique app design decisions. These decisions included (1) requiring providers to upload background checks and proof of palliative care training to their app profiles, (2) facilitating flexible scheduling through asynchronous messaging and self-contracting, (3) providing respite care provider incentives such as allowing respite care providers to set their own schedules and rates above the established minimum $25/hour, (4) including specific questions on family profiles and visit request forms regarding how the care-receiver is feeling that day and how to manage any cancer symptoms, and

(5) including a chatbot to engage with families and assess awareness of and readiness for respite in the context of palliative care.

9.5 Relevance to Nursing

This research directly aligns with the recent call by the Canadian Nurses Association for nurse clinicians and scientists to lead in the design and development of digital health technologies that address the complex needs of nurses, patients, and families (Nagle, 2024). This work also aligns with the ideals of Strengths-Based Nursing to focus on families' strengths and goals, by supporting families' strengths and wishes to remain in their home environments for as long as possible (Gottlieb & Gottlieb, 2017). By leveraging user-centered design, we have collaboratively constructed a proof-of-concept for a new app-based respite care platform with families, nurse clinicians, and other key informants. This approach ensures that the app is designed with the strengths, needs, and perspectives of the end-users in mind, helping ensure that they ultimately engage with the service, thus making the service accessible.

My work is also in keeping with Fawcett's metaparadigm of nursing, of integrating the *nurse*, the *person*, and their *environment*, all towards improving the *health* and well-being of families and communities (Fawcett, 1984). The iRespite app is designed to support *persons* and families coping with an advanced *health* issue (i.e., advanced and palliative cancers), by improving families' access to appropriate respite care services in their home *environments*. This work is relevant to *nurses*, because palliative homecare services like respite care are typically overseen by nurses (Wolkowski & Carr, 2017). Furthermore, the concept analysis (Paper 2) highlighted that nurses have a key role to play in helping family caregivers to self-identify as caregivers, and to seek out supportive services like respite care, which is a nursing implications finding that other respite care scholars have noted (Whitmore, 2022). By having nurses lead the design of the iRespite app, and by partnering with nurse clinicians and nursing organizations throughout the design and implementation process, we are helping ensure that nurses are aware of iRespite and of other palliative respite care organizations in the agencies navigator across Quebec (Figure 5.1.1; Paper 3). Thus, clinical nurses will be able to use these research artifacts to support families in their care to access appropriate respite care services that can meet families' palliative respite needs.

9.6 Next Steps for iRespite

We currently have engineering students coding a higher fidelity, interactive prototype for usability testing next year, based on this proof-of-concept design research. For my postdoctoral work, I will be bringing this research to the Université de Montréal's Faculty of Nursing. With the support of Dr. Anne Bourbonnais, Canada Research Chair in Care for Older People (2020), I will be conducting usability testing, co-designing an implementation plan with key community stakeholders, and pilot testing iRespite in urban and rural settings of Quebec. We may also explore opportunities to recruit care providers amongst students in healthcare programs, as well as the chèque emploi-service program, as was suggested by our participants to increase provider availability (*Chèque emploi*, 2022; McGrane et al., 2021; Winston et al., 2023). With successful testing and implementation, iRespite could be scaled up to support families nationwide. By improving access to respite care, iRespite has the potential to enhance caregivers' well-being and help families coping with advanced illnesses remain at home for longer.

Quebec scholars and entrepreneurs seem to have a burgeoning interest in respite care ICTs, creating fertile opportunities for us to lead in this field nationally and internationally. I plan to approach the Université de Sherbrooke Research Centre on Aging scholars who have recently used the (Levesque et al., 2013) access framework to study flexible respite care services. These scholars also appear to be working with a small Montreal company to develop a website-based platform for directly coordinating respite care services for families of older adults with dementias (Viens, Carrier, et al., 2024). Furthermore, a Montreal-based app was one of the 40 we identified worldwide in the app store search. I plan to approach this company, Damava, to share our findings for respite care app design, especially for advanced cancer families (Damava, 2024). Perhaps we will be able to scale up respite care access across Quebec and Canada, via the rigorous design and implementation of respite care ICTs, together.

9.7 Trustworthiness and Rigor of this Dissertation

Given that the qualitative content analyses across the papers of this dissertation were guided by the detailed methods shared by (Elo & Kyngäs, 2008b), I will use their suggested guidelines to share key aspects of trustworthiness in this dissertation. Credibility of these analyses was supported by providing detailed descriptions of the coding decision processes, as shown by the description of the preliminary deductive categories and the final categories for themes in Papers 2, 4, and 6. Transferability of these methods and results was supported by detailed descriptions of the context of the iRespite research conducted, the innovative methods used for Papers 1 (protocol), 3 (environmental scan), 5 (app store search), and 6 (iRespite design), and a detailed description of the study participants (Paper 6) (Elo & Kyngäs, 2008b). Trust in the credibility and dependability of these analyses was also supported by multiple relevant knowledge syntheses that informed and complemented the proof-of-concept results, as well as iterative guidance and feedback from the Expert Council, and providing rich quotes from participants to exemplify themes relating to access in Paper 6 (Elo & Kyngäs, 2008b). Further aspects of rigor and relevance of the research methods are reported in Paper 6.

9.8 Limitations of this Dissertation

Limitations of the specific studies within this publication have been embedded within the above manuscripts. However, there are a few limitations of my overall dissertation research program that should be acknowledged.

Our sample has a few limitations. As noted in Paper 6, ideally we would have used purposive sampling to ensure broader participant perspectives. However, due to time and resource constraints with our multi-phase iterative research design, we ultimately used convenience sampling among eligible participants. These time constraints were caused in part by timeline delays, including requiring additional IRB amendments for Phases 2 and 3 of the iterative design (amendments which sometimes took 3-6 months to acquire, during which time we worked on the Rigor Cycle literature reviews); as well family and health challenges; and the COVID-19 pandemic overwhelming everyone and de-prioritizing research activities. Still, formative design research is typically conducted first with convenience sampling of target end-users who will be highly interested in the problem-solving artifact; later, usability and refinement research is conducted to improve the design of the intervention for broader populations than the original target participant/end-users (Cornet et al., 2020). Therefore, beginning this research with convenience sampling is not a strong limitation.

The features of iRespite for coordinating respite care, i.e., CareNOW and CareMATCH, do not address broader social issues of part-time and gig-economy labor, such as a lack of benefits or guaranteed wages for a care provider workforce composed of women who are disproportionately racialized (Ticona & Mateescu, 2018). Homecare services in Canada are frequently contract-based with part-time employment, and iRespite is not a radical strategy for overhauling this complex and entrenched state (Afzal et al., 2018); instead, advocacy strategies to advance that parallel work were noted in the discussion of Paper 6. Rather, iRespite is designed to offer pragmatic solutions to challenges that exist within the homecare context we currently have, such as addressing challenges of: flexibility, appropriate provider training, provider recruitment (e.g., providers setting their own rates and schedule, and engaging in an online community of practice), families' awareness of services, and families' engagement with services.

The digital divide also presents a limitation of this research. Participants had to have access to and be able to use a device capable of videoconferencing over the Internet. Apps ultimately are for people with smartphones and Internet access, which most people in Canada have now, but not all do (*Statcan*, 2023; *Statcan*, 2021). As of 2022, 94% of Canadian households had home Internet access in Canada (*Statcan*, 2023). However, older adults, those living in northern or rural regions, and those with fewer financial resources, are all less likely to have reliable Internet or smartphone access (Singh & Chobotaru, 2022; *Statcan*, 2023; *Statcan*, 2021). Given that the aim of this research was focused on appropriate digital health design for those who will engage with this digital health intervention, requiring participants to have access to digital tools to participate made sense. However, this restriction still limits the ability of this research to support families without Internet or smartphone access. To partially address this digital divide issue, one of the key modules for the app – the respite care agencies navigator – was built to both be a printable .pdf and an interactive, searchable database (Figure 5.1.1 in Chapter 5) (Castro, Lalonde-LeBlond, et al., 2024). However, some aspects of the app, such as CareNOW and CareMATCH are inherently dependent on end-users already having access to a smartphone and the Internet.

10.0 Conclusion

This research aimed to address noted challenges in respite care access for families with advanced and palliative cancers, by designing a digital health platform to help families more easily access in-home respite care services. The goal of this participatory research was to rigorously design a formative proof-of-concept of a bilingual app that families and nurses perceive to be relevant for facilitating access to in-home respite care services for families coping with advanced cancers in Quebec. Over the course of our work on six manuscripts, three grant applications (two funded, totalling $120,000), 15 trainees, three Expert Council meetings, and 26 participant interviews, I have accomplished this goal.

Working closely with a transdisciplinary research team and Expert Council, we iteratively interviewed nurses, family caregivers, and care-receivers, to co-create a proof-of-concept of the app that includes features to directly coordinate respite care, provide support through a chatbot, and connect families with a database of palliative respite care agencies. Overall, iRespite shows promise for improving access to essential respite care services for families coping with advanced and palliative cancers. With successful testing and implementation, iRespite could be scaled up to support families nationwide. By improving access to respite care, iRespite has the potential to enhance caregivers' and care-receivers' well-being, helping families coping with advanced and palliative cancers to remain at home together.

11.0 Comprehensive Bibliography of This Dissertation

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12.0 Appendices

12.1 Appendix 1: Blog post for Paper 2: Evolving the label of "informal" care towards a strengths-based connotation

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Featured currently in ANS is the article titled "'Informal Caregiver' in Nursing: An Evolutionary Concept Analysis"*, authored by Aimee R. Castro, MSc(A), RN; Antonia Arnaert, PhD, RN; Karyn Moffatt, PhD; John Kildea, PhD; Vasiliki Bitzas, PhD, RN, and Argerie Tsimicalis, PhD, RN. Here, Nurse and PhD candidate Castro reflects on how knowledge products – including this concept analysis – keep evolving, just as Rogers argues in her methodology.*

Evolving the label of "informal" care towards a strengths-based connotation

Given that April 4th was National Caregiver Day in Canada, and President Biden also declared April as Care Workers Recognition Month, April seems like an appropriate time to further reflect on the spectrum, boundaries, and potential of informal and formal caregiving work.

I think it's important for academics – professionals whose job it is to become leading experts in specific areas of knowledge – to take theoretical leaps. We should take big swings at ideas that maybe don't always "reveal themselves in the data" but that, based on our years of rigorous study and lived experience, bubble to the surface of our minds as potential expansions of knowledge. These inspirations most often occur in collaboration with others, and they develop slowly over time.

I was privileged enough to have just such a theoretically enriching collaboration. This conversation expanded my ideas of how the concept of "informal caregiver" might evolve even further than we suggested in our original publication, which was based on data from 48 articles. **Specifically, in this post, I argue that the "informal" label can and should be reclaimed as having its own strengths that complement weaknesses arising from "formal" labels and rules.**

This reflection came about during a lunch and learn presentation of our concept analysis with the palliative care research network of Quebec (RQSPAL). The moderator, Psychology PhD candidate Émilie Cormier, pointed out that we had defined "informal" by what it was not – i.e., not paid, not trained, and not formally organized. But what if we had defined it by what it is - more individualized, and perhaps, creative, than formalized or standardized roles can be? She also shared how in her work with palliative care populations experiencing homelessness, she's noticed that sometimes clients' formal care providers (such as their social workers and nurses) become clients' informal caregivers during end-of-life. Such formal roles may transition into more informal relationships over the years, because of these populations' often more limited informal support networks.

We talked about the freedom and opportunities that can arise when we're allowed to drop the boundaries and responsibilities created by our formal titles, and instead be informal creative collaborators in the life journeys of others. And we reflected on the moral distress that can also arise, when our clinician orders and institutional rules tie our hands, preventing us from truly supporting patients' individual needs (homeless shelters that restrict certain prescriptions comes to mind; as do hospital units that don't allow pets to be with patients at end-of-life, and standards that require waking patients up early to take their blood pressure or give insulin, but that ignore the consequences of sleep deprivation). There's also something here to consider about how patient-centered care necessitates critical thinking and adaptations of formal rules. After all, no set of guidelines can ever fit every patient's unique needs.

As Rodgers' methodology recognizes, no paper or concept is ever "finished". So, having authored this initial concept analysis of "informal caregiver", I'd like us to consider evolving it further: What if "informal" can be seen as a strength, not just less-than-or-equal-to "formal" work, but rather – offering creative opportunities to color outside the lines of formal guidelines? What if we need both, informal (freer and more creative) and formal (standards and structure) dimensions in all of our caring roles?

For further information on Aimee Castro's research, as well as to connect, please follow her on Twitter (@AimeeRCastro*) and visit:* https://aimeecastro.com/irespite-services-irepit/ .