Exploring the Outcomes of Proxy Online Health Information Seeking Behaviour

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Abstract

Background

The Internet is now the first source of health information for over two-thirds of the North American population. People can use online health information in many ways, most commonly in discussion with healthcare providers or to become actively engaged in their own healthcare. Using online health information is generally associated with positive outcomes such as increased empowerment of seekers and their families, and improved health outcomes. Proxy information seekers are those who informally seek information on behalf of or because of others without necessarily being asked to do so. Proxy information seekers in a person's social circle may help this person overcome information-seeking barriers (e.g., when they have a low level of e-health literacy) and illness challenges (e.g., when they are too physically weak or mentally incapacitated to search themselves). Stated otherwise, people may be able to overcome difficulty related with seeking, finding, understanding, and appraising information on the internet by discussing the information found by proxy-seekers. However, little is known of the context, use, and reported outcomes of proxy online health information seeking. Moreover, there is no comprehensive model on proxy online health information seeking outcomes.

Objectives

The overarching research question of this thesis is: "What are the outcomes of proxy online health information seeking behaviour"? The specific research objectives are: (1) to develop and validate a theoretical model explaining the outcomes of proxy online health information seeking behaviour., (2) to explore and compare the outcomes reported by proxy seekers and self-seekers in the context of a parenting information website, and (3) to explore the outcomes of proxy seeking behaviour as well as the motivators and contexts from the perspective of proxy seekers.

Methods

To achieve these objectives, two main steps were followed. First, a mixed studies literature review integrating qualitative and quantitative evidence with framework synthesis of the

findings of 28 studies was conducted (Manuscript 1). This review allowed to develop an initial theoretical model on proxy online health information seeking outcomes. Second, a convergent mixed methods study was conducted and included qualitative and quantitative components that were analyzed separately and concomitantly, and then integrated. This study was conducted in partnership with Naître et Grandir (an online parenting resource) where the validated 'Information Assessment Method' (IAM) questionnaire had been implemented since 2014 to assess feedback from the readers. A two-year quantitative observational component compared IAM responses on information outcomes between parents of 0- to 8-year-old children and members of their entourage (grandparents, family members, friends, neighbours, or professionals working with children) (Manuscript 2). A qualitative descriptive component analyzed interviews with entourage members who had provided at least one IAM response from the quantitative study (Manuscript 3). The two components were integrated in two ways: by comparison of results to identify convergences and potential divergences, and by assimilation of quantitative data into qualitive data to produce vignettes describing typical scenarios of proxy online health information seeking.

Findings

In the quantitative study, 51,325 IAM responses were analyzed. Compared to parents, the entourage are more likely to report using the information in discussion with others. The differences in perceived benefits of online parenting information by the entourage, depends on how they access the information. Respondents who were actively seeking the information were more likely to report that the information will help them be less worried, will help them handle a problem, and help them decide what to do with someone else. Respondents who passively acquired the information through a weekly newsletter were more likely to report the information would help improve the health or well-being of a child. In the qualitative study, 14 entourage members were interviewed. Participants were proxy-seeking for reassurance, out of personal curiosity, as part of their professional role, or following an explicit request from the parents. Participants described their online seeking strategies, including how they usually assessed websites for credibility. They used the information to provide informational support (either by sharing the webpage directly or discussing its content), or to provide practical support for a child in their care (e.g.,

playing games with a child), or to provide emotional support. In some cases, they did not share the information to avoid tensions with the parents in question. Finally, they generally reported positive outcomes of using the information. The most common outcome reported was improvement in the relationship with others. Moreover, some interpersonal tensions were described as a result of sharing the information, specifically when it was unsolicited.

Discussion and Conclusion

Three main themes were explored across the three manuscripts: (1) the context and motivations of proxy online health information seeking, (2) the use of online health information by proxy seekers, and (3) the outcomes of this use. Findings between the quantitative and qualitative components converged in general, and new qualitative findings led new response items being proposed to adapt the IAM questionnaire to proxy online health information seekers. The first contribution of this dissertation is theoretical: findings from this study advances scientific knowledge on proxy online health information seeking behaviour and outcomes. The initial theoretical model was revised to incorporate findings from the mixed methods study. The second contribution is methodological: integrating quantitative and qualitative components by assimilation through storytelling to produce four vignettes covering the main findings. This is a rarely used technique in mixed methods research. The third contribution is practical: this is an important topic for both information specialists and health care practitioners. By better understanding how people and their entourage use information together, information providers can better adapt information to meet both their needs, and health care practitioners (e.g., family physicians) can target patients' entourage with information for dissemination and use. Patients can be encouraged to turn to their entourage for support using online health information.

Résume

Contexte

Internet est désormais la première source d'informations sur la santé pour plus de deux tiers de la population nord-américaine. Les gens peuvent utiliser les informations de santé en ligne de nombreuses façons, le plus souvent en discutant avec les professionnel.les de la santé ou pour s'engager activement dans leurs propres soins de santé. L'utilisation de l'information en ligne sur la santé est généralement associée à des effets positifs, tels qu'une plus grande responsabilisation des gens et de leur famille, et une amélioration de l'état de santé. Les personnes qui recherchent des informations par procuration sont celles qui, de manière informelle, recherchent des informations au nom ou à cause d'autres personnes sans qu'on leur demande nécessairement de le faire. Les gens qui recherchent des informations par procuration (agents mandataires) dans l'entourage d'une personne peuvent l'aider à surmonter les obstacles à la recherche d'informations (par exemple, lorsque cette personne a un faible niveau de littéracie numérique en santé) et les difficultés liées à la maladie (par exemple, lorsque cette personne est trop faible physiquement pour chercher elle-même). En d'autres termes, les personnes peuvent surmonter les difficultés liées à la recherche, à la compréhension et à l'évaluation des informations web en discutant des informations trouvées par ceux et celles qui le font pour elles. Cependant, on sait peu de choses sur le contexte, l'utilisation et les effets des recherches d'informations web trouvées par procuration. En outre, il n'existe pas de modèle théorique expliquant ces effets.

Objectifs

La question de recherche principale de cette thèse est la suivante : Quels sont les effets des recherches d'informations web trouvées par procuration? Les objectifs spécifiques de cette recherche doctorale sont les suivants : (a) développer et valider un modèle théorique expliquant ces effets, (b) explorer et comparer les effets rapportés par gens qui cherchent des informations par procuration versus les personnes qui cherchent des informations pour elles-mêmes dans le contexte d'un site web d'informations parentales, et (c) explorer les effets des recherches d’informations web par procuration ainsi que les motivations et les contextes du point de vue des gens qui cherchent par procuration.

Méthodes

Pour atteindre ces objectifs, deux étapes principales ont été suivies. Premièrement, une revue mixte de la littérature a été réalisée. Cette revue a inclus des études qualitatives et quantitatives. Les résultats des 28 études inclues ont été synthétisés (Manuscrit 1). Cette synthèse a permis de développer un modèle théorique initial sur les effets des recherches d’informations web par procuration. Deuxièmement, une étude utilisant des méthodes mixtes (devis convergent) a été mise en œuvre. Elle a inclus des composantes qualitatives et quantitatives qui ont été menées séparément de manière concomitante, puis intégrées. Cette étude a été réalisée en partenariat avec Naître et Grandir (N&G) qui produit un magazine, un site web et une infolettre incluant des informations pour les parents de jeunes enfants. Le questionnaire validé de la Méthode d'évaluation de l'information (MEI) est disponible depuis 2014 sur le site web de N&G pour faciliter l’évaluation des fiches N&G (pages web) par les personnes qui les lisent. Une étude quantitative observationnelle longitudinale a permis de comparer les réponses MEI recueillies pendant deux ans sur les effets perçus des fiches N&G entre deux groupes : les parents d'enfants âgés de 0 à 8 ans versus les membres de leur entourage (grands-parents, membres de la famille, ami.es, voisin.es ou professionnel.les travaillant avec des enfants) (Manuscrit 2). Une étude qualitative descriptive a recueilli et analysé les entrevues avec des membres de l'entourage qui avaient fourni au moins une réponse MEI (Manuscrit 3). Les deux études ont été intégrées de deux façons : en comparant les effets des informations pour identifier les convergences et les divergences entre les deux groupes, et en fusionnant les données quantitatives et qualitatives pour produire des vignettes qui décrivent les scénarios typiques des recherches d’informations web par procuration.

Résultats

Dans l'étude quantitative, 51 325 réponses MEI ont été analysées. Par rapport aux parents, l'entourage est plus susceptible de déclarer utiliser le contenu des fiches N&G dans le cadre

de discussions avec d'autres personnes. Les différences dans les bénéfices perçus des informations parentales en ligne par l'entourage, dépendent de la manière dont ils accèdent à l'information. Les répondant.es qui recherchaient activement de l'information directement sur le site web étaient plus susceptibles de déclarer que l'information les aiderait à être moins inquiets, les aiderait à gérer un problème et les aiderait à décider quoi faire avec quelqu'un d'autre. Les répondant.es qui ont acquis passivement l'information par le biais de l'infolettre hebdomadaire étaient plus susceptibles de déclarer que l'information les aiderait à améliorer la santé ou le bien-être d'un enfant. Dans l'étude qualitative, 14 membres de l'entourage ont été interrogé.es. Les participant.es disaient chercher de l'information pour se rassurer, par curiosité personnelle, dans le cadre de leur rôle professionnel ou suite à une demande explicite des parents. Les participant.es ont décrit leurs stratégies de recherche en ligne, notamment la façon dont ils évaluaient habituellement la crédibilité des sites web. Ils ont dit utiliser le contenu des fiches N&G pour apporter un soutien informationnel (soit en partageant directement la page web, soit en discutant de son contenu), ou pour apporter un soutien matériel à un enfant dont ils avaient la charge (par exemple, en jouant à des jeux avec un enfant), ou pour apporter un soutien émotionnel. Dans certains cas, ils n'ont pas partagé l'information pour éviter les tensions avec les parents. Enfin, ils ont généralement rapporté des effets positifs de l'utilisation de l'information. L'effet le plus souvent rapporté est l'amélioration de la relation avec les autres. Par ailleurs, certaines tensions interpersonnelles ont été décrites comme résultant du partage de l'information, en particulier lorsque celui-ci n'était pas sollicité.

Discussion et conclusion

Trois thèmes principaux ont été explorés dans les trois manuscrits : (1) le contexte et les motivations de la recherche d'information web sur la santé par procuration, (2) l'utilisation de cette information par les gens qui cherchent par procuration, et (3) les effets de cette utilisation. Les résultats des composantes quantitatives et qualitatives convergeaient en général, et des résultats qualitatifs ont permis de proposer des nouvelles questions pour adapter le questionnaire MEI aux recherches d'information par procuration. La première

contribution de cette thèse est théorique : les résultats de cette recherche doctorale font progresser les connaissances scientifiques sur le comportement et les effets de la recherche d'information web sur la santé par procuration. Le modèle théorique initial a été révisé pour intégrer les résultats des études quantitatives et qualitatives. La deuxième contribution est d'ordre méthodologique : l'intégration des composantes quantitatives et qualitatives par assimilation pour produire quatre vignettes couvrant les principaux résultats. Il s'agit d'une technique rarement utilisée dans la recherche utilisant les méthodes mixtes. La troisième contribution est d'ordre pratique : il s'agit d'un sujet important pour les spécialistes de l'information et les clinicien.nes. Mieux comprendre comment les personnes et leur entourage utilisent ensemble l'information permet deux choses : (a) les fournisseurs d'information peuvent mieux adapter le contenu informationnel pour répondre à leurs besoins respectifs, et (b) les clinicien.nes (par exemple, les médecins de famille) peuvent cibler l'entourage des patients en partageant de l’information fiable facile à lire, écouter, diffuser et utiliser. Les patient.es peuvent être encouragé.es à se tourner vers leur entourage pour obtenir un soutien dans l'utilisation des informations web sur la santé.

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List of Abbreviations

CMIS: Comprehensive Model of Information Seeking
IAM : Information Assessment Method
IRB : Institutional Review Board OHI: Online health information
MMR : Mixed Methods Research
N&G: Naître et grandir
OHI: Online health information
OPR: Organizational Participatory Research

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Chapter 1: Introduction

The majority of the population now turn to the Internet as their first source of health information. These online health information users seek information for themselves (self-seekers) or on behalf of others in their social circle (proxy-seekers). While the use of online health information is generally associated with positive outcomes for self-seekers, little is known on how proxy-seekers use the information and what outcomes they report. The general objective of this thesis is to explore proxy online health information seeking behaviour and its outcomes.

This objective emerged while working on two previous projects. The first was my MSc project: a qualitative interpretive study that explored the negative outcomes of online health information (OHI). I conducted 19 interviews with members from the general public and 10 health care providers and health librarians. Negative outcomes included tensions in the relationship with others and one of the strategies proposed to reduce negative outcomes is to discuss the OHI with a health professional or someone in their social network. The following quotes highlighted these two themes:

> *"One of my aunts that I'm really close to takes online health info way too far, she stays with us a couple of weeks every year with her son and everything online, she follows, it doesn't matter where it's from which is horrible because the Internet has all sort of things… This situation caused stress between family members worried about the information she used…* [I educated her on OHI and] *… she had another baby, and now her research has become moderated and is not so extreme… She's became a little less naive as she's seen that people can post whatever they want. I always try to see if sites have actual backup for what they say."* –Vanessa (pseudonym)

> *"My own solution is asking family and friends if they have answers and for their opinion* [on the information], *if they think I should consult a doctor then I probably would."*- Mariah (pseudonym)

The second project is an ongoing partnership with Naître et Grandir, a Quebec-based parenting website, that implemented a validated evaluation questionnaire on their website inviting their readers to provide feedback on the information content. I have been preparing reports on the questionnaire responses since 2014, and I have found that each year, between 25% and 50% of respondents are not parents, they identify as entourage members (grandparents, family members, friends or professionals who work with children). The following is an example of some of the comments they have provided:

> *"Thank you for all the information you share with us in Naître et Grandir. I am a new grandmother of twins who is helping the new little family as best she can with her experience. But your information comforts me and helps me to accompany the new parents, who have had to take on the role in an accelerated manner. Because two babies are something! Thank you again!" – Grandmother1 (translated from French)*
>
> *"This is a very informative piece of writing that helps to ease the guilt of parents who feel "helpless" or "incapable". I didn't have a baby myself, but I was very present for my sister's babies, and I had the opportunity to soothe the cries of my two nephews on many occasions. I was reminded of some of those moments when I read this text, which confirmed or denied what I believed at the time." – Aunt (translated from French)*

As a result of working on these two projects, my curiosity was sparked: when and how do people seek online health information for others in their social circle? How do they use information they deem relevant? And what outcomes (positive and negative) do they report as a result of this use?

Online Health Information

Online health information (henceforth OHI) is the term generally used to refer to the information found online on health and diseases created for and directed to the general public (HLWIKI, 2015). There are generally two main categories of OHI: expert systems and general information. Expert or decision support systems use patient-specific data (e.g., their lifestyle) to make personalized recommendations or programmed decision-making (Simon, 1980). General information, on the other hand, is for non-programmed decision-making and is available in many formats: written, audio (e.g., podcasts) and video. It is available in government health sites, professional organizations websites, health journals, online forums, and blogs among other sources.

Moreover, people are also being passively exposed to OHI 'posts' being shared by their social network through social media platforms such as Facebook (Fox & Jones, 2012). This thesis is about general OHI.

Two-thirds (67%) of respondents to the American Health Information National Trends Survey between 2008 and 2017 reported turning to the Internet first for health information (Finney Rutten et al., 2019). Similarly, 69% of Canadians reported using the Internet to search for health information in 2020 (Statistics Canada, 2020). People can use OHI in many ways, most commonly in consultation with health practitioners, for engagement in healthcare, compliance with or modification of management plan, or support of relatives or friends with health conditions (Pierre Pluye et al., 2013). Using OHI is generally associated with positive outcomes (perceived effects of using OHI) such as increased empowerment of people and their families, and improved health outcomes (Amante et al., 2015; Case & Given, 2016; Pluye et al., 2020; Prescott & Mackie, 2017). There may be negative outcomes (referred to as tensions in previous work), such as increased anxiety or worsening of the patient-physician relationship, but there are strategies to reduce these tensions such as providing reliable resources or teaching people how to evaluate OHI (El Sherif et al., 2018).

In this thesis, health is conceived as mental, physical and social wellbeing (in accordance with classical definition of the World Health Organization), which includes parenting and child development. Therefore, I focus on parenting and child development online information as a subset of OHI. This is primarily due to the nature of the existing partnership with Naître et Grandir who provide this information, but also because parents of young children are one of the largest groups of OHI consumers (Kubb & Foran, 2020). Findings on consumers of this information would likely be generalizable to the larger population of OHI seekers.

Proxy Online Health Information Seeking

Several contextual factors are associated with health outcomes such as age, education, income, e-health literacy and social support (Pluye et al., 2019). Social support is an important factor because one of the main reasons people search for and use OHI is to support their relatives or friends with health conditions (Pierre Pluye et al., 2013). Moreover, findings from a study exploring Internet use trends between 2008 and 2013 shows a significant increase in the mobilization of family and friends to obtain health information (Massey, 2016). People are sometimes more likely to turn to their social circle to make sense of information they find, rather than discuss it with a health professional (Abrahamson et al., 2008; Reifegerste et al., 2017).

Proxy information seekers can be defined as "those who seek information in a non-professional or informal capacity on behalf (or because) of others without necessarily being asked to do so" (Abrahamson et al., 2008). Proxy seekers may also be "experts", such as health librarians or healthcare professionals, with the specialized knowledge or skills to use the information with the person with whom they share a personal relationship (Wyatt et al., 2005). People may be able to overcome low e-health literacy by discussing the information they find with others (El Sherif et al., 2018). Proxy-seekers in a person's social circle may help them overcome information-seeking barriers and illness challenges (e.g., they are too physically weak or mentally incapacitated to search themselves) (Abrahamson et al., 2008).

While this phenomenon of proxy information seeking behaviour has been explored in the literature, especially as related to health information, little is known of the proxy information seekers context of seeking OHI, use of OHI and subsequent reported outcomes. Moreover, there is no comprehensive model on OHI proxy seeking outcomes. By better understanding how proxy-seekers and people in their social circle use information together, information providers can better adapt the information to meet both needs, and public health interventions can target patients' friends and family with information for dissemination and use (Kim et al., 2015).

Research Problem and Research Questions

In summary, the Internet has become a worldwide information pull and push technology, the use of which has increased exponentially over the past decade. In the health sector, numerous studies and literature reviews on Internet access, quality of information, and patients' information needs and seeking behaviour have been conducted. From this work, we know that Internet use generates important positive outcomes and unintended negative consequences from the perspective of self-seekers. However, we do not know how proxy-seekers use OHI and what outcomes they report. Moreover, while there are a number of models and frameworks on proxy information seeking, few focus on OHI and none incorporate outcomes of using OHI. Therefore, the overarching research question of this thesis is: "What are the outcomes of proxy online health information seeking behaviour"? The specific research objectives are:

1. To explore the motivators, contexts and outcomes of proxy seeking behavior from the perspective of proxy seekers,
2. To explore and compare the outcomes reported by proxy seekers and self-seekers in the context of a parenting information website, and
3. To develop and validate a conceptual framework on the outcomes of proxy OHI seeking behaviour.

Table 1 provides a mapping of the research gaps to the research objectives and corresponding dissertation chapters and manuscripts.

Table 1. Map of Research Gaps to Research Objectives and Corresponding Manuscripts

Research Gap	Research Objective	Corresponding Chapter/Manuscript
No comprehensive model on OHI proxy seeking outcomes	To develop and validate a conceptual framework	Chapter 3 – Manuscript 1
Few studies comparing OHI use, and outcomes reported by self- and proxy-seekers	To explore and compare the outcomes reported by proxy seekers and self-seekers	Chapter 5 – Manuscript 2

Few studies exploring information needs, contexts, and outcomes of OHI proxy seeking behaviour	To explore the motivators, contexts and outcomes of proxy seeking behavior	Chapter 6 – Manuscript 3

Epistemological Assumptions

My doctoral journey has allowed me to reflect on my worldview, specifically as related to my choice of research project, methodology and research partners. I have been a teaching assistant on a graduate course on scientific worldviews in mixed methods research since 2017, which has provided me with a venue for rich discussions on this topic, and which spawned several research projects with my supervisor and colleagues (P et al., 2021). We have explored five main worldviews in depth: post-positivism, social constructionism, pragmatism, critical realism, and critical theory.

Although I am still on this journey of self-discovery (and will likely continue to be so for the rest of my career), I found early on that it was *pragmatism* that resonated with me the strongest. Pragmatism, in summary, emphasizes the connection between thought and action (Kilpinen, 2008). It has been referred to as the “anti-philosophy” by Johnson and Onwuegbuzie (in a paper cited over 19,000 times), as it prefers action to philosophizing, (Johnson & Onwuegbuzie, 2004) and it places more importance on finding a working solution rather than adhering to one paradigmatic stance (Giddings & Grant, 2007).

It is this pragmatist worldview and focus on action that has guided my choice of research project, which was born from a real knowledge gap uncovered during a previous research project and an ongoing research partnership. The results of this doctoral project will be applied directly with our research partners, Naître et Grandir (described in detail in Chapter 4). This has also guided my choice of research approach: an organizational participatory approach (described in Chapter 4) allows for ongoing interaction with and feedback from the research partners that would lead to quicker implementation of the project findings. Finally, this has also guided my choice of research methodology: a mixed methods research study (described in Chapter 4). In pragmatism, knowledge is viewed as “being both constructed and based on the reality of the world we experience and live in" (Johnson & Onwuegbuzie, 2004). To address my research questions, I draw from two diverse sources of evidence which allows me to paint a full picture of the phenomenon I am studying. With pragmatism, researchers "derive knowledge from their analysis of participants' actions and seek to use this knowledge to improve these actions, e.g., developmental evaluation of programs with iterative cycles 'planning, implementation, evaluation, improvement'" (Pluye et al., 2021).

Structure of this Dissertation

This dissertation is organized into eight chapters:

- Chapter 1 introduces this project by providing an overview of the relevant constructs explored (online health information and proxy seeking). The research problem and research questions are stated, as are the epistemological assumptions guiding this dissertation. Finally, the potential impact of this research project in terms of practical and theoretical contributions are explained.
- Chapter 2 provides an overview of the current state of knowledge on three main constructs: information seeking, online health information outcomes, and social support. The intersection of these three constructs is the focus of this thesis. Relevant conceptual models and theoretical frameworks are explored, and the terms used throughout this thesis are defined. This chapter ends with three knowledge gaps that are uncovered by the literature.
- Chapter 3 focuses on the first knowledge gap uncovered: the lack of comprehensive conceptual model on the role proxy seekers in the context of online health information. It describes a literature review with framework synthesis. This framework was used to guide the subsequent phases of this dissertation project. This chapter comprises the first manuscript in this dissertation which was submitted to the Journal of Medical Internet Research (JMIR) in October 2021.

- Chapter 4 addresses the methodology of this project. The organizational participatory approach used is described, including details of the partnership between Naître et Grandir and McGill University. The overall study design consisting of a convergent mixed methods research study is described. Then, the methodology used in each component (qualitative and quantitative) as well as integration strategies are presented. This chapter ends with the ethical considerations.
- Chapter 5 describes the first component of the mixed methods research study: a quantitative observational study exploring the outcomes of proxy information seekers of the Naître et Grandir website. This chapter comprises the second manuscript in this dissertation. It was accepted for publication in JMIR Parenting and Pediatrics in October 2021.
- Chapter 6 describes the second component of the mixed methods research study: a qualitative descriptive study exploring the contexts, behaviours and outcomes reported by proxy information seekers recruited from the dataset of Naître et Grandir readers. This chapter comprises the third manuscript in this dissertation. It was submitted for publication to the Journal of Health Communication.
- Chapter 7 describes the integration of the two components of the mixed methods research study and discusses the findings of this project and presents a revised version of the conceptual framework on the outcomes of proxy information seeking behaviour. The main limitations, strengths and contributions of this project are discussed.
- Chapter 8 concludes this dissertation with some final remarks and directions for future research.

Contributions of the authors

I am the primary author of all the chapters in this thesis, including the manuscripts that make up Chapters 2, 4 and 5. I am grateful for the strong support and constructive feedback provided by my supervisor Dr. Pierre Pluye who, in addition to reviewing every single chapter of this thesis, has engaged me in endless hours of discussion on this topic and provided me with countless relevant references over the years.

- <u>Chapters 1 (introduction), 2 (review of the literature), 4 (methods), 7 (discussion) and 8 (conclusion):</u>

I am the sole author of these chapters, and feedback was provided by Dr. Pluye who reviewed the initial versions as well as the revised versions of these chapters. I am also grateful for the feedback that was helpfully provided by Dr. Quan Nha Hong on Chapters 1, 4 and 7.

- <u>Chapter 3 (Manuscript 1 – literature review with framework synthesis):</u>

I am the first author of this manuscript. Dr. Pluye and Dr. Ibekwe are co-authors who contributed to the review design and interpretation of findings, and who provided constructive feedback on the manuscript. I gratefully acknowledge Ms. Vera Granikov and Dr. Quan Nha Hong for their help in reviewing this manuscript and providing constructive feedback. I also acknowledge Dr. Suzanne Rivard who reviewed an initial version of the framework as part of a graduate course in the Hautes études commerciales de Montréal business school (HEC) on Theory Development in Winter 2018, and who provided extremely valuable feedback.

- <u>Chapter 5 (Manuscript 2 – quantitative study):</u>

I am the first author of this manuscript, and I performed the statistical analysis. Drs Pluye and Grad contributed to the data collection. Dr. Pluye, Dr. Schuster, and Dr. Grad contributed to the study design and review of this manuscript, as well as in the interpretation of the findings. I gratefully acknowledge the contributions of Dr. Fidelia Ibekwe to the study protocol.

- <u>Chapter 6 (Manuscript 3 – qualitative study)</u>

I am the first author of this manuscript, and I performed the qualitative analysis. Drs Pluye and Grad contributed to the data collection. Ms. Virginie Paquet is a health librarian and information specialist who provided feedback on the interview guide and conducted the interviews in French. Ms. Paquet, Dr. Pluye, Dr. Ibekwe, and Dr. Grad contributed to the study design and review of this manuscript, as well as in the interpretation of the findings.

List of appendices

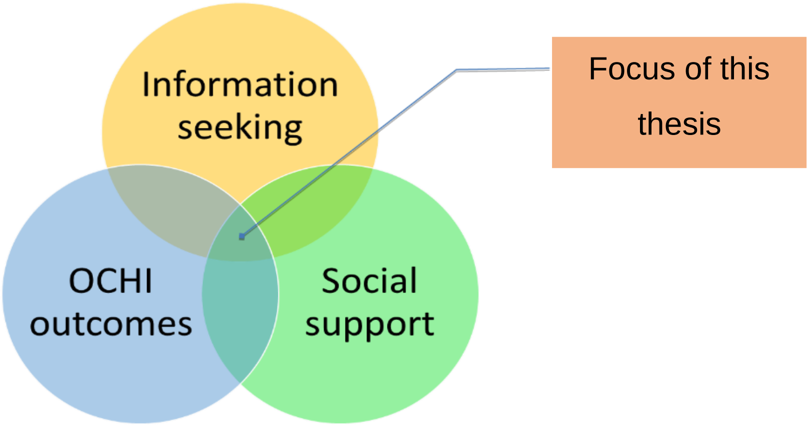
Appendices 1 to 5 at the end of the thesis contain additional files associated with Chapters 3-6 and are referenced in their corresponding chapter.

- Appendix 1: Includes the table describing the characteristics of the studies included in the literature review described in Manuscript 1.
- Appendix 2: Includes the N&G-IAM Questionnaire v.2019 implemented by Naître et Grandir and used in the quantitative study described in Manuscript 2.
- Appendix 3: Includes the Interview Guide used in the qualitative study that is described in Manuscript 3.
- Appendix 4: Includes the documents related to the Institutional Review Board ethical approval submission for the studies described in Manuscripts 2 and 3. This includes ethics certificates and consent forms.
- Appendix 5: Includes the codebook developed and used during the qualitative analysis in the study described in Manuscript 3.
- Appendix 6: Includes figures of some of the relevant information seeking behaviour models referenced in the Discussion.

Chapter 2: Review of the Literature

I elaborate on three main constructs in this section because I am interested in studying their intersection in this thesis (Figure 1). Several models are described in this chapter that act as tools to guide the analysis and our understanding of these constructs. First, I summarize the construct of information seeking, and more specifically proxy information seekers from the discipline of information science. I summarize two relevant models on proxy information seeking behaviour. Next, I describe OHI outcomes and an existing conceptual model. Finally, I introduce the construct of social support and define the key related concepts that will be used in this thesis.

Figure 1 The intersection between three main constructs



Information Seeking

Information seeking encompasses “all the information that comes to a human being during a lifetime, not just in those moments when a person actively seeks information” (Bates, 2002, p. 3). Information seeking could be summarized as a user perceiving an information need, who will then interact with a formal or an informal source of information, to successfully locate (or not) a relevant piece of information, and potentially use this information. Case and Given suggest that since information need is fundamental, information seeking can be simply defined as "what people do in response to a need for information"(Case & Given, 2016).

The focus of my work is on the interaction between proxy-seeker and the person, so the concept of "information need" is very important. I specifically selected Bates' model as she includes the information needs in her model and provides a simple and clear definition and classification of information seeking. She proposes an integrated model to organize information seeking into four modes (Table 2): passive, active, directed, and undirected (Bates, 2002). In the active mode, a person does "anything actively to acquire information"; in passive seeking, the person is "passively available to absorb information, but does not seek it out" (Bates, 2002). In directed seeking, the person seeks specific information; while undirected, people are "randomly exposing themselves to information" (Bates, 2002). An important feature that differentiates directed and undirected seeking is the information need, known in the former and unknown in the latter.

After setting up the four modes, Bates associates different seeking methods with each mode (e.g., browsing), which allows her to call the model "integrated" (Table 2). Monitoring and directed searching are ways to answer a known information need (information that we know we need to know). Browsing and being aware are ways to answer unknown information needs (information that we do not know we need to know). Throughout these modes, there are intervening variables which may be related to personal characteristics, to social or interpersonal issues, or to environmental considerations (Wilson, 1999). Table 3 summarizes the key constructs related to information behaviour.

Table 2. Bates's integrated model of information seeking

	Active	**Passive**
Directed (known information need)	Searching	Monitoring
Undirected (unknown information need)	Browsing	Being aware

Table 3. Summary of the key constructs related to information seeking

Construct	Definition	Source
Information need	A condition in which "certain information contributes to the achievement of a genuine or legitimate information purpose". These needs may be explicitly stated or implicitly understood based on a person's status or situation. Curiosity is considered a precursor to needs.	(Case & Given, 2016; Derr, 1983)
Information seeking	Describes the actions people take in response to an information need, and can be passive, active, directed, and undirected	(Bates, 2002)
Information searching	Also referred to as information retrieval. "Finding material (usually documents) of an unstructured nature (usually text) that satisfies an information need from within large collections (usually stored on computers)".	(Larson, 2010)
Relevance/ pertinence	A measure of how well a retrieved information, document or set of documents meets the information need of the user	(Mizzaro, 1997)

Proxy Information Seeking

The role of proxy information seeking has been explored in the literature and has also been referred to as surrogate seeking or lay information mediation (Cutrona et al., 2015; Wathen et al., 2008). To our knowledge, there is no existing model of proxy OHI seeking behaviour that includes outcomes of using OHI for the proxy seeker and the individual(s) for whom they are seeking information. There are, however, three models that are relevant to this project: the Abrahamson & Fisher model where proxy information seeking behaviour in general is described, the Reifegerste model where characteristics of proxy OHI seekers are described and the Kubb model of parents as proxy-seekers.

Models of Proxy Information Seeking

A. Lay Information Mediary Behavior (LIMB) Model (Abrahamson & Fisher, 2007)

The authors reviewed past research and existing models and proposed a general model of lay information mediary information behaviour. They constructed their model over two views as shown in Figure 2:

- View 1 shows the information seeker, who is affected by contextual factors: cognitive, affective, physical, and social. The seeker engages with the information system through needs and information seeking behaviour.
- The seeker from View 1 becomes the imposer in View 2. View 2 depicts the general model of lay information mediary behaviour and includes the participants, stages, contexts, and characteristics, including motivations, challenges, and effects of lay information mediary behaviour. The definitions of these constructs are detailed in Table 4.

Figure 2. Lay Information Mediary Behavior Model

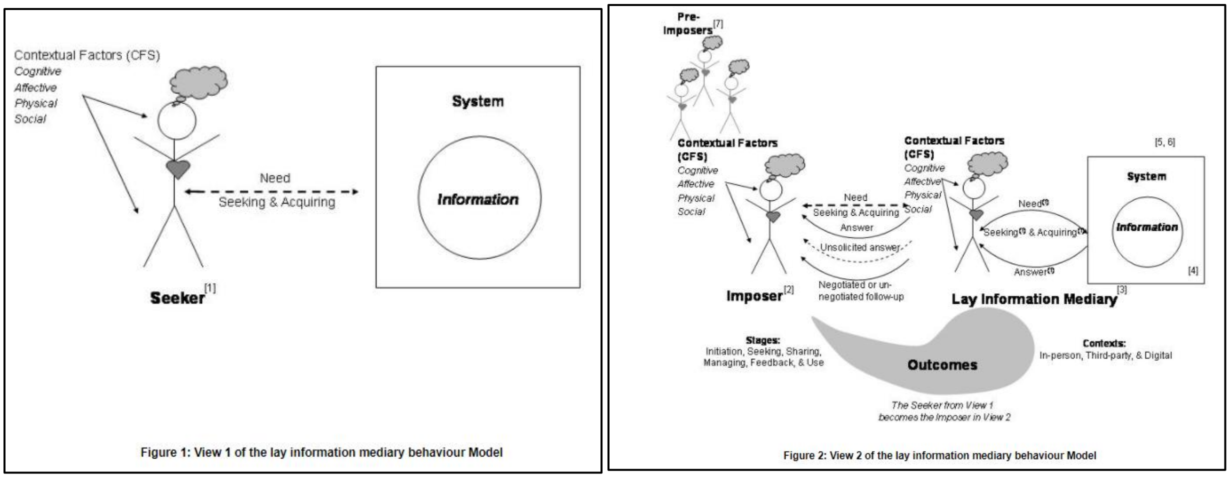


Figure 1: View 1 of the lay information mediary behaviour Model

Figure 2: View 2 of the lay information mediary behaviour Model

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Table 4. Concepts of the Abrahamson & Fisher model

Model Concepts	Definition
Participants	Participants include the "imposer" (the seeker from View 1) who imposes their information need on the "lay information mediary". Other participants include information systems, professional intermediaries, other stakeholders, and "pre-imposer" (e.g., a teacher giving the student/imposer an assignment). Lay information mediaries are more likely to be female, to have multilingual abilities as well as higher levels of education and income than imposers.
Stages	Stages include initiation, seeking, sharing, managing, feedback, and use of information. Seeking may be unintentional/serendipitous. The imposer may not be involved at all, e.g., when the lay information mediary behaviour is internally motivated (the imposer's information need is not made explicit). Feedback loops exist such that "the imposer may repeatedly request, seek, share, manage,

Model Concepts	**Definition**
	or use information as can the lay information mediary". The model highlights the nonlinear, iterative nature of lay information mediary behaviour and its effects.
Contexts	Related to the participants' particular cognitive, affective, social, and other factors at the time of information seeking, processing, and use.
Motivations for Help or Information Seeking	The motivations for lay information mediary behaviour for both lay information mediaries and imposers can include various barriers to information seeking such as general, information, and health. Other barriers include education, language skills, culture, affective load, illness, time constraints, information, and technology access.
Cognitive Factors	If mediary work is intrinsically (self) motivated cognitive factors include perceived barriers for an imposer if. If the mediary work is solicited by the imposer cognitive motivations may be related to a lay information mediary's desire to learn or to fill a knowledge gap.
Affective Factors	These include uncertainty (including irritation, anxiety, and rage), ambiguity and information overload are triggers or deterrents in information seeking. When the affective load is high, the imposer may directly or indirectly request help from the mediary. Information monitoring (for lay information mediaries) and blunting (for imposers) may also be included here as affective factors.
Physical Factors	These are related to health of the imposer (illness may be a barrier to information seeking) or the mediary (healthy individuals are more likely to be mediaries). Additional physical factors relate to geographic location in relation to the availability of information resources and services.
Social Factors	Social factors for lay information mediary behaviour may include "motivations to build or strengthen relationships, social capital, and social networks". External social barriers include socioeconomic (e.g., lack of access) and internal barriers are social and psychological (e.g., personality, motivation, interest, and involvement with others).
Needs	Any need that may require information to be fulfilled, and therefore broadly includes information problems or problem situations.
System and Sources	The system includes a variety of information sources including formal sources such as databases, books, and various types of media. Informal lay information mediary sources \ include interpersonal networks and mass media.
Effects/ Outcomes	Positive effects include **actions** such "as problem-solving, decision-making, task completion, building social capital in personal and occupational networks, instrumental help in the form of goods and services, and improved economic and **health outcomes**". Negative are related principally to "information flow, either too much (information overload) or too little (withheld information)".

Model Concepts	**Definition**
	"Information filtering by the mediary can produce either positive or negative effects. Time may be a factor in determining effects, as processing and use may be delayed, which should be considered when assessing the value of any lay information mediary information sharing. In addition, effects may be magnified such that sharing information with one person becomes sharing with many when resources, answers, and knowledge gains are shared by imposers. Answers and questions may or may not be solicited; follow-up between the lay information mediary and imposer may be requested or negotiated."

Limitation of this model in relation to my project: it focuses on information seeking in general rather than OHI. In addition, the outcomes described in this model are subsequent to the information seeking behaviour in general and include cognitive outcomes, different ways of using the information and outcomes of using the information.

B. Applying the Comprehensive Model of Information Seeking to Proxy Online Health Information Seeking (Reifegerste 2020)

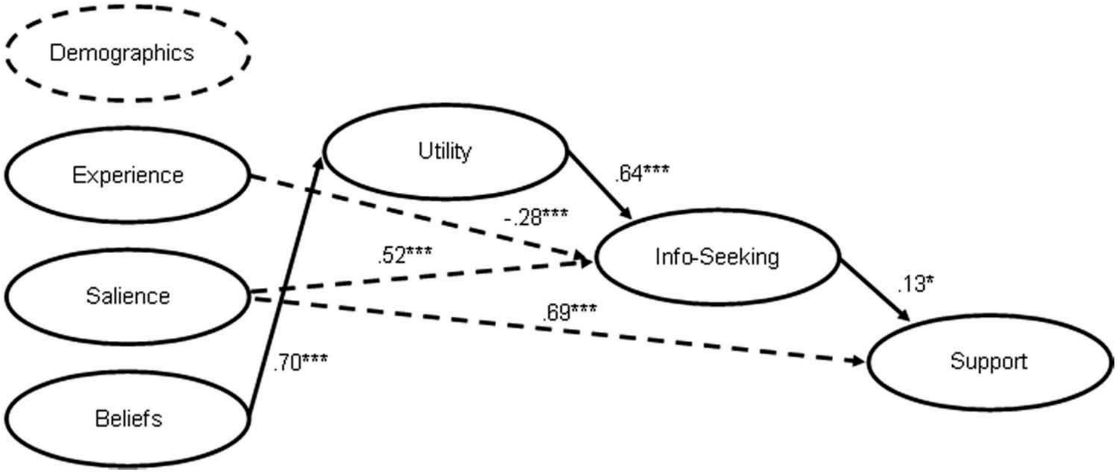
The comprehensive model of information seeking (CMIS) is a model where the focus is on the individual seeker and predicts information seeking behaviour by the health-related characteristics of the seeker and the information carrier factors. The authors modified and extended this model with concepts of social network ties to predict proxy information seeking and the resulting social support intentions. They developed hypothetical scenarios (n=607) of people with varying severity in depression and with varying relationship closeness. Structural equation modelling was used to test the associations between the health-related factors, proxy health information seeking intentions and support intentions. These constructs are defined in Table 5.

Table 5. Concepts of the Reifegerste Model

Model Concepts	Definition
Demographics	Several demographic characteristics have been associated with surrogate health information seeking in previous work, such as age, education, gender, family roles and relationship related variables (e.g., living with someone).
Direct Experience	Disease-related experience (e.g., health knowledge and medical expertise) can be associated with surrogate seeking and involvement in decision making.
Salience	Defined as "the subjective probability and fear that motivate HIS", i.e., worry and risk perception. In surrogate seeking this is the perceived risk for others.
Beliefs	Defined as "an individual's efficacy beliefs in medical procedures or illness management", this was also modified to refer to perception of being able to seek out health information (i.e., having a high self-efficacy).
Utility	Utility describes the ways in which information provided fulfills the seeker's needs, i.e., perceived usefulness of the information.
Informational and Esteem Support	These constructs were added to the CMIS model by the authors, based on Abrahamson & Fisher, 2007 and other work: "family members and friends actively seek information about a specific health problem to support the patient directly or indirectly." Thus, the authors hypothesized that support is the resulting action of surrogate OHIS.

In the final structural equation model in Figure 3, demographics, salience, and beliefs were not related to the utility of surrogate OHIS; however, beliefs were positively related to the utility of the information channel. Utility had a positive effect on surrogate OHIS, which in turn had a positive effect on support intentions. This is an important study that modifies an existing information seeking model to proxy-seeking, however, seeking and support were measured only as intentions. Moreover, the demographic characteristics were not found to be relevant, potentially due to the low variance of the study sample. Limitations of this model in relation to my project: while it adds the "use" of OHI in terms of providing support, this model does not include any outcomes of this use.

Figure 3. Modified CMIS Model (structural equation model)



Info-Seeking = Surrogate health information seeking intention. Support = Intentions to support with information. Demographics did not form a latent variable. The dashed line indicates a post hoc model addition. Insignificant paths are not shown in this figure. *p < .05, ***p < .001.
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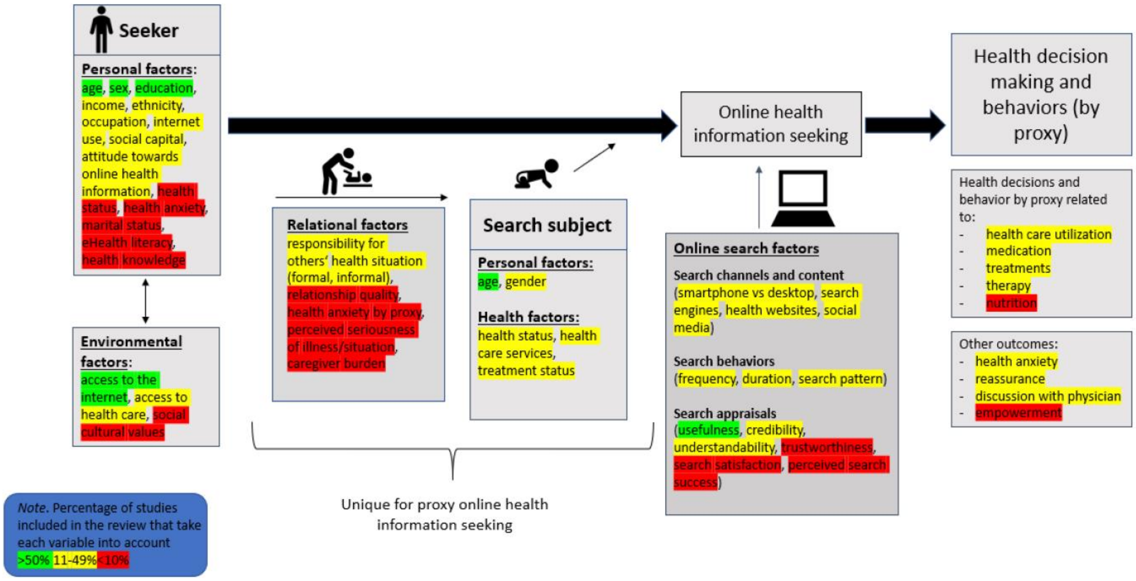
C. Online Health Information Seeking by Parents for Their Children (Kubb & Foran, 2020)

One of the largest groups of OHI consumers is parents of young children. This systematic review on how parents find, use, and evaluate OHI for their children, reported that parents worldwide are heavy OHI users across diverse circumstances (Kubb & Foran, 2020). In their review, they defined parents as proxy-seekers on behalf of their children, and only included studies that clearly distinguished between parents as self-seekers and as proxy-seekers. They developed the model in Figure 4 which is comprised of consists of 6 categories: personal factors within the seeker, environmental factors, relational factors between seeker and search subject, factors within the search subject (i.e., the child), online search factors (search channels, content, behaviors, and appraisals), and outcomes (such as health care utilisation and health anxiety).

Figure 4. Model of proxy online health information seeking and decision making by parents for their young children



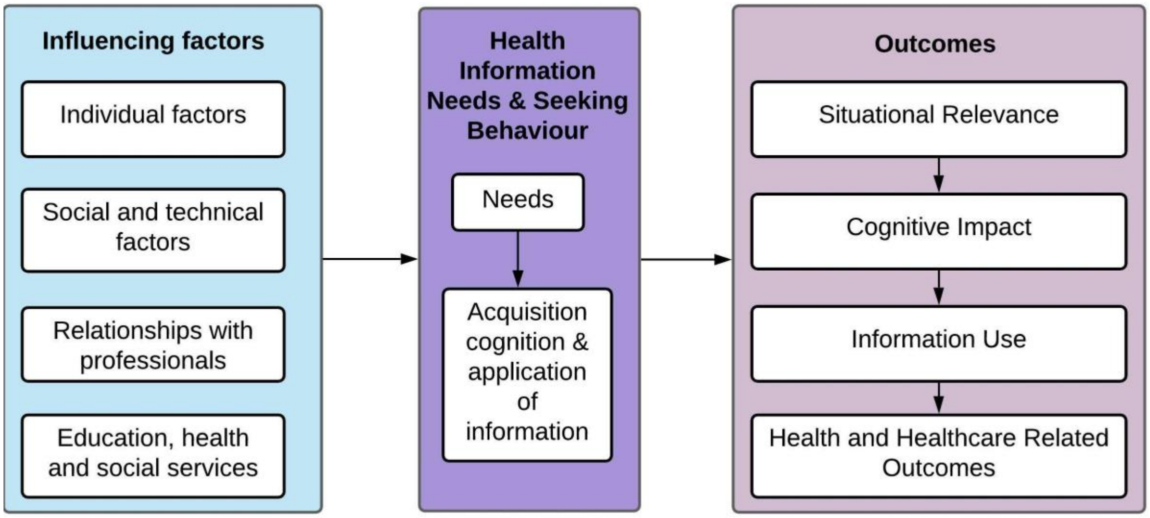
The most frequently reported limitation across the included studies is the lack of generalizability as they included convenience samples in clinical environments with specific populations of ill children. The authors report the need for larger and more diverse and representative samples in further studies. Furthermore, they conclude that it is unclear if findings related to parents as proxy seekers can be applied to other proxy seekers.

Online Health Information Outcomes

A theoretical framework of outcomes of OHI was previously developed using studies with health professionals, and few interviews with information users such as parents of pre-school children (Bujold et al., 2018; P Pluye et al., 2013; Pluye et al., 2014). It is consistent with contemporary multifaceted approaches to human information behaviour, which combine cognitive approaches (e.g., psychological and behavioral factors) and social approaches (e.g., affective and contextual factors)

(Pettigrew et al., 2001). This framework is derived from information studies, e.g., the 'Acquisition Cognition Application' model (Saracevic & Kantor, 1997), which has been adapted for health sciences to include four levels of outcomes of information delivery and retrieval: situational relevance, cognitive/affective impact, use, and subsequent health/well-being outcomes of information (Pierre Pluye et al., 2013; Pluye et al., 2014). These levels are illustrated in Figure 5 and reflect the value of information (how information is valuable) from the users' viewpoint. For each level, different types of outcomes were identified and validated using systematic mixed studies reviews, and qualitative, quantitative, and mixed methods primary research studies; these outcomes are presented in Table 6 (Bujold et al., 2018; Pluye et al., 2014). This model is unique because it describes four levels of outcomes of OHI from an individual perspective, as well as four types of contextual factors that influence OHI outcomes.

Figure 5 OHI Outcomes Conceptual Framework



As previously defined, information needs may be explicitly stated or implicitly understood based on an individual's health status or situation (Derr, 1983). OHI seeking is the purposive and active searching for information as a consequence of an information need or to satisfy a goal (Wilson, 2000). In the context of OHI, there are several reasons for starting the OHI seeking process, e.g., to answer a question about one's own health or someone else's health (Pierre Pluye et al., 2013).

In this framework, there are four types of contextual factors: individual characteristics (e.g., age and income), socio-technical factors (e.g., e-health literacy or social support), patient-professional relationships, and education-health-social services. As an example of factor, e-health literacy integrates computer literacy, information literacy and e-health literacy, which are interdependent (e.g., a person with a low literacy level also has a low level of e-health literacy). Literacy level is generally defined as the degree to which a person has the ability to acquire, understand, evaluate, and use information needed to obtain services and make appropriate decisions (Ronson McNichol & Rootman, 2016). Together, these factors determine the extent to which information is accessed and how it is used by patients.

Table 6. Types of OHI Outcomes

Levels of OHI Outcomes	**Types of OHI Outcomes**
1. Situational Relevance	• Relevant (the information addresses the information need) • Not relevant
2. Cognitive Impact	• Impact on learning • Impact on memory • Impact on motivation to learn • Impact on satisfaction with information • Impact on safety • Impact on worry
3. Information Use	• Use for decision-making • Use for confirmation • Use for change of health management • Use for discussion with a health professional • Use for providing social support
4. Health and health-care related Outcomes	• Outcome for satisfaction with care • Outcome for relationship with health professional • Outcome for involvement • Outcome for problem management • Outcome for prevention of health problem or its worsening • Outcome for health improvement

By way of illustration, any individual can experience an information need: to answer a personal health question before an encounter with a professional (a problematic health situation). She then directly searches for and accesses a particular webpage (by direct information-seeking). She then experiences a sequence of outcomes at four levels. Level-one: the information answers their question (situational relevance of information). Level-two: she understands the information and learns something new about health care (cognitive impact of information). Level-three: she applies the information to modify a health management plan and to consult a professional (information use). Level-four: due to this information use, her worries decrease (health outcomes).

A qualitative study conducted during the development of this framework focused on potential negative outcomes of OHI use, and included interviews with OHI seekers, health care practitioners, and health librarians. This study uncovered that negative outcomes of OHI may occur at three levels of tensions: internal (such as increased worrying), interpersonal (such as a tension in the patient-clinician relationship), and service-related (such as postponing a clinical encounter). Participants also proposed three types of strategies to reduce the occurrence of these negative outcomes, namely, providing consumers with reliable OHI, educating consumers on how to assess OHI websites, and helping consumers present and discuss the OHI they find with someone else in their formal or informal social network. Interpersonal tensions could potentially be experienced by proxy OHI seekers as they discuss the information found with someone else.

The framework is focused exclusively on the individual’s perspective: it is the individual that starts the OHI seeking process and experiences the outcomes of this process. Studies that tested this framework therefore focused on individuals who used the OHI for their own health care and reported the health outcomes they themselves experienced. Little is known about what happens when the information need is to answer a question about someone else’s health, or what is involved when the information use is used for providing social support. Therefore, little is also known about what happens next: what are the health outcomes that occur to the individual doing the OHI seeking (proxy information seeker) or the individual for whom they are seeking OHI (social support recipient).

Social Support

Social support is one of the positive products of "social relationships" which may have short- and long-term effects on health, for better and for worse, depending on their quality and quantity (Umberson & Karas Montez, 2010). A model by Uchino (2004) describes two broad dimension of support: structure and function (Uchino, 2004). Structural aspects of support are the extent or composition of one's social network (size, contact, type, density, and strength) and interconnections among them.

Functions are organized along two levels: perceived support and actual support and have four aspects that are highly related to each other: emotional, informational, tangible and belonging. Most relevant to this review is informational support which includes the provision of advice or guidance, and which may provide direction and may carry an emotional message when received from a close source. Informational support could be construed as supportive, unsupportive, or mixed depending on context (Dubois & Loiselle, 2009; Loiselle et al., 2006; McKinley & Wright, 2014).

Social support has consistently been linked with better health (Drentea & Moren-Cross, 2005; House, 2001; Uchino, 2004). Several theories have been proposed to explain why this occurs; e.g., social support can act as a mediator of stress that reduces the impact of stress which improves mental health (Umberson & Karas Montez, 2010). Several studies have reported that low perceived social support is correlated with increased stress and reporting a greater number of stressful events, while those who feel more satisfaction with received social support report fewer emotional problems (Dunst et al., 1986; Hamlett et al., 1992; Kiecolt-Glaser et al., 1987; Oprescu et al., 2013).

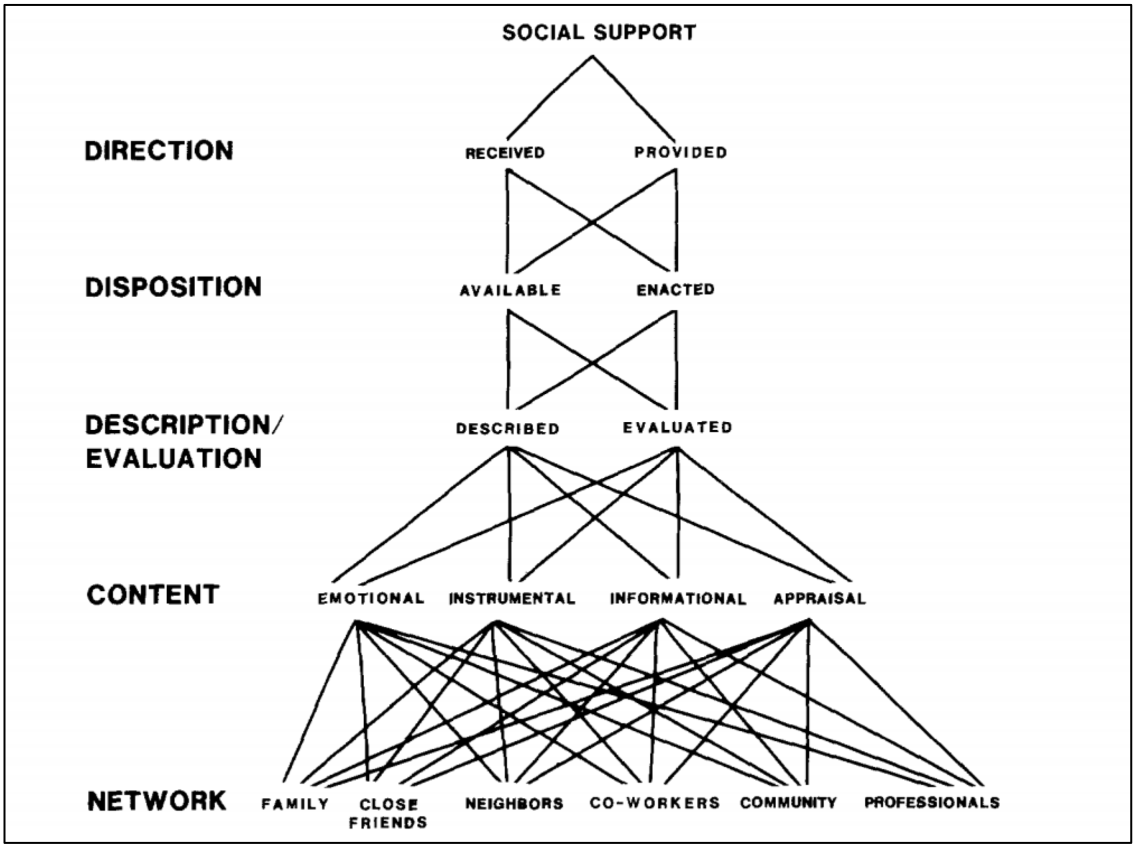
Another theory to explain the link between social support and better health is the provision of informational support which encourages the receivers to manage their health. If we use pregnant women as an example, those who were more satisfied with perceived and received social support initiated prenatal care earlier than those who were less satisfied (Cutrona & Suhr, 1992). Pregnant women who received more informational support from people in their social network delivered babies with higher APGAR scores (appear healthy five minutes after birth) and higher birth weights (Cutrona & Suhr, 1992; Guillory et al., 2014).

Social support has been defined and measured in multiple ways in the literature by researchers in many fields (e.g., anthropology, epidemiology, medicine and psychology) (Barrera, 1986). The definition employed in this thesis is "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979). Social support is one of the **positive** products of "social relationships" which may have short- and long-term effects on health, for better and for worse, depending on their quality and quantity (Umberson & Karas Montez, 2010). I will describe two models of social support that have been cited more than 1000 times and which encompass several levels of social support. Table 7 highlights and summarizes the key constructs of social support that will be used in this research proposal. These terms are derived from the literature and originate in research outside the context of OHI. They may, therefore, be updated to reflect the OHI seeking context as a result of this project.

A. Tardy's 'Aspects of social support' Model

In Tardy's model in Figure 6 (1985) there are five aspects in the conceptualization of social support: direction, disposition, description/evaluation, network, and content. Direction refers to whether one is giving or receiving social support (the individual). Disposition refers to whether social support is simply available to someone (perceived) or if it is actually being used (actual or enacted). Description/evaluation refers to whether one is evaluating his or her social support or just describing it with no evaluation. The network refers to the sources or members of an individual's support network, hereafter the entourage members, e.g., friends and family. Finally, the content of social support that refers to what type of social support was provided using existing categories: emotional, informational, appraisal, and instrumental types of support (Tardy, 1985).

Figure 6. Tardy's 'Aspects of social support' Model



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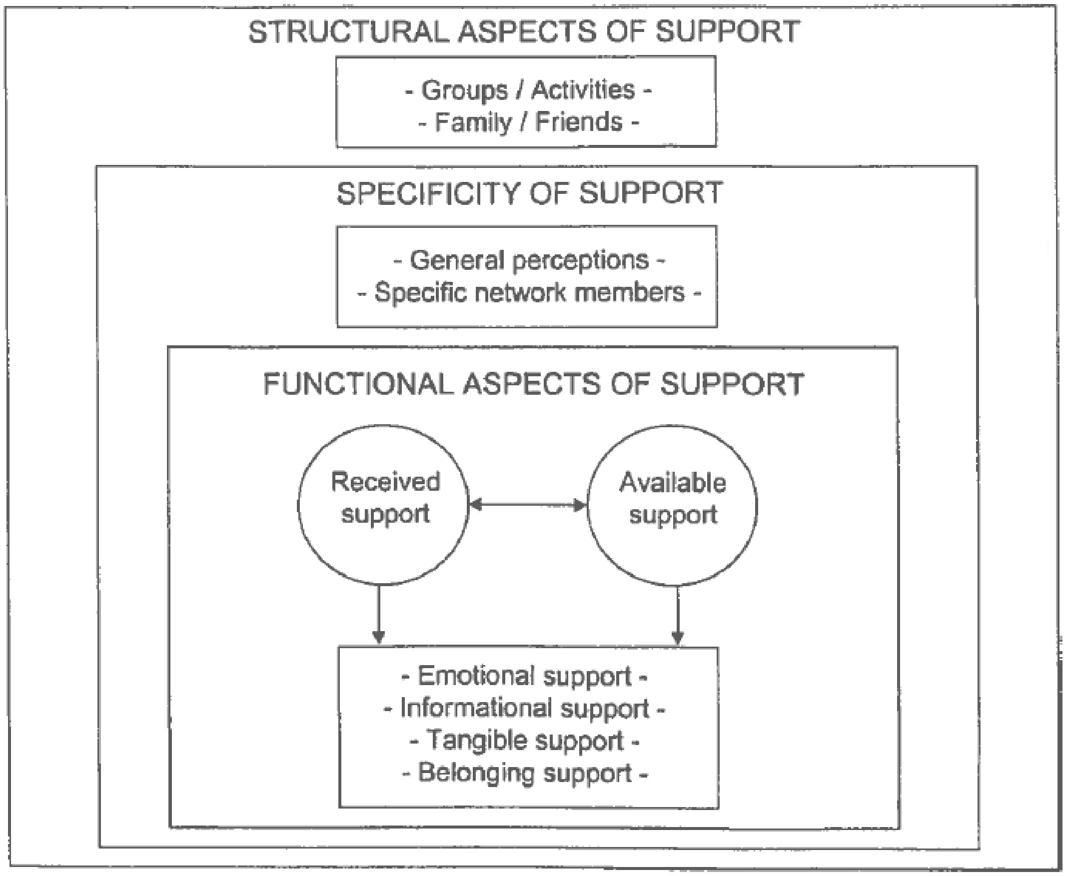
B. Uchino's 'Measures of social support' model

Uchino (2004) describes two broad dimension of support: structure and function (Uchino, 2004). Structural aspects of support are the extent or composition of one's social network (size, contact, type, density, and strength) and interconnections among them. Functions are organized along two levels: perceived support and actual support and have four aspects that are highly related to each other: emotional, informational, tangible and belonging. These dimensions and the links between them are illustrated in Figure 7. The innermost box represents the functional types of support that can be exchanged between individuals, which can be either received or available or both. The next box indicates that these functional aspects can be measured at different levels of specificity ranging from the network as a whole to specific network members. The outermost box specifies the structural aspects of support and provides a socio-cultural context for all other measures.

Figure 7. Uchino's 'Measures of social support' model



There is overlap between the concepts in Uchino's and Tardy's models, yet Uchino's model's contribution lies in its integrated measurement approach. Uchino emphasizes that these measures (structural aspects, specificity, and functional aspects) are embedded, and that it is important to include as many as possible to capture a more complete picture of the phenomenon of social support.

Table 7. Key Concepts of Social Support

Key concept	**Definition**	**Source**
Direction of social support	Direction refers to whether one is giving or receiving social support (operationalized here as 'provider' and 'receiver').	(Tardy, 1985)
Network of social support	Network refers to the sources or members of an individual's support network, the providers of social support, e.g., friends and family.	(Tardy, 1985)
Available/perceived support	Helping behavior or actions that an individual believes might happen or the belief that such helping behaviors would be provided when needed.	(Barrera, 1986; Tardy, 1985)
Received (enacted or actual) support	Naturally occurring helping behaviors that are happening or being provided, likely to be provided when individuals face adversity or experience an information need. Examples of this received support include emotional and informational support.	(Barrera, 1986; Tardy, 1985)
Informational support	A type of support which includes the provision of advice or guidance, and which may provide direction and may carry an emotional message when received from a close source. Informational support could be construed as supportive, unsupportive, or mixed depending on context. It can be initiated by either the person who provides it or by the individual who seeks it.	(Dubois & Loiselle, 2009; Loiselle et al., 2006; McKinley & Wright, 2014)
Emotional support	Emotional support is the offering of warmth and nurturance, including encouragement, empathy, trust, affection, and other positive facets that can reduce stress or other negative emotions.	(Tardy, 1985; Uchino, 2004)
Tangential support	Provision of material (practical) aid.	(Tardy, 1985; Uchino, 2004)

In 1985, Cohen and Willis published an important paper (cited over 15,000 times to date) that described social support as two *measurable* aspects: structural and functional (Cohen & Wills, 1985). Structural aspects focus on "the existence or interconnection among various social ties" while functional measures assess the various behaviours of social network members. While I will primarily explore the functional aspect of social support in my project, it is important that I also explore the structural aspect. The structural aspect of social support focusses on the description of the providers of social support, who I refer to as the “entourage”.

The functional aspects I am interested in exploring are the specific supportive behaviours and their outcomes (described in Table 8) rather than a general (more global) description of social support received. The main reason for this decision is the following: by exploring global social support, I may miss potentially important supportive behaviours; e.g., the observation that people request informational support from close friends and family when they also require emotional support (Burleson & MacGeorge, 2002).

Table 8. Examples of specific supportive behaviours

	Social support receiver	**Social support provider**
Enacted informational support	Discussing OHI with someone else	Discussing/sharing OHI found for someone else with that person
Enacted instrumental support	Requesting practical support from someone else based on OHI recommendations	Providing practical support to someone based on OHI recommendations
Enacted emotional support	Turning to someone else for emotional support after finding relevant OHI	Providing emotional support to someone else after relevant OHI
Perceived social support	Belief that support would be available when needed by the receiver	N/A as it is the perception of the receiver

Social Support and Health Outcomes

Social support has consistently been linked with better health (Drentea & Moren-Cross, 2005; House, 2001; Uchino, 2004). Several theories have been proposed to explain why this occurs; for example, social support can act as a mediator of stress that reduces the impact of stress which improves mental health (Umberson & Karas Montez, 2010). Several studies have reported that low perceived social support is correlated with increased stress and reporting a greater number of stressful events, while those who feel more satisfaction with received social support report fewer emotional problems (Dunst et al., 1986; Hamlett et al., 1992; Kiecolt-Glaser et al., 1987; Oprescu et al., 2013). Moreover, recent systematic review on the links between loneliness and mental health outcomes found substantial evidence that people with depression who had lower perceived social support had worse outcomes (Wang et al., 2018).

Another theory to explain the link between social support and better health is the provision of informational support which encourages the receivers to manage their health. If we use pregnant women as an example, those who were more satisfied with perceived and received social support initiated prenatal care earlier than those who were less satisfied (Cutrona & Suhr, 1992). Pregnant women who received more informational support from people in their social network delivered babies with higher APGAR scores (appear healthy five minutes after birth) and higher birth weights (Cutrona & Suhr, 1992; Guillory et al., 2014).

Informational support can occur in two ways: an individual can request informational support from the provider (by discussing health information with them and asking for their help) or can be unsolicited (the provider searches on behalf of and shares it with the individual). In the first case, for example, an individual's selection of the source of information depends on the individual's needs and expectations, so they may consult their friends and families when they need "more tailored emotional support in obtaining complex and serious health information" (Burleson & MacGeorge, 2002; Johnson, 1997). In the second case, a social support provider is aware of the individual's information need (e.g., recently diagnose health condition), and searches for information on their behalf to share with them to support their health care management. While informational support has been explored in the past, few studies have focused on its outcomes in an OHI context, and none have looked at it from the perspective of both the provider and the receiver.

Social support providers

Although the focus of my project is social support, another important construct that reflects social relationships is social capital. Social capital is a construct that originates from research in sociology and refers to the resources in someone's social network, both their structure and content, as well as the personal attributes that are learned through socialization and which position a person socially within hierarchies of social class (Bourdieu, 2011; Lin, 2017; Utz & Breuer, 2017). Social support, on the other hand, comes from psychology, and is considered by sociologists as a possible *effect* of social capital (Adler & Kwon, 2002). While I may encounter some of the literature on social capital in my literature review, it is not the construct I will be focusing on as it does not encompass the supportive behaviours, I am interested in exploring.

In Table 9, I identify some of the ways providers of social support have been defined and assessed in the literature in various contexts outside OHI and in various disciplines.

Table 9. Terms used for social support providers

Source	Term used for social support providers	Definition and examples
Psychology (Cohen & Wills, 1985)	Structural aspect of social support	The existence or interconnection among social ties e.g., the number of close friends or strength of family ties.
Psychology (Tardy, 1985)	Social support network	The network refers to the sources or members of an individual's support network, the entourage members, e.g., friends and family.
	Social support providers	The concept of direction focuses on who is giving the social support and who is receiving it. E.g., differentiating between provider and receiver.
Child psychology (Demaray et al., 2010)	Social network/sources/providers	The people who are providing (or are available for providing) social support. e.g., there are differences in the support that children and adolescents perceive from parents versus friends, or that they perceive from teachers versus parents.
Epidemiology	Social network	The authors identify two elements of structure of social relationships: (a) social integration, which

Source	Term used for social support providers	Definition and examples
(House et al., 1988)		refers to their existence or quantity and (b) social network structure characteristics which may be dyadic (reciprocity, multiplexity, durability) or network variables among the focal person and two or more others (density, homogeneity, multiplexity, or dispersion)
Family Medicine (Broadhead et al., 1988)	Providers of social support	The authors introduce and validate a questionnaire that focuses on the quantity of support from providers, as well as informational support, emotional support, and instrumental support.
Public health (Sherbourne & Stewart, 1991)	Sources of social support	Family, friends, neighbours, community, social groups, or others who provided a type of social support
Sociology (Lin, 2002, 2017)	Sources of social capital	Social capital can be defined as "resources embedded in a social structure which are accessed and/or mobilized in purposive actions"
Management (Adler & Kwon, 2002)	Sources of social capital	Social capital refers to the resources in someone's social network, both their structure and content.

Entourage characteristics

There are two dimensions of characteristics that are relevant to this work: relationship characteristics and individual characteristics. The relationship characteristics describe the structure of the social relationships between entourage and receiver, e.g., strength of ties. Examples of these characteristics include frequency of contact, multiplexity (relationships that share multiple roles), reciprocity (degrees of exchange of support), and strength of ties (voluntary/forced, strong/weak) (Uchino, 2004).

Individual characteristics, on the other hand, consist of one of the four contextual factors that influence OHI seeking and OHI outcomes from the OHI framework (El Sherif et al., 2018). These individual characteristics are specific to the person undergoing the OHI seeking process, specifically in the context, i.e., the entourage member seeking OHI. In Table 10, I have identified the characteristics that could be studied. I will also explore other individual characteristics that may be identified by participants in the interviews as being relevant such as kindness and empathy.

Table 10. Individual characteristics

Individual characteristics	Definitions or examples from the literature	How it can be studied
Gender	Information studies usually show that women are more likely to search for OHI for themselves and others (compared to men), while findings of this study suggest men participants were more likely discussing OHI with health professionals (Chung, 2013).	Self-reported gender
Age	Information studies usually show that people aged 31-45 years are more likely to search for OHI (compared to other age groups) (Iverson et al., 2008).	Self-reported age
Level of education	Information studies usually show that people with a higher level of education are more likely to search for OHI (Baker et al., 2003).	Self-reported highest diploma attained and field of study
Socioeconomic status	Information studies usually show that people with a higher socioeconomic status (and knowledge of information available in the locally dominant language and culture) are more likely to search for OHI; e.g., a study suggests wealthier participants were more likely to search for and use OHI (Murray et al., 2008).	Self-reported income level
Health status	Person's state of physical, mental, and social well-being. A study found that participants who reported their general health as being fair or poor sought OHI more often than participants who reported their health as being excellent, very good or good (Bansil et al., 2006). Another study found that participants who reported one or more chronic diseases (e.g., depression) were more likely to search OHI compared to participants without chronic disease (Bansil et al., 2006).	Self-reported health status (number of acute or chronic health conditions, medications, etc.)
eHealth literacy	Person's ability to seek, find, understand, and appraise OHI and apply the knowledge gained to	Using questions from a validated

Individual characteristics	Definitions or examples from the literature	How it can be studied
	addressing health issues. In one study, participants that had lower information literacy and computer literacy skills relied on others (intermediaries) to find and appraise OHI (Hart et al., 2004).	tool (eHEALS) – not used in this dissertation (Chung & Nahm, 2015)
Confidence in OHI	A study found that 7% did not trust OHI and some reported the lack of trust in OHI as a reason for not using it (Dolan et al., 2004).	Interview questions regarding trust in OHI in general

Knowledge gaps

Based on this review of the literature in information studies and health sciences the following knowledge gaps were uncovered:

1. There appears to be no comprehensive conceptual model on the role proxy seekers in the context of OHI and with a description of outcomes,
2. Many studies exist on online communities sharing health information and support, but few studies focus on the OHI outcomes of offline social support on both the individual and the proxy seeker, and
3. No comprehensive research-based tool exists that aims to help people search for and use OHI with someone else.

In summary, this review chapter defines three main constructs that support the focus of the thesis, i.e., the intersection between these constructs: information seeking, OHI outcomes and social support (the center of Figure 1). This chapter suggests it is only partially understood how an individual and their entourage generally use OHI together, and which characteristics of social support are associated with positive outcomes. By addressing these knowledge gaps, OHI providers can better adapt the information to meet both individual and group needs, and health care practitioners can target patients' entourage with information for dissemination and use.

Chapter 3: Conceptual Framework – Manuscript 1

Preface

This chapter describes a literature review that was conducted to address the knowledge gaps uncovered in the previous chapter. As mentioned, there is no comprehensive literature review or conceptual model on proxy OHI seeking outcomes. The objective of this review was to develop such a conceptual model.

This manuscript describes a mixed studies literature review on the contexts and outcomes of proxy OHI seeking behaviour. After conducting a literature search in five bibliographic databases, 28 studies with diverse designs were included in the final analysis. Thematic analysis explored four main themes related to the characteristics of proxy-seekers, the context of proxy OHI seeking, the use of OHI to provide social support, and the outcomes of proxy OHI seeking. These outcomes are generally positive in situations where the information need is explicit and the proxy-seeker has high health literacy, and informational support is associated with positive emotional support. Negative outcomes are rarely reported, and were related to information overload, or a disconnection between the information needs of the proxy-seeker and the recipient of support.

These themes were used to build on previous work (specifically the OHI outcomes framework described in Chapter 2) and develop a revised conceptual model of proxy OHI outcomes. This initial model served as the conceptual model for the subsequent empirical studies that are described in Chapters 5 and 6. In Chapter 7, this initial model was revised using the findings from this thesis.

A revised version of this manuscript was published in the *Journal of Medical Internet Research* in June 2022 (El Sherif, Pluye, & Ibekwe, 2022). One reviewer referred to this review as “overdue in this field of research” and that “it is very important to be published”.

Contexts and Outcomes of Proxy Online Health Information Seeking: A Mixed Studies Review with Framework Synthesis

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Abstract

Background: High quality online health information (OHI) can reduce unnecessary visits to health professionals and improve health. One of the ways people use OHI is to support others with health conditions, through proxy OHI seeking. Members of a person's social circle may help them overcome information-seeking barriers and illness challenges. There are several models on proxy information seeking. Yet, we know little on the subsequent use and outcomes of OHI on behalf of someone else.

Objective: The objectives of this paper are to explore, and to revise a framework on, the context and outcomes of proxy OHI seeking.

Methods: We conducted a mixed studies literature review integrating qualitative and quantitative evidence with thematic analysis of the findings of 28 studies, followed by framework synthesis incorporating the derived themes.

Results: Four main themes were explored: characteristics of proxy-seekers, the context of proxy OHI seeking, the use of OHI to provide social support, and the outcomes of proxy OHI seeking. Our conceptual framework incorporates these themes and builds on previous work.

Conclusions: By better understanding how people use information together, information providers can adapt information to meet both their needs.

Keywords: online health information; information seeking behavior; proxy information seeking; surrogate seekers; information outcomes; social support

Introduction

Two-thirds (67%) of respondents to the American Health Information National Trends Survey between 2008 and 2017 reported turning to the Internet first for health information (Finney Rutten et al., 2019). Similarly, 69% of Canadians reported using the Internet to search for health information in 2020 (Statistics Canada, 2020) and the proportion of adults seeking online health information (OHI) in other OECD countries has more than doubled between 2008 and 2017 (OECD, 2017). The use of OHI can improve quality of life and is generally associated with positive outcomes such as increased empowerment of seekers and their families, and improved health outcomes (Amante et al., 2015; Case & Given, 2016; Pluye et al., 2020; Prescott & Mackie, 2017).

Based on the results of a recent systematic review on the outcomes of OHI seeking (hereafter, OHI outcomes), several contextual factors associated with these outcomes were identified such as age, education, income, and e-health literacy (Pluye et al., 2019). Another contextual factor is social support defined broadly as "support accessible to an individual through social ties to other individuals, groups, and the larger community"(Lin et al., 1979). Social support is an important factor as one of the ways people uses OHI is to support their relatives or friends with health conditions (Pluye et al., 2013). In fact, recent studies report that 61-66% of OHI seekers are proxy seekers, meaning they seek OHI on behalf of someone else (S. Cutrona et al., 2015; Reifegerste et al., 2017). Moreover, findings from a study exploring Internet use trends between 2008 and 2013 show a significant increase in use of family and friends to obtain health information (Massey, 2016).

However, while proxy information seeking has been explored in the literature, especially as related to health information, little is known of its relationship with the outcomes of OHI. This is a critical knowledge gap: previous research examining how to reduce negative outcomes of OHI suggests that OHI seekers may be able to overcome low e-health literacy by discussing the information they find with others (El Sherif et al., 2018). Members of a person's social circle may help them overcome information-seeking barriers and illness challenges (e.g., they are too physically weak or mentally incapacitated to search themselves) (Abrahamson et al., 2008). Furthermore, people are sometimes more likely to turn to their social circle to make sense of information they find, rather than discuss it with a health professional (Abrahamson et al., 2008; Reifegerste et al., 2017).

By better understanding how people and their social circle use information together, information providers can better adapt the information to meet both their needs, and public health interventions can target patients' friends and family with information for dissemination and use (Kim et al., 2015). In light of this, the purpose of this paper is to contribute to our understanding of the role of social support in online health information outcomes by focusing on the outcomes of proxy OHI seeking.

Conceptual Background

This review will focus on the intersection of three main constructs: proxy information seeking, social support, and OHI seeking outcomes.

Proxy Information Seeking

Information seeking encompasses "all the information that comes to a human being during a lifetime, not just in those moments when a person actively seeks information" (Bates, 2002, p. 3). In active information seeking mode, monitoring, and directed searching are ways to answer known information needs (that are recognized and articulated). There are intervening variables which may be related to personal characteristics, to social or interpersonal issues, or to environmental considerations (Wilson, 1999). It can be defined as "those who seek information in a non-professional or informal capacity on behalf (or because) of others without necessarily being asked to do so" (Abrahamson et al., 2008). Proxy seekers may also be "experts", such as health librarians or healthcare professionals, with the specialized knowledge or skills to use the information with the person with whom they share a personal relationship (Wyatt et al., 2005).

The role of proxy information seeking has been explored in the literature and has also been referred to as surrogate seeking or lay information mediation (S. Cutrona et al., 2015; Wathen et al., 2008). In one of the earliest models on information seeking behavior, Wilson uses pathways to explain different patterns of information seeking (Wilson, 1981). In his model, the user encounters “information systems” that can be technology (e.g., the Internet) and mediators, and these systems connect the user to “information resources” or actual information. Two out of ten pathways proposed in this model indicate seeking that is “conducted by a mediator to fulfill an information request” (Wilson, 1981). This phenomenon is also described in McKenzie’s two-dimensional model of information practices of women pregnant with twins (McKenzie, 2003). In her model, one of the modes of information practice is “by proxy” where the person interacts with information through another agent, including “intermediaries or gatekeepers” such as friends or family members.

Social Support

Social support is one of the positive products of “social relationships” which may have short- and long-term effects on health, for better and for worse, depending on their quality and quantity (Umberson & Karas Montez, 2010). A model by Uchino (2004) describes two broad dimensions of support: structure and function (Uchino, 2004). Structural aspects of support are the extent or composition of one’s social network (size, contact, type, density, and strength) and interconnections among them. Functions have four aspects that are highly related to each other: emotional, informational, tangible and belonging. Most relevant to this review is informational support which includes the provision of advice or guidance, and which may provide direction and may carry an emotional message when received from a close source. Informational support could be construed as supportive, unsupportive, or mixed depending on context (Dubois & Loiselle, 2009; Loiselle et al., 2006; McKinley & Wright, 2014).

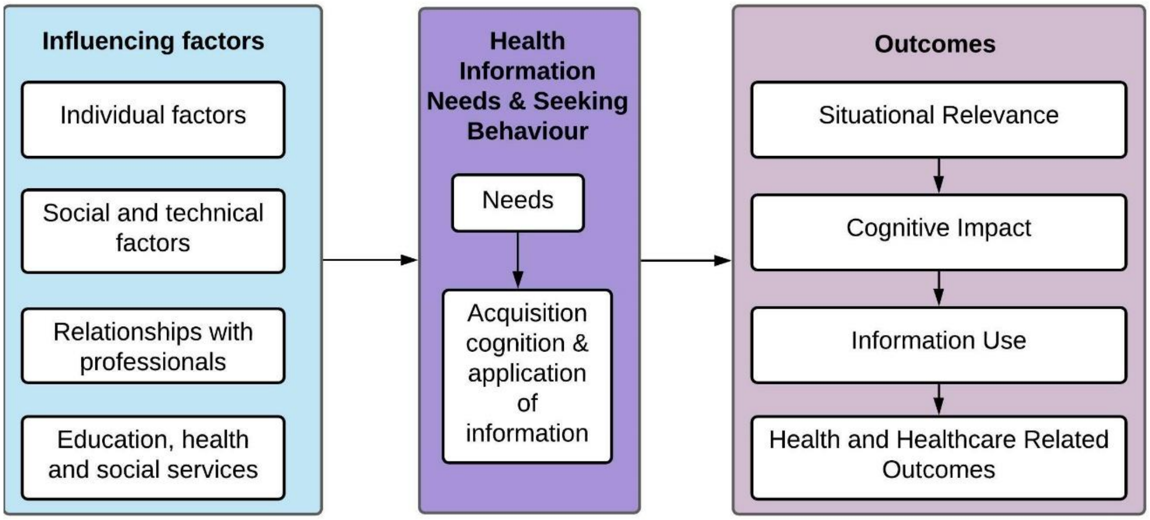
Social support has consistently been linked with better health (Drentea & Moren-Cross, 2005; House, 2001; Uchino, 2004). Several theories have been proposed to explain why this occurs; for example, social support can act as a mediator of stress that reduces the impact of stress which improves mental health (Umberson & Karas

Montez, 2010). Several studies have reported that low perceived social support is correlated with increased stress and reporting a greater number of stressful events, while those who feel more satisfaction with received social support report fewer emotional problems (Dunst et al., 1986; Hamlett et al., 1992; Kiecolt-Glaser et al., 1987; Oprescu et al., 2013). Another theory to explain the link between social support and better health is the provision of informational support which encourages the receivers to manage their health. If we use pregnant women as an example, those who were more satisfied with perceived and received social support initiated prenatal care earlier than those who were less satisfied (Cutrona & Suhr, 1992). Pregnant women who received more informational support from people in their social network delivered babies with higher APGAR scores (appear healthy five minutes after birth) and higher birth weights (Cutrona & Suhr, 1992; Guillory et al., 2014).

Online Health Information Outcomes

A theoretical framework on OHI outcomes and the factors associated with these outcomes was developed by Pluye and colleagues based on a systematic review with a framework synthesis (Pluye et al., 2019). This framework was derived from previous research by the authors and combines an information theory and a psychosocial theory of behavior. It includes four types of contextual factors that influence OHI outcomes: individual factors (e.g., health literacy), social and technical factors (e.g., access to the Internet), relationships with professionals (e.g., satisfaction with healthcare provider), and education, health, and social services (e.g., access to a family doctor). It also includes four levels of individual outcomes of information delivery and retrieval: situational relevance, cognitive/affective impact (e.g., being able to understand the information or not liking the information found), use (e.g., in discussion with a healthcare provider, or to make a medical decision), and subsequent health/well-being outcomes (e.g., improved health or reduced worrying) of information. These levels are presented in Figure 8. For each level, different types of outcomes were identified and validated using systematic mixed studies reviews, and qualitative, quantitative, and mixed methods primary research studies (Bujold et al., 2018; Pluye et al., 2013; Pluye et al., 2014).

Figure 8 OHI Outcomes Conceptual Framework



However, this framework is focused exclusively on an individual perspective: it is the same person that starts the OHI seeking process and experiences the outcomes of this process. Studies that tested this framework therefore focused on people who used the OHI for their own health care and reported the health outcomes they themselves experienced. Little is known about what happens when the information need is to answer a question about someone else's health, or what is involved when the information is used with someone else (for providing social support) (El Sherif et al., 2018).

Knowledge gap

There appears to be no comprehensive conceptual model on the outcomes of proxy OHI seekers using OHI to provide social support. Reifegerste et al modified and extended the existing comprehensive model of information seeking (CMIS) with concepts of social network ties to predict proxy information seeking and the resulting social support intentions (Reifegerste et al., 2020). They developed hypothetical scenarios (n=607) of people with varying severity in depression and with varying relationship closeness. Structural equation modelling was used to test the associations between the health-related factors (including demographics), proxy health information seeking intentions and social support intentions. Thus, they hypothesized that support is the resulting action of proxy OHIS. This is an important study that modifies an existing information seeking model to proxy-seeking, however, seeking and support were measured only as intentions. Moreover, the demographic characteristics were not found to be relevant, potentially due to the low variance of the study sample. This review aims to build on this work by further exploring the context of proxy OHI seeking and the outcomes of using OHI to provide social support.

Methods

Design

A mixed studies review was conducted using a data-based convergent synthesis design where qualitative and quantitative data was analyzed together using a qualitative thematic analysis (Hong et al., 2017; Pluye et al., 2016). A mixed studies review is ideal in this context because the evidence is from diverse fields of inquiry and use diverse methods and provides a rich and highly practical understanding of complex health interventions (Grant & Booth, 2009; Pluye & Hong, 2014). Framework synthesis was then conducted to produce a revised conceptual framework.

Eligibility Criteria

Table 11 lists the inclusion and exclusion criteria that were deemed appropriate for identifying relevant studies.

Table 11. Inclusion and exclusion criteria

	Inclusion criteria	**Exclusion criteria**
Research methods	Primary and secondary research (i.e., qualitative, quantitative, and mixed methods empirical studies, and literature reviews)	Not empirical research or a literature review (e.g., commentary, editorials, reports)
OHI	• Focus on online health information SEEKING • Online resource about health and medical topics	• No mention of OHI • Offline health information resources, e.g., books or pamphlets • Studies that tested specific online interventions e.g., testing the use of an e-kiosk or e-mental health services
Proxy OHI seeking	Explore the phenomenon of proxy OHI seeking: • Characteristics of proxy seekers	• No mention of proxy OHI seeking • No mention of seekers that are physical members of the social

	Inclusion criteria	Exclusion criteria
	• Context of proxy OHI seeking • Use of OHI • Outcomes of OHI	circle that the person knows and is in contact with on a regular or semi-regular basis e.g., anonymous social media or online forum members • Exclude parents of young children or surrogate decision-makers of incapacitated adults (e.g., unconscious patients in an ICU)

Sources and Search Strategy

Papers were searched in five databases (Medline, PsycInfo, CINAHL, LISA and Scopus) from inception through May 25th, 2021. A search strategy was compiled with the help of a health librarian and included two main concepts: OHI and (proxy OHI seeking or social support). The sets were combined using Boolean operators depending on the database being searched as presented in Table 12. The search was limited to English and French languages, with no limit on years. All the records were transferred to a reference manager software (EndNote x8) and duplicates were removed using the Bramer method (Bramer et al., 2016). After the selection stage, additional potentially relevant records were retrieved by tracking the citations (snowballing) of the selected documents.

Table 12. Search strategy

Database	Date of latest search	Search terms	Number of records
Medline	20-05-2021	*social support/ AND online.mp. AND "Health Information".af.	82
		"informational support".mp. AND online.mp. AND "Health Information".af.	14
CINAHL	20-05-2021	"online health information" AND “social support”	16
		"online health information" AND “informational support”	5
PsycInfo	20-05-2021	*social support/ AND online.mp. AND “Health Information”.af.	141
		“informational support”.mp. AND online.mp. AND “Health Information”.af.	36
LISA	20-05-2021	“proxy” AND “information seeking” AND “online health”	54
		“social support” AND “online health” AND Information	294
Scopus	20-05-2021	“surrogate” or “proxy” AND “information seeking” AND “online health”	25
		mediator AND “online health information”	118

Selection of Relevant Studies

The 775 records were then imported into Distiller SR, a web-based application for conducting systematic reviews (http://distillercer.com/), for selection. For each record, eligibility codes were assigned according to the criteria described in Table 11. For every included record, the corresponding full-text publications were retrieved. Again, full texts were imported into DistillerSR and coded using the same eligibility criteria. Included studies were then exported into NVivo (Version 12).

Data Extraction and Synthesis of Included Studies

Characteristics of the included studies and results as related to the role of social support in OHI seeking and outcomes were coded in NVivo. A deductive-inductive analytical approach was adopted for thematic analysis of the extracted evidence (Fereday & Muir-Cochrane, 2006). A coding manual was developed following the framework proposed by Pluye et al, that included (1) characteristics of proxy-OHI seekers, (2) context of proxy-OHI seeking, (3) use of OHI by proxy-seekers, and (4) outcomes of OHI use for the seeker and recipient. The codes were then progressively clustered into major themes and subthemes.

Framework Synthesis

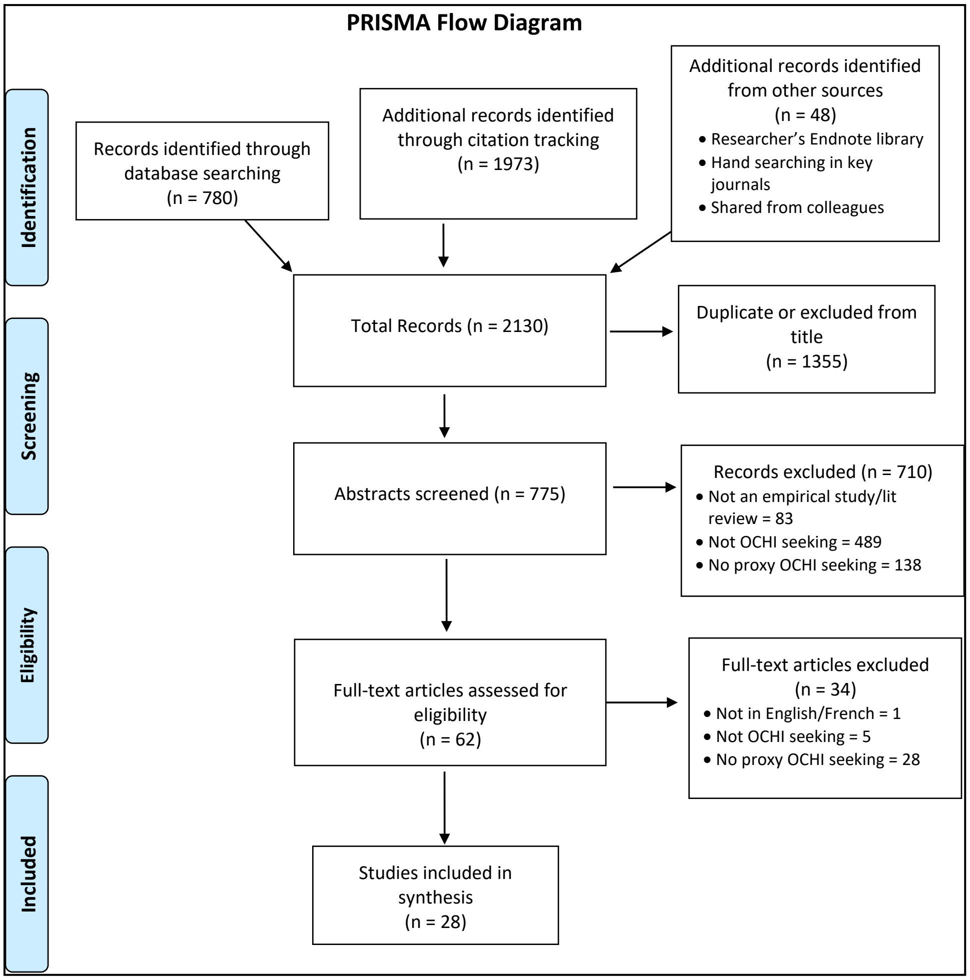
The initial framework in Figure 8 was revised following the qualitative synthesis stage. An iterative collaborative process was adopted over a series of meetings. All major themes were placed into textboxes and added to the figure representing the initial framework. Alternative figures were proposed until consensus was reached among the authors. The framework was then reviewed by two peer-reviewers and presented at two research meetings (one local and one international), and the feedback received was used to produce the final framework.

Results

Characteristics of Included Studies

Of 775 unique records identified in our search, 28 were deemed relevant and included in our review (Figure 9). Those referred to 15 quantitative studies (including 1 experimental study), 10 qualitative studies, 1 mixed methods study, and 2 systematic reviews. Over half of the empirical studies were conducted in North America (n=16). The corresponding 28 full-text articles were divided into three groups depending on who the focus of the study was: OHI proxy-seekers (n=9), OHI recipients (n=2) or both (n=17). Full details of study characteristics are in presented in the online supplementary material.

Figure 9. PRISMA Flow Diagram



Characteristics of proxy-seekers

Results of a telephone survey of 18,750 European citizens show that 61% of those seeking OHI searched on behalf of someone else, and of those, 26.6% exclusively searched on behalf of someone else. These surrogate OHI seekers were more likely to live with others and were more likely to search on behalf of their partners, children, or other family members, rather than for friends or colleagues (Reifegerste et al., 2017). This finding was echoed in several studies that reported that the proxy-seeker was most often a member of the same household or with whom the person had close ties (Abrahamson et al., 2008; Chua et al., 2020; S. Cutrona et al., 2015; Cutrona et al., 2016; Kirschning et al., 2007; Nicholas et al., 2003; Sadasivam et al., 2013; Song et al., 2019).

This was especially highlighted in relationships where the proxy seeker considered themselves responsible for someone else's health. Five studies focused on informal (unpaid) caregivers who reported higher and more constant proxy seeking behavior than non-caregivers (Bangerter et al., 2019; James et al., 2007; Sadasivam et al., 2013). A study exploring information seeking in families affected by multiple sclerosis describes the disease as a shared concern or responsibility which necessitated sharing information about it (Mazanderani et al., 2019). Dutta et al described 3G households in Singapore (three generations of family members residing together), where the children and grandchildren play vital roles as sources of health information for grandparents (Dutta et al., 2018).

Several other proxy-seeker characteristics influenced OHI seeking behavior. One important factor is gender: it was reported in seven studies that most people who searched OHI on behalf of others were female (Abrahamson et al., 2008; Cutrona et al., 2016; Mazanderani et al., 2019; Nicholas et al., 2003; Oh, 2015; Reifegerste et al., 2017; Turner et al., 2018). Proxy seekers were generally younger and more educated (Abrahamson et al., 2008; Chua et al., 2020; Cutrona et al., 2016; James et al., 2007; Li, 2015; Oh, 2015; Reifegerste et al., 2017) although one study reported that age, education, and income were not significant factors that influenced proxy OHI seeking behavior (S. L. Cutrona et al., 2015). Another is related to the proxy seeker's experience with OHI: the respondents in several of the included studies were reported as having higher health literacy (S. Cutrona et al., 2015; Mazanderani et al., 2019) and engaging in frequent OHI seeking behavior (Reifegerste et al., 2017).

Information needs and triggers of proxy-seeking

OHI seeking was triggered by different reasons and at different times in the included studies (Table 13). The proxy-seeker may be asked explicitly to search for OHI on behalf of someone who is unable to search for themselves, who has a complex health situation, or who needs to confirm information they had found online themselves (Carpenter et al., 2015; Dutta et al., 2018; Kinnane & Milne, 2010; Song et al., 2019). On the other hand, more studies report that the proxy-seeker initiates the search unsolicited out of interest (Abrahamson et al., 2008; Kinnane & Milne, 2010), when they do not have enough information to support a person living with a health condition (Chua et al., 2020; Mazanderani et al., 2019), immediately following a diagnosis (Coder, 2020; Dolce, 2011; Schook et al., 2014; Simon & Schramm, 2008), or following a visit with a healthcare provider (Bouju et al., 2014; Dolce, 2011). Finally, the proxy-seeker may also initiate the search themselves as coping mechanism to help deal them with their emotions following a diagnosis of their loved ones (James et al., 2007; Kinnane & Milne, 2010).

Table 13. Information needs and triggers of proxy-seeking

Code	Excerpt
Explicit request	"The carer may be asked to search for information on behalf of the person with cancer. This mostly occurs in situations where the patient does not have access to the Internet or is not Internet savvy or the person with cancer finds they are too ill to search." (Kinnane & Milne, 2010)
To make a decision	"Both patients and caregivers also mentioned that they surfed the Internet again at specific moments later during the lung cancer treatment trajectory, such as during chemotherapy, at the appearance of new symptoms or disease progression, or when having to make a choice between two treatment options." (Schook et al., 2014)
To support someone with a health condition	"A high percentage of the 795 caregivers (87%) had used Internet to search for information about the disease of the patient they were taking care for in the last year prior to the survey." (Chua et al., 2020)
Out of interest or obligation	"For Gina,1a 26-year-old Chinese participant, her role as a granddaughter constitutes her interpretation of HIS as she mostly seeks out information for

Code	Excerpt
	her grandparents. Jamila, a 37-year-old Malay woman, seeks out health information from the internet when one of her family members is not feeling well.” (Dutta et al., 2018)
Following a healthcare practitioner visit	“Patients and caregivers mentioned that their need to seek information often arose once they had time to rest and think about what they had been told, often at a time when their questions could not directly be answered by the treating specialist anymore: “Once you have come home, you have forgotten half of what you have been told, which is exactly the moment you would want to ask something.”” (Schook et al., 2014)
Coping mechanism	“Carers also tended to act as ‘gate keepers’ of information, and constantly sought new information as a means of coping.” (James et al., 2007)

How proxy-seekers use OHI

The proxy-seeker used OHI to better understand someone else’s illness or to help them feel more empowered in their roles as caregivers (Coder, 2020; Kirschning et al., 2007; Simon & Schramm, 2008; Tonsaker et al., 2017). Several studies reported the sharing of information between caregiver and patient either directly by sending them a link or print-out, or indirectly by discussing the information found (Brown & Veinot, 2021; Carpenter et al., 2015; Kirschning et al., 2007; Nicholas et al., 2003; Simon & Schramm, 2008; Turner et al., 2018). One study describes sharing and resharing the information among a social network, so that it reaches a larger number of people (Dutta et al., 2018) or so that a larger number of people are involved in making sense of the information (Turner et al., 2018).

One aspect of providing informational support involved acting as gatekeeper and controlling incoming information flow for the person (Abrahamson et al., 2008). A included literature review exploring the role of caregivers of cancer patients identified this role in three included studies, potentially as a way to manage the cancer experience of the patient (Kinnane & Milne, 2010). Families developed strategies for controlling information sharing, either explicitly with the patient or implicitly, especially if the information was potentially distressing or could lead to conflict (Mazanderani et al., 2019; Schook et al., 2014).

Proxy-seekers used the information in discussion with healthcare providers at a clinical visit (Dolce, 2011; Dutta et al., 2018; Kinnane & Milne, 2010; Kirschning et al., 2007; Simon & Schramm, 2008). This led to asking more questions and feeling more empowered during the visit, as well as involving the provider in interpretation of the information (Kinnane & Milne, 2010; Kirschning et al., 2007; Tonsaker et al., 2017). In some cases, it led to requesting more testing or to trying a new treatment plan (Coffey et al., 2017; Dolce, 2011). On the other hand, especially if the provider was not receptive to discussing the information, it also led to confronting or challenging the provider's decision (Dolce, 2011).

Proxy-seekers also used the information to provide emotional support (Dolce, 2011; Song et al., 2019) and practical support, especially as informal caregivers (Kinnane & Milne, 2010; Sadasivam et al., 2013) to the person. They used the information to change that person's lifestyle, for example, mothers in one study would cook healthier food and encourage their family to walk together as a form of exercise (Dutta et al., 2018). In one study, the authors report that family members used the information to exert control on the patient, using techniques such as pushing or guilting (Brown & Veinot, 2021).

Outcomes of OHI use

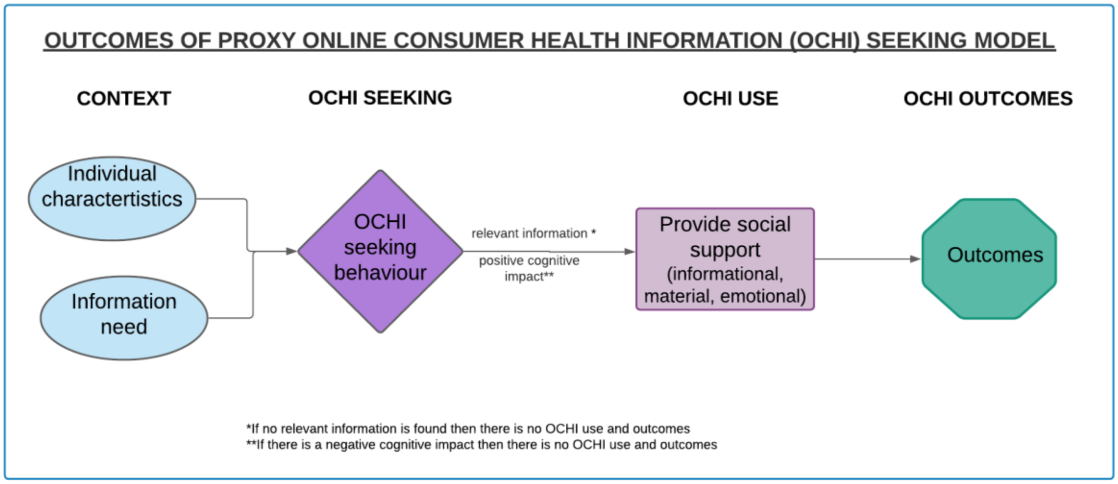
The outcomes reported by the included studies are overwhelmingly positive. Empowered by the informational they received, people and proxy seekers felt better informed and more confident and were able to discuss the information with their healthcare providers and request different management options (Coffey et al., 2017; Dolce, 2011; Kinnane & Milne, 2010). Information helped people make a health behavior change like quitting smoking (Abrahamson et al., 2008). It also helped lessen worry about their own health (Abrahamson et al., 2008; Bouju et al., 2014), one study describes an 87-year-old participant who feels calmer when her grandchildren print out information and explain treatment options for her (Dutta et al., 2018). People describe how having proxy-seekers "care so much" about their health made them feel supported (Song et al., 2019), and how it allowed them to have someone to talk to about their health (Simon & Schramm, 2008).

Negative outcomes are rarely reported: a literature review found limited reports of patients' anxiety or decisions to refuse cancer treatment (Kinnane & Milne, 2010). There were two studies that reported that the proxy-seekers themselves experienced more anxiety, sometimes as a result of information overload (Bouju et al., 2014; Coder, 2020). The proxy-seeker and the person did not always have the same approach to OHI: in situations where the person did not want to "know" or ignored the information, this led to tensions and conflict (Brown & Veinot, 2021; Mazanderani et al., 2019).

Revised conceptual framework

The revised conceptual framework on the outcomes of proxy OHI seeking framework is presented in Figure 10.

Figure 10. Outcomes of proxy online health information (OHI) seeking framework



*If no relevant information is found then there is no OCHI use and outcomes
**If there is a negative cognitive impact then there is no OCHI use and outcomes

Who are the proxy seekers? Proxy-seekers are more likely to be female, who are also are more likely to share health information with others as they are considered the “central nodes” of health information within a community (Altizer et al., 2014; Colon-Ramos et al., 2009). They are also more likely to be more educated, with higher e-health literacy, and to be frequent Internet users in general. Proxy-seekers were likely to be in frequent contact with the people for whom they were seeking OHI, and to report strong social ties with these people (e.g., family members in the same household).

Why and when does proxy-seeking happen? The OHI seeking process is triggered by an information need, which may be explicit or implicit. Explicit information needs may be communicated to the proxy-seeker with or without a request for informational support. Proxy-seekers who were also informal caregivers may also initiate OHI seeking as part of their caregiving responsibilities. The proxy-seeker may also initiate the search themselves out of curiosity, for reassurance, or as coping mechanism to help deal with their emotions following a diagnosis of their loved ones.

How do proxy-seekers use information? When they find a situationally relevant information object that has a positive cognitive impact, they can use it to provide social support for someone else. This support is most commonly informational support: either by sharing the OHI found directly or discussing it with the person to help them make sense of it. Support may be emotional or practical support, for example, by offering to cook meals. The proxy-seeker also acts as an information gatekeeper by filtering the information for the person to reduce information overload stress.

What are the outcomes of OHI use by proxy-seekers? Using the information will lead to separate outcomes experienced by the person and the proxy-seeker, that are generally positive, e.g., feeling more confident discussing the information at a clinical visit. In situations where the information is conflicting, or unsolicited this may lead to negative outcomes such as increased worrying or worsening of an interpersonal relationship.

Discussion

Principal Results

To our knowledge, this is the first review to explore the outcomes of proxy OHI seeking and use of OHI to provide social support to others. We adapt a framework on individual OHI outcomes to proxy seekers and describe and explain the context, use and outcomes. Although there are two included reviews that reported interesting results, they did not fully address our question: one explored the role of the Internet in supporting and informing carers of people with cancer (Kinnane & Milne, 2010), and the second explored how informal caregivers of children with health care needs used Internet-based health care services and resources (Park et al., 2016). Another recent study adapted the existing Comprehensive Model of Information Seeking model to surrogate health information seeking yet did not explore the outcomes of social support (Reifegerste et al., 2020).

Comparison to Existing Models on OHI Seeking Outcomes

In his revised 1996 model, Wilson adds "information processing and use" (Wilson, 1997). Our conceptual framework goes further and, in addition to describing the context of information seeking behavior by the proxy-seeker, also explores OHI use and outcomes. Similar to Pluye's OHI Outcomes framework, our framework includes factors that influence information seeking behavior and leads to four levels of outcomes (Pluye et al., 2019). The use of OHI in our framework revolves around types of social support, and the health and healthcare related outcomes are reported by both the proxy-seeker and the person. Moreover, we identified two additional consequences of informational support: sharing misleading information and acting as a gatekeeper to the information.

Our findings echo similar findings from other studies exploring proxy health information seeking: in situations where the information need is explicit and the proxy-seeker has high health literacy, informational support is associated with positive emotional support and other outcomes are generally positive. First, people who can discuss the information they found with others are more likely to better understand the information, use the information found to make decisions about their health care, and experience better health outcomes such as reduced worries (Iverson et al., 2008; Sillence et al., 2007; Tanis et al., 2016; Thapa et al., 2020). Other potential outcomes include improvement in the receiver's health, the buffering of potential negative outcomes and the increase in perceived social support (Cohen & Wills, 1985; Dunst et al., 1986; Lin et al., 1979). This is especially true if the provider has higher health literacy than the receiver: they are thus better able to explain, contextualize or validate the information (Agius & Stangeland, 2016; Fox & Duggan, 2013). Some people may prefer information avoidance, defined as "any behavior designed to prevent or delay the acquisition of available but potentially unwanted information" (Sweeny et al., 2010), which may lead to tensions between person and proxy-seeker.

Second, for the seekers themselves, these outcomes include a change in their relationship with the person (improvement or worsening) and feeling more involved in health care of others (Hether et al., 2014). Moreover, the social support providers who report feeling more satisfied with their interaction with the person and who felt better about themselves after providing informational support were more likely to continue doing so and more likely to seek information from other sources (Hether et al., 2014). Negative outcomes for the seekers reported include increased anxiety as a result of information overload. This is defined as "when the information processing demands on time [..] exceed the supply or capacity of time available for such processing" (Schick et al., 1990).

In situations where the informational support is unsolicited and the person does not feel that the information is relevant to their situation, interpersonal tensions may develop (El Sherif et al., 2018). This may also occur in relation to sharing sensitive or intimate information with family members, for example, a study examining the effects of discussing information on sexuality and contraception on mother-daughter relationships reported that a strain in the relationship may develop (Amsellem-Mainguy, 2006). In addition, sharing misleading health information from unreliable sources may also lead to negative health outcomes, as described in two recent systematic reviews (Swire-Thompson & Lazer, 2020;

Wang et al., 2019). More specifically, in this context, the seekers do not intend to cause harm and are in fact spreading misinformation which may lead to delayed care, decreased quality of life and increased risk of mortality.

Limitations

We have identified some limitations in our review. Unlike in a systematic review, only one reviewer conducted the selection phase, therefore relevant studies may have been missed. However, our goal was to revise a framework and not necessarily to be exhaustive (in contrast to the needs of being systematic when a review is aimed to measure effectiveness of an intervention). Similar to other reviews, there may have been an underreporting of negative outcomes due to publication bias. Finally, systematically reviewing all the models on information seeking behavior was beyond the scope of this review, but we reviewed and discussed the most common models with a specialized expert librarian.

Directions for Future Research

Most studies on information seeking behavior do not explore how the information is used by proxy-seekers, and what happens next (Case & O'Connor, 2016). While this review explores the outcomes of OHI proxy seeking, few studies report outcomes for the seekers themselves: future empirical studies can focus on these outcomes from the seekers' perspectives. Furthermore, little is known on which contextual factors or seeker characteristics are associated with positive and negative OHI outcomes. By testing our framework in different contexts, future work can revise our framework, and propose research-based solutions to help the proxy-seekers use OHI with others.

Conclusion

The outcomes of proxy OHI seeking constitute an important topic for both information specialists and health care practitioners. Members of a person's social circle may help them overcome information-seeking barriers and illness challenges (e.g., when they are too physically weak or mentally incapacitated to search themselves) (Abrahamson et al., 2008). People are sometimes more likely to turn to members of their social circle to make sense of OHI they find, rather than discuss it with a health professional (Reifegerste et al., 2017). By better understanding how people and their social circle use OHI together, OHI providers can better adapt their platforms and information to meet both their needs, and health care practitioners can target patients' social circle with information for dissemination and use (Kim et al., 2015).

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Conflicts of Interest

None declared

Abbreviations

OHI: online health information

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Chapter 4: Methodology

In this chapter I will provide details on the methodology used in this mixed methods research study conducted within an existing partnership. I will discuss the Organizational Participatory Research approach used with our partners, as well as the details of this partnership. I will also include a description of the methods used for each component of the study, as well as ethical considerations made throughout.

Organizational Participatory Research Approach

Participatory research describes different collaborative approaches where academic researchers partner with stakeholders who do not necessarily have any formal research training. In Organizational Participatory Research (OPR), researchers collaborate with organizations who participate to varying degrees in the different stages of a research project: identifying the problem and formulating the research questions, selecting the research methods, collecting the data, analysing the data, interpreting the results, and applying and disseminating results (Bush et al., 2018).

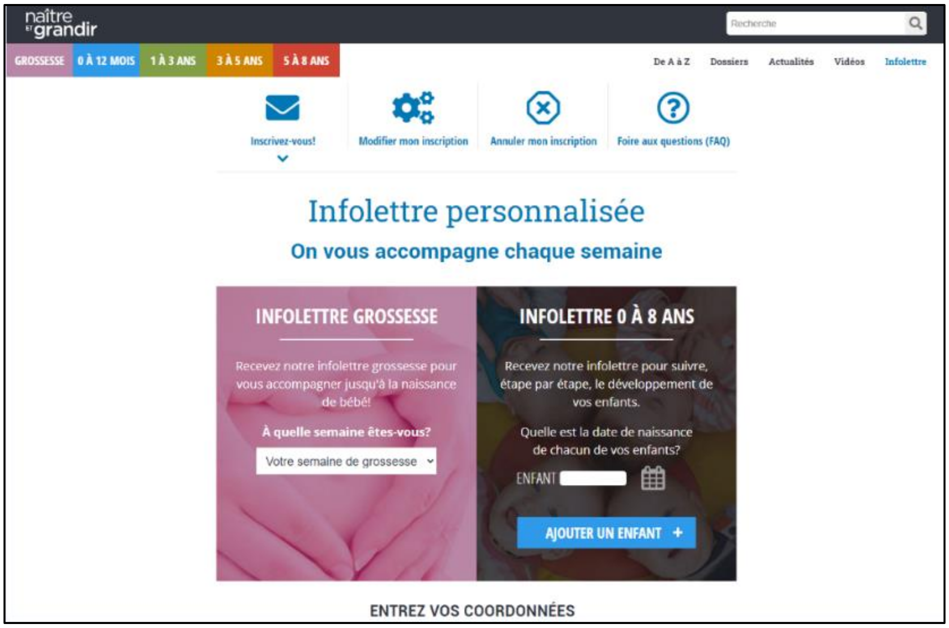
There are two modes of participation in research decisions by organizations: (1) co-construction where the organization members work closely with researchers in at least three of the previous stages, and (2) consultation where organization members are consulted by researchers and provide input that influences research decisions (Bush et al., 2017). The main goals of OPR are “to implement organizational changes and practice improvement or to develop and implement innovations or interventions” (Bush et al., 2017). A systematic review on the benefits of OPR reports that when the organization partners are involved up-front (e.g., when setting the research project objectives), additional benefits from OPR were reported including working together on subsequent projects (Bush et al., 2017). OPR is also a form of knowledge translation as it ensures that the gaps identified address a real-world need of the organization [75].

Our team at McGill University has been working in partnership with Naître et Grandir since 2014, producing several OPR projects. Naître et Grandir is a Quebec based organization producing trustworthy easy-to-read, listen to and watch, online parenting information through a magazine, newsletters, and a website. The editors at Naître et Grandir are key partners involved in all stages of these OPR projects, from conception to dissemination and implementation of findings, and are thus co-constructors of the research. I have been producing bi-annual reports for the organization since 2015 and findings from these reports highlighted the knowledge gap that this PhD thesis aimed to address. Our mature and strong partnership, and frequent interactions ensure that the recommendations produced will be implemented.

Naître et Grandir Website and Newsletter

The Naître et Grandir website (N&G) provides parents with support in bringing up their children, from the time they are conceived until they are 8 years old. In addition to the website, its modes of dissemination include a personalized electronic weekly newsletter containing links to N&G webpages tailored to their child's age (Figure 11 and Figure 12). N&G is funded by the 'Lucie and André Chagnon' Foundation, a philanthropic organization that seeks to contribute to the prevention of poverty through the creation of conditions and environments that are favorable to educational success of children, specifically from socially vulnerable families and communities. N&G provides parenting information on child development, education, and health. It follows principles of public health proportionate universalism (Marmot & Bell, 2012), i.e., supports all parents while it is oriented for parents with a low literacy level. On the website, each webpage provides evidence and expert-based information on a topic. Webpages are grouped into five age-categories: pregnancy, child 0-1 year, 2-3 years, 4-5 years, and 6-8 years. Our team at McGill University and N&G have worked in partnership to implement the validated Information Assessment Method (IAM) questionnaire for assessing and improving webpages of parenting information.

Figure 11. Naître et Grandir newsletter subscription



Infolettre personnalisée

On vous accompagne chaque semaine

INFOLETTRE GROSSESSE

Recevez notre infolettre grossesse pour vous accompagner jusqu'à la naissance de bébé!

À quelle semaine êtes-vous?

Votre semaine de grossesse

INFOLETTRE 0 À 8 ANS

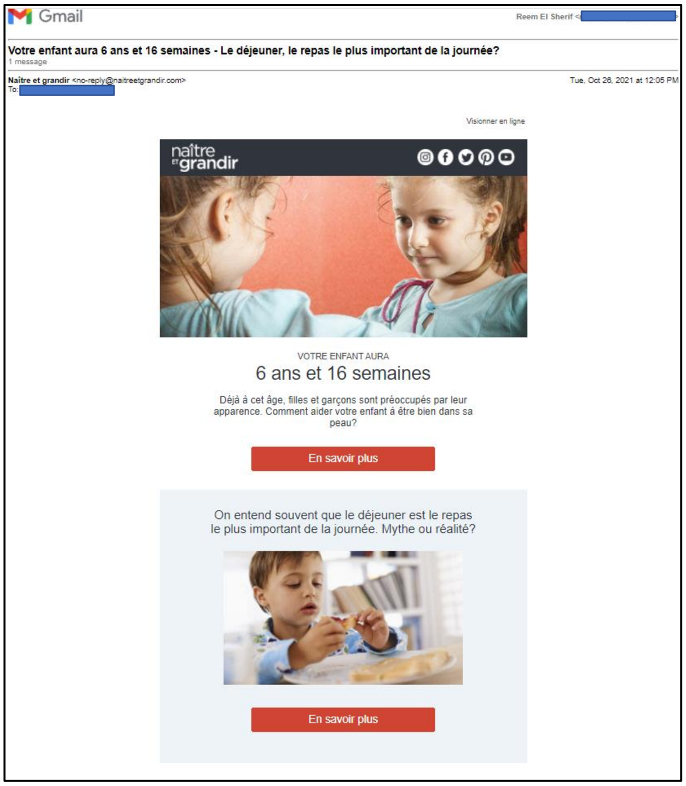
Recevez notre infolettre pour suivre, étape par étape, le développement de vos enfants.

Quelle est la date de naissance de chacun de vos enfants?

ENFANT

ENTREZ VOS COORDONNÉES

Figure 12. Example of the weekly newsletter



Reem El Sherif <[redacted]>

Votre enfant aura 6 ans et 16 semaines - Le déjeuner, le repas le plus important de la journée?
1 message

Naître et grandir <no-reply@naitreetgrandir.com>
To: [redacted]

Tue, Oct 26, 2021 at 12:05 PM

VOTRE ENFANT AURA

6 ans et 16 semaines

Déjà à cet âge, filles et garçons sont préoccupés par leur apparence. Comment aider votre enfant à être bien dans sa peau?

On entend souvent que le déjeuner est le repas le plus important de la journée. Mythe ou réalité?

Information Assessment Method

The OHI outcomes framework in Figure 5 is operationalized in the Information Assessment Method (IAM) questionnaire that is used to evaluate the OHI outcomes from the viewpoint of the information seeker. The IAM invites the user to rate a specific OHI piece of information, e.g., a webpage, by stimulating their reflection on its value (how it is valuable) and providing feedback comments. These ratings and comments are then used by information providers to improve their content, a phenomenon referred to as "two-way knowledge translation" (El Sherif et al., 2017; Granikov, Grad, et al., 2020).

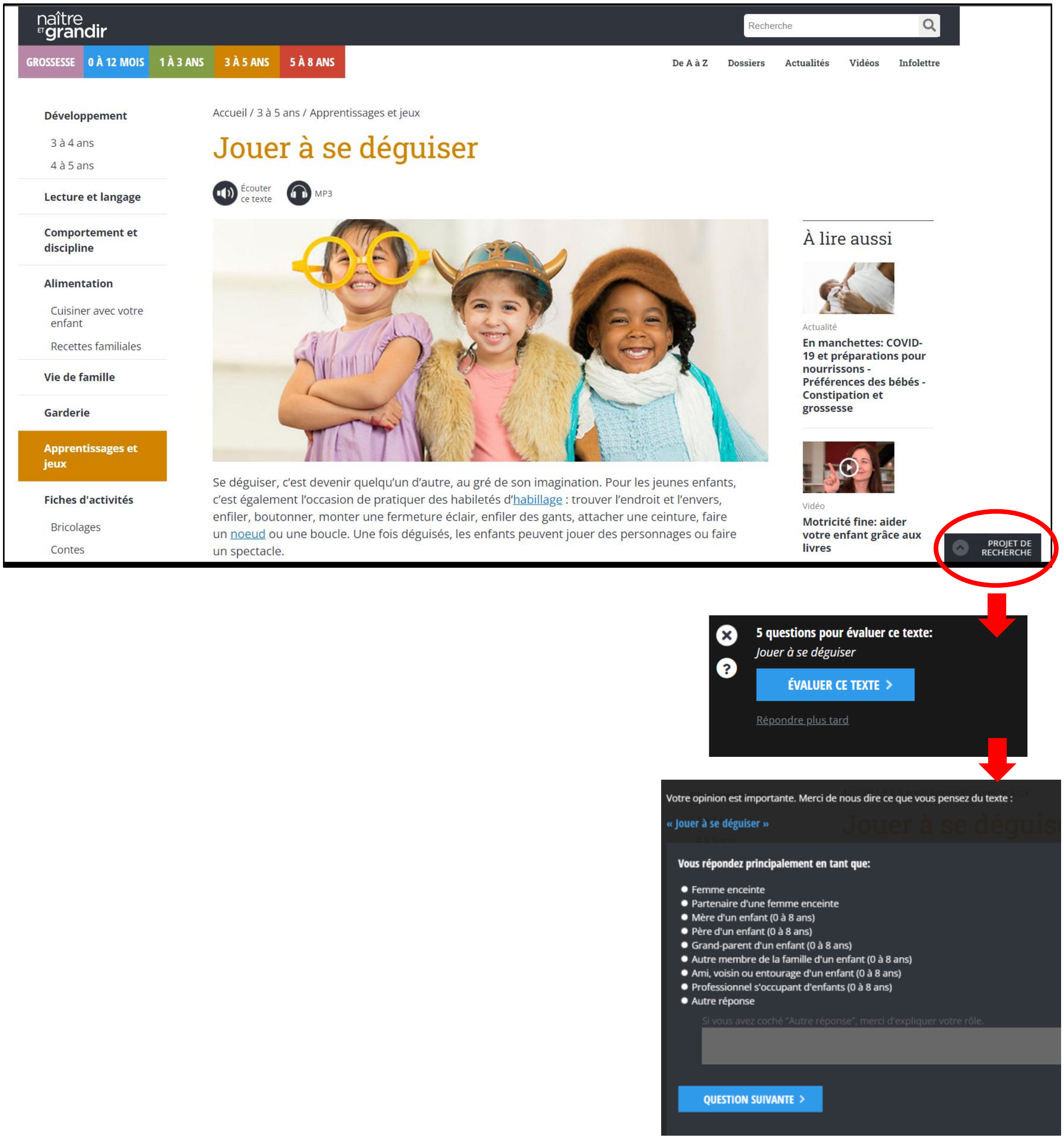
The IAM was first developed and implemented in 2006 and has since been implemented with 19 partners who produce information products such as clinical summaries and guideline recommendations. IAM users in these partnerships include healthcare providers (such as physicians and pharmacists), and information seekers such as parents and cancer survivors (Granikov, Grad, et al., 2020). The IAM questionnaire has been content validated for these different audiences using participatory mixed methods reviews and studies, integrating quantitative survey data with qualitative insights (Granikov, Grad, et al., 2020; Pluye et al., 2014).

The validity of the IAM for the Naître et Grandir audience has been assessed on two occasions: it was first validated specifically for parents in 2015 using quantitative data (raters' responses) and qualitative data (raters' comments and qualitative interviews), producing the IAM4parents-v2015 (Bujold et al., 2018). It was then validated again specifically for parents of lower socio-economic status (SES) using qualitative data from interviews with low-SES parents, producing the IAM4parents-v2019 used in this study (Pluye et al., 2020). The IAM4parents-v2019 was validated in French (as it is implemented with N&G) and underwent a transcultural adaptation into English. The full questionnaire is presented in Appendix 2. When N&G readers land on a webpage corresponding to a specific topic (directly or through the newsletter link), a lateral tab appears as shown in Figure 13, inviting them to complete a survey. The first question asks the respondents to identify with one role for the purpose of this specific webpage they are rating:

(a) Pregnant woman
(b) Partner of a pregnant woman
(c) Mother of a child (0 to 8 years old)
(d) Partner to the mother of a child (0 to 8 years old)
(e) Grandparent of a child (0 to 8 years old)
(f) Other family member of a child (0 to 8 years old)
(g) Friend, neighbour, or entourage of a child (0 to 8 years old)
(h) Professional who cares for children (0 to 8 years old)
(i) Other response (comment box)

Respondents who selected (a)-(d) where in the parents' group, those who selected (e)-(h) were entourage members, and comments from those who selected (i) where analyzed to place them in the appropriate group or exclude them from the dataset, e.g., a child who is 12 years old. This dataset was used as the source of data for the mixed methods research study.

Figure 13. Lateral tab inviting readers to complete the IAM questionnaire



Jouer à se déguiser

Se déguiser, c'est devenir quelqu'un d'autre, au gré de son imagination. Pour les jeunes enfants, c'est également l'occasion de pratiquer des habiletés d'habillage : trouver l'endroit et l'envers, enfiler, boutonner, monter une fermeture éclair, enfiler des gants, attacher une ceinture, faire un noeud ou une boucle. Une fois déguisés, les enfants peuvent jouer des personnages ou faire un spectacle.

En manchettes: COVID-19 et préparations pour nourrissons - Préférences des bébés - Constipation et grossesse

Motricité fine: aider votre enfant grâce aux livres

5 questions pour évaluer ce texte:

Jouer à se déguiser

Votre opinion est importante. Merci de nous dire ce que vous pensez du texte :

« Jouer à se déguiser »

Vous répondez principalement en tant que:

○ Femme enceinte
○ Partenaire d'une femme enceinte
○ Mère d'un enfant (0 à 8 ans)
○ Père d'un enfant (0 à 8 ans)
○ Grand-parent d'un enfant (0 à 8 ans)
○ Autre membre de la famille d'un enfant (0 à 8 ans)
○ Ami, voisin ou entourage d'un enfant (0 à 8 ans)
○ Professionnel s'occupant d'enfants (0 à 8 ans)
○ Autre réponse

Si vous avez coché "Autre réponse", merci d'expliquer votre rôle.

Mixed Methods Research Study

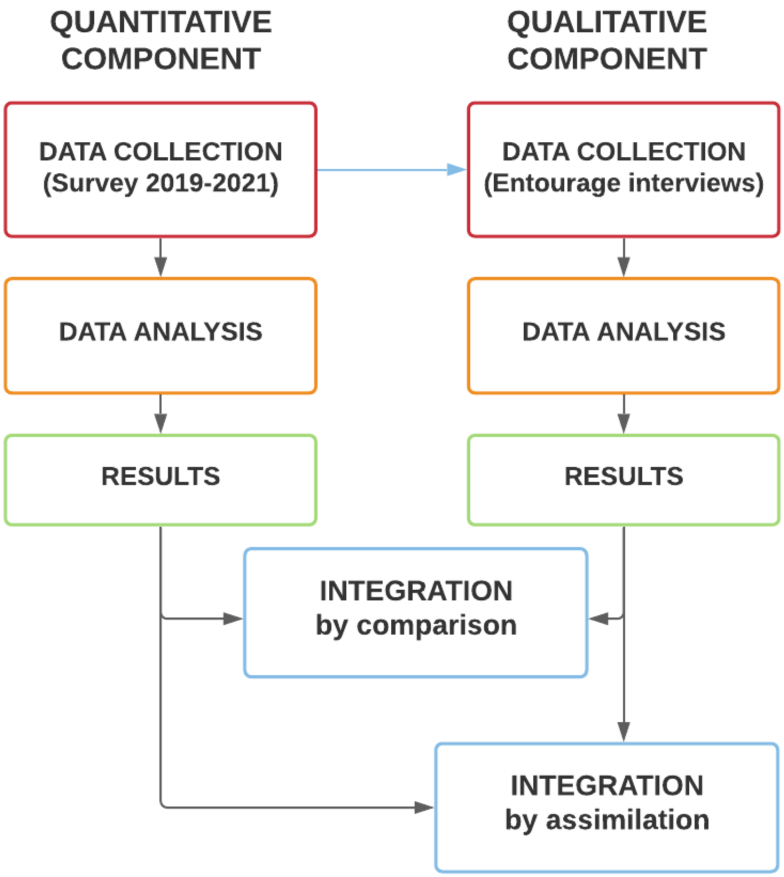
Mixed methods research (MMR) allows us to take into account “the socio-cultural context and the real-world environment”, and provides a more complete understanding of the phenomenon being explored (Vedel et al., 2019). MMR is becoming increasingly popular across different fields including primary care research and information science (Granikov, Hong, et al., 2020; Vedel et al., 2019). MMR studies must satisfy three conditions: combine at least 1 qualitative method and 1 quantitative method, each method must be used rigorously, and integration occurs at the data collection/data analyses/results or phases (Pluye & Hong, 2014). There are three common MMR study designs (Pluye & Hong, 2014):

- Sequential explanatory design where the initial results from the quantitative phase are explained in more depth in the subsequent qualitative phase.
- Sequential exploratory design where the quantitative phase is built on the results from the initial qualitative phase that explores a phenomenon.
- Convergent design where qualitative and quantitative components are usually (but not necessarily) conducted concomitantly and independently (but not necessarily) of each other.

Integration (explicitly interrelating the quantitative and qualitative phases or components) is a core characteristic of MMR, it is the justification for conducting MMR in the first place (Creswell & Clark, 2011). There are three main types of integration strategies: 1) connecting phases (connecting results of the first phase to the data collection of the second phase), 2) comparing results obtained from separate or interdependent data collection and analysis, and 3) assimilating data (e.g., transforming qualitative data into quantitative data) (Pluye et al., 2018).

I conducted a convergent mixed methods study summarized in Figure 14. This design was used because the goal of my study was to explore the same phenomenon from different angles and compare the findings. The qualitative and quantitative components were conducted and analyzed separately and concomitantly, and each was reported separately as a stand-alone manuscript. Then, the results from both components were integrated to answer the overarching research question, and to revise the conceptual framework presented in Chapter 3. Two integration strategies were used: comparison of results and assimilation of results (described later in this chapter).

Figure 14. Convergent Mixed Methods Study Design



Quantitative Component

A two-year quantitative observational study was conducted in the context of the previously described OPR partnership between Naître et Grandir and our team at McGill University. Ethical approval was obtained from the Institutional Review Board at the Faculty of Medicine, McGill University, prior to the start of data collection. This study is reported using the STROBE checklist for reporting observational studies [26].

Study Participants and Data Collection

Participants in this study were N&G readers who had completed an the IAM-parent-v2019 questionnaire asking them to evaluate a specific N&G webpage between April 13th, 2019, to March 30th, 2021. Using their IP address, the country they were responding from was specified, and we only included IAM questionnaires completed in Canada and four other OECD countries with francophone populations, a similar health and social system, and comparable average household incomes, Internet access and reported social support levels as shown in Table 14 (France, Belgium, Switzerland, and Luxembourg) (OECD, 2020).

Table 14. Income, internet access and social support in included countries

Country	Average household income*	Internet access**	Average social support***
Canada	$31,573	80.1%	92.3%
France	$32,332	81.3%	91.0%
Belgium	$31,856	83.7%	92.2%
Switzerland	$38,008	89.6%	92.9%
Luxembourg	$42,102	92.9%	91.2%

*Household net adjusted disposable income, per capita USD at 2017 Purchasing Power Parity
**Household with high-speed internet access, share of households with broadband internet access at home, percentage
***Share of people reporting that they have relatives or friends they can count on to help them in times of need, percentage
Source: OECD. How's Life? 2020. 2020; https://www.oecd-ilibrary.org/content/publication/9870c393-en

All completed questionnaires were included in the analysis, hereafter referred to as IAM responses. Among them, participants were divided into two groups: those who had identified themselves either as a parent of 0-8-year-old children, or as an entourage member. A second analysis was conducted in the entourage group between those who had accessed the N&G webpage and IAM questionnaire through the weekly newsletter and those who had landed directly on the N&G website. Variables included in the analysis correspond to the IAM questions (Figure 15).

Figure 15. IAM questions and response options

Q1. Is this information relevant? (Choose only one)
Very relevant (this is the information I expected)
Relevant
Somewhat relevant
Very little relevant (this is not the information I expected)

Q2. Did you understand this information? (Choose only one)
Very well (I understood everything)
Well
Poorly
Very poorly (I did not understand much)

Q3. What do you think about this information? Check all that apply.
This information allowed me to validate what I do or did
This information taught me something new
This information reassured me
This information refreshed my memory
This information motivated me to learn more
I do not like this information

Q4. Will you use this information? (Choose only one)
Yes
No

Q4a. How will you use this information for you or for a child in your care? Check all that apply.
This information will help me to better understand.
I will use this information to do something.
I will use this information to do something in a different manner.
I will use this information in a discussion with someone else.
I will use this information in another way.

Q5. Using this information, do you expect any benefits for you and at least one child (0-8 years)? (Choose only one)
Yes
No

Q5a. Which benefits do you expect for you and at least one child (0-8 years)? Check all that apply.
This information will help me to improve the health or well-being of my child.
This information will help me to be less worried.
This information will help me to prevent a problem or the worsening of a problem.
This information will help me to handle a problem.
This information will help me decide what to do with someone else.
Another benefit.

Statistical Analysis

The primary study endpoint, comparison of IAM responses between parents and entourage, and between entourage IAM responses via newsletter and website, were assessed using frequency analyses. Difference in proportions and 95% confidence intervals for differences in the proportion of IAM responses of both groups were calculated (Lowry, 2019; Newcombe, 1998). To take multiplicity of comparisons into account and retain a global Type I error level of 5%, confidence levels were corrected using Bonferroni adjustment. In addition, a Pearson's chi-squared test was used to determine whether the differences between two groups of participants were statistically significant. Test results were deemed statistically significant when p-values (p) were less than 0.001. All statistical analyses were completed using SAS software (version 9.4).

Hypotheses

Based on our previous work exploring information outcomes, we hypothesized that, when the information is considered relevant and easy to understand, the entourage would be more likely to report discussing the information with others. We also hypothesize that, similar to previous work on parents' responses, there will be a difference in entourage responses based on mode of access.

Qualitative Component

A qualitative descriptive study was conducted using semi-structured remote interviews with entourage members who were identified from the same dataset used in the quantitative component. This type of study is used to provide an accurate account of events or experiences of participants attributes to those events (Sandelowski, 2000). Methods and results are reported using the Consolidated criteria for reporting qualitative studies (COREQ) (Tong et al., 2007).

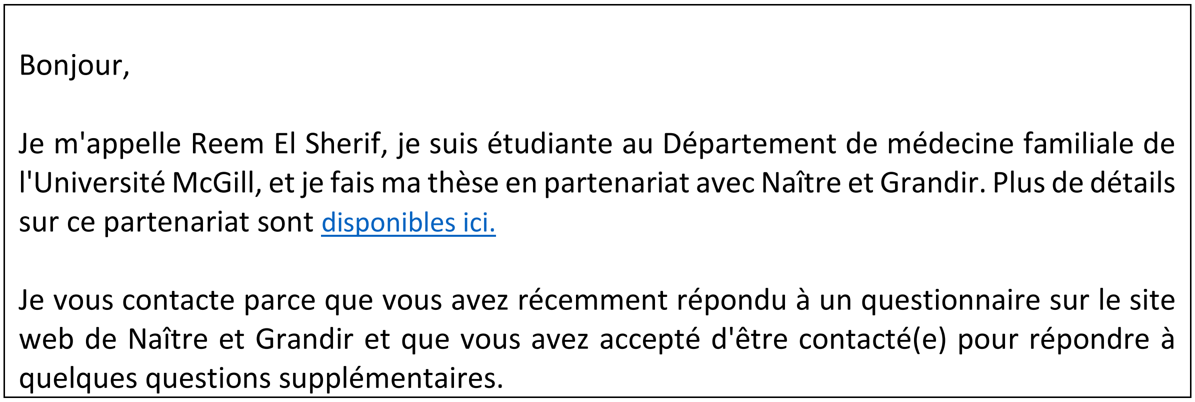
Study participants

Study participants were identified from the data set used in the quantitative study. They were selected from the sample of entourage members who agreed to be contacted for an interview and provided contact information. A table containing the following columns from the original dataset was produced:

1. Respondent type (i.e., grandparent, family member, friend/neighbour/other entourage, or professional working with children 0-8 years old)
2. Email provided
3. Date of the latest IAM questionnaire completed
4. How many IAMs were completed (in the 2-year study period)
5. N&G webpage that was evaluated
6. IAM completed through the website or newsletter
7. Comments provided

I used a purposive sampling strategy to recruit participants using this table and sent out four invitation emails a week (Figure 16). First, I emailed the participants who had completed the most IAM questionnaires; there were three participants who had completed 14, 13 and 9 IAM questionnaires and who agreed to be interviewed. Then, I emailed participants in the order of the date of completed questionnaires, starting with least recent date. The interviews were conducted, transcribed, and analyzed three at a time until saturation was reached (where no new themes were developed).

Figure 16. Invitation email sent to potential participants



Bonjour,

Je m'appelle Reem El Sherif, je suis étudiante au Département de médecine familiale de l'Université McGill, et je fais ma thèse en partenariat avec Naître et Grandir. Plus de détails sur ce partenariat sont disponibles ici.

Je vous contacte parce que vous avez récemment répondu à un questionnaire sur le site web de Naître et Grandir et que vous avez accepté d'être contacté(e) pour répondre à quelques questions supplémentaires.

Je travaille sur un projet qui vise à mieux comprendre comment les gens partagent les informations de Naître et Grandir avec les autres membres de leur réseau social, et quels en sont les effets.

Si vous êtes toujours intéressé(e) et disponible, nous pouvons organiser un entrevue téléphonique ou virtuel confidentiel, en français ou en anglais selon votre préférence, au moment qui vous conviendra le mieux.

Nous vous verserons la somme de 50 $ pour compenser le temps que vous accorderez à cet entretien.

Si vous souhaitez participer ou si vous avez des questions, merci de répondre à ce courriel. Cette étude a été approuvée par le Bureau de l'éthique en recherche de l'Université McGill.

Merci et bonne journée,
Reem

Reem El Sherif, MSc. MBBCh.
PhD candidate, Department of Family Medicine, McGill University

In total, the table contained 71 potential participants (25 grandparents, 17 family members, 15 friends/neighbours, and 14 professionals). Invitation emails were sent to 45 potential participants, and when they responded I sent them the consent form and requested their approval. Once they had sent back that they agreed with the contents of the consent form and had no further questions or concerns, the interview time was planned. In total 14 interviews were conducted (saturation was reached after 12 interviews).

Data collection

Individual semi-structured interviews were conducted over the phone or via Zoom depending on the participant's preference. The original protocol had included a face-to-face option for the interviews as well, but the interviews were conduced during the COVID-19 pandemic, so it was considered unnecessary to expose the participants or researchers to such a risk. Moreover, a research note that compared interview transcripts obtained by face-to-face and phone interviews found no significant differences in the interviews (Sturges & Hanrahan, 2004).

The interview guide was developed using an iterative process based on the OHI conceptual framework (Chapter 2) and the proxy OHI seeking outcomes framework (Chapter 3). The initial version was developed with the help of my supervisor, then reviewed by members of our McGill research team and revised based on their feedback. Finally, I pilot-tested the guide with two graduate students in our department (both proxy OHI seekers not familiar with my project). I received feedback from the participants on how to improve the questions and took notes during the pilot interviews. For example, one participant suggested we add a comment on how the pandemic may have changed the participant's social interactions. The final version of the interview guide was then produced (presented in Appendix 3).

The interviews lasted between 25 and 55 minutes long and were conducted in French by my Francophone colleague (Ms. Virginie Paquet). Ms. Paquet is a health librarian who had completed an MSc in Information Studies and had experience conducting remote interviews. We had several meetings to discuss the study objectives and the interview guide. She conducted a third pilot-testing interview which was video-recorded, and we discussed the experience prior to starting the study interviews. The pilot interviews were not included in the analysis. Ms Paquet and I met following every interview to discuss her notes and observations.

After introducing the purpose of the study, the participants were asked general questions about online health information, and the context and resources of their information seeking behaviour. They were asked about their role as entourage member and who were the members of their social circle that they were frequently in contact with. They were reminded of the N&G webpage they had rated and were asked to describe how and why they had landed on that page. Finally, they were asked how they used the information on the page, and what outcomes they perceived as a result.

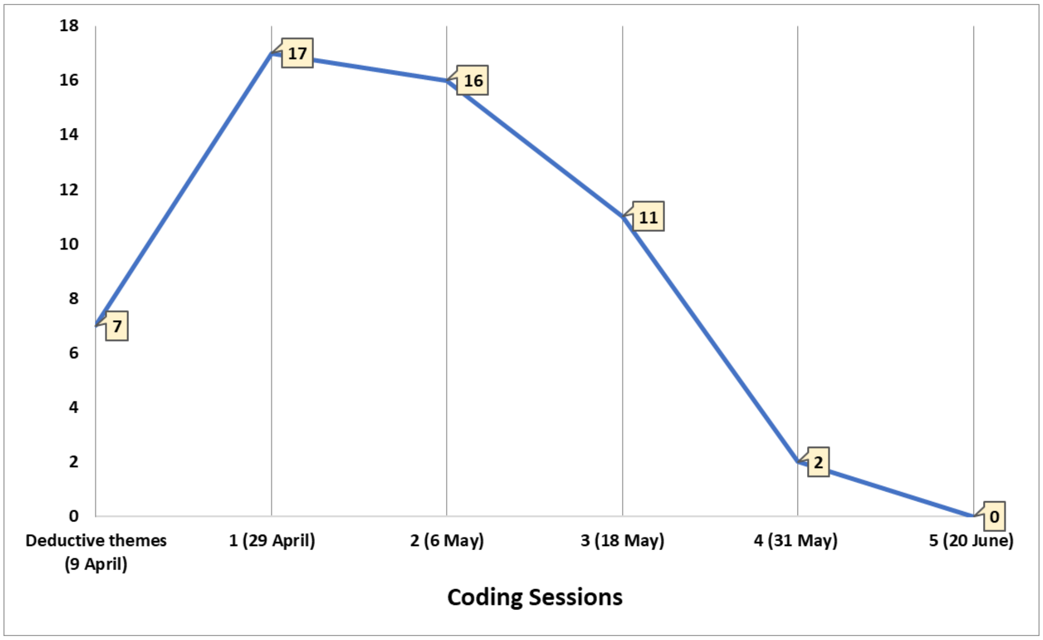
The interviews were recorded using two methods: a phone recorder app or the Zoom recording, and an external audio recorder. After the interview, we would upload the interview recordings to a password-protected McGill OneDrive folder and delete the first recording on the app or computer. The recordings on the external recorder were kept until the end of the study and then deleted. The audio files were anonymized and edited to remove the first few minutes containing identifying details of the participant and sent via secure transfer to a professional transcriber. The transcripts were also stored in the password protected OneDrive folder.

Data analysis

The original transcripts as well as their translations were imported into NVivo (Version 12, Release 1.5); and the analysis was conducted on the translated version but I referred to the original transcripts at several points throughout the analysis. A hybrid deductive-inductive thematic analysis was performed (Boyatzis, 1998; Fereday & Muir-Cochrane, 2008). There are six stages of data coding and identification of themes as described by Fereday and Muir-Cochrane: (1) developing the coding manual; (2) testing the reliability of codes; (3) summarizing data and identifying initial themes; (4) applying templates of codes and additional coding; (5) connecting the codes and identifying themes; (6) corroborating and legitimizing coded. Each theme refers to a coherent and meaningful pattern in the data relevant to the research question in that it directly answers it or provides a context (Clarke & Braun, 2013). Themes were derived from the conceptual framework on OHI outcomes and the preliminary model on proxy OHI seeking presented in Chapter 3 (deductive coding). New themes were developed from the data (inductive coding).

The NVivo project was first created on April 9th, 2021, and seven themes major themes were added before analysis began. Then the interviews were analyzed over five coding sessions. During the fourth session (after 12 interviews had been conducted and analyzed), only two new themes were developed as shown in Figure 17. Two more interviews were conduced and analyzed, and no new themes were developed, so we believed saturation had been reached and data collection stopped.

Figure 17. Qualitative data analysis: saturation of themes reached after 4 coding sessions



Major themes were related to characteristics of the entourage member, types of information needs, sources of OHI searched, how OHI was used, and OHI outcomes reported. After I coded the first five interviews, the coding manual and coding results were discussed with my supervisor. His feedback was used to refine coding definitions and analysis of the remaining interviews was completed.

Reflective practice by the interviewer

Following the standard of practice in qualitative research, I kept a reflexive diary throughout the data collection phase (Nadin & Cassell, 2006; Ortlipp, 2008). Before each interview, I took brief notes of the participant based on short questionnaire responses. I used these notes to personalize the interview questions for each interviewee. During the interview, I also took brief notes of my thoughts during the conversation, as well as any points made by the interviewee that I thought were relevant and needed more exploration. This was done to help me clarify the purpose of specific questions. After each interview, I took further notes of the main ideas while they were fresh in my mind and highlighted any specific idea, I felt I should then add to the interview guides. When the interviewee preferred to conduct the interview in French and my colleague conducted the interview, I asked her to follow the same process of taking notes during and after the interview. We had a brief meeting after every interview to discuss these notes, and longer meetings after I had reviewed the interview to discuss any issues. For example, after four interviews, my colleague asked for a meeting to discuss the order of the questions in the interview guide and suggested moving them around depending on how the interview was going.

Integration of Quantitative and Qualitative Components

The qualitative and quantitative components were conducted and analyzed separately and concomitantly, and each was reported separately as a stand-alone manuscript. The quantitative component compared entourage reported outcomes with parents (self-seekers) and compared two sub-groups of entourage members who accessed the information differently (active searching versus passive monitoring). The qualitative component produced complementary results on the entourage proxy-OHI seeking behaviour context and outcomes. There were two integration strategies used:

1. Comparison of results: in this strategy the similarities, differences, and contradictions between both sets of results are explored. Each of the outcomes from the IAM were elaborated with corresponding excerpts from the participant interviews. New IAM responses were proposed using the themes produced in the qualitative analysis. Finally, the proxy OHI seeking outcomes model was revised based on this integration.
2. Assimilation of data: the qualitative and quantitative data are transformed into a single form, in this case into qualitative data. This was done by re-analysing the findings through ‘multiple lenses’ and developing vignettes to represent four types of entourage members (McCormack, 2000; Sandelowski, 1991). Vignettes are short stories of hypothetical scenarios describing the key aspects of decision-making processes used by people in everyday situations. Although they are useful as “a tool for integration, representation, and utilization of

participant voices in a multiphase design", they are still seldom used in mixed methods research (Ling & Pang, 2021)

Using notes from my reflexive diary and the revised proxy OHI seeking outcomes model, I created four scenarios to represent every finding from across the mixed methods study.

Ethical considerations

Prior to starting this study, Institutional Review Board (IRB) approval from McGill University was obtained (IRB study number A12-B73-18A in Appendix 4). When respondents agreed to participate, I emailed them the consent form. The consent discussion took place at the beginning of the interview, and their verbal consent was audio-recorded. The interviews were recorded using a digital voice recorder. A number was allotted to participants and all names mentioned were removed during the transcription. This also applied to any names or identifying information on members of the entourage mentioned during the interview.

Participation in this study was completely voluntary. The participants' personal information will remain confidential, e.g., no identifying information will be published in scientific articles or disclosed during presentations. All data study is stored on a password protected external hard drive for the duration of the study, and any paper copies are destroyed. Only my supervisor and I have access to this data. Data will be retained for 7 years after publication as per university policy stored securely, on a USB key that will be stored in a locked file cabinet at the Department of Family Medicine at McGill University. In addition to ensuring the above ethical considerations and disclosing them to the participants, we were mindful of the researcher-participant relationship during interviews [133]. Information on the objectives and purpose of my study, and why they were selected as participants was provided at the beginning of the interview and any further questions or concerns were addressed.

Chapter 5: Outcomes of Proxy Information Seeking by Users of an Online Parenting Information: A Quantitative Observational Study - Manuscript 2

Preface

This manuscript describes the quantitative component of the MMR study described in Chapter 4, which was conducted concomitantly with the qualitative component that is described in Chapter 6. The aim of this manuscript is to describe online health information outcomes reported by proxy-seekers using an online parenting website, and to compare them with the outcomes reported by self-seekers.

In this study I analyzed 51,325 IAM questionnaires completed in a two-year period: April 13th, 2019, to March 30th, 2021. In the first analysis, responses from parents were compared with responses from entourage members. As hypothesized, the parents were more likely to report using the information to do something with their children, while the entourage were more likely to report using the information in discussion with others. In the second analysis, I compared responses from entourage members who had actively searched for information and landed on the website directly (known information need), with those who had passively received the information via newsletter (unknown information need). Website respondents were likely to report that the information will help them be less worried, will help them handle a problem, and help them decide what to do with someone else. Newsletter respondents were more likely to report the information would help improve the health or well-being of a child. This highlights the role of the information need and mode of information seeking on proxy-OHI seeking outcomes. The results from the study are integrated with findings from the qualitative study described in Chapter 6, to provide an overview of this phenomenon of proxy OHIS.

After one round of revisions, this manuscript was accepted for publication by the JMIR Pediatrics and Parenting journal in October 2021 (El Sherif, Pluye, Schuster, et al., 2022).

What are the Outcomes of Proxy Information Seeking by Users of an Online Parenting Information Website? A Quantitative Observational Study

Reem El Sherif, Pierre Pluye, Tibor Schuster, Roland Grad

Abstract

Background: The Internet is one of the most frequently accessed platforms for finding consumer health information. The use of trustworthy online consumer health information is generally associated with benefits, yet barriers such as low health literacy may reduce these benefits. One of the largest groups of online health information consumers are parents of young children, as well as people in their social circle (grandparents, family members, friends, neighbours, or professionals working with children). The concept of proxy-seeking (on behalf of others) has been explored in the literature, yet little is known on the outcomes.

Objective: The main aim of this study is to describe online consumer health information outcomes reported by proxy-seekers using an online parenting website.

We compare the outcomes reported by parents with those reported by members of their social circle after consulting an online parenting information website. A secondary objective was to explore if the method of accessing the information by the proxy-seekers (active searching through the website or passive seeking through a weekly newsletter) changed the outcomes reported.

Methods: A two-year quantitative observational study was conducted in the context of an ongoing partnership between Naître et Grandir (an online parenting resource) and the research team. Participants were parents of 0- to 8-year-old children and members of their entourage (grandparents, family members, friends, neighbours, or professionals working with children) in Canada who had accessed N&G through the website or through a weekly newsletter. For each N&G webpage, the participants' perception regarding the outcomes of seeking and using specific N&G webpages was gathered using a content-validated Information Assessment Method (IAM) questionnaire. Comparison of survey responses was assessed using frequency analyses. For key primary survey items, a chi-square test was conducted and differences in relative frequencies of responses were computed along with confidence intervals.

Results: A total of 51,325 completed IAM questionnaires were included in the study analysis, pertaining to 1079 N&G webpages (mean 48; range 1-637). Compared to parents, the entourage are more likely to report using the information in discussion with others. Parents, on the other hand, were more likely than the entourage to report using the information to do something for their child. In addition, results suggest that the differences in perceived benefits of N&G online parenting information by the entourage, depends on how they access the information. Respondents who were actively seeking the information (through the website) were more likely to report that the information will help them be less worried, will help them handle a problem, and help them decide what to do with someone else. Respondents who passively acquired the information (through the newsletter) were more likely to report the information would help improve the health or well-being of a child.

Conclusions: From a practical standpoint, this is an important topic for information specialists, primary health care practitioners and public health officials. By better understanding how a consumer and their entourage use information together, information providers can better adapt the information to meet both individual and group needs, and health care practitioners can target patients' entourage with online health information resources for dissemination and use. Public health interventions aimed at supporting parents can do so by extending social structures to facilitate collective information sharing.

Keywords: online consumer health information; proxy information seeking; child development; child health; information outcomes

Introduction

In 2017, almost all (99.0%) of Canadian households had fixed broadband Internet access (Canadian Radio-television and Telecommunications Commission, 2020), and 75%-96% of Canadians aged 15-64 years use the Internet on a daily basis (Statistics Canada, 2017). This is in line with other OECD countries where more than 80% of households have access to high-speed internet (OECD, 2020b). In these countries, the proportion of adults seeking online health information (OHI) has more than doubled between 2008 and 2017 (OECD, 2017). The Internet is a frequently accessed platform for finding consumer health information, in addition to common health information sources such as health care professionals or members of one's social circle, and other offline sources such as books and television (Amante et al., 2015; Canadian Internet Registration Authority, 2020). The use of trustworthy OHI can improve quality of life and is generally associated with increased empowerment of consumers and their families, and improved health outcomes (Amante et al., 2015; Case & Given, 2016; Prescott & Mackie, 2017).

There are, however, still barriers to experiencing benefits of OHI. These include illness challenges, such as someone being too physically or mentally incapacitated to start a search for themselves. A second barrier may be lower e-health literacy, meaning a consumer's ability to seek, find, understand, and appraise OHI and apply the knowledge gained to addressing health issues. At least one third of the population of 18 OECD countries may have low health literacy (Moreira, 2018). Moreover, when faced with a stressful situation, consumers may experience transitory low literacy level, as the interdependence between information and emotion is well-established in the literature (Nahl & Bilal, 2007). Finally, there are negative outcomes (or tensions) reported by OHI users and healthcare practitioners. Our recent qualitative study on the topic described personal tensions such as increased anxiety, interpersonal tensions between patients and physicians as a result of discussing OHI, and service-related tensions such as postponing a clinical visit (El Sherif et al., 2018).

One of the strategies proposed in our recent work to reduce these OHI tensions is discussing the information with someone in one's social circle (El Sherif et al., 2018). Around 90% of individuals in OECD countries report having access to social support providers (e.g., relatives or friends) who can help them in times of need (OECD, 2020a). Access to these social support providers is positively linked to Internet access and use as these providers are Internet users themselves and would provide relevant support and awareness (Chen, 2013). "Proxy" OHI seeking is a common phenomenon: almost two-thirds of OHI seekers have reported searching on behalf of someone else to provide informational social support (Cutrona et al., 2015; Reifegerste et al., 2017; Selwyn et al., 2016). This proxy OHI seeking may overcome the previously mentioned barriers. This is especially true if the provider has higher e-health literacy than the receiver: they are thus better able to explain, contextualize or validate the information (Agius & Stangeland, 2016; Fox & Duggan, 2013). However, while there are several studies exploring proxy OHI seeking behavior, few studies explore how the seeker uses the information with others, and what outcomes they report as a result of this use.

Parents and Proxy OHI Seeking Behavior and Outcomes

One of the largest groups of OHI consumers is parents of young children. A recent systematic review and several empirical studies on how parents find, use, and evaluate OHI for their children, reported that parents worldwide are heavy OHI users across diverse circumstances (Haluza & Böhm, 2020; Kubb & Foran, 2020; Pehora et al., 2015). Parents find the information themselves or reach out to their social circle (hereafter their "entourage") for tailored advice, emotional support, and culturally relevant parenting information (Kirchner et al., 2020). A Quebec 2015 survey of a representative sample of 23,693 parents of preschool children showed that only 1.5% of parents do not know where to find online information about children, either directly or mediated by someone else (Lavoie & Fontaine, 2016). This mediation of information is referred to as proxy information seeking: "seeking information in a non-professional or informal capacity on behalf (or because) of others without necessarily being asked to do so" (Abrahamson et al., 2008).

Our previous work highlights that the use of high-quality parenting OHI by mothers can lead to benefits such as decreased worries, and increased self-confidence in decision making, regardless of socio-economic status (Pluye et al., 2020). However, little is known on the outcomes of proxy information seeking by the entourage of parents. The main objective of this study is to explore these OHI outcomes as reported by users of an online parenting information website. A secondary objective is to explore if the method of obtaining the information influences the reported OHI outcomes of proxy information seeking.

Methods

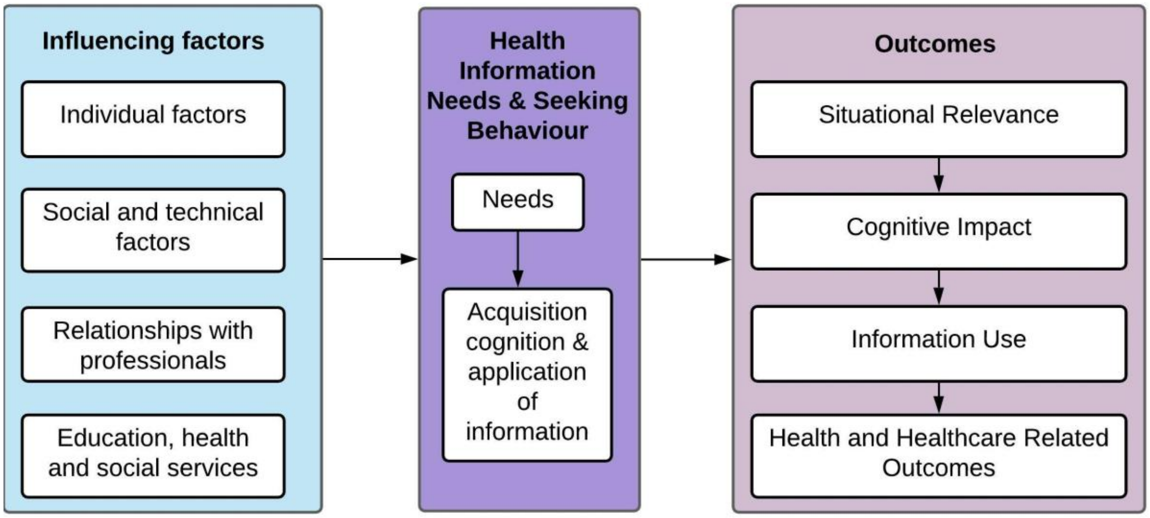
Design

We conducted a 2-year quantitative observational study in the context of an ongoing partnership between Naître et Grandir (an online parenting resource) and our team at McGill University (developers of the Information Assessment Method). Ethical approval was obtained from the Institutional Review Board at the Faculty of Medicine, McGill University, prior to the start of data collection. This study is reported using the STROBE checklist for reporting observational studies (Von Elm et al., 2007).

OHI outcomes framework

The conceptual framework guiding this work is the OHI outcomes framework developed by Pluye et al. and adapted in Figure 18 (Pluye et al., 2019). There are four types of influencing factors: individual characteristics (e.g., age and income), socio-technical factors (e.g., e-health literacy and social support), patient-professional relationships, and education-health-social resources. Together, these factors determine the extent to which information is accessed and how it is used by patients. An information need is a condition in which "certain information contributes to the achievement of a genuine or legitimate information purpose" (Derr, 1983). These needs may be explicitly stated or implicitly understood based on an individual's health status or situation (Derr, 1983). OHI seeking is the purposive and active searching for information as a consequence of an information need or to satisfy a goal (Wilson, 2000). Finally, there are four individual levels of OHI outcomes: situational relevance, cognitive impact, and use of information, and health and healthcare related outcomes.

Figure 18. OHI outcomes framework



Setting: Naître et Grandir

The Naître et Grandir website (N&G) provides parents with support in bringing up their children, from the time they are conceived until they are 8 years old.

N&G is funded by the 'Lucie and André Chagnon' Foundation, a philanthropic organization that seeks to contribute to the prevention of poverty through the creation of conditions and environments that are favorable to educational success of children, specifically from socially vulnerable families and communities. Low health literacy levels in parents are detrimental to child health education, healthy behaviors, health, and medication, thus N&G is an important resource for French-speaking parents and their entourage (Connelly & Turner, 2017). In addition to directly accessing the website, N&G readers can sign up to receive a weekly newsletter containing links to N&G webpages tailored to their child's age. N&G provides free online parenting information content produced using an expert-based process and a low literacy editorial process that caters to lower health literacy levels (Grade 8 reading levels) with additional audio and video formats(Pluye et al., 2020).

Since 2014, our team at McGill University and N&G have worked in partnership to implement the Information Assessment Method (IAM) questionnaire for evaluating the pages of parenting information. In addition, N&G have been able to improve their informational content based on the comments provided by IAM users, which are coded by two editors in an online system. This is referred to as two-way knowledge translation (El Sherif et al., 2017).

Instrumentation: The Information Assessment Method (IAM)

The OHI outcomes framework is operationalized in the IAM questionnaire used to evaluate health information outcomes from the viewpoint of information users (clinicians, managers, patients and public)(Granikov et al., 2020). The IAM questionnaire has been content validated for different audiences using participatory mixed methods studies, integrating quantitative survey data with qualitative insights (Pluye et al., 2014). It has been implemented by different information providers to allow information users to rate specific health information content online (e.g., a webpage), stimulate their reflection, and collect feedback comments (Granikov et al., 2020). Consequently, responses and comments can be used by information providers to improve content.

The validity of the IAM has been assessed on two occasions: it was first validated specifically for parents in 2015 using quantitative data (raters' responses) and qualitative data (raters' comments and qualitative interviews), producing the IAM4parents-v2015 (Bujold et al., 2018). It was then validated again specifically for parents of lower socio-economic status (SES) using qualitative data from interviews with low-SES parents, producing the IAM4parents-v2019 used in this study (Pluye et al., 2020). The IAM4parents-v2019 was validated in French (as it is implemented with

N&G) and underwent a transcultural adaptation into English. The full questionnaire is presented in the Appendix. When N&G readers land on a webpage corresponding to a specific topic (directly or through the newsletter link), a lateral tab appears as shown in Figure 19, inviting them to complete a survey.

Figure 19. Screenshot from a N&G page

Accueil / 0 à 12 mois / Développement / 1 mois /

1 mois: motricité fine

Le développement de la motricité fine signifie que l'enfant apprend à utiliser certains petits muscles des doigts et des mains pour faire des mouvements précis afin d'atteindre, d'agripper et de manipuler de petits objets. Les nouveau-nés maîtrisent très peu leur motricité fine, mais votre bébé apprendra, au cours des prochains mois, à

Study Participants and Data Collection

Participants in this study are all N&G readers in Canada and four other OECD countries with francophone populations, a similar health and social system, and comparable average household incomes, Internet access and reported social support levels (France, Belgium, Switzerland, and Luxembourg) (OECD, 2020a).

Each participant had arrived at a specific N&G webpage (either directly through the website), had clicked on the lateral tab shown in Figure 19, and had completed the IAM-parent-v2019 questionnaire asking them to evaluate that specific N&G webpage during the study period (April 13th, 2019, to March 30th, 2021). All completed questionnaires were included in the analysis, hereafter referred to as IAM responses. Among them, participants were divided into two groups: those who had identified themselves either as the parent of 0-8-year-old children, or as an entourage member (grandparent, family member, friend, neighbour, or professional working with children). A second analysis was conducted in the entourage group between those who had accessed the N&G webpage and IAM questionnaire through the weekly newsletter and those who had landed directly on the N&G website. Variables included in the analysis correspond to the IAM questions. No incentive was provided to participate.

Statistical Analysis

The primary study endpoint, comparison of IAM responses between parents and entourage, and between entourage IAM responses via newsletter and website, were assessed using frequency analyses. Difference in proportions and ninety-five percent confidence intervals for differences in the proportion of IAM responses of both groups were calculated (Lowry, 2019; Newcombe, 1998). To take multiplicity of comparisons into account and retain a global Type I error level of 5%, confidence levels were corrected using Bonferroni adjustment. In addition, a Pearson's chi-squared test was used to determine whether the differences between two groups of participants were statistically significant. Test results were deemed statistically significant when p-values (p) were less than 0.001. All statistical analyses were completed using SAS software (version 9.4).

Hypotheses

Based on our previous work exploring information outcomes, we hypothesized that, when the information is considered relevant and easy to understand, the entourage would be more likely to report discussing the information with others. We also hypothesize that, similar to previous work on parents' responses, there will be a difference in entourage responses based on mode of access.

Results

All Respondents

Over the 2-year study period, 69,260 IAM questionnaires were completed. Questionnaires completed by participants outside the countries of interest in this study, and by participants who did not identify as parents or entourage members were excluded (Figure 20). Finally, 51,325 completed IAM questionnaires were included in the study analysis, pertaining to 1079 N&G webpages (mean 48; range 1-637). As shown in Figure 21, most of the participants were in Canada (58.4%) and France (36%). Parents comprised 81% of participants and grandparents were the most common entourage members (12%) as shown in Figure 22. Finally, the response rate of parents and entourage followed a similar pattern as shown in Figure 23.

Figure 20. Included IAM questionnaires

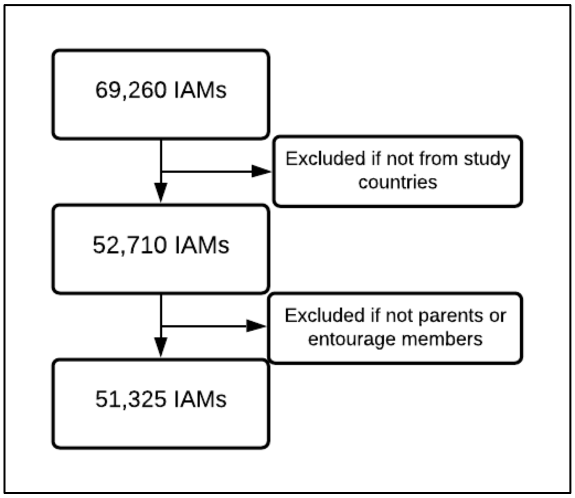
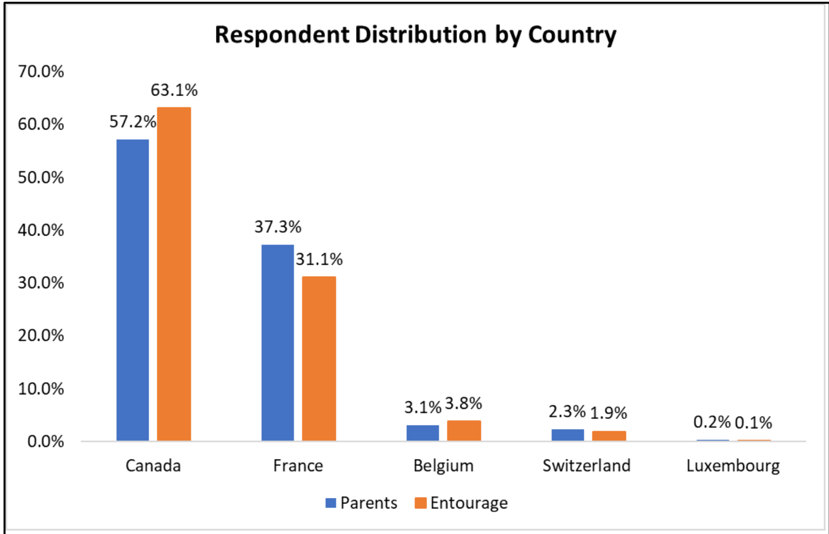


Figure 21. Respondent Distribution by Country



Country	Parents	Entourage	Total N
Canada	23226	6751	29972
France	15138	3323	18461
Belgium	1243	411	1654
Switzerland	924	202	1126
Luxembourg	97	10	197

Figure 22. Proportion of IAM Respondents

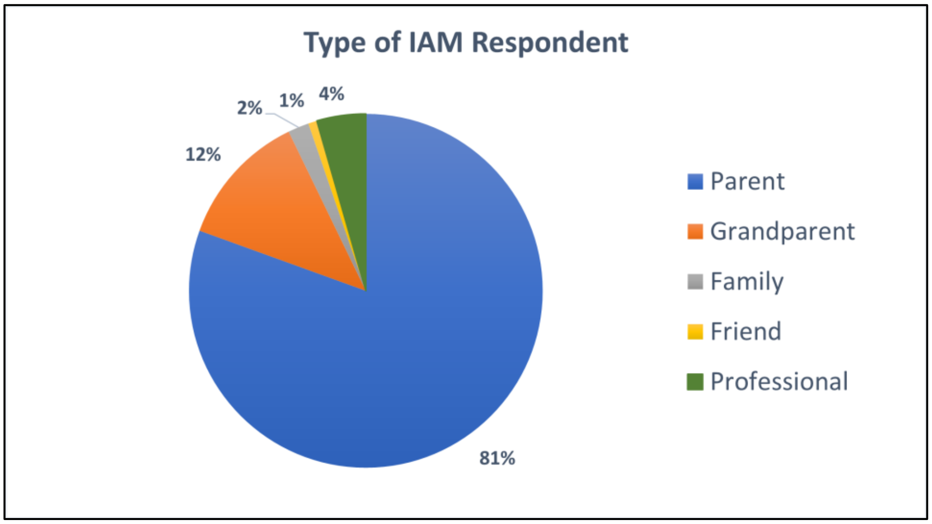
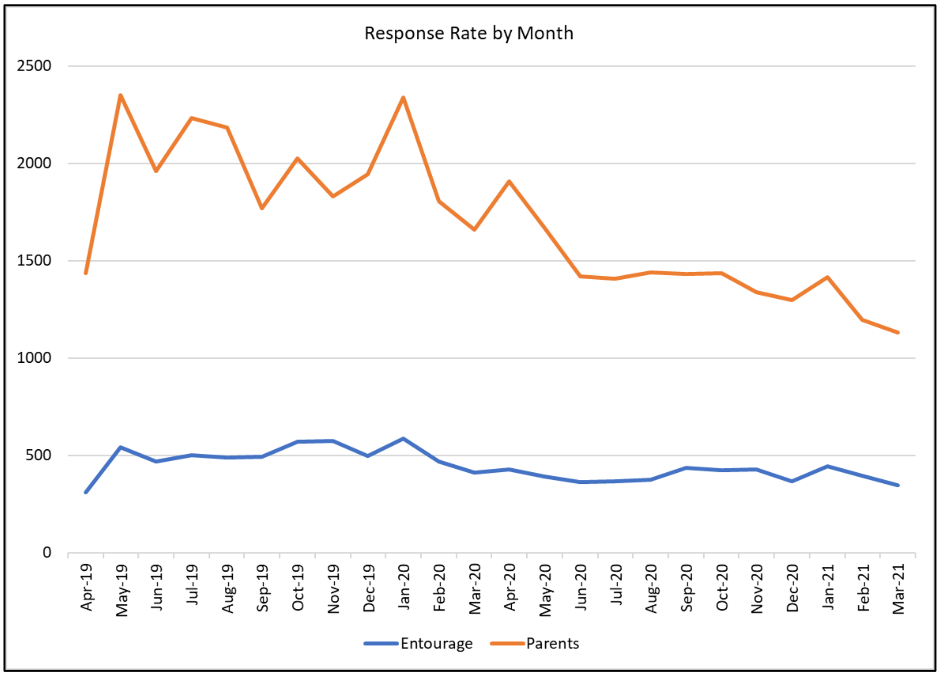


Figure 23. Response rate by month



Comparing parents and entourage

Of 51325 completed IAM questionnaires completed, 40628 (79.2%) were by parents and 10697 (20.8%) were by entourage members. They rated 1079 unique N&G webpages, with a mean of 48 completed IAM questionnaires per webpage (range 1-637).

Comparison of the responses by both groups is presented in Table 15, outcomes that were significantly different are highlighted (p<0.001). Parents were more likely to report using parenting information to better understand (mean difference 0.084; 95% CI 0.073-0.094), to decide to do something (mean difference 0.156; 95% CI 0.146-0.166) or to do somethings in a different manner (mean difference 0.052; 95% CI 0.042-0.061) . They were also more likely to report that it helped them improve the health or well-being of a child (mean difference 0.039; 95% CI 0.028-0.049) and to be less worried (mean difference 0.104; 95% CI 0.093-0.114). The entourage members were more likely to use the information in discussion with someone else (mean difference 0.166; 95% CI 0.155-0.176), and report that information helped them decide what to do with someone else. Thus, our first hypothesis was supported.

Table 15. Perceived information outcomes: IAM responses of all entourage members versus all parents.

IAM questions and response options	Entourage members (10697 IAM responses), n (%)	Parents (40628 IAM responses), n (%)	All participants (51325 IAM responses), n (%)
Q1. Is this information relevant? (Choose only one)			
Very relevant (this is the information I expected)	7444 (69.6%)	27817 (68.5%)	35261 (68.7%)
Relevant	2993 (27.9%)	11707 (28.8%)	14700 (28.6%)
Somewhat relevant	123 (1.1%)	654 (1.6%)	777 (1.5%)
Very little relevant (this is not the information I expected)	137 (1.3%)	450 (1.1%)	587 (1.1%)
Q2. Did you understand this information? (Choose only one)			
Very well (I understood everything)	9870 (92.3%)	37834 (93.1%)	47704 (92.9%)
Well	777 (7.3%)	2698 (6.6%)	3475 (6.8%)
Poorly	26 (0.2%)	51 (0.1%)	77 (0.2%)
Very poorly (I did not understand much)	24 (0.2%)	45 (0.1%)	69 (0.1%)
Q3. What do you think about this information? Check all that apply.			
This information allowed me to validate what I do or did	5611 (52.5%)*	25922 (63.8%)	31533 (61.4%)
This information taught me something new	4753 (44.4%)*	22869 (56.3%)	27622 (53.8%)
This information reassured me	2966 (27.7%)*	17037 (41.9%)	20003 (39.0%)
This information refreshed my memory	3811 (35.6%)*	9348 (23.0%)	13159 (25.6%)
This information motivated me to learn more	2550 (23.8%)*	8846 (21.8%)	11396 (22.2%)
I do not like with this information	204 (1.9%)	900 (2.2%)	1104 (2.2%)
Q4. Will you use this information? (Choose only one)			
Yes	10082 (94.3%)	38970 (95.9%)	49052 (95.6%)
No	615 (5.8%)	1658 (4.1%)	2273 (4.4%)
Q4a. How will you use this information for you or for a child in your care? Check all that apply.			
This information will help me to better understand.	4691 (46.5%)*	21208 (54.4%)	25899 (52.8%)
I will use this information to do something.	3637 (36.1%)*	20143 (51.7%)	23780 (48.5%)

IAM questions and response options	**Entourage members (10697 IAM responses), n (%)**	**Parents (40628 IAM responses), n (%)**	**All participants (51325 IAM responses), n (%)**
I will use this information to do something in a different manner.	3026 (30.0%)*	13585 (34.9%)	16611 (33.9%)
I will use this information in a discussion with someone else.	4264 (42.3%)*	9473 (24.3%)	13737 (28.0%)
I will use this information in another way.	356 (3.5%)*	760 (1.9%)	1116 (2.3%)
Q5. Using this information, do you expect any benefits for you and at least one child (0-8 years)? (Choose only one)			
Yes	10044 (93.9%)	38477 (94.7%)	48521 (94.5%)
No	653 (6.1%)	2151 (5.3%)	2804 (5.5%)
Q5a. **Which benefits do you expect for you and at least one child (0-8 years)? Check all that apply.**			
This information will help me to improve the health or well-being of my child.	6690 (62.5%)*	26976 (66.4%)	33666 (65.6%)
This information will help me to be less worried.	3480 (32.5%)*	17424 (42.9%)	20904 (40.7%)
This information will help me to prevent a problem or the worsening of a problem.	3184 (29.8%)	12406 (30.5%)	15590 (30.4%)
This information will help me to handle a problem.	3226 (30.2%)	12966 (31.9%)	16192 (31.6%)
This information will help me decide what to do with someone else.	2137 (20.0%)*	5597 (13.8%)	7734 (15.1%)
Another benefit.	408 (3.8%)*	871 (2.1%)	1279 (2.5%)

*p-value<0.001

Comparing website and newsletter respondents

Of 10,697 IAM questionnaires completed by the entourage, 1,953 (18.3%) accessed the webpage through the newsletter and 8,744 (81.7%) directly through the website. Comparison of responses is presented in Table 16; statistically significant different outcomes are highlighted (p<0.001). Respondents through the newsletter were more likely to report using the information to do something (mean difference 0.117; 95% CI 0.092-0.141) or do something differently (mean difference 0.067; 95% CI 0.044-0.090) and that they expected that the information would help to improve the health or well-being of a child (mean difference 0.090; 95% CI 0.067-0.112).

Respondents who accessed N&G directly through the website were more likely to report that using the information would help them be less worried (mean difference 0.047; 95% CI 0.024-0.069), help them handle a problem (mean difference 0.083; 95% CI 0.062-0.104) and help them decide what to do with someone else (mean difference 0.040; 95% CI 0.020-0.058). Both groups were equally likely to report using the information in discussion with someone else.

Table 16. Perceived information outcomes: IAM responses of entourage newsletter vs website respondents

IAM questions and response options	**Entourage newsletter (1953 IAM responses), n (%)**	**Entourage website (8744 IAM responses), n (%)**	**All entourage (10697 IAM responses), n (%)**
Q1. Is this information relevant? (Choose only one)			
Very relevant (this is the information I expected)	1547 (79.2%)	5897 (67.4%)	7444 (69.6%)
Relevant	390 (20.0%)	2603 (29.8%)	2993 (28.0%)
Somewhat relevant	7 (0.4%)	116 (1.3%)	123 (1.2%)
Very little relevant (this is not the information I expected)	9 (0.5%)	128 (1.5%)	137 (1.3%)
Q2. Did you understand this information? (Choose only one)			
Very well (I understood everything)	1891 (96.8%)	7979 (91.3%)	9870 (92.3%)
Well	59 (3.0%)	718 (8.2%)	777 (7.3%)
Poorly	1 (0.1%)	25 (0.3%)	26 (0.2%)
Very poorly (I did not understand much)	2 (0.1%)	22 (0.3%)	23 (0.2%)
Q3. What do you think about this information? Check all that apply.			
This information allowed me to validate what I do or did	1118 (57.3%)*	4493 (51.4%)	5611 (52.5%)
This information taught me something new	898 (46.0%)	3855 (44.1%)	4753 (44.4%)
This information reassured me	519 (26.6%)	2447 (28.0%)	2966 (27.7%)
This information refreshed my memory	839 (43.0%)*	2972 (34%)	3811 (35.6%)
This information motivated me to learn more	427 (21.9%)	2123 (24.3%)	2550 (23.8%)
I do not like with this information	29 (1.5%)	175 (2.0%)	204 (1.9%)

IAM questions and response options	**Entourage newsletter (1953 IAM responses), n (%)**	**Entourage website (8744 IAM responses), n (%)**	**All entourage (10697 IAM responses), n (%)**
Q4. Will you use this information? (Choose only one)			
Yes	1902 (97.4%)	8180 (93.6%)	10082 (94.3%)
No	51 (2.6%)	564 (6.5%)	615 (5.8%)
Q4a. How will you use this information for you or for a child in your care? Check all that apply.			
This information will help me to better understand.	865 (45.5%)	3826 (46.8%)	4691 (46.5%)
I will use this information to do something.	850 (44.7%)*	2787 (34.1%)	3637 (36.1%)
I will use this information to do something in a different manner.	659 (34.7%)*	2367 (28.9%)	3026 (30.0%)
I will use this information in a discussion with someone else.	754 (39.6%)	3510 (42.9%)	4264 (42.3%)
I will use this information in another way.	53 (2.8%)	303 (3.7%)	356 (3.5%)
Q5. Using this information, do you expect any benefits for you and at least one child (0-8 years)? (Choose only one)			
Yes	1891 (96.8%)	8153 (93.2%)	10044 (93.9%)
No	62 (3.2%)	591 (6.8%)	653 (6.1%)
Q5a. **Which benefits do you expect for you and at least one child (0-8 years)? Check all that apply.**			
This information will help me to improve the health or well-being of my child.	1365 (69.9%)*	5325 (60.9%)	6690 (62.5%)
This information will help me to be less worried.	561 (28.7%)*	2919 (33.4%)	3480 (32.5%)
This information will help me to prevent a problem or the worsening of a problem.	605 (31.0%)	2579 (29.5%)	3184 (29.8%)
This information will help me to handle a problem.	456 (23.4%)*	2770 (31.7%)	3226 (30.2%)
This information will help me decide what to do with someone else.	327 (16.7%)*	1810 (20.7%)	2137 (20.0%)
Another benefit.	77 (3.9%)	331 (3.8%)	408 (3.8%)

Discussion

Principal Findings

Results support our first hypothesis that the entourage are more likely to report using the information in discussion with others. Parents, on the other hand, were more likely to report using the information to do something. This may reflect the trustworthiness of the information on N&G: the entourage feel comfortable sharing it and parents feel comfortable applying it.

Our second hypothesis was also supported. Results suggest that the differences in perceived outcomes of online parenting information reported by the entourage, depends on how they access the information. When the information is acquired through active seeking by the respondents through the N&G website, there were statistically significant differences in use and benefits reported. These findings can be explained by the literature on information seeking behavior, specifically Bates's integrated model of information seeking. In this model (Table 17), there are two forms of information seeking: directed through searching and monitoring when there is a known information need, and undirected through browsing and being unaware when the information need is unknown (Bates, 2002).

Table 17. Applying Bate's modes of information seeking to the study's context

	N&G website	**N&G newsletter**
Information need	Known	Unknown
Information seeking mode	Directed & active	Undirected & passive

In our study, respondents arrived on the website through directed and active searching that was likely triggered by a *known* information need such as an existing health problem. The entourage responding through the website were also aware of the information need by the parents, either because it was stated explicitly by the parents or understood implicitly through social interactions. The entourage members in this context may have closer social ties and may be involved in the decision making either directly, or indirectly by providing social support. The entourage in this group were thus more likely to report that the information they found would help them to be less worried, help them handle a problem and help them decide what to do with someone else. On the other hand, entourage respondents through the newsletter were less likely to have a known information need and would have clicked on one of the relevant articles out of interest or curiosity (undirected and passive information seeking). This group were more likely to report that the information will help them improve the health or well-being of a child.

Comparison with Prior Work

This study identifies the role of a known and unknown information needs on the outcomes of proxy information seeking by the entourage, by comparing entourage website and newsletter users. This is the first unique contribution of our study, as most studies focus on directed OHI seeking triggered by a known information need. Our study also describes these outcomes from the entourage or proxy-seeker's perspective. Another study exploring negative OHI outcomes from the individual's perspective reports that in situations where the informational support from the entourage is unsolicited and the individual does not feel that the information is relevant to their situation, interpersonal tensions between both parties may develop (El Sherif et al., 2018).

A second unique contribution of this study: we explore the phenomenon of proxy OHI-seeking using an evidence-based OHI source in N&G that caters to lower health literacy. Thus, common barriers to positive OHI outcomes such as health literacy and misinformation are somewhat removed, and we can describe the outcomes experienced by parents and their entourage in this context. A recent scoping review exploring parents' online health information-seeking behaviors to inform vaccination choices for their children reported significant misinformation on the topic online and suggested parents' digital health literacy may influence their decision (Ashfield & Donelle, 2020).

A third contribution is the transferability of our results to other contexts. While we do not claim statistical generalizability as the study sample was self-selected, N&G-IAM respondents were not limited by demographic criteria and thus represent a diverse sample of parents and their entourage. Moreover, our respondents rated webpages presenting a wide number of health and well-being topics, not focused on any specific illness or condition. A recent systematic review exploring online health information seeking by parents for their children identified lack of generalizability as the most frequently mentioned limitation of the studies included in the review. In fact, an agenda item for future research studies was the need for studies with generalizable samples outside clinical environments with specific populations of ill children (Kubb & Foran, 2020). While that review explores parent OHI seeking as a form of proxy seeking, the authors cannot claim that their findings apply to other types of proxy seeking (Kubb & Foran, 2020). In this study, we provide insight into another type of proxy seeking and the reported outcomes.

Limitations

Our study has three main limitations. First, participants were self-selected volunteers who completed one questionnaire at one point of time (a source of selection bias). This would likely lead to an over-estimation of positive outcomes due to social desirability bias (Nederhof, 1985). However, this bias will have influenced both parents and the entourage in the same manner and thus did not affect the comparative analysis. Moreover, we cannot assume website users and newsletter users are mutually exclusive. Second, we did not explore relational variables like strength of the social ties between the entourage and the parents and child for whom they are using N&G. Other studies have reported that proxy information seekers are likely to have strong ties with the people they are helping and tend to provide other forms of social support such as emotional support (Criss et al., 2015; Dolničar et al., 2013; Selwyn et al., 2016). This limitation will be addressed in a future study with entourage members.

Finally, while the data collection was co-constructed with N&G in the course of the ongoing partnership, the data analysis and interpretation were conducted by researchers without N&G influence.

Conclusions

The results will be used to refine and improve the existing conceptual framework on OHI outcomes by filling in the gap on the role of the information need in proxy OHI seeking outcomes. From a practical standpoint, this is an important topic for information specialists, primary health care practitioners and public health officials. By better understanding how a consumer and their entourage use information together, information providers can better adapt the information to meet both individual and group needs, and health care practitioners can target patients' entourage with online health information resources for dissemination and use. Public health interventions aimed at supporting parents can do so by extending social structures (e.g., by facilitating longitudinal relationships with proxies such as other parents or extended family members) to facilitate collective information sharing.

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Conflicts of Interest

RG and PP are consultants for N&G.

Abbreviations

IAM: Information Assessment Method

N&G: Naître et Grandir

OHI: online health information

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Chapter 6: How Do People Use Online Parenting Information to Support Others in their Social Circle? A Qualitative Descriptive Study - Manuscript 3

Preface

This manuscript describes the qualitative component of the MMR study described in Chapter 4, conducted concomitantly with the quantitative study in Chapter 5. The aim of this study was to describe the motivations, contexts and OHI outcomes reported by proxy-seekers using an online parenting website.

In this qualitative study we conducted 14 interviews with entourage members of parents of young children: five grandmothers, four family members, four professionals and one friend. The thematic analysis was conducted using the conceptual model described in Chapter 3. Participants were proxy-seeking for reassurance, out of personal curiosity, as part of their professional role, or following an explicit request from the parents. Participants described their OHI seeking strategies, including how they usually assessed websites for credibility. They used the information to provide informational support (either by sharing the webpage directly or discussing its content), or to provide practical support for a child in their care (e.g., playing games with a child), or to provide emotional support. In some cases, they did not share the information to avoid tensions with the parents in question. Finally, they generally reported positive outcomes of using the information. The most common outcome reported is improvement in the relationship with others. Other positive outcomes included feeling less worried and feeling more confident in future interactions. Some interpersonal tensions were described as a result of sharing the information, specifically when it was unsolicited and when it was shared in the context of a personal relationship rather than a professional one. Findings from this study and the study in Chapter 5 are integrated in the subsequent chapter to revise the conceptual model.

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How Does People Use Online Parenting Information to Support Others in their Social Circle? A Qualitative Descriptive Study

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Abstract

Background: Almost two thirds of the North American population have searched for health information online, and the majority report searching on behalf of someone else in their social circle, a phenomenon referred to as proxy seeking. Little is known on how proxy seekers use online health information and what outcomes they experience.

Objective: The main aim of this study was to explore why proxy seekers used a parenting website on behalf of parents in their social circle, and what outcomes they reported.

Methods: A qualitative descriptive study was conducted in the context of a partnership with an online parenting resource to explore the context and motivations for proxy online health information seeking, use of information and subsequent outcomes. Fourteen participants who self-identified as family members and friends of parents of young children, or professionals who work with young children were interviewed and thematic analysis was conducted.

Results: Four reasons for proxy seeking were uncovered: reassurance, out of personal curiosity, as part of a professional role, or following an explicit request from the parents. Information was used to provide informational support for parents, or to provide material support for a child. Positive outcomes of using the information were described, as were some of the resulting interpersonal tensions.

Conclusions: This study provides an in-depth look at proxy seeking behavior and outcomes among users of an online parenting resource.

Keywords: consumer health information; information seeking behavior; child development; child health; information outcomes; health information; digital health; parenting; online information

Introduction

In 2020, over two-thirds of Canadians (69%) reported searching for health information online (Statistics Canada, 2020). This is in line with results from the Health Information National Trends Survey in the USA between 2008 and 2017 where two-thirds of respondents reported turning to the Internet first for health information (Finney Rutten et al., 2019). Online health information (OHI) is the term generally used to refer to information on all aspects of health (including mental, physical, and social aspects) created for and directed to the general public (HLWIKI, 2015). OHI is available in many formats, such as text and video, and is available at government health sites, from professional organizations, health journals, and blogs among other sources. Moreover, individuals are also exposed to OHI 'posts' shared by their network through social media platforms such as Facebook (Fox & Jones, 2012).

People can use OHI in many ways, most commonly to discuss with health care providers, to engage in their own healthcare, to modify or comply with a management plan, or to support relatives or friends with health conditions (Pluye et al., 2019). Using OHI is generally associated with positive perceived outcomes such as increased empowerment of consumers and their families, and improved health outcomes (Amante et al., 2015; Case & Given, 2016; Pluye et al., 2020; Prescott & Mackie, 2017). There may be negative outcomes (referred to as tensions in previous work), such as increased anxiety or worsening of the patient-physician relationship, but there are strategies, such as providing trustworthy resources, to reduce these tensions (El Sherif et al., 2018).

Several contextual factors are associated with these OHI outcomes. These include age, education, income, e-health literacy, and social support (Pluye et al., 2019). Social networks are an important factor because one of the main reasons people search for and use OHI is to support their relatives or friends with health conditions (Pluye et al., 2013). Moreover, findings from a study exploring Internet use trends between 2008 and 2013 show a significant increase in the involvement of family and friends to obtain health information (Massey, 2016). Individuals are sometimes more likely to turn to their social circle to make sense of information they find, rather than discuss it with a health professional (Abrahamson et al., 2008; Reifegerste et al., 2017).

Proxy information seekers can be defined as "those who seek information in a non-professional or informal capacity on behalf (or because) of others without necessarily being asked to do so" (Abrahamson et al., 2008). Proxy seekers may also be "experts", such as health librarians or healthcare professionals, with the specialized knowledge or skills to use the information with the individual with whom they share a personal relationship (Wyatt et al., 2005). While this phenomenon of proxy information seeking behavior has been explored in the literature, especially as related to health information, few studies have explored the context of proxy OHI seeking linked to the use of OHI and subsequent health outcomes.

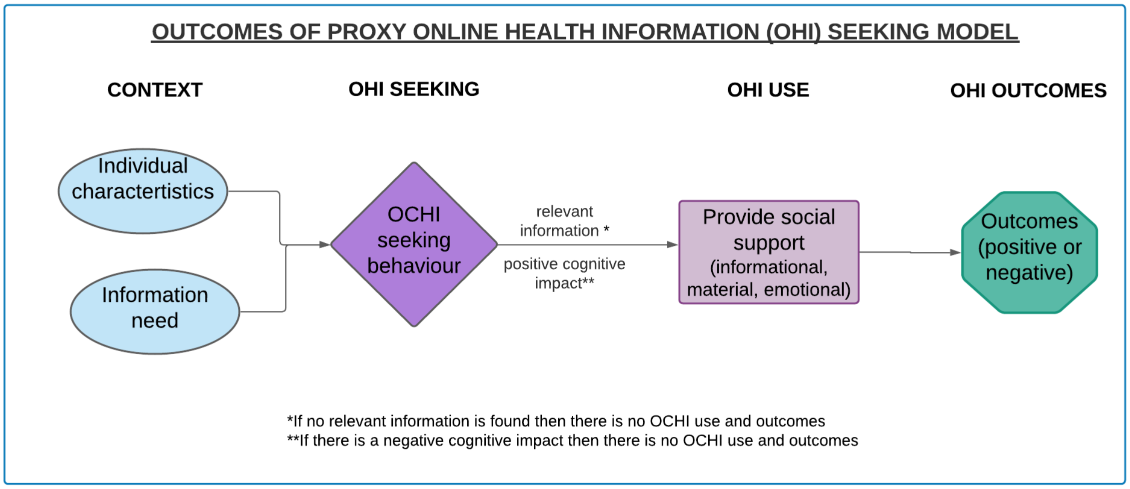
This is a critical knowledge gap. People may be able to overcome low e-health literacy by discussing the information they find with others (El Sherif et al., 2018). Proxy-seekers in a person's social circle may help them overcome information-seeking barriers and illness challenges (e.g., they are too physically weak or mentally incapacitated to search themselves) (Abrahamson et al., 2008). By better understanding how proxy-seekers use information with people in their social circle, information providers can better adapt the information to meet their needs, and public health interventions can target patients' friends and family with information for dissemination and use (Kim et al., 2015). Thus, the objective of this qualitative study is to explore the motivations, contexts and outcomes of proxy seeking behavior from the perspective of proxy seekers.

Methods

Theoretical model

The model guiding this work was developed by the authors following a mixed studies literature review on proxy OHI seeking behavior. The findings from the thematic analysis of 28 included studies were used to revise an existing conceptual framework (Pluye et al., 2019). Our Outcomes of Proxy OHI Seeking model is presented in Figure 24. Individual characteristics such as age and gender influence proxy OHI seeking, e.g., most studies report that proxy-seekers are more likely to be female and between 31 and 64 years old (S. Cutrona et al., 2015; Reifegerste et al., 2017). The OHI seeking process is triggered by another individual's information need, which may be explicit (stated to the proxy-seeker) or implicit (e.g., observed by the proxy-seeker). The proxy-seeker will then be actively searching or passively monitoring OHI to fulfil this information need. When they find a situationally relevant information object that has a positive cognitive impact, they will use it to provide informational, tangible, or emotional support for someone else. Most relevant to this model is informational support which includes the provision of advice or guidance, and which may provide direction and may also have an element of emotional support when received from a close source. Informational support could be construed as supportive, unsupportive, or mixed depending on context (Dubois & Loiselle, 2009; Loiselle et al., 2006; McKinley & Wright, 2014). OHI use will lead to separate outcomes experienced by the individual and the proxy-seeker, that are generally positive but could also be negative outcomes, e.g., with conflicting information. The proxy-seeker also act as information gatekeepers for the individual to reduce the burden of information overload.

Figure 24. Outcomes of Proxy OHI Seeking model



Resource: Naître et Grandir

The Naître et Grandir website (N&G) provides free, expert-based, online parenting information content in French that caters to people at lower health literacy levels (Grade 8 reading levels) with additional audio and video content (Pluye et al., 2020). Online parenting information, which encompasses all mental, physical and social aspects of children's' health, is a large subset of online health information on the Internet (Kubb & Foran, 2020). In addition to directly accessing the website, N&G readers can sign up to receive a weekly newsletter containing parenting tips and links to N&G webpages tailored to their child's age and evolution.

N&G is funded by the 'Lucie and André Chagnon' Foundation, a Quebec based philanthropic organization that seeks to create conditions and environments that are favorable to the educational success of children. Since 2014, the research team of three co-authors (Pluye, Grad and El Sherif) have worked in partnership to implement the Information Assessment Method (IAM) questionnaire for evaluating this parenting information. When N&G readers land on a webpage corresponding to a specific topic (directly or from the newsletter link), a lateral tab appears, inviting them to complete a survey. The first question asks the respondent to identify with one role for the purpose of this specific webpage they are rating: parent, grandparent, family member, friend/neighbor or professional who works with children aged 0 to 8. N&G editors have been able to improve their informational content using the comments provided by readers through the IAM questionnaire (El Sherif et al., 2017). Further details on the IAM and quantitative analysis of responses from parents and entourage have been published elsewhere (Pluye et al., 2020).

Study Design

A qualitative descriptive study was conducted using semi-structured remote interviews with IAM respondents who identified as entourage members. This type of study is used to provide an accurate account of events or experiences of participants attributed to those events (Sandelowski, 2000). Institutional Review Board (IRB) approval from McGill University was obtained prior to the start of the study (IRB study number A12-B73-18A). Methods and results are reported using the Consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

Study Participants

A purposive sampling strategy was used to select potential participants from a dataset of IAM questionnaires received between April 13th, 2019, to March 30th, 2021. IAM responses that were completed by (1) an entourage member and (2) agreed to be contacted for an interview were exported into a separate Excel file. After exclusion of those with no valid email, the final list included 71 potential participants (25 grandparents, 17 family members, 15 friends/neighbors, and 14 professionals caring for children). An invitation email was sent to these potential participants, four per week, in the order they had completed the questionnaire, from oldest to most recent. Interviews were audiotaped, transcribed, and analyzed over five coding sessions. During the fourth session (after 12 interviews had been conducted and analyzed), only two new themes were developed. Two more interviews were conducted and analyzed, and no new themes were developed; saturation had been reached and data collection stopped.

Data Collection

An interview guide was developed using an iterative process based on the Outcomes of Proxy OHI Seeking model. The guide was pilot tested with two graduate students and the researcher's notes and interviewee's feedback were used to revise it and produce the final version (see Appendix). Individual semi-structured interviews were conducted in French over the phone or video conference (Zoom), depending on each participant's preference. When participants responded to the invitation email, they were sent the consent form and asked to respond with their written consent and any questions they had.

After introducing the purpose of the study, the participants were asked general questions about online consumer health information, and the context and resources of their information seeking behavior. They were asked about their role as entourage member and who were the members of their social circle that they were frequently in contact with. They were reminded of the N&G webpage they had rated using the IAM questionnaire and were asked to describe how and why they had landed on that page. Finally, they were asked how they used the information on the page, and what outcomes they perceived as a result. The interviews were recorded, and the recordings were transcribed by a professional transcriber and translated to English for analysis.

Data analysis

Transcripts were imported into NVivo (Release 1.5), and a deductive-inductive analytical approach was adopted for coding (Boyatzis, 1998; Fereday & Muir-Cochrane, 2008). A coding manual was created and discussed with another co-author (VP). The codes were progressively clustered into themes and subthemes. Coding was conducted by the first author by participant and by coding meaningful extracts into the major themes first, then the extracts in each theme were then coded into subthemes.

Results

Fourteen participants were interviewed comprising of five grandmothers, four family members, four professionals and one friend. The majority were female (12/14 participants) and had a bachelor's degree or higher (8/14 participants). Respondents completed an average of 4 IAM questionnaires in the two years of the study period (range 1 to 14). Full details on the participants are presented in Table 18.

Table 18. Participant Characteristics

Pseudonym	Age group	Income	Education	Profession	Entourage type	Average Internet Use
Alisson	26-44	>$60,000	Bachelor's	Teacher	Family	2 hours/day
Sarah	26-44	<$60,000	High school diploma	Retailer	Family	5-6 hours/day
Mark	26-44	<$60,000	College	Practical technician	Family	3 hours/day
David	>45	<$20,000	High school diploma	Unemployed	Friend	2-3 hours/day
Mary	>45	>$60,000	College	Admin in adult education center	Grandmother	3 hours/day
Nadia	>45	>$60,000	Master's	Research coordinator on aging	Grandmother	3 hours/day
Sophie	>45	n/a	Bachelor's	Spanish interpreter	Grandmother	5 hours/day
Nathalie	>45	>$60,000	Master's	Retired	Grandmother	2-3 hours/day
Joelle	>45	>$60,000	Master's	Retired school principal	Grandmother /professional	3 hours/day
Florence	26-44	>$60,000	High school diploma	Kinder garden child educator	Mother /Professional	1-2 hours/day
Norma	26-44	>$60,000	Bachelor's	Nurse	Professional	4 hours/day
Alice	26-44	>$60,000	Master's	Psychoeducator (0-7 yrs. old)	Professional	3-4 hours/day
Emilia	26-44	<$60,000	Certificate	Kindergarten educator	Professional /Friend	>8 hours/day (work + personal)
Mathilde	<25	<$60,000	CEGEP*	Student	Sister	1 hour/day

*CEGEP is the equivalent of Grade 13 in Quebec, Canada

Context and motivations of proxy OHI seeking behavior

Two main themes were discussed related to the context of proxy information seeking behavior: individual characteristics of the entourage members and the information needs that triggered the seeking of online parenting information. The entourage members were reminded of the N&G webpage they had landed on before completing the IAM questionnaire and prompted to recall the reason they were on that topic. The specific N&G webpages and the reason they landed there are reported in Table 19.

Table 19. Latest N&G webpage rated by the participants

Participant	Last N&G page rated	Context
Alisson (family)	Development: Around 5 years old	"It was really from the beginning of [my nephew's] life, when he was very small, because he came into the world prematurely and he had some pretty close follow-ups in the first months of his life."
Sarah (family)	Learning to walk	[Could not recall the specific N&G page so referenced another page] Nephew: "Well, when he first started teething, I was wondering if it was normal, say, for him to have a lot of fever, rashes, things like that, what to do to help with the toothache."
Mark (family)	Verbal dyspraxia	"Yes, it was about my son's behavioral problems… It was one of the few times that it was pretty clear that I was overwhelmed by the situation. The calls to the family didn't inform me well enough, in my opinion, about the situation, which was still pretty sharp and pretty specific, so I went looking for very specific information on a specialized and credible site that I knew and came straight to it."
David (friend)	Tantrums: Understanding them to better intervene	Friend's child: "This is not the first time I've seen a child have a meltdown. It was because she was coming up to three years old and I was wondering what the age range really is in that."
Mary (grandmother)	The benefits of music	"My interest in the education of this grandson"
Nadia (grandmother)	The benefits of reading with your child	"Granddaughter of a child who is one and a half years old… She comes to spend, usually, one day a week on weekends at my house."
Sophie (grandmother)	2 to 2 1/2 years: intellectual development	Grandchild: "How to understand her, but also how to interact well so that I can give her all the... so that her development is as good as possible. "

Participant	Last N&G page rated	Context
Nathalie (grandmother)	The child who doesn't like kisses	“With the [grand]children I live with now, they have two completely different personalities. Bella, the little one, she is extremely affectionate. She always wants to be stuck to us. Matteo is the complete opposite. He's a very independent child, who has to be approached gently, and me, anyway, I don't want to impose my kisses and all that.”
Joelle (grandmother /professional)	Grief in children	“It was my daughter-in-law who passed away... So, I shared that information first with my son and his girlfriend. I sent them the link.... The child lives with them full time now. I sent him the link to Naître et Grandir to encourage him to go see it…”
Florence (mother /professional)	The child who doesn't talk yet	“I have my own private home daycare … As far as my son or my friends' children are concerned, because we talk about it a lot, or the kids I currently have in my daycare, because we are confronted with little viruses, little bacteria, and big worries from parents as well, Naître et grandir is a great, great source”
Norma (professional)	The basics of breastfeeding	“I'm a nurse. I work in early childhood. I've always worked in the childcare setting.”
Alice (professional)	Sleep: effects on development and behavior	“I am a psychoeducator for young children aged 0-7. My clientele is mostly children with autism spectrum disorders and their families as well. Yes, it was for one of my families that I'm following up with.”
Emilia (professional/ friend)	Yogurt: Which one to choose? & Food rewards	“It's because basically in a course where I'm going to be doing observations, there's also the health element, and I talk to students sometimes about nutrition and being able to offer a variety without necessarily threatening to take the dessert away.”
Mathilde (sister)	Lessons and homework: accompanying your child	"Sometimes, also, on health, it's more my little brother. But for kids in general, it's mostly for my babysitting."

All participants described who they considered as their social circle, and in addition to family members and friends, some professionals included their work colleagues and clients (parents of children in their care). All entourage members were in close contact with the people for whom they were proxy-seeking information. This contact may be in-person, but many also described remote contact either due to geographic location or restrictions imposed by the pandemic:

> "Let's say they don't live that far away, but with the COVID context, what I was doing, I was Face Timing with them on the weekends, because, among other things, their mother was extremely strict about visitation and all that. But let's just say in a context, if I look at past years, we would see each other almost every week, we would go for a little walk, but that hasn't been the case since March 2020" - Nathalie (grandmother).

Proxy information seeking was triggered by different motivations falling under four broad themes: for reassurance, out of personal curiosity, for work as a caregiver and following an explicit request from someone else. Excerpts corresponding to each of these themes are presented in Table 20. Several entourage members described wearing multiple hats, as professionals who worked with children and as family members or friends with children in their personal circle.

Table 20. Motivations for proxy-information seeking

Theme	**Excerpt**
For reassurance	"I was clearly overwhelmed by the situation. It was one of the few times that it was pretty clear that I was overwhelmed by the situation. The calls to the family didn't inform me well enough, in my opinion, about the situation, which was still pretty sharp and pretty specific, so I went looking for very specific information" – Mark (family member).
Out of personal curiosity	"It's more of a special interest, because now I'm a grandmother and the context is that I don't have a spouse anymore, so my priority now is my children and my grandchildren" – Nathalie (grandmother).
For work as a caregiver	"It was to go and get ideas for games to incorporate into my program, because I was going to explain something… Learning, active play, we explain that a little bit, and here I had to give examples of games" – Alisson (professional).
Following an explicit request	"Actually, it was to reassure a pregnant friend about COVID vaccine" – Norma (professional).

OHI seeking behavior

Participants described their strategies for searching for OHI, and how they assessed the credibility of the information they found. Many participants would typically start searching for OHI by entering one or more keyword into a search engine (e.g., “Googling the word ‘vaccine’”), and clicking on the first few links or selecting links to resources they recognized. On the other hand, two participants mentioned that they start from websites they have bookmarked, including N&G, rather than Google.

Participants had different ways of thinking about the credibility of a website, and for the most part, preferred websites from institutions they recognized: “Mostly I look for it to be recognized, for it to be something I've heard of or seen before, if it's a medical clinic I know, Mayo Clinic in the United States,” – Alice (professional). Some participants would check the credentials of the authors, and the validity of the references. Websites that had “too many ads” or “several spelling mistakes” were considered less credible. Several described employing a critical attitude when assessing websites: “There's a bit of intuition, there's a bit of experience. I have a little trouble believing anything too. There's a lot of quackery on the Internet, and I'm wary of sites that aren't officially licensed” -Mary (grandmother).

After checking a few sites, or trying different keywords, the seeker would decide they had found something relevant after triangulating from different resources: “After three references that talk about the same thing, that give about the same result” – Alice (professional). Some participants described a cognitive impact of the information, which gave them personal satisfaction to know more, or allowed them to learn something new or confirmed something they already knew.

> “It's because of what I've already studied and what I know, and then I'm mostly looking for either validation of the information I already have or to see if it's already out there in the mainstream at this point, if there is another way to explain it more easily” – Alice (professional/aunt).

Using Relevant Online Parenting Information

Participants described how they used the information they found on a N&G webpage they recently rated in symbolic and instrumental manners. *Symbolic use:* The majority used the information to provide informational support to someone in their social circle. They sometimes shared the link to a relevant webpage directly with the child's parent: "A lot of times I'll send her [the child's mother] a little message on Facebook in a private message, I'll send her the link outright" – Sophie (grandmother). The four professionals described situations where they would share the links to N&G webpages with the parents of children in their care after the parent had mentioned specific concerns on the topic.

> "I have a child who went to get vaccinated, and the mom was worried because he had had a reaction to his vaccines before and now, he was on the next vaccine. So, to reassure her, I sent the link two days ago to the mother which came from Naître et grandir" – Florence (professional).

Other times participants discussed the content of the webpage without sharing the link itself: "I share my perspective [with my son], but my perspective is kind of informed by that information" from N&G – Nadia (grandmother). The entourage member would sometimes also discuss the information they found with people other than the individual for whom they were searching, to help them make sense of it: "I am lucky enough to work with professionals in speech therapy, special education, and psychology, so at work it's fun to have a credible second opinion, to confirm or to refute" – Mark (family).

On the other hand, in some situations, they did not share the information at all, often to avoid tension or conflict with the individual. For example: "I'll take on the role of the specialist with respect to my sister, so sometimes that leads to discussions that are less pleasant" – Emilia (professional). Two grandmothers discussed not sharing the information because they didn't want to appear too intrusive or too judgmental of their children's parenting. As one of them said, "Giving out information that is not sought after is, in my opinion, a waste of time" – Nathalie.

Instrumental use: Another way participants used the information was to provide practical support. This was specifically true for family members who were occasionally entrusted with the care of a child. Mathilde described using the information she found to help her brother with his homework while she was babysitting him in the evenings. Four grandmothers described learning new ways to interact with their grandchildren while they were spending time with them: "I'm going to make him do a recipe. We're not going to do math, we're not going to do written problems, we're going to do a muffin recipe" – Alisson. Finally, one grandmother described providing emotional support to her bereaved son after she read relevant information on N&G: "It was more with my son that I talked about it, but really, him, it wasn't so much about where I found the information as it was about discussing the grief" - Joelle.

Outcomes of Using Online Parenting Information

The reported outcomes of using N&G information were generally positive. The most common outcome was improvement in the relationship with others. In the case Sophie, reading the information on her granddaughter's intellectual development allowed her to better understand her behavior. This allowed her to change her interactions with her granddaughter which led to them being more comfortable with each other. Another grandmother, Nadia, explained how the information allowed her to be more reassuring and supportive of her son and daughter-in-law. After sharing information a few times and feeling validated, one grandmother described feeling more comfortable discussing what she had read with her son again in the future A professional described how sharing information with parents of a child in her care led to better discussions: "In the relationship, it's clearer when we talk. They already know what we're talking about" – Alice.

Another commonly reported outcome was reassurance. Sarah, a family member, described feeling reassured after finding answers to her questions about miscarriage online. She discussed the information she had found with her partner and they both felt reassured as a result. Norma, a professional, was approached by her pregnant friend who was concerned about the Covid vaccine. After Norma shared the N&G webpage on the safety of the vaccine during pregnancy, her friend was reassured and proceeded to keep her vaccination appointment.

Some participants also felt more confident making decisions with others, and with being more involved in the care of the child. As one grandmother described: "Yes, it gives me more confidence that I'm doing it the right way and that it's okay to do it, let's say. I guess it gives me more confidence in how I'm intervening with her" – Nadia. One professional reported that the parents in her care were the ones who felt more confident in their interventions with their child following a discussion of the information she had shared:

> "Yeah, it's not perfect, they don't all change their behavior, because it's still a loop, but they quietly start to realize, and then the kids' behavior starts to decrease, and then the parents become more confident in their interventions" – Alice.

Two participants described negative outcomes or tensions as a result of sharing information. Alisson who shared information with her sister describes one such outcome: "I have to be careful, because she didn't take it very well. She, she thought I was doubting her... she wasn't too keen on me telling her about it after all." Emilia, who is a proxy seeker both as a professional and as an aunt, described how her sister would sometimes be resistant to advice and information she shared: "At one point she told me he wasn't that bad, but sometimes when she feels exhausted about it, she tells me about it like it's a mountain, and other times, once I bring the information, it seems like she doesn't want to." Emilia concluded that she has a better experience sharing information in a professional context than in a personal one.

Discussion

The present study explored the motivations, context and outcomes of proxy seeking behavior from the perspective of 14 entourage members of parents of young children, seeking information on an online parenting resource. Most respondents played one or more roles as family members, friends or professionals who worked with younger children. They were proxy-seeking for reassurance, out of personal curiosity, as part of their professional role, or following an explicit request from the parents. They used the information to provide informational support (either by sharing the webpage or discussing its content), or to provide practical support for a child in their care. In some cases, they did not share the information to avoid causing tensions with the parents in question. Furthermore, they generally reported positive outcomes of using the information: feeling less worried, finding an improvement in their relationship with the parent or child, and feeling more confident in future interactions. Some interpersonal tensions were described because of sharing the information, specifically when it was unsolicited and when it was shared in the context of a personal relationship.

This study highlights the role of social support in the context of online health information seeking outcomes. Social support has consistently been linked with better health (Drentea & Moren-Cross, 2005; House, 2001; Uchino, 2004). Several theories have been proposed to explain why this occurs; for example, social support can act to reduce the impact of stress which subsequently improves mental health (Umberson & Karas Montez, 2010). Another theory to explain the link between social support and better health is the provision of informational support which encourages the receivers to manage their health. If we use pregnant women as an example, those who were more satisfied with perceived and received social support initiated prenatal care earlier than those who were less satisfied (C. E. Cutrona & Suhr, 1992). Pregnant women who received more informational support from people in their social network delivered new-born infants with higher APGAR scores (a measure of health five minutes after birth) and higher birth weight (C. E. Cutrona & Suhr, 1992; Guillory et al., 2014). While informational support has been explored in the past, few studies have focused on its outcomes in an OHI context.

Negative outcomes were reported by two participants after proxy OHI use, specifically related to interpersonal tension. In general, negative outcomes are rarely reported: a literature review found limited reports of patient anxiety or decisions to refuse cancer treatment (Kinnane & Milne, 2010). There were two studies that reported that the proxy-seekers themselves experienced more anxiety, sometimes due to information overload (Bouju et al., 2014; Coder, 2020). The proxy-seeker and the individual did not always have the same approach to OHI: in situations where the individual did not want to "know" or ignored the information, this led to tensions and conflict (Brown & Veinot, 2021; Mazanderani et al., 2019). Moreover, a mixed methods study in the context of diabetic patients reported that the greater the proxy OHI seeking, the less supportive family members were perceived to be, due to attempted influence and interference by the proxy seekers (Veinot et al., 2011).

To our knowledge, this is the first qualitative study to focus on the entourage of parents of young children, in the context of online parenting information. A recent review of the literature conducted by the authors on proxy OHI seeking behavior included ten qualitative studies: six explored the perspectives of both proxy-seekers and self-seekers, three explored the perspective of proxy-seekers only and one explored the perspective of self-seekers who relied on others to make sense of the information. Most studies (7/10) focused exclusively on caregivers of patients diagnosed with a chronic or acute illness, two focused on the care of elderly family members, and only one explored the health information seeking behavior in a general population. The latter explored how Singaporeans come to make sense of online health information seeking and described how people's roles within family relationships necessitated proxy seeking (Dutta et al., 2018). Similar to our findings, that study reported positive outcomes of proxy OHI seeking and use, such as feeling less worried.

In the present study, the majority of the participants were grandparents, who also represent 12% of N&G-IAM survey respondents. One contribution of this study is the perspective of older OHI consumers as the proxy seekers rather than the recipients of support. In 2018, almost 71% of Canadians 65 years and older used the Internet, and in 2020 almost 50% searched for health information online (Statistics Canada, 2020; Wavrock, Schellenberg, & Schimmele, 2021). The grandparents in our study were frequent Internet users who used the information they found online to provide informational and practical support to their children and grandchildren and reported benefits such as improved relationships and increased confidence in their abilities. A recent study that explored online health information seeking in older adults reports that self-seeking and proxy-seeking was an active coping strategy to reduce health risks and improve health promotion in healthcare (Young Sam Oh & Lim, 2021).

Another strength of our work is the partnership with N&G. One major limitation of empirical studies on OHI is the inability to access the quality of the OHI used by participants. N&G is an expert based OHI source, for people with a low health literacy level with additional audio and video content (Pluye et al., 2020). By decreasing the health literacy gap, people are better able to process information and use it (Meppelink et al., 2016). This provides a context in which the phenomenon of proxy-OHI seeking can be explored without major concerns about the quality of the information. Moreover, N&G is neither a traditional scientific/medical resource nor a blog. In previous research, the comments from readers of websites and blogs have been analyzed, but few researchers have conducted interviews with users of parenting websites to explore their motivations and outcomes in-depth (Jenkins & Moreno, 2020).

Moreover, our study has allowed us to test the Outcomes of Proxy OHI Seeking model in the context of entourage members of parents of young children. The context, OHI seeking behavior, OHI use, and outcomes described in this study provide tangible examples to illustrate the different outcomes. This work therefore provides empirical support for the outcomes of proxy OHI seeking model. In addition, we can now improve the IAM questionnaire to allow for response items catered to the entourage members, as the IAM was originally developed and validated with parents.

There are three main limitations to our study. Most participants were female (12/14) which corresponds to the gender of the respondents to the IAM questionnaire (on average, 90% of respondents are female). Although this lack of heterogeneity may be considered a limitation, studies consistently report that the majority of OHI proxy seekers are female as reflected in our sample (S. L. Cutrona et al., 2016; Y. S. Oh, 2015; Reifegerste et al., 2017; Turner et al., 2018). This highlights the need to target male OHI seekers with reliable information and to explore their use of OHI in future studies, The second limitation is that we only explore the viewpoint of proxy seekers and do not interview the parents for whom they are searching. These interviews may have provided a fuller picture of this phenomenon but were beyond the scope of this study. The third limitation is that the author who conducted the qualitative data analysis (in English) was not the author who conducted the interviews (in French). To mitigate this, the authors held frequent meetings throughout the study: before and after each interview, and returned to the original transcripts for clarification during the qualitative data analysis.

Conclusion

This study supported our Outcomes of Proxy OHI Seeking model. We plan to use this work to improve the IAM questionnaire implemented by information providers in Canada. From a practical standpoint, this is an important topic for information specialists, primary health care practitioners and public health officials. By better understanding how an individual's entourage uses information and experiences subsequent outcomes, information providers can better adapt their information to meet their needs, while health care practitioners can target the patients' entourage with online health information resources. Public health interventions aimed at supporting parents can do so by improving their social network (e.g., by facilitating longitudinal relationships with proxies such as other parents or extended family members).

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Disclosure statement

The authors report there are no competing interests to declare.

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Chapter 7: Discussion and Insights

In this chapter, I discuss the theoretical and practical contributions of the thesis, following the threads across the three manuscripts. First, I describe how this research expanded our understanding of proxy OHI seeking outcomes following the literature review (Manuscript 1), the quantitative component (Manuscript 2), and the qualitative component (Manuscript 3). Then, I integrate findings from the qualitative and quantitative components using a mixed methods approach (two integration strategies). As a result, I provide recommendations on improving response items for the IAM questionnaire to accommodate entourage members completing it. In addition, I revise the theoretical model and produce four vignettes on proxy OHI seeking scenarios. This discussion also includes a strengths and limitations section, and a final summary of the contributions of this doctoral research.

Summary of Findings Across the Three Manuscripts

Internet use has become a staple of everyday life, and this is especially true in health care and management. People search for themselves and for others in their social circle, for OHI on general health (mental, physical, and social well-being) or, for those with a specific illness of condition, for research about their diagnosis, treatment, and prognosis. There are subsequent positive outcomes such as being reassured, and negative such as increased interpersonal tensions. Harnessing our understanding of these outcomes, and the contextual factors leading to them, remain the priorities for research into OHI use. Over two-thirds of OHI users are proxy-seekers, (Reifegerste et al., 2017) either as formal caregivers of patients or as members of an informal entourage, with the intention of providing social support. Although there is research on the role of social support in online communities and on social media, there is less research on social support in 'offline' interactions between proxy-seekers and people in their social circle. Therefore, the overarching objective of this dissertation was to explore the context and outcomes of proxy OHI seeking behaviour.

Literature review (Manuscript 1) findings

This review led to propose a unique and innovative theoretical model explaining the outcomes of proxy OHI seeking (Chapter 3, Figure 10). The objective of the review was to explore, and to revise an initial conceptual framework on, the context and outcomes of proxy OHI seeking. The review included 28 articles that were deemed relevant: 15 quantitative studies, 10 qualitative studies, 1 mixed methods study, and 2 systematic reviews. Analysis revealed that in situations where the information need is explicit and the proxy-seeker has higher health literacy, informational support is associated with positive emotional support and other outcomes are generally positive. Discussing the information found with others led to better understanding of the information, using the information found to make decisions about their health care, and experiencing better health outcomes such as reduced worries. Other potential outcomes include improvement in the receiver's health, the buffering of potential negative outcomes and the increase in perceived social support. This is especially true if the provider has higher health literacy than the receiver: they are thus better able to explain, contextualize or validate the information. Some people may prefer information avoidance, which may lead to tensions between them and the proxy-seeker.

For the seekers themselves, these outcomes include a change in their relationship with the person (improvement or worsening) and feeling more involved in health care of others. Moreover, the social support providers who report feeling more satisfied with their interaction with the person and who felt better about themselves after providing informational support were more likely to continue doing so and more likely to seek information from other sources. Negative outcomes for the seekers reported include increased anxiety as a result of information overload.

In situations where the informational support is unsolicited and the person does not feel that the information is relevant to their situation, interpersonal tensions may develop. This may also occur in relation to sharing sensitive or intimate information with family members. In addition, sharing misleading health information from unreliable sources may also lead to negative health outcomes.

Quantitative study (Manuscript 2) findings

This study shows that a known information need led to more specific positive outcomes, such as being less worried. The study was aimed to explore and compare the outcomes reported by proxy seekers and self-seekers by comparing questionnaire responses from of parents of young children and their entourage members, seeking information on an online parenting website. Results showed that the entourage are more likely to report using the information in discussion with others. Parents, on the other hand, were more likely to report using the information to do something (all respondents). This may reflect the trustworthiness of the information on N&G: the entourage feel comfortable sharing it and parents feel comfortable applying it.

Results also suggested that the differences in perceived outcomes of online parenting information reported by the entourage, depends on how they access the information. When the information was acquired through active seeking by the respondents through the N&G website, there were statistically significant differences in use and benefits reported. Respondents arrived on the website through directed and active searching that was likely triggered by a *known* information need such as an existing health problem. The entourage responding through the website were also aware of the information need by the parents, either because it was stated explicitly by the parents or understood implicitly through social interactions. The entourage members in this context may have closer social ties and may be involved in the decision making either directly, or indirectly by providing social support. The entourage in this group were thus more likely to report that the information they found would help them to be less worried, help them handle a problem and help them decide what to do with someone else. On the other hand, entourage respondents through the newsletter were less likely to have a known information need and would have clicked on one of the relevant articles out of interest or curiosity (undirected and passive information seeking). This group were more likely to report that the information will help them (more generally) improve the health or well-being of a child.

Qualitative study (Manuscript 3) findings

This study suggests that close ties between proxy-seeker and people in their social circle was usually linked to positive outcomes. The purpose of the study was to explore the motivations, contexts and outcomes of proxy seeking behavior from the perspective of 14 entourage members of parents of young children, seeking information on an online parenting website. The majority of the study participants were grandparents, who also represent 12% of N&G-IAM survey respondents in Manuscript 2. Most respondents played one or more role as family members, friends or professionals who worked with younger children.

Participants were proxy-seeking for reassurance, out of personal curiosity, as part of their professional role, or following an explicit request from the parents. They would most commonly start searching for OHI by entering one or more keyword into a search engine and clicking on the first few links or links to resources they recognized. On the other hand, two participants mentioned that they start from websites they have bookmarked, including N&G, rather than Google. They had different ways of deciding the credibility of a website, and for the most part, preferred websites from institutions they recognized. After checking a few sites, or trying different keywords, the seeker would decide they had found something relevant after triangulating from different resources.

Participants used the information to provide informational support (either by sharing the webpage directly or discussing its content), or to provide practical support for a child in their care (e.g., playing games with a child), or to provide emotional support. In some cases, they did not share the information to avoid tensions with the parents in question. Two grandmothers discussed not sharing the information because they did not want to appear too intrusive or too judgemental of their children's parenting.

Finally, they generally reported positive outcomes of using the information. The most common outcome reported is improvement in the relationship with others. Other positive outcomes included feeling less worried and feeling more confident in future interactions. In contrast, some interpersonal tensions were described as a result of sharing the information, specifically when it was unsolicited and when it was shared in the context of a personal relationship rather than a professional one.

Integration of Findings from Quantitative and Qualitative Studies

Two integration techniques are used in this chapter: (1) comparison of results by exploring the similarities, differences, and contradictions between both sets of results, and (2) assimilation of data by transforming the qualitative and quantitative data into qualitative data using a story telling technique.

Comparison of quantitative and qualitative findings - New IAM Items

In this section, I compare how each of nine main findings is supported by the findings from the quantitative and qualitative studies (thereby highlighting convergences between quantitative and qualitative findings). The results from analyzing the IAM responses are elaborated with findings from the participant interviews in a table format. Next, new IAM items are proposed as a result.

As highlighted in Table 21, six findings were convergent between the quantitative and qualitative studies. There were three findings (5, 6, 8, and 9) from the qualitative study that were not documented in the quantitative study because there were no corresponding IAM response items. Two relate to OHI use: providing emotional support to the parent (Finding 5 in the table) and deciding not to share the information found to avoid tensions (Finding 6 in the table). One relates to an outcome of OHI use: experiencing a negative outcome, a tension, after using the information (Finding 7 in the table). The last one relates to the context of proxy OHI seeking and is difficult to capture in a single response item: the strength of the social ties between entourage and person (Finding 9 in the table). These findings suggest new IAM items that are specific to the entourage and would not necessarily be relevant to parents or other people completing the IAM as self-seekers. However, one finding and the corresponding item is not known by the OHI user until the information has been used (Finding 7 in the table). The IAM invites N&G users to select the expected use and benefits of the information, so this response item is not relevant at the time of the completion of the questionnaire. In future applications of the IAM which involve retrospective responses from participants (i.e., after they have used the information), this item will be relevant.

Table 21. Main findings: quantitative and qualitative evidence

Finding (green row: convergence pink row: complementarity)	**Quantitative**	**Qualitative**
1. When the information is acquired through active directed seeking by the respondents through the N&G website, it is usually because there is a known information need, usually a specific problem. When they find something relevant, they are then likely to use it and report positive outcomes related to an existing problem.	Respondents who accessed N&G directly through the website were more likely to report that using the information would help them be less worried, help them handle a problem and help them decide what to do with someone else.	Participants would most commonly start searching for OHI by entering one or more keyword into a search engine (e.g., "Googling the word 'vaccine'"), and clicking on the first few links or links to resources they recognized. On the other hand, two participants mentioned that they start from websites they have bookmarked, including N&G, rather than Google. "Going to see that information really reassured me. I was kind of full of questions and stuff and I wasn't sure about everything, [the information] put some answers to my questions, and I was better with myself after reading that and I felt much better." -Sarah
2. Sometimes there is no known information need and the entourage members access an N&G webpage through browsing and through the weekly newsletter. In that case they used the information on their own to do something and reported more general positive outcomes.	Respondents through the newsletter were more likely to report using the information to do something or do something differently and that they expected that the information would help to improve the health or well-being of a child.	"It was my daughter who subscribed me [to the newsletter], who told me about N&G. I was really interested in having the information to follow up on the development of my grandchildren." -Sophie (grandmother). They sometimes shared the link to a relevant webpage directly with the child's parent: "A lot of times I'll send her a little message on Facebook in a private message, I'll send her the link outright," – Sophie.

Finding **(green row: convergence** **pink row: complementarity)**	**Quantitative**	**Qualitative**
3. Regardless of how they access the information, entourage members are likely to share the information they find or discuss it with others (without sharing the direct link).	The entourage members were more likely than parents to use the information in discussion with someone else. Both groups (newsletter and entourage) were equally likely to report using the information in discussion with someone else.	The majority used the information to provide informational support to someone in their social circle. They sometimes shared the link to a relevant webpage directly with the child's parent. Other times participants discussed the content of the webpage without sharing the link itself: "I share my perspective [with my son], but my perspective is kind of informed by that information," – Nadia (grandmother).
4. In addition to providing informational support to the parents, the entourage members also used the information to provide practical support to parents and the children in their care.	The entourage members were less likely to report using the information to do something or do something differently compared to parents, but the related response items were still frequently selected (by 30%-36% of entourage members).	Another way participants used the information was to provide practical support. This was specifically true for family members who were occasionally entrusted with the care of a child. Mathilde described using the information she found to help her brother with his homework while she was babysitting him in the evenings. Four grandmothers described learning new ways to interact with their grandchildren while they were spending time with them.
5. In addition to providing informational support to the parents, the entourage members also used the information to provide emotional support to parents and the children in their care.	There are no IAM items related to emotional support, so this was not assessed.	One grandmother described providing emotional support to her bereaved son after she read relevant information on N&G: "It was more with my son that I talked about it, but really, him, it wasn't so much about where I found the information as it was about discussing the grief." -Joelle.
6. Some entourage members did not share the information they found, to avoid tension and other negative outcomes.	There are no IAM items related to not sharing the information, so this was not assessed.	In some situations, they did not share the information at all, often to avoid tension or conflict with the person, e.g., "I'll take on the role of the specialist with respect to my sister, so sometimes that leads to discussions that are less pleasant," – Emilia (professional). Two grandmothers discussed not sharing the information because they didn't want to appear too intrusive or too judgemental of their children's parenting. As one of them said, "Giving out information that is not

Finding **(green row: convergence** **pink row: complementarity)**	**Quantitative**	**Qualitative**
		sought after is, in my opinion, a waste of time,” – Nathalie.
7. One of the positive outcomes reported by the entourage after using the information is that they felt more confident or supported in their decision-making with someone else.	The entourage members were more likely to report that information helped them decide what to do with someone else.	Some participants felt more confident making decisions with others, and with being more involved in the care of the child. After sharing information a few times and feeling validated, one grandmother described feeling more comfortable discussing what she had read with her son again in the future. One professional reported that the parents in her care were the ones who felt more confident in their interventions with their child following a discussion of the information she had shared.
8. Some entourage members reported negative outcomes such as change in the interpersonal relationship with someone else.	There are no IAM items related to negative outcomes of using the information, so this was not assessed.	Two participants described negative outcomes or tensions as a result of sharing information. Alisson who shared information with her sister describes one such outcome: “I have to be careful, because she didn't take it very well. She, she thought I was doubting her... she wasn't too keen on me telling her about it after all.”
9. Most entourage members reported strong social ties with the parents they were supporting either geographical proximity, strong family bonds or a close professional relationship.	Limitation: we did not explore relational variables like strength of the social ties between the entourage and the parents and child for whom they are using N&G.	All entourage members were in close contact with the people for whom they were often proxy-seeking information online. This contact may be in-person, but many also described remote contact either due to geographic location or restrictions from the pandemic. “I live in a big generational house with my son's family. I'm in this situation because I lost my spouse [recently]… and I have another son who lives a little further away from here, who also has children.” -Nathalie
10. Entourage members used both mobile devices and computers, but since their information needs were rarely	Parents were more likely to complete an IAM questionnaire over a mobile device (n=35,528;	“Sometimes I like my laptop better because it's bigger, so often I feel like I can do better research on it than my phone because it's smaller. I feel like, and this is really in my

Finding (green row: convergence pink row: complementarity)	Quantitative	Qualitative
urgent and they were often older (grandparents), they were more likely to use computers.	87.5%) compared to the entourage (n=5,745; 53.7%).	head, that I would have more options on my computer, which is bigger, and it would be easier to find certain information than on my phone. My phone, it's just going to be quick little things." – Sarah

Therefore, I propose two new IAM items based on findings 5 and 6:

Q4a. How will you use this information for you or for a child in your care? Check all that apply.

This information will help me to better understand.
I will use this information to do something.
I will use this information to do something in a different manner.
I will use this information in a discussion with someone else.
I will use this information to provide emotional support to a parent or child
I will use this information for myself, but I will not share this information with another parent
I will use this information in another way.

Q5a. Which benefits do you expect for you and at least one child (0-8 years)? Check all that apply.

This information will help me to improve the health or well-being of a child.
This information will help me to be less worried.
This information will help me to prevent a problem or the worsening of a problem.
This information will help me to handle a problem.
This information will help me decide what to do with someone else.
Another benefit.

Assimilation of Data of Quantitative Data into Qualitative Data

The following four vignettes, represent four scenarios of proxy OHI seeking through four entourage members that cover all the findings from Table 21. The vignettes were developed after assimilating the quantitative results into qualitative findings, and then conducting a secondary analysis of the combined findings through an interpretive story-telling lens. The sources of evidence for each vignette are mapped in Table 22. Based on these vignettes, the Proxy OHI Seeking Outcomes model is revised.

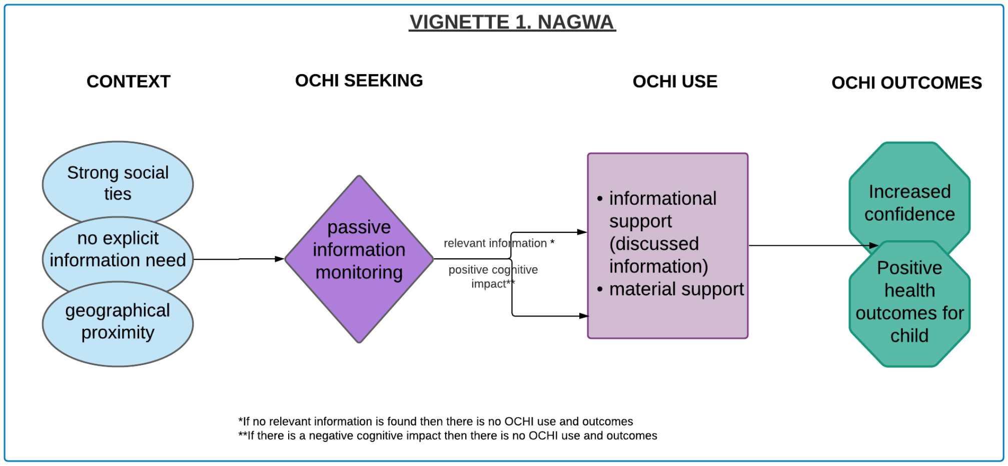
Table 22. Mapping Vignettes across Findings from Qualitative and Quantitative Studies

Vignette	Finding	Quantitative	Qualitative
V1	2, 3, 4, 9, 10	Entourage newsletter IAM responses	Sophie, Nadia, Nathalie, Mary
V2	1, 3, 5, 7	Entourage website IAM responses	Sarah, Joelle, David, Mark
V3	1, 3	Entourage IAM responses compared to parents	Norma, Alice, Mathilde, Florence
V4	6, 8	Not covered	Emilia, Alisson

Vignette 1: Nagwa the grandmother

Nagwa is the grandmother of a two-year old child, Hassan, the first grandson from her eldest daughter. Nagwa lives near her daughter's family and is very involved in her grandson's life: they video chat every day and visit every two weeks. She subscribed to the N&G newsletters on a weekly basis, to help her daughter with her parenting information needs and to follow Hassan's development. One day Nagwa reads an article online on her tablet describing the importance of exposing two-year old children to sunlight during the winter months. She calls her daughter to describe the article to her and to recommend taking the child out to the park and offers to do so a couple of times a month. Her daughter is delighted by this suggestion, it gives her time to run errands as well. Nagwa feels great after this call, she feels more confident about her involvement in the care of the child and is more likely to pass along other interesting health information she finds. This vignette can be illustrated in Figure 25 below.

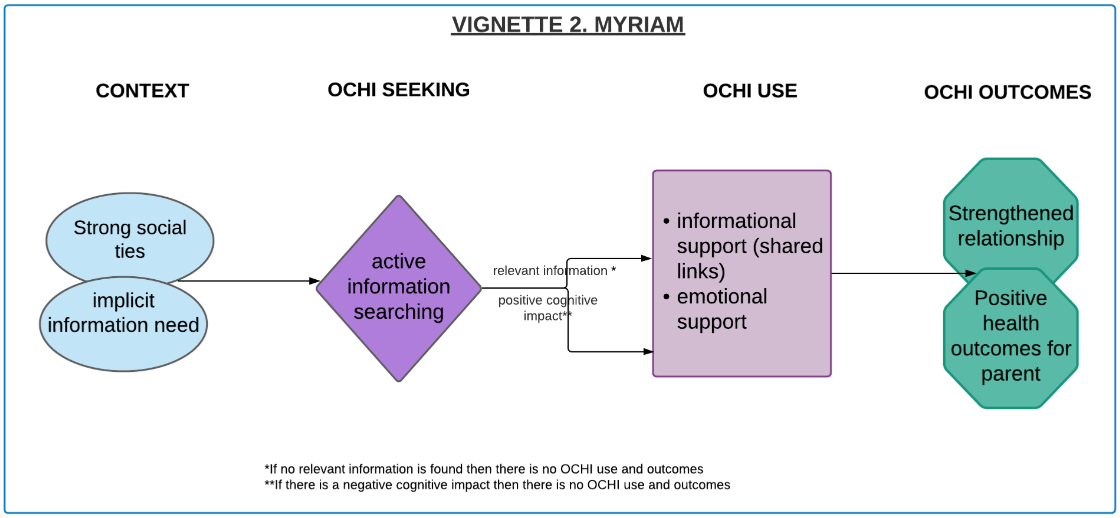
Figure 25. Vignette 1 - Grandmother passively monitoring information



Vignette 2: Myriam the best friend

Myriam’s best friend Samantha lives across the country and just had her first baby a few months ago, alone with no family nearby. They talk frequently, but since becoming a mother, Samantha has understandably been less available. After a quick Facetime chat, Myriam became worried about Samantha’s mental health, especially since she started crying halfway through the call, and decided to do some research. A colleague recommended a website that discussed postpartum blues and depression. Myriam assessed the website and found it to be credible with updated references and expert input. The next time she spoke to Samantha she shared the website, highlighting some of the more relevant topics for her friend. She also suggested they have a daily “check-in”, where Samantha would send a photo and a voice note to Myriam updating her on what was happening. A few months later, Samantha confided to Myriam how reading others who described and validated how she was feeling and having a daily check in with Myriam “saved her sanity”. She was finally feeling like herself again. Vignette 2 can be illustrated in Figure 26 below.

Figure 26. Vignette 2: Myriam providing emotional and informational support

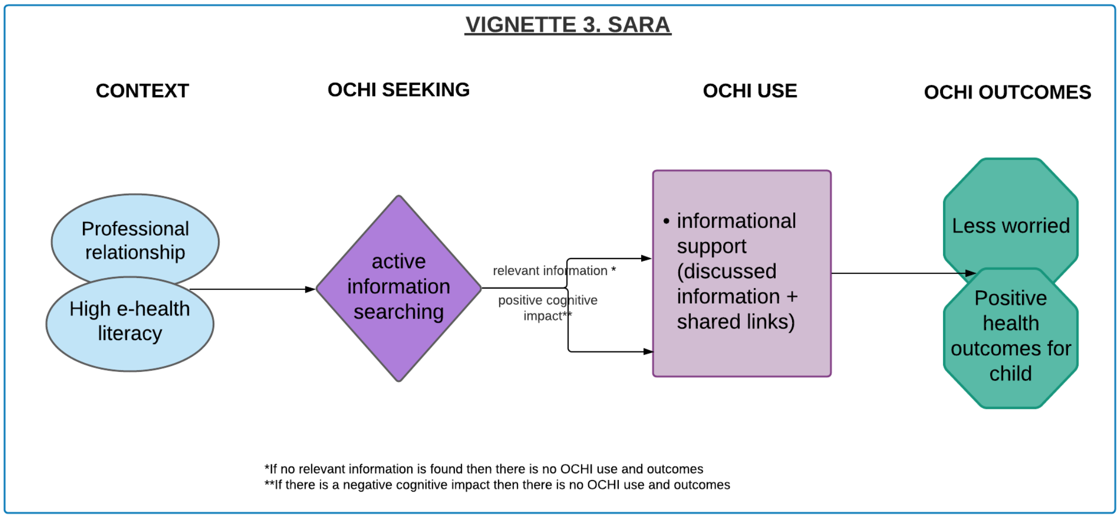


*If no relevant information is found then there is no OCHI use and outcomes
**If there is a negative cognitive impact then there is no OCHI use and outcomes

Vignette 3: Sara the professional

Sara has a home daycare and is very beloved by the children in her care and by their parents. One of the children who has been in her care the longest is three-year-old Eva, who has always been a confident and happy child. Last month Eva's parents delivered a new daughter, Emma, and although they had all been preparing Eva for this addition, she still could not understand what was happening. Sara noticed that Eva was now more insecure, she hit two of the other younger children, and would cry every time her father dropped her off. Sara asked the parents if they noticed anything unusual, and they mentioned she had had a few night-time incidents although she was toilet trained. They mentioned they were worried because she was crying more often and appeared to "hate" the baby. Sara went back to her training resources and found several articles on this topic. She discussed her findings with Eva's parents and offered to share these links with them, which they happily accepted. All three made small changes to their attitudes and behaviour with Eva which helped her eventually adjust better to her new sister's presence and still feel loved. Vignette 3 can be illustrated in Figure 27 below.

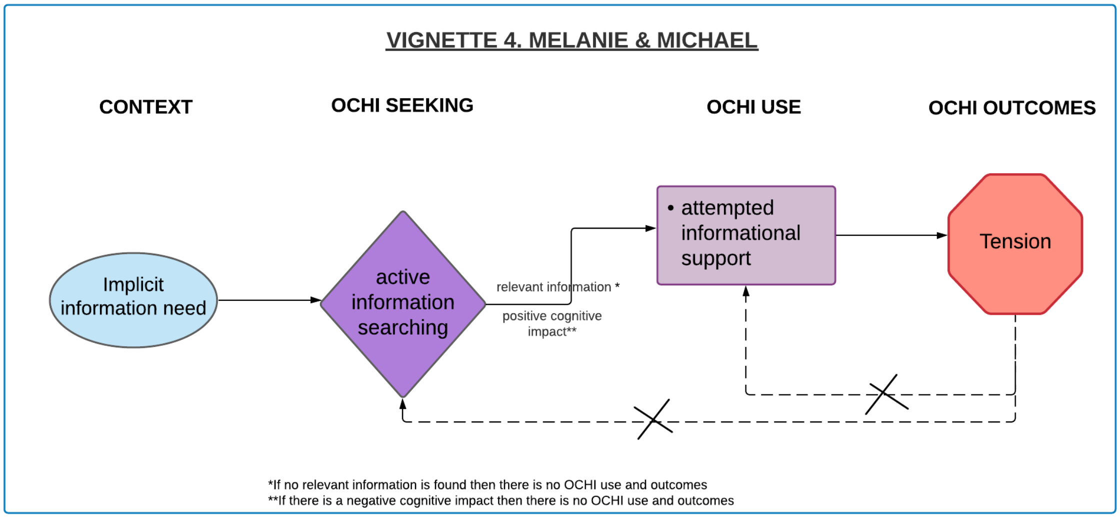
Figure 27. Vignette 3: Sara the professional providing informational support



Vignette 4: Melanie the cousin

Melanie’s friend Michael has a 3-year-old daughter who goes to the same daycare as Melanie’s son. They have a playdate every few weeks and the parents catch up during those playdates. At the last playdate, Michael mentioned how picky his daughter was when it came to new food. Melanie did a quick search on her phone and shared a few links on picky eaters with Michael. He wasn’t too eager to read them and mentioned he doesn’t really trust online information, he thinks people who do are not smart, and prefers to discuss issues with their family doctor. Melanie was offended by this and felt attacked by this comment. A few days later Melanie came across an article on picky toddlers in her N&G newsletter but decided not to share it with Michael after his previous comments. Vignette 4 can be illustrated in Figure 28 below.

Figure 28. Vignette 4: Negative outcomes of proxy OHI Seeking



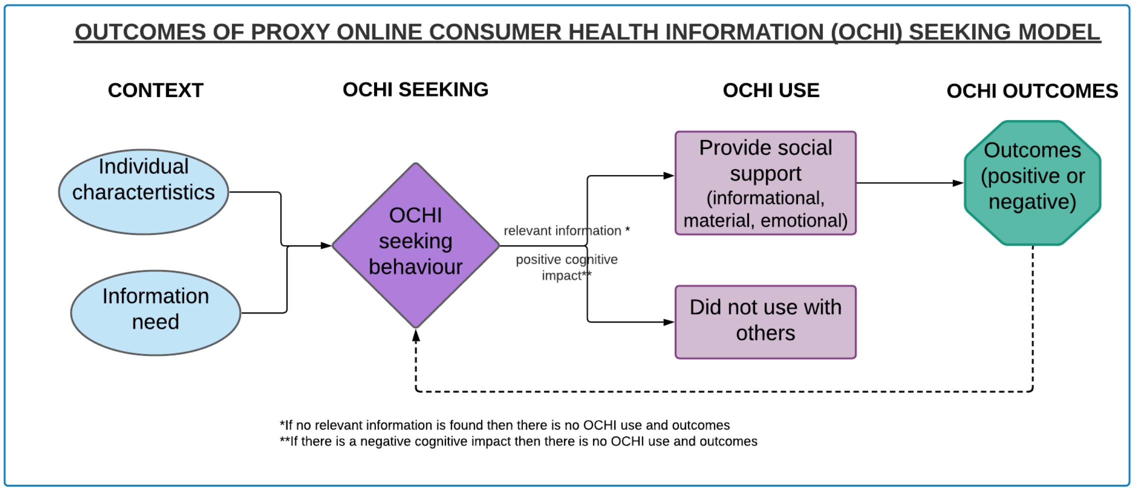
Revised Proxy OHI Seeking Outcomes model

After mixing the quantitative and qualitative findings, I revisit the Proxy OHI Seeking Outcomes model derived from the literature review (Manuscript 1). There are no changes to the main concepts (individual characteristics, information needs, OHI seeking behaviour, use, and outcomes). However, eight new dimensions are added (highlighted in yellow in Table 23) and the relationships between the dimensions is now clearer. The revised model is presented in the Figure 29 below, and it attempts to explain the who-when/why-where-how-what of proxy-seeking outcomes, in line with Gregor's definition of a theory that 'explains' a phenomenon (Gregor, 2006).

Table 23. Concepts and Dimensions of Proxy OHI Seeking Outcomes Model

Individual characteristics	Information needs	OHI seeking	Use	Outcomes
Geographic proximity	Explicit request	Active searching	Informational support	Better informed and more confident
Close social ties	To make a decision	Passive monitoring	Practical support	Less worried
Informal caregivers	To support someone with a health condition	Triangulation with multiple sources	Emotional support	Improved health
Gender	Out of interest or curiosity		In discussion with HCPs	Improved interpersonal relationship
Age	Following a healthcare practitioner visit		Information gatekeeping	Increased worrying
Education	Coping mechanism		Not used with others	Interpersonal tensions
e-health literacy	Implicit need			Influence future proxy OHI seeking
Professional role				

Figure 29. The Revised Proxy OHI Seeking Outcomes Model



Who are the proxy seekers? Our findings suggest that several individual characteristics influence proxy OHI seeking behaviour. Proxy-seekers are more likely to be female, who are also are more likely to share health information with others as they are considered the "central nodes" of health information within a community (Altizer et al., 2014; Colon-Ramos et al., 2009). They are also more likely to be more educated, with higher e-health literacy, and to be frequent Internet users in general. Proxy-seekers were likely to be in frequent contact with the people for whom they were seeking OHI, and to report strong social ties with these people (e.g., family members in the same household). They could also be professionals who acted as information mediators.

Why and when does proxy-seeking happen? The OHI seeking process is triggered by another person's information need, which may be explicit or implicit. Explicit information needs may be communicated to the proxy-seeker with or without a request for informational support. Proxy-seekers who were also informal caregivers may also initiate OHI seeking as part of their caregiving responsibilities. Finally, the proxy-seeker may also initiate the search themselves out of curiosity, for reassurance, or as coping mechanism to help deal with their emotions following a diagnosis of their loved ones.

Where and how do proxy-seekers find relevant OHI? The proxy-seeker is actively searching or passively monitoring OHI to fulfill the information need. Proxy-seekers will usually start from a search engine using one or more keyword(s), or they start from specific websites they deem as credible. These websites are usually from institutions they recognize, e.g., the Mayo clinic. They tend to be skeptical or have higher e-health literacy and use several techniques for assessing the credibility of a website: checking for spelling mistakes, references, too many ads, expert authors, etc. Proxy-seekers usually ‘check’ more than one webpage and triangulate the information before deciding they had found something relevant. They either consciously or unconsciously feel a cognitive impact of the information, e.g., it gave them personal satisfaction to know more, or allowed them to learn something new or confirmed something they already knew.

How do proxy-seekers use information? When they find a situationally relevant information object that has a positive cognitive impact, they can use it to provide social support for someone else. This support is most commonly informational support: either by sharing the OHI found directly or discussing it with the person to help them make sense of it. Support may be emotional if there is a strong personal relationship between the proxy-seeker and the person. Practical support may also be provided based on the information, e.g., by offering to babysit a child. The proxy-seeker also acts as an information gatekeeper by filtering the information for the person to reduce information overload stress. In some cases, the proxy-seeker does not use the information with others, and instead uses it for themselves, e.g., their own knowledge on an issue.

What are the outcomes of OHI use by proxy-seekers? Using the information will lead to separate outcomes experienced by the person and the proxy-seeker, that are generally positive. These include reduced worrying, improvement in the relationship between proxy-seeker and the person, and improved health and well-being of the person. Moreover, both the proxy-seeker and the person report feeling increased confidence in their decision-making. In situations where the information is conflicting, or unsolicited this may lead to negative outcomes such as increased worrying or worsening of an interpersonal relationship. The outcomes experienced by the proxy-seeker may also influence their future OHI seeking, e.g., they may feel more involved in a person's healthcare and thus more motivated to seek OHI on their behalf in the future. On the other hand, when the outcome is negative, the proxy-seeker is hesitant about sharing OHI in the future.

Comparison of the Revised Proxy OHI Seeking Outcomes Model with Existing Models

Our model goes further than existing models. In addition to describing the context of information seeking behavior by the proxy-seeker, it also explains OHI use and outcomes. This presents a significant contribution to the field of information science, as few studies examine the ultimate outcomes of information including health outcomes (Case & Given, 2016; Urquhart & Turner, 2016).

The concept of information seeking by a mediator is not unique to our model. In one of the earliest models on information seeking behavior, Wilson uses pathways to explain different patterns of information seeking (Wilson, 1981). In his model, the user encounters "information systems" that can be technology (e.g., the Internet) and mediators, and these systems connect the user to "information resources" or actual information. Two out of ten pathways proposed in this model indicate seeking that is "conducted by a mediator to fulfill an information request" (Wilson, 1981). In his revised 1996 model, Wilson adds "information processing and use", but did not link information use to outcomes (Wilson, 1997). This phenomenon is also described in McKenzie's two-dimensional model of information practices of women pregnant with twins (McKenzie, 2003). In her model, one of the modes of information practice is "by proxy" where the person interacts with information through another agent, including "intermediaries or gatekeepers" such as friends or family members. These models do not mention outcomes of information use. They are presented in Appendix 6.

Reifegerste also describes intention of using OHI to provide support in his model described in Chapter 2 (Figure 3) (Reifegerste et al., 2020). Similar to Pluye's OHI Outcomes framework, our model includes factors that influence information seeking behavior and leads to levels of outcomes (Pluye et al., 2019). In contrast to this framework our model focusses on proxy seeking, and revolves around types of social support, and the positive and negative health and healthcare related outcomes that are reported by both the proxy-seeker and the people in their entourage.

Strengths of this dissertation

This dissertation includes a literature review and a convergent mixed methods research project with concomitant quantitative and qualitative components. This allowed me to compare the findings on proxy OHI seeking outcomes from three distinct sources: existing literature, survey results and individual interviews. The findings complemented and supported each other, and this approach allowed me to achieve high internal validity (credibility) by describing the same phenomenon from different perspectives in a comprehensive manner. The convergence between findings allowed me to develop and revise a theoretical model that can be further tested and validated in future research in different proxy OHI seeking contexts.

The mixed methods research study was conducted in partnership with Naître et Grandir which offers free and trustworthy information, independent of industry funding.

> "N&G is widely read by French-speaking parents across Canada, the United States, and more than 100 other countries. In the 2018 calendar year, 61.6 million N&G webpages were viewed during 35.3 million visits to the N&G website by 15.2 million unique internet protocol (IP) addresses across the world. Among those, 20.2 million webpages were viewed during 11.2 million visits to the N&G website by 3.3 million unique IP addresses in Quebec. More than 213,000 N&G weekly newsletters were emailed to parents in Quebec. *SOM Recherche & Sondages* (personal communication, 2015) conducted a survey of a representative random sample of the population of parents of young children in Quebec,

> which showed that 82% of respondents knew N&G and that 76% consulted it.” (Pluye et al., 2020)

There are three main advantages to this partnership: the high quality of the OHI being explored in the study, the generalizability of the study samples, and the benefits of an organizational participatory research approach. First, the prevalence of low-quality information and misinformation online (Daraz et al., 2019; Suarez-Lledo & Alvarez-Galvez, 2021) influences the outcomes of OHI use, and adds an extra layer of complication to this phenomenon. The ability to explore proxy-seeking with the knowledge that the OHI being used is somewhat trustworthy, allowed me to focus exclusively on the interactions between the people and the information. Second, the study was conducted in a real world setting with a general sample of entourage members of parents. According to a recent systematic review exploring parental OHI use, almost all studies on this topic are conducted in clinical settings, and there is a strong need for research on representative samples of parents and proxy seekers (Kubb & Foran, 2020). Third, the organizational participatory research approach will allow us to incorporate the N&G editors feedback to the application of the findings. This highlights the relevance of the research objective to information providers and provides an avenue for integrated knowledge translation.

For N&G, there are two consequences of this project on their work. First, the new IAM responses, that are specific to the entourage, will allow them to better understand how this population uses their information. Second, the findings will directly impact how they present the information on their website, so that it doesn’t only target parents, but also responds to the entourage’s needs.

Limitations of this dissertation

Several challenges and limitations were encountered during this project. In Manuscript 1, the literature review used to develop the initial model was not a systematic review and only one reviewer conducted the selection phase, therefore relevant studies may have been missed. However, the goal was to revise an existing framework and not necessarily to be exhaustive (in contrast to the needs of being systematic when a review is aimed to measure effectiveness of an intervention). Systematically reviewing all the models on information seeking behavior was beyond the scope of the project, but I reviewed and discussed the most common models with my supervisor, a specialized expert librarian and during a graduate course in the School of Information Studies.

In the empirical studies of Manuscripts 2 and 3, there are several limitations. In the quantitative study participants were self-selected volunteers who completed one questionnaire at one point of time (a source of selection bias). This would likely lead to an over-estimation of positive outcomes due to social desirability bias (Nederhof, 1985). However, this bias will have influenced both parents and the entourage in the same manner and thus did not affect the comparative analysis. In the qualitative study I could not conduct interviews myself as my conversational French is not perfectly fluent. However, the interviewer and I conducted meetings prior to and following each interview to exchange notes, and I listened to the recorded interviews prior to translation of transcripts. In addition, the original protocol had included a face-to-face option for the interviews as well, but the interviews were conduced during the COVID-19 pandemic, so it was considered unnecessary to expose the participants or researchers to such a risk. Moreover, a research note that compared interview transcripts obtained by face-to-face and phone interviews found no significant differences in the interviews (Sturges & Hanrahan, 2004).

For both studies participants were recruited from only one OHI resource related to online parenting information, and thus the findings may not to be generalizable or transferable to the entourage of other populations (non-parents). To overcome this, during qualitative interviews participants were asked about other sources of OHI and other instances of proxy OHI seeking. Moreover, the initial model was developed following a literature review on revise OHI resources. The model was tested and revised only in the context of online parenting information and should be tested in other settings and populations in future work.

Additionally, the contextual factors and outcomes were assessed at a cross-sectional moment in time, no participant was followed over time which may have provided a more in-depth look at the phenomenon. However, the quantitative study was longitudinal as results were collected over 2 years. Moreover, a saturation of themes was realised in the qualitative study which highlights the dependability of the findings.

Finally, most participants in the qualitative study were female (12/14) which corresponds to the gender of the respondents to the IAM questionnaire (on average, 90% of respondents are female). Although this lack of heterogeneity may be considered a limitation, studies consistently report that the majority of OHI proxy seekers are female as reflected in our sample (S. L. Cutrona et al., 2016; Y. S. Oh, 2015; Reifegerste et al., 2017; Turner et al., 2018). In a recent analysis of IAM responses by N&G users with low socioeconomic status, our team reported that fathers were more likely to report benefits of N&G information than mothers (Pluye et al., 2022). This highlights the need to target male OHI seekers with inclusive information and to explore their use of OHI in future studies.

Impact of this Research and Potential Interventions

Perceived and actual social support are linked to generally positive health outcomes for the recipient of the support (as described in Chapter 2). Exploring the outcomes for the social support provider, in this case from the viewpoint of proxy OHI seekers allowed me to identify the potential benefits from their perspective. Previous empirical research findings suggest that helping others may reduce stress for the provider and contribute to their good health, as well as encourage their OHI seeking behaviour (Taylor, 2011). Our work confirms that it may also improve personal relationships between people and their social network and allow them to be more involved in future decision-making. These outcomes highlight the need to facilitate proxy OHI seeking and use.

Few studies have explored the negative outcomes of proxy OHI seeking use, which represents an important finding of this work. Previous work has explored the potential negative effects of social support efforts, which may be well intentioned but may be perceived as unhelpful by the person receiving the support (Taylor, 2011). People may give unwanted or misleading advice in an attempt to provide informational support, and they may provide excessive or insufficient emotional or practical support (Boutin-Foster, 2005). Effective social support requires an appropriate balance between the needs of the person receiving the support and the actions of those in their social network (Cohen & Wills, 1985). Some people work in collaboration with their social network to seek or avoid information, while others find themselves in conflict, especially when the proxy seeker does not recognise the person's needs (Palant & Himmel, 2019). In the context of OHI and in this dissertation, it was confirmed that when the OHI was unsolicited, this led to tensions between people and their entourage.

Potential intervention strategies can focus on two objectives: (1) improving proxy OHI seeking and OHI use to promote positive outcomes for proxy seekers and the people they seek for, and (2) extend social support networks for people without an effective entourage. The first objective can be achieved through strategies that help proxy OHI seekers find relevant OHI, evaluate it, and use it appropriately. The second objective can be achieved by identifying social support interventions from previous work that may be applicable in the context of proxy OHI seeking.

Strategies to improve proxy OHI seeking outcomes

These interventions target different stages of the OHI seeking process and draw on the findings from a systematic review on OHI outcomes and a qualitative study on reducing negative OHI outcomes (El Sherif et al., 2018; Pluye et al., 2019). The corresponding three strategies are implemented in an evidence-based educational website and summarised as follows (Dai et al., 2019). First, before starting OHI seeking, it is important to provide reliable OHI sources that the proxy seeker can access before running a search. This is in line with other studies that recommend that health care providers, specifically doctors, guide patients to reliable sources of OHI (Agius & Stangeland, 2016; Iacovetto & Allen, 2015; Silver, 2015). It is mostly organizations, institutes or professional associations doing the effort to provide reliable health information online, such as the Heart and Stroke Foundation, the College of Family Physicians of Canada, or the US National Library of Medicine (Medline Plus). A great limitation to this is social media which has become a popular forum for sharing misinformation. Another limitation is that there is a wide variety of practitioners involved in the support of parents regarding their child's development and well-being, and their parenting behaviour and experience, which has an impact on the diversity of sources of information and the challenge to identify the most reliable ones.

Thus, the second strategy is to teach seekers to evaluate OHI sources. In the literature it has been reported that evaluation interventions (aimed at teaching "how to evaluate search results, information and source") led to a more critical evaluation of online information (Walraven et al., 2010; Wiley et al., 2009). There are several online resources available in the form of guidelines and checklists to follow while evaluating a website. However, many consumers, especially those in a lower socioeconomic strata, may not be aware of these resources or the fact that they are not correctly evaluating resources (Diviani et al., 2015).

Third, OHI seekers are encouraged to discuss the information with others, ideally with people with a higher level of e-health literacy to help them contextualize and understand the information. This is also applicable for proxy OHI seekers who are likely to discuss the information with others. Directing proxy OHI seekers to high-quality Internet-based resources that are better designed for sharing, e.g., that allow for downloading, may be an effective way to support dissemination of health information (Cutrona et al., 2016).

To reduce negative outcomes I will draw on recommendations from other types of social support interactions: proxy OHI seekers should be encouraged to identify the needs of the people they are seeking OHI for, and people should be encouraged to explicitly state the amount, and timing of the informational support they need from the proxy seekers (Boutin-Foster, 2005).

Interventions that increase social support networks

The focus of this dissertation was people with existing social support providers. Therefore, the findings are not applicable for people without such providers who may act as proxy OHI seekers, so I will briefly describe interventions that have been used to increate social support structures for such individuals. Twenty years ago Hogan et al reviewed social support interventions and recommended that interventions are most effective when they involve people from the "natural" support network either by including them in the intervention, improving existing relationships or developing new relationships (Hogan et al., 2002). This is supported by a review of social support interventions that confirmed that "informal" social support systems were the most important source for migrant populations. The development of programmes to "strengthen the informal support system is emphasized as an alternative to integrating formal and informal resources in social work practice with migrant populations" (Hernández-Plaza et al., 2006). The following interventions were identified from the aforementioned reviews as potentially useful in the context of proxy OHI seeking:

1. Identifying key sources of support in each community and providing them with reliable OHI sources and training on evaluating OHI. This is especially important in socially disadvantaged communities where the social network members that people rely on are equally disadvantaged and resource poor (Chen, 2013). Providing training on the strategies mentioned earlier to improve proxy OHI outcomes is essential for this community.
2. Encouraging more people to volunteer their assistance with helping others with internet use– especially with adults outside of family and professional

networks. Proxy OHI seeking could be promoted as a valuable form of neighbourhood and community volunteering (Selwyn et al., 2016).

3. The inclusion of a family member or friend as a source of support as an adjunct to an existing treatment for a specific problem, with additional behavioral training on OHI seeking and using OHI for support.
4. Interventions that target social skills attempt to improve naturally occurring support systems by teaching relationship skills, with combined psychoeducation, social skills training, and cognitive-behavioral techniques.
5. Other OHI mediators such as health librarians or other professionals with high e-health literacy. The integration of health librarians into the health information seeking process may ensure that the information the proxy-seekers have is reliable and suited to their level of health literacy.

Chapter 8: Conclusion

Proxy OHI seeking is one of the most common ways people use the Internet today. Harnessing our understanding of positive outcomes such as improved health, and potential negative outcomes such as increased interpersonal tensions, must remain a priority for OHI research. The COVID pandemic has accelerated the trend towards more availability and use of internet-based health care information, and now more than ever, it is critical that OHI be presented in a way that is most beneficial to people and their social networks. This dissertation, thus, explores a topic that is important in the fields of Primary Care and Information Studies.

The first contribution of this dissertation is, therefore, theoretical: findings from this study advance scientific knowledge on proxy online health information seeking behaviour and outcomes. An initial theoretical model was proposed following a mixed studies literature reviews on proxy OHI seeking. This model was then revised to incorporate additional findings from a mixed methods study conducted in the context of an online parenting resource. Four vignettes covering the main findings and providing an overview of the model are proposed and can be used in the development of interventions to promote proxy OHI seeking.

The second contribution is methodological. I conducted a convergent mixed methods study, qualitative and quantitative components were conducted and analyzed separately and concomitantly, and the results from both components were integrated using wo integration strategies: comparison of results and assimilation of results. Assimilation through storytelling to produce vignettes is a technique that is rarely used in mixed methods research. These vignettes cover the main findings from both components and provide an explanation of the model that can be used in training researchers or designing interventions.

The third contribution is practical: this is an important topic for both information specialists and primary health care practitioners. By better understanding how an individual and their entourage use information together, information providers can better adapt the information to meet both their needs, and health care practitioners (e.g., family physicians) can target patients' entourage with information for dissemination and use. Patients can be encouraged to turn to their entourage for support using online health information. Community interventions can promote volunteer and training programs to improve the positive outcomes of proxy OHI seeking. Other professionals involved in the support of parents and their children (e.g., daycare educators and social workers) can be specifically targeted with reliable OHI to promote positive outcomes.

I propose three avenues for future research. First, the proxy OHI seeking outcomes model was tested in the context of online parenting information and revised. Future projects can test the model in different contexts and revise it accordingly. More vignettes on proxy OHI seeking can be developed to further explain the model and may be used for designing interventions. Second, the IAM was revised to include response items that are geared towards the entourage. This revised IAM will be implemented by N&G in the near future and the subsequent IAM responses will be analyzed and reported. This revised IAM will also be implemented with other online information providers and the analysis of the entourage responses will be used to provide further insight on the outcomes of proxy OHI seeking behaviour. Finally, the mixed methods study conducted in this dissertation was cross-sectional in design. Future work can employ social network analysis and more in-depth case analysis to explore the characteristics of people's entourage, their proxy OHI seeking behaviour, how they use OHI and what outcomes they report.

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Appendix 1. Manuscript 1 - Characteristics of Included Studies

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Abrahamson 2008 USA	MMR	Motivations for, barriers to, and effects of OHI seeking and explored lay information mediary behavior (LIMB) characteristics in the consumer health information domain.	People seeking for information on behalf or because of someone else; & direct users: and & service providers	Female (77%, n=533), age 45–54 (33%, n514), and college graduates (30%, n513).		Out of interest or obligation. Explicit request	LIMs share, store, or use health information that they determine is potentially useful; they also monitor information related to others' needs and appear to assist others in processing information.	Affective: related to emotions (e.g., lessened worry about health care/procedures) Cognitive: improved understanding of issues, terminology, etc. Physical: led to a lifestyle or health behavior change, such as quitting smoking
Bangerter 2019 USA	Cross-sectional survey	Examine health information –seeking behaviors among caregivers and to identify caregiver characteristics that contribute to difficulty in seeking	Nationally representative sample drawn from the Health Information National Trends Survey (HINTS). Caregivers (n=391)	Caregivers that were non-white, less educated, privately insured, and without a regular health care provider reported lower confidence seeking health information. Caregivers with higher income reported more confidence seeking health information.				

Study ID **Country**	**Study Design**	**Study Objective**	**Participants**	**Entourage characteristics**	**OHIS behaviour**	**Reasons for OHIS or context**	**OHI use**	**OHI outcome**
		health information						
Brown 2021 USA	Qualitative	To investigate information behaviors in the context of health-related social control and the impact of control on patient health behavior	38 family clusters with a total of 97 individuals. Eligible patients (Veterans Affairs Medical Center) were diagnosed with either Type 2 diabetes or HIV/AIDS and were willing to recruit family members involved in their care.	All families mentioned health-related social control-related behaviors in at least one interview contact. The most common form was pushing (telling patients what to do), questioning patient behavior, structuring the environment, and raising concerns. Guilting and repeating to reinforce points were the least commonly discussed.	Family gathered information individually or interactively, using methods including searching online, attending patients' healthcare appointments, and observing patients.	Family members acquired information to define problems and facilitate other information behavior that enacted social control	Information sharing took the form of persuasive social control strategies such as raising concerns and repeating points. When leveraging expertise, participants shared information from sources they deemed credible. Family often sought information individually when patients were first diagnosed “to set [their] mind [s] at ease….”, shared through two persuasive strategies, proxy informing and teaming up.	Ignoring was one response to norm enforcement; this involved simply refusing to listen to family directives or to take them into account, a form of passive resistance to control.

Study ID **Country**	**Study Design**	**Study Objective**	**Participants**	**Entourage characteristics**	**OHIS behaviour**	**Reasons for OHIS or context**	**OHI use**	**OHI outcome**
Carpenter 2015 USA	Cross-sectional survey	Describe the medication information-seeking behaviors of arthritis patients' partners and explore whether partner medication information-seeking and information-sharing are associated with patient medication adherence	87 patient–partner dyads: Eligible patients had osteoarthritis (OA) or rheumatoid arthritis (RA), were ~18 years old, could read English, had Internet access, and were currently taking ~1 medication. Patients' partners were recruited by a snowball technique.	Partner information-seeking and information-sharing were positively associated (r = 0.51, p < 0.001). Partners sought more information about the patient's arthritis medications if the patient reported a more complex medication regimen (r = 0.33, p = 0.002). Older partner age was associated with sharing more information with the patient (r = 0.25, p = 0.03). No other variables were associated with partner information-seeking or information sharing (supplementary materials).		Medication effectiveness was the topic partners discussed most with patients. A complex regimen may cause patients to explicitly ask their partners for treatment-related support, which may trigger partners to seek treatment-related information.	Most partners (97.7%) shared arthritis medication information with the patient; 15.1% shared rarely, 41.9% shared sometimes, and 40.7% shared often.	Neither partner information-seeking (r = 0.21, p = 0.06) nor partner information-sharing (r = 0.12, p = 0.31) were significantly associated with patient medication adherence.

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Cutrona 2015 USA	Cross-sectional survey	To identify those characteristics which differentiate surrogate seekers from those who seek information only for themselves.	Health Information National Trends Survey (HINTS) in 2011-2012. Among the 2,171 respondents who reported using the Internet to seek health or medical information in the previous 12 months, 66.6 % (n=1,461) had acted as a surrogate seeker.	59.1 % of surrogate seekers were aged 35–64 compared to 49.7 % of self-seekers; p= 0.002). Those living with others were significantly more likely to report seeking information online for someone else Online surrogate seekers and self-seekers showed no significant differences in how they perceived their experience of information-seeking. Surrogate seekers and self-seekers were also equally confident that they could get advice or information about health or medical topics, if needed				

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Cutrona 2016 USA	Cross-sectional survey	To examine sociodemographic characteristics, health information seeking behaviors, and other online behaviors among health information brokers.	Health Information National Trends Survey (HINTS). Our final sample included 3142 respondents. Approximately half (54.8 %) of the respondents reported acting as health information brokers.	Brokers were more frequently female, reported higher incomes and higher educational levels. Respondents between the ages 35 and 64 acted as brokers most frequently. Compared to non brokers, a higher percentage of brokers were married. Compared to those with high school or less education, those with greater than high school education more frequently acted as brokers.				
Dolce 2011 USA	Qualitative	To describe the experiences of cancer survivors and caregivers with healthcare providers in the context of the Internet as a source of health	Purposive sample of 488 cancer survivors, with varying cancer types and survivorship stages, and caregivers.			Several participants shared stories about not receiving the most up-to-date cancer information.	Collaborative healthcare providers were receptive to survivors and caregivers bringing knowledge and information gathered from the Internet to the clinical encounter. Participants exercised power through direct confrontation with	

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
		information.					their healthcare providers, which included behaviors such as questioning, persuasion, and coercion. Participants influenced their care and treatment plan by exerting persuasive power in their relationship with healthcare providers.	
Dutta 2018 Singapore	Qualitative	Our study explores how meanings are assigned to HIS behavior: how do Singaporeans come to make sense of HIS?	Stratified snowball sampling strategy targeting participants (n = 100) that fit into a nationally representative demographic composition of the population wide census in Singapore.	In 3G (referred to as three generations of family members residing together) families, grandchildren play vital roles as sources of health information for grandparents, often themselves seeking out health information in response to a request from a grandparent. Living together across generations shapes the context of HIS and sharing.		When asked about their understanding of HIS, most participants referred to the roles they played within relationships, and the ways in which these roles necessitated HIS. E.g., granddaughter, family members, professional. "This is what we do in our culture. We	Mary, a 35-year-old Chinese woman, seeks out health information whenever her 72-year-old mother needs to know something. For Rani, a 55-year-old Indian woman, it is her husband who seeks out information from the internet and then educates her about various health-promoting habits.	"She gets scared these days. At least, I can be there for her, and get the information on the treatment, the side effects. That calms her." "We will talk as a family about my health condition, and that makes me feel secure."

Study ID **Country**	**Study Design**	**Study Objective**	**Participants**	**Entourage characteristics**	**OHIS behaviour**	**Reasons for OHIS or context**	**OHI use**	**OHI outcome**
						have to take care of our grandparents".	"I will pull out information from my mother's health screening tests and discuss, I will also share this with my friends, and they will become part of the decision-making." This back-and-forth process of information sharing serves as a framework for interpreting the information, and for collective sense making.	
James 2007 **UK**	Qualitative	To examine cancer patients' and carers' use of, and attitudes to, the Internet as an information source compared with other media	The study was set up in three Birmingham teaching hospitals: recruited 800 recently diagnosed patients, with any primary cancer, and 200 carers attending with a randomly chosen subset of the patients.	Significantly more carers (48%) used the Internet compared with only 4.8% of patients. Carers were more likely to be the information seekers. Use of the Web among carers increased with level of education and also among those in 'white collar' as opposed to manual or skilled jobs.			Carers also tended to act as 'gate keepers' of information, and constantly sought new information as a means of coping.	

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Mazanderani 2019 **UK**	Qualitative	Explore the intra-familial dynamics of managing health information in the context of chronic illness	77 interviews with people affected by Multiple Sclerosis in the UK (patients, partners, family members and close friends).	When one member of a couple (either the patient or their partner) avoided or ignored information, the other usually compensated by taking on the responsibility of managing it. Conversely, in cases where the patient was an avid information seeker, other family members tended to take a back seat, allowing the patient to take the lead. For many of our interviewees, it was a matter of personality and 'natural' abilities and inclinations, with the key information worker perceived as having better research, technical (especially Internet) or communication skills.		MS was seen as something that individuals within a relationship experienced differently, but faced 'together', and sharing a 'life with MS' often went hand-in-hand with the sharing information about it.	Our interviewees' emphasis on sharing information (as well as on labouring through it) was balanced by an equally pronounced stress on controlling its flow into, within and beyond the family unit, with families developing their own idiosyncratic strategies for doing so. In some cases, these strategies emerged spontaneously with little overt discussion, while in others they were the result of an explicit agreement.	Differences in approaches to health-related information could sometimes result in tensions and even conflict. This was especially notable in situations where one or more family member (commonly the patient) resisted receiving or sharing health-related information.

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Turner 2018 USA	Lit Review	Report on the types of HI sources and information seeking practices used by older adults and the FF that support them.	88 in-person interviews with older adults and 52 telephone interviews with FF	FF had an average age of 67.4 years, and were predominantly female (77%), white (87%) and had at least a bachelor's degree (73%). 77% of FF reported using the internet on a daily basis. Several older adults mentioned that they placed a higher priority on HI from FF who were also healthcare professionals.	FF often sought input from other FF regarding HI. FF served as sounding boards for each other in thinking through HI for the older adult.	Older adults frequently chose to involve FF with their HI seeking. Older adults often used peers to "compare notes" about HI. Some older adults asked FF to find HI on their behalf. In addition, older adults frequently asked FF to suggest HI sources, and to help them make sense of HI.	FF frequently searched for health information for older adults. "…I researched the drug that they wanted to put her on. And I helped her make up a list of questions that she wanted to ask when she went to her next appointment." (FF14, daughter) FF often consulted with other FF to obtain and share information regarding the older adult's health.	
Schook 2014 Netherlands	Qualitative	To explore the reasons why lung cancer patients and caregivers search the Internet for information and ask online lung specialists questions on the	The sample comprised 5 lung cancer patients and 20 caregivers who posed a question on the interactive page of the DLIC website.		An element they mentioned with regard to the available information on the Internet was the difficulty of understanding or interpreting online information correctly, as they were lacking a doctor's	Both patients and caregivers also mentioned that they surfed the Internet again at specific moments later during the lung cancer treatment trajectory, such as during chemotherapy, at the appearance of new symptoms or	Both patients and caregivers also talked about the occurrence of tension when meeting their own information needs by searching the Internet. Specifically, caregivers realized that their needs were not always the same as the	

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
		DLIC's interactive page, "Ask the Physician", rather than consulting with their own specialist.			knowledge and felt overwhelmed by the vast amount of information given. Patients and caregivers mentioned that sometimes they postponed or stopped their Internet search, for instance, because the information they encountered was too much. Not searching helped them to stay positive.	disease progression, or when having to make a choice between two treatment options. Patients and caregivers mentioned that their need to seek information often arose once they had time to rest and think about what they had been told.	patients' and experienced difficulties in dealing with the information they had collected. They felt torn by the dilemma of disclosing sensitive information or hiding it from the patients, as they wanted to protect them from (unwelcome) confrontations. For example, one caregiver said that he did not share the death of someone from his mailing group as he thought that this would be too much to handle for the patient.	

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Nicholas 2003 UK	Cross-sectional survey	To obtain information on the characteristics of the users of health information Web sites, to obtain feedback regarding for what they used online health sites and what were the perceived outcomes associated with using online health information.	A population of Internet users residing in the UK, yielding a sample of 1,322 respondents	Women were more likely to find information that helped someone else: 60% said they had done so compared with 53% of men. This was also true of those respondents with children: 63% said this compared with 53%. Older respondents also were found to be more likely to find information that helped someone else. This was further true of those in a relationship.			A total of 58% said that information found enabled them to help someone else, while 51% said that it gave them information that the doctor had not given them.	
Oh 2015 USA	Cross-sectional survey	To investigate various factors predicting online health information seeking for	The data used in this study were taken from the Health Information National Trends Survey 4. A total of	Having surrogate OHIS was significantly correlated with lower age, being female, being married, being employed, better self-rated health, higher attention to the				

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
		themselves and online health information seeking for others in family caregivers to cancer survivors.	1,113 family caregivers were included in this study.	Internet, and higher trust in the Internet.				
Reifegerste 2017 EU	Cross-sectional survey	RQ1: Does surrogate seeking also occurs in an offline context? RQ2: Are there differences between countries? RQ3: Are there differences between offline and online surrogate seekers and interactions of the information source type with social, demographi	Using a large-scale representative survey from the 28 member states of the European Union (N= 26,566), our data comprise all respondents who reported seeking health information online or offline (n = 18,750; 70.6%).	The results of the multilevel model indicate that living together is the most important predictors of surrogate health information seeking. People who lived with others were more likely to seek health information on behalf of someone else than those living in single-person households. In addition, being female or having a higher health status, higher health knowledge, and higher education were all positively associated with a higher likelihood of surrogate seeking.				

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
		c, and media-related characteristics?						
Reifegerste 2020 Germany	Experimental	To apply and test the Comprehensive Model of Information Seeking to surrogate OHIS	The final sample comprised 607 German participants.	Direct experience was negatively related to OHIS intentions, thereby indicating that those with more experience had lower intentions regarding surrogate OHIS.	Beliefs had a direct effect on utility; however, no direct effects were observed of demographic factors, salience, or experience on utility. Additionally, utility predicted surrogate OHIS intentions, and OHIS predicted social support intentions.	It should be also noted that the direct effects of the relationship between surrogate OHIS intentions and social support intentions, although statistically significant, were small. However, the direct effect of salience on support intentions was relatively strong. The support intentions seemed to go beyond the prerequisite of information seeking.		
Sadasivam 2012 USA	Cross-sectional survey	To assess differences between self seekers versus those that act also as	Our analysis was conducted using data from the Pew Internet and American Life Project 2008	In the bivariate analysis, gender, age, and education were not significantly associated with surrogate seeking the last time the				Of the Internet health information seekers, 57% (N = 724) reported some impact of the health information. Out of

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
		surrogate seekers.	Health Survey. N=1250 information seekers who reported looking for health information online. Out of these, 56% (N = 705) reported looking for health information for others the last time they sought health information on the Internet.	respondent went online Increasing household income was positively associated with surrogate seeking. Information seekers who reported being married and a parent were more likely to be surrogate seekers. Information seekers who self reported health status as good or excellent were more likely to be surrogate seekers. Information seekers having someone close to them with a medical or chronic health care problem were also more likely to be surrogate seekers Information seekers who reported being married/being a parent were more likely to be surrogate seekers.				these, 22% (N = 158) reported a major impact. There were no significant differences in self-reported impact between the self seekers and surrogate seekers (P = 0.48).

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Bouju 2014 France	Cross-sectional survey	To determine the proportion of family members who carried out medical information Internet searches during the first days of the ICU stay.	During the study period, 726 patients stayed in the ICU for over 48 h. The questionnaire was completed by 222 (36 %) visitors.	Before the sixth day, 45 % had used the Internet to search for medical information. Some patient and family member characteristics were associated with increased Internet use, including family age and education as well as patient length of stay				According to responders, the Internet seemed to have limited impact on the physician–family relationship, and only 49 % thought that Internet use was unavoidable.
Chua 2020 Singapore	Cross-sectional survey	To establish the prevalence of health-information-seeking behaviours among caregivers of cancer patient and their resource preference in order to guide practice.	Data were obtained via a self-reported questionnaire from caregivers of cancer patients at the National Cancer Centre Singapore. N= 986	Compared with caregivers who have ever searched for cancer information, the non-searchers tended to be older, had primary and below qualifications. A high percentage of caregivers who have ever searched for cancer information were children taking care of their parents with cancer.	A high percentage (46%) of these caregivers was concerned about the quality of information they have found on the Internet.	A high percentage of the 795 caregivers (87%) had used Internet to search for information about the disease of the patient they were taking care for in the last year prior to the survey. The top three topics being searched are treatment (35.6%), disease (35.6%) and side effects (26.5%)		

Study ID **Country**	**Study Design**	**Study Objective**	**Participants**	**Entourage characteristics**	**OHIS behaviour**	**Reasons for OHIS or context**	**OHI use**	**OHI outcome**
7 : Coder 2020 USA	Cross-sectional survey	Explore the information needs and seeking behaviors of family members and friends who experienced a terminal cancer diagnosis of a loved one that included a predicted lifespan.	Respondents were parents (32%), children (23%), friends (5%), spouses/partners (4%), and siblings (4%), with 32% representing other family members like grandparents and grandchildren		Among those participants who experienced problems, 31% (n = 12) felt too overwhelmed/anxious to research, 18% (n = 7) were unable to formulate question(s) and did not know which search terms/keywords to use, and 15% (n = 6) stated they did not have access to certain resources.	When asked if they wanted to immediately seek out medical information to understand the diagnosis, the majority answered Yes (72%, n = 54), followed by Maybe (13%, n = 10), No (7%, n = 5).	When asked how the medical information was used, to Better understand illness represented the largest response rate (33%, n = 55), followed by Cope with illness (25%, n = 43), Talk with physicians/other health-care providers (22%, n = 38), and to make medical decisions (17%, n = 29). Other (2%, n = 4) responses included researching optimal treatment plans and using the information to support the patient.	47% (n = 28) of the participants stated that they did not experience information overload whereas 42% (n = 25) noted that they did experience information overload. Most respondents that reported information overload experienced negative effects: 48% (n = 24) experienced stress and anxiety, followed by 34% (n = 17) who could not absorb the information, and 16% (n = 8) quit the task at hand.
Coffey 2017 USA	Qualitative	To identify the preferred sources of health information for caregivers supporting	32 caregiver interviews, of which 16 providing care to a person with a TBI, 10 providing care to a person with a SCI, and		The majority of subjects (n=30) received injury-related information via the Internet through sites found using search engines	Caregivers researched information that was directly related to supporting the individual receiving care. “Treatment”	Caregivers reported instances of reliance on their own judgment based on independent research. This sometimes led to negotiation or	

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
		individuals with injuries and to explore how access to this information could be improved.	6 providing care to a person with a burn injury.		(n=20) and medical websites (n=20).	(n=14), "rehabilitation" (n=13), and "medication" (n=11) were reported as dominant themes, "long-term care" (n=15).	collaboration with medical professionals.	
Kernisan 2010 USA	Qualitative	To better understand what types of information are sought by those visiting a website focused on elder-care issues and to identify overarching themes that might inform future development of Internet resources related to caregiving and aging.	Data were obtained from Caring.com (a comprehensive resource for adults caring for aging parents). Of 2161 submitted surveys, 1467 of 1838 free-text comments (80%) were included in the content analysis.	Those caring for parents were more likely to be female.		Many respondents indicated that they were looking for specific advice on the practical aspects of managing the daily living needs of another person, with a majority of these making reference to caring for parents with dementia or other frailty.		

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Kinnane Milne 2010 Various	Lit Review	To review the best available evidence for how carers use the Internet for cancer-related information and support.	Articles in English concerning family, carer, friends of cancer patient's use of the Internet were identified.			The carer may be asked to search for information on behalf of the person with cancer (where the patient does not have access to the Internet or is not Internet savvy or the person with cancer finds they are too ill to search). Acting out of concern or kindness, the carer may initiate the search themselves and provide the patient with details of what they have found.	Of note, although carers may access the Internet for information for the patient, they can also act as 'gatekeepers' and may not pass on certain information. The information found is used in a variety of ways: to inform treatment-related decisions, to check up on medical decisions and to increase knowledge. Other uses included confirming existing treatments and treatment-related decisions for the patient as the best possible options.	Reading Internet information obtained by carers can result in a small percentage of patients requesting tests or treatment. Rarely does reading information found on the net result in patient decisions to refuse or stop cancer treatments. Reading the information can lead to increased confidence, being better informed and being able to discuss the information with a health care professional. There were limited reports of anxiety or confusion after reading information found on the net.

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
Kirschning 2007 Germany	Cross-sectional survey	Why do the family members conduct research on the net? Do they use the net for themselves, or do they pass on Internet-based information to the patients? How does the information passed on influence the therapy decisions?	It was focused on the internet use of family members of women with breast cancer and men with prostate cancer (n=113).	More than half of the respondents were between 40 years and 60 years old. Significantly more than half of the respondents were employed; only one out of five women questioned was a housewife. The respondents lived overwhelmingly in a partnership, somewhat more than half lived in a family. Half of the respondents had a household income of over €2,500/month. The women respondents were overwhelmingly daughters, daughters-in-law, and friends of women with breast cancer. The men questioned were overwhelmingly partners of women with breast cancer.	Most of the respondents printed out the important information (86%). Half set up a collection (50%). Each fifth respondent mailed or e-mailed the information to the patient.	The results relate to a spectrum of people who had experiences with all disease phases. Often, they researched for a patient who was not familiar with the medium (60%).	The family members used the Internet primarily to inform themselves (91%) but also to convey information to the sick person (78%). Half of the respondents integrated Internet information into a medical consultation (56%). Significantly more than half produced a printout of the information they wanted to talk about (62%). Those respondents tried actively to involve the physicians in the interpretation of the information.	The detectable reactions were surprising. Fewer than half noticed an interested reaction from the physician (41%).These differing aspects can clarify why, with a third of the respondents, there was the predominating impression that the physician was overwhelmed (36%).
Li 2015 USA	Cross-sectional survey	Describes the online caregiving information that	800 informal caregivers for community-residing older adults aged 65	The majority of caregivers were White (60.4%) and female (65.5%). Three-quarters of the		The information that interested the searchers most included care receivers’		

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
		caregivers searched for and identifies factors related to their search.	and over. This study is a secondary data analysis of the Caregiving in the U.S. 2009 survey	caregivers (74.3%) had some college education, and two-thirds (68.0%) were employed at some point during the time they provided caregiving. Nearly four in 10 (40.0%) had annual household incomes less than $50,000. The main contribution of this study is its focus on the relationship between caregivers' use of the Internet and their information and service needs and caregiving contextual factors.		conditions or treatments (77.2%), available services for care receivers (52.7%), and care facilities (35.3%). Nearly 11% of caregivers looked for information about support for themselves. This study shows that caregivers who reported higher levels of information/ service needs are likely to conduct more frequent Internet searches.		
Tonsaker 2017 Canada	Qualitative	This study investigated how caregivers' access and use information on the Internet about caregiving and their perspectives on the	Three focus groups of caregivers for a total of 16 participants in a university-affiliated hospital in Quebec.		They begin their search using a general information portal where they type in a question or keyword and choose amongst websites, they compare content and also incorporate external		Participants in the present study experienced empowerment by enhancing interactions with doctors or other health care professionals, through managing their own health, their care recipient's health, and their role as a	

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
		design and features of a new personal health experiences (PHEx) website.			influences, including personal background and preferences, as well as suggestions from family and friends.		caregiver, as well as by developing social connections and receiving support online.	
Simon-Schramm 2008 USA	Cross-sectional survey	This study considers cancer-related Internet use among families and friends of cancer patients, and how that use of the Internet may affect patients and patient care	The questionnaire was administered to 120 patients who were treated in a cancer center in Ohio, USA.	In 73% of all cases, patients reported receiving some online information from their social networks. This online information was received from a spouse or partner (n = 33; 38%), an older child (n = 14; 16%), another relative (n = 10; 12%), a friend (n = 9; 10%), or other individuals (e.g., parents, siblings, and co-workers; n = 21; 24%) who helped access, provide, and/or interpret online information	Of the 86 patients who reported receiving personal Internet-use support, most (n = 63; 73%) did not ask their personal caregivers to provide this support. Instead, caregivers took the initiative in accessing the Internet for information to share with patients.		Online information obtained by personal caregivers was typically shared with patients telephonically and/or through face-to-face contact (n = 77; 89%), or through computer printouts (n = 55; 63%). Only 23 (26%) patients reported receiving emailed cancer-related information from their personal caregivers. Less than one third (n = 35; 29%) of all patients reported	Of the 36 patients asked this question, roughly half (n = 19; 53%) reported that the information was ‘‘very helpful,’’ more than one third (n = 13; 36%) felt that the information was ‘‘somewhat helpful,’’ and three (8%) believed the information was ‘‘not too helpful.’’ Several patients commented that their caregivers, rather than they themselves, found it useful and informative to go online. It helped

Study ID Country	Study Design	Study Objective	Participants	Entourage characteristics	OHIS behaviour	Reasons for OHIS or context	OHI use	OHI outcome
							having talked to their health care providers about their use, or their family's use, of the Internet.	stimulate and give structure to interactions with family and friends.
Song 2019 **China**	Qualitative	To explore the factors that influence the old people to adopt proxy internet health information seeking (PIHIS)	20 old people in rural areas of Xuzhou City, Jiangsu Province who have experience in proxy health information seeking			"I lack the knowledge and skills to use computers and smartphones. If I need to search health information online, I can only ask my children to help me"	"My daughter often searches some information on the Internet and tells me how to pay attention to my body and what food I can't eat. I'm glad to see that my children care so much about me"	"My daughter often searches some information on the Internet and tells me how to pay attention to my body and what food I can't eat. I'm glad to see that my children care so much about me"

Appendix 2. Manuscript 2: N&G-IAM Questionnaire v.2019

Vous répondez principalement en tant que :

☐ Femme enceinte
☐ Partenaire d'une femme enceinte
☐ Mère d'un enfant (0 à 8 ans)
☐ Partenaire d'une mère d'un enfant (0 à 8 ans)
☐ Grand-parent d'un enfant (0 à 8 ans)
☐ Autre membre de la famille d'un enfant (0 à 8 ans)
☐ Ami, voisin ou entourage d'un enfant (0 à 8 ans)
☐ Professionnel s'occupant d'enfants (0 à 8 ans)
☐ Autre réponse

Si vous avez coché "Autre réponse", merci d'expliquer votre rôle.
ZONE DE TEXTE

Q1. Est-ce que ce texte est pertinent?

☐ Très pertinent (c'est ce que j'espérais)
☐ Pertinent
☐ Peu pertinent
☐ Très peu pertinent (ce n'est pas ce que j'espérais)

Q2. Est-ce que vous avez compris ce texte ?

☐ Très bien (j'ai tout compris)
☐ Bien
☐ Mal
☐ Très mal (je n'ai pas compris grand-chose)

Q3. Que pensez-vous de ce texte?
Vous pouvez cocher plusieurs réponses.

Ce texte m'a:

☐ appris quelque chose de nouveau
☐ permis de valider ce que je fais ou j'ai fait
☐ rassuré(e)
☐ rafraîchi(e) la mémoire
☐ donné(e) le goût d'en apprendre plus sur le sujet
☐ Je n'aime pas ce texte ou une partie de ce texte

Si vous n'avez pas aimé ce texte ou une partie de ce texte, merci d'expliquer votre réponse ci-dessous.

ZONE DE TEXTE

Q4. Est-ce que vous utiliserez ce qui est dit dans ce texte pour vous et au moins un enfant (0 à 8 ans)?

☐ Oui
☐ Non

Si oui, merci de nous dire comment vous utiliserez ce texte.
Vous pouvez cocher plusieurs réponses.
J'utiliserai ce texte pour:
☐ mieux comprendre quelque chose
☐ faire quelque chose
☐ faire les choses d'une autre façon
☐ discuter avec quelqu'un d'autre
☐ autre réponse

Si vous avez coché « autre réponse », merci de l'expliquer.
ZONE DE TEXTE

Q5. En utilisant ce texte, espérez-vous des effets positifs pour vous et au moins un enfant (0 à 8 ans)?

☐ Oui
☐ Non

Si oui, merci de nous dire quel(s) bénéfice(s) vous espérez.
Vous pouvez cocher plusieurs réponses.

Ce texte m'aidera à:
☐ améliorer le bien-être ou la santé de l'enfant
☐ être moins inquiet(e)
☐ prévenir un problème (éviter qu'il arrive)
☐ gérer un problème ou à empêcher qu'il s'aggrave
☐ décider quoi faire avec quelqu'un d'autre
☐ autre réponse

Si vous avez coché « autre réponse », merci de l'expliquer.
ZONE DE TEXTE

Merci de commenter vos réponses si vous le souhaitez.
Vous pouvez aussi donner des suggestions pour améliorer ce texte.
ZONE DE TEXTE

Accepteriez-vous d'être contacté(e) pour participer à une discussion sur ce texte?
☐ Oui
☐ Non

Si oui, merci de nous donner une adresse courriel.
ZONE DE TEXTE

Appendix 3. Manuscript 3: Interview Guide

PRÉSENTATION DU FORMULAIRE DE CONSENTEMENT

Merci beaucoup de participer à notre recherche. Vous nous aidez à améliorer le site Internet *Naître et Grandir.* Ce site donne des informations sur plusieurs sujets aux parents d'enfants de 0 à 8 ans.

Les objectifs de ce projet de recherche sont de mieux comprendre comment les gens partagent leurs informations sur la santé avec les personnes qui les entourent (amis, voisins, collègues de travail ? etc.) Nous allons commencer par des questions générales sur vous et sur vos habitudes de recherche d'information, puis nous parlerons plus précisément de Naître et Grandir »

L'entrevue durera environ une heure. Nous allons vous donner $ 50 quand nous aurons terminé. Nous vous donnons cet argent pour vous remercier d'avoir répondu à nos questions et pour votre temps.

Pouvez-vous me dire quelle est la meilleure façon de vous envoyer ce montant ?

- Virement électronique Interac ?
- Chèque envoyé par la poste ?
- Carte cadeau de son choix ?

(In all cases we will follow-up after the interview for details).

Je vais enregistrer la suite de notre conversation, si vous êtes d'accord. Ça m'évitera d'écrire tout ce que vous dites. Je risque aussi d'oublier des choses. L'enregistrement est confidentiel. Personne ne pourra l'écouter sauf les membres de notre équipe de recherche. L'entrevue sera gardée dans un ordinateur avec un mot de passe. Votre nom restera confidentiel. On ne le verra nulle part.

Ma collègue vous avait envoyé le formulaire de consentement par courriel et vous lui aviez donné votre consentement pour participer à ce projet par courriel. Je vais maintenant vous demander votre consentement verbal : acceptez-vous d'être interviewé pour cette étude ?

Avez-vous des questions avant que nous commencions ?

Avez-vous des questions sur l'étude ou l'entrevue ?

MISE EN RELATION INTERVIEWER-INTERVIEWÉE

Est-ce que c'est la première fois que vous participez à une recherche? Ce n'est pas très compliqué. Je vous pose des questions et vous me répondez ce que vous pensez. Il n'y a pas de bonnes ou de mauvaises réponses. Ce qu'on veut savoir, c'est vraiment ce vous pensez, ou ce que vous faites dans certaines situations. Je vous demanderai souvent pourquoi vous dites ceci ou cela. Ce n'est pas parce que ce que vous avez répondu n'est pas correct. Ce n'est pas vous qu'on évalue. Si je vous demande pourquoi vous dites ceci ou cela, c'est juste que je veux en savoir plus. J'aimerais avoir plus de détails. Je veux bien comprendre ce qui vous fait dire ceci ou cela. Est-ce que ça va? On commence avec la première question?

Question 1 (CARACTÉRISTIQUES INDIVIDUELLES)

Parlez-moi un peu de vous.

Question 2 (SOUTIEN SOCIAL PERÇU)

Parlez-moi un peu des membres de votre entourage.

- *Explorer :* Avec qui vivez-vous ?
- *Explorer* : Combien y a-t-il de personnes dans votre famille ou votre entourage ? Combien d'enfants? Quel âge ont-ils?
- *Explorer* : Avez-vous des personnes dans votre entourage vers lesquelles vous pouvez vous tourner en cas de besoin ?
- *Explorer :* Dans le contexte de la pandémie, avez-vous des personnes à qui vous parlez fréquemment (une fois par semaine) ?

Question 3 (UTILISATION D'INTERNET)

Selon vous, combien de temps passez-vous sur Internet :

- Par jour?
- Par semaine?

- *Explorer* : depuis combien de temps utilisez-vous Internet ? À quel âge environ avez-vous commencé à aller sur Internet ?
- *Explorer* : quel genre d'information consultez-vous (ex : médias sociaux, nouvelles/actualités, recettes, etc.) ?
- *Explorer* : en général, utilisez-vous Internet seul(e) ou de temps en temps avec d'autres personnes de votre entourage (ex. : conjoint, enfant, parent ou voisin) ? Pour quelles raisons?
- *Explorer* : sur quel appareil allez-vous sur Internet (téléphone, ordi, tablette) ? Pour quelles raisons?
- *Explorer* : est-ce plutôt facile ou difficile pour vous d'avoir accès à Internet ? Pour quelles raisons?

Question 4 (LITÉRATIE e-SANTÉ)

En général, quels sites visitez-vous quand vous cherchez de l'information sur la santé ?

Comment faites-vous pour évaluer l'information de santé que vous trouvez sur Internet ?

Au moment d'utiliser une information de santé que vous trouvez sur Internet, comment décidez-vous si cette information est digne de confiance ou non ? (relance : quels sont vos critères pour établir que cette information est digne ou non de confiance ?)

Question 5 (BESOIN D'INFORMATIONS)

Selon vous, combien de fois avez-vous eu besoin d'informations sur un enfant dans votre entourage dans la dernière année (ex.: information sur son développement, sa santé, ses apprentissages, ses comportements, l'éducation, les jeux, la lecture, l'activité physique, l'alimentation) ?

- *Explorer* : est-ce qu'il s'agit d'un enfant de votre famille ou de l'enfant de quelqu'un de votre entourage / cercle social ?

  Pouvez-vous m'en dire plus sur votre relation avec cet enfant ? Le gardez-vous pendant la semaine ou le week-end ? Des visites occasionnelles ? Quelle est votre lien avec le(s) parent(s) ?)

Quel(s) type(s) d'information cherchez-vous à propos de cet enfant (ex.: information sur son développement, sa santé, ses apprentissages, ses comportements, l'éducation, les jeux, la lecture, l'activité physique, l'alimentation) ?

Question 6 (HABITUDES DE RECHERCHE OHI ET PERTINENCE DE L'INFORMATION)

Lorsque vous cherchez de l'information en lien avec la santé sur Internet, par où commencez-vous vos recherches ? Quel est votre premier réflexe ?

Une fois que votre recherche a commencé, pouvez-vous décrire ce qui se passe ensuite ?

- Quels sont les sites web auxquels vous accédez directement / en premier ?
- Que cherchez-vous sur Google ?
- Quels sites web avez-vous choisi de lire/consulter et pourquoi ?
- Quand décidez-vous que vous avez trouvé la réponse à votre question ? Autrement dit, quels sont vos critères pour décider que votre recherche d'informations est terminée ?

À quelle fréquence consultez-vous le site *Naître et Grandir* ? Combien de fois environ par semaine ? Combien de fois environ par mois ?

Vous souvenez-vous pourquoi vous avez consulté le site la dernière fois (ex. : inquiétude pour un problème spécifique, besoin d'aide pour adresser une situation particulière) ?

QUESTION 7 (UTLISATION OHI ET EFFETS)

a) Une fois que vous avez trouvé l'information que vous cherchiez, que faites-vous ? Donnez-moi des exemples.

Maintenant, nous allons parler plus spécifiquement du site Internet *Naître et grandir*.

[lire le titre de la dernière page de N&G consultée]

b) Ceci est une page que vous avez notée sur le site. Est-ce que vous vous rappelez avoir consulté cette page ?

   Y a-t-il un parent ou un enfant autour de vous qui avait besoin de cette information ?

Si oui, avez-vous partagé la page avec cette personne ?

- Pour quelles raisons avez-vous partagé la page avec cette personne ?

- Comment très concrètement avez-vous partagé la page avec cette personne (envoi du lien URL, consultation de la page en même temps que la personne, discussions, etc.) ?

Si vous n'avez pas partagé cette page, pouvez-vous me dire pourquoi ?

c) Pouvez-vous me dire de quelle autre manière vous avez utilisé ces informations ?

- *Explorer* : parlez-vous à quelqu'un de ces problèmes ?
- *Explorer* : grâce à ces informations, fournissez-vous à une personne une aide pratique, par exemple en lui amenant des repas ou en lui achetant des articles ?

QUESTION 8 (EFFETS OHI)

Pouvez-vous me raconter ce qui s'est passé après avoir partagé/utilisé les informations que vous avez trouvées sur le site de N&G ?

- *Exemples*:
  - Vous êtes mieux en mesure de faire face à un problème,
  - Vous êtes moins ou plus inquiet / inquiète à propos de quelque chose,
  - Il y a eu un changement dans la relation avec quelqu'un (amélioration ou aggravation)

INFORMATIONS SOCIO-DÉMOGRAPHIQUES

Scolarité complétée :

☐ Aucun diplôme
☐ Diplôme d’études secondaires
☐ Diplôme d’une école de métier
☐ Diplôme collégial
☐ Certificat
☐ Baccalauréat
☐ Diplôme universitaire supérieur au baccalauréat

Occupation actuelle : ______________________________

Revenu familial annuel (somme totale des revenus disponibles pour la famille avant impôts) :

☐ 0 à moins de 10 000 $
☐ 10 000 $ à moins de 20 000 $
☐ 20 000 $ — à moins de 30 000 $
☐ 30 000 $ — à moins de 40 000 $
☐ 40 000 $ — à moins de 50 000 $
☐ 50 000 $ — à moins de 60 000 $
☐ Plus de 60 000 $
☐ Je préfère ne pas répondre

COMMENTAIRES

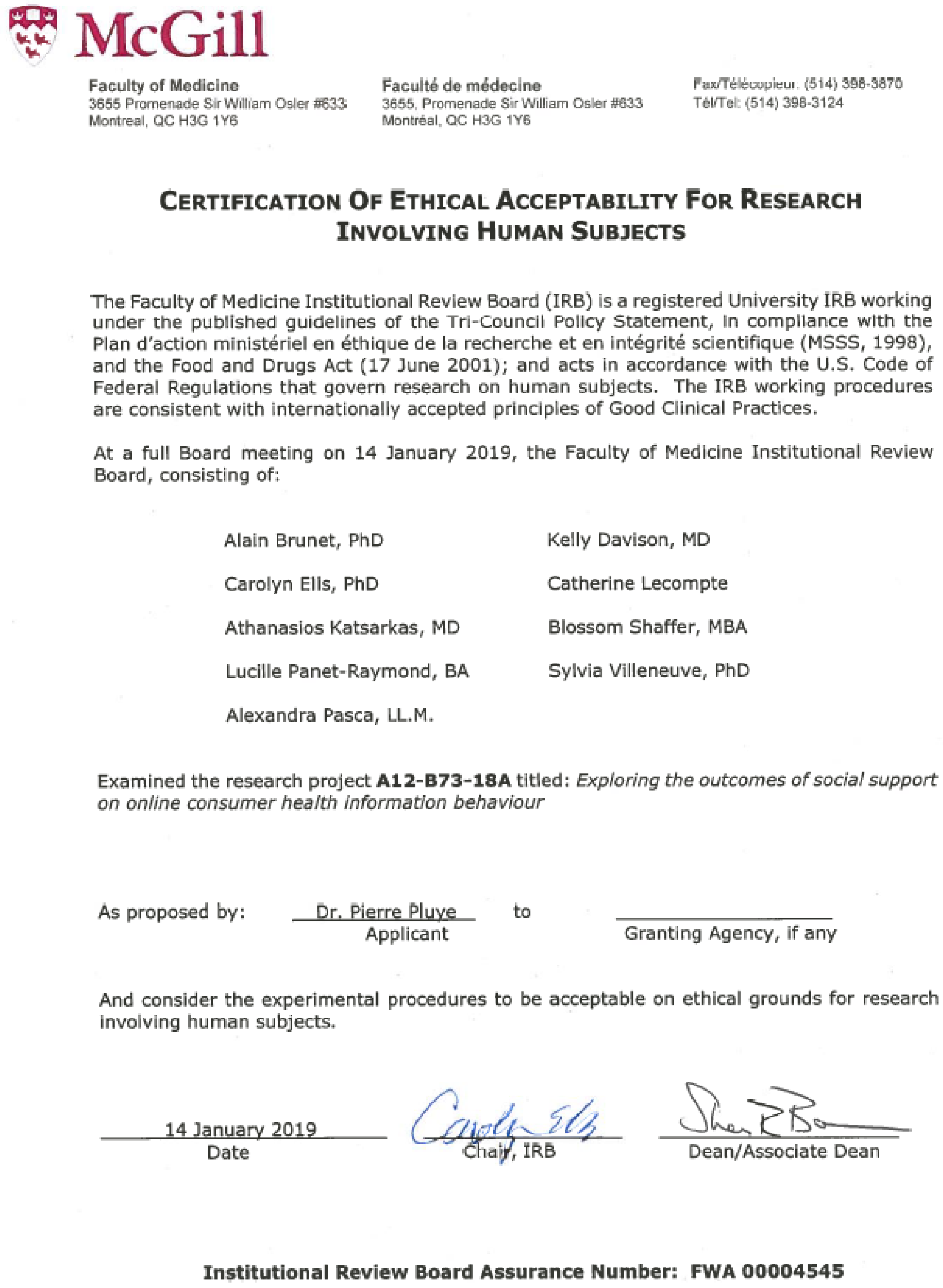
J’ai maintenant terminé de poser toutes les questions que j’avais préparées. De votre côté, avez-vous des choses à ajouter sur ce dont nous avons discuté durant l’entrevue? Avez-vous des commentaires ou des suggestions sur l’étude? Sur le site Internet *Naître et grandir*? Sur le questionnaire/formulaire d’évaluation des informations ?

Finalement, par curiosité, pouvez-vous me dire ce qui vous a motivé à compléter le questionnaire d’évaluation de N&G ?

REMERCIEMENTS

Je vous remercie encore une fois d’avoir participé à cette entrevue. Les informations que vous nous avez fournies aideront à améliorer le site *Naître et grandir*.

Appendix 4. Manuscripts 2 and 3: Ethics Certificates and Consent Forms



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CERTIFICATION OF ETHICAL ACCEPTABILITY FOR RESEARCH INVOLVING HUMAN SUBJECTS

The Faculty of Medicine Institutional Review Board (IRB) is a registered University IRB working under the published guidelines of the Tri-Council Policy Statement, in compliance with the Plan d'action ministériel en éthique de la recherche et en intégrité scientifique (MSSS, 1998), and the Food and Drugs Act (17 June 2001); and acts in accordance with the U.S. Code of Federal Regulations that govern research on human subjects. The IRB working procedures are consistent with internationally accepted principles of Good Clinical Practices.

At a full Board meeting on 14 January 2019, the Faculty of Medicine Institutional Review Board, consisting of:

Alain Brunet, PhD
Carolyn Ells, PhD
Athanasios Katsarkas, MD
Lucille Panet-Raymond, BA
Alexandra Pasca, LL.M.

Kelly Davison, MD
Catherine Lecompte
Blossom Shaffer, MBA
Sylvia Villeneuve, PhD

Examined the research project **A12-B73-18A** titled: *Exploring the outcomes of social support on online consumer health information behaviour*

As proposed by: Dr. Pierre Pluye (Applicant) to ____________________ (Granting Agency, if any)

And consider the experimental procedures to be acceptable on ethical grounds for research involving human subjects.

14 January 2019
Date

Chair, IRB

Dean/Associate Dean

Institutional Review Board Assurance Number: FWA 00004545

Formulaire de consentement Étude

Comment les gens utilisent-ils les informations de santé des consommateurs en ligne avec d'autres, et quels sont les résultats?

Chercheur principal:
Reem El Sherif, PhD Candidate,
Département de médecine familiale, Université McGill
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(514) 632-3616

Superviseur:
Pierre Pluye MD PhD, professeur titulaire
Département de médecine familiale, Université McGill
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(514) 398-8483

BUT GÉNÉRAL DE LA RECHERCHE

Les objectifs de ce projet sont de mieux comprendre comment les gens partagent leurs informations sur la santé avec les autres membres de leur cercle social, quels en sont les résultats et les caractéristiques du soutien social les plus associées à des résultats positifs ou négatifs.

INTRODUCTION

Naître et grandir (N&G) est entre autres un site Internet qui s'adresse aux parents de jeunes enfants. N&G est financé par la « Fondation Lucie et André Chagnon », une organisation de bienfaisance à but non lucratif qui veut prévenir la pauvreté. N&G offre aux parents des informations gratuites, indépendantes, fiables et validées scientifiquement pour les soutenir dans leur rôle parental.

Un formulaire, *Méthode d'Évaluation des Informations* (MEI), disponible sur chaque page d'information permet aux parents d'évaluer l'information qu'ils trouvent sur le site Internet N&G (http://Naître etgrandir.com) et qu'ils reçoivent par courriel (Infolettre N&G). La MEI permet de recueillir l'évaluation des parents sur la pertinence, l'utilisation et les effets associés aux informations disponibles sur le site N&G.

PROCÉDURE(S)

Vous participerez à une entrevue individuelle d'environ une (1) heure. La date et l'heure de l'entrevue seront convenues avec vous. Durant l'entrevue, un chercheur ou une chercheure de notre équipe vous posera des questions sur votre expérience en tant qu'utilisatrice du site N&G. Vous vous êtes identifié en tant que membre de l'entourage d'un parent. Nous explorerons pourquoi et comment vous avez cherché N & G et ce que vous avez fait avec les informations que vous avez trouvées. L'entrevue sera enregistrée, puis transcrite à l'ordinateur sans qu'il soit possible de vous identifier.

CONFIDENTIALITÉ

Les informations que vous nous donnerez resteront confidentielles. Les résultats de l'étude pourront être publiés ou communiqués lors de présentations, mais aucune information pouvant vous identifier ne sera dévoilée. Les enregistrements, leur transcription, ainsi que les formulaires de consentement seront conservées sur ordinateur dans un dossier protégé par un mot de passe. Seuls les membres de notre équipe de recherche y auront accès. Ces documents confidentiels seront détruits sept (7) ans après la fin de l'étude.

PARTICIPATION VOLONTAIRE

Votre participation à ce projet est totalement volontaire. Vous pouvez décider de ne pas participer ou de vous retirer de l'étude à n'importe quel moment sans aucune conséquence.

AVANTAGES et RISQUES

Votre participation nous aidera à mieux comprendre l'utilisation du contenu du site Web de N&G et de l'MEI par l'entourage. Il y a peu ou pas de risque à participer à cette étude. Le personnel de recherche de notre équipe remplacera votre nom avec un pseudonyme et retirera toute information susceptible de vous identifier dans vos réponses aux questions de l'entrevue.

COMPENSATION FINANCIÈRE

Vous recevrez une compensation de 50 $ pour votre participation à cette étude lors d'une entrevue téléphonique.

DES QUESTIONS SUR LE PROJET OU SUR VOS DROITS ?

Vous pouvez contacter les responsables du projet par courriel ou téléphone si vous avez des questions additionnelles sur le projet (reem.elsherif@mail.mcgill.ca, (514) 632-3616 ou pierre.pluye@mcgill.ca, (514) 398-8483). L'étude à laquelle vous participerez a été approuvée par le Bureau de l'éthique en recherche de l'Université McGill (514-398-3124).

REMERCIEMENTS

Nous sommes très reconnaissants de votre participation à notre étude et nous tenons à vous en remercier.

POUR UNE ENTREVUE TÉLÉPHONIQUE

Si vous acceptez de participer à cette étude en étant contacté pour un entretien, veuillez répondre à ce courriel avec la déclaration suivante.

«J'ai lu les informations ci-dessus et j'accepte d'être interviewé pour cette étude. Mon consentement verbal sera donné et enregistré sur cassette au début de l'entretien téléphonique.»

Le chercheur vous enverra ensuite un courriel pour connaître votre disponibilité pour l'interview téléphonique.

Une discussion sur le consentement aura lieu au début de l'entretien téléphonique et votre consentement verbal sera enregistré.

Appendix 5. Manuscript 3: Qualitative study codebook

In this table I present the codebook with codes derived from the qualitative analysis of the transcripts and an illustrative excerpt for each code.

Code	Excerpt
1. Individual characteristics	
Entourage role	
Aunt or uncle	“My nephew, it's a relationship... Ah, my dear, we could talk to you about that for hours. We love him so much, this little guy. It's a special relationship.” - Alisson
Child educator	“Actually, most of the information I use is mostly for my families of ASD children.” - Alice
Grandchildren	“I have two children, and each has a grandchild. I have a six-year-old grandson and a one-and-a-half-year-old grandson. That's my close circle, and I still have my parents.” - Joelle
HCP	“I'm a nurse. I work in early childhood. I've always worked in the childcare setting.” -Norma
Sister	“I have a little brother who is eight years old and a little sister and two other little brothers. My siblings are the main reason I like Naître et grandir, but also because I babysit and it helped me a lot to know how to take care of kids,” - Mathilde
Internet Use	“Internet per day, you can put in an hour and a half or two hours, but it depends on the day,” - Alisson
Device use	“Sometimes I like my laptop better because it's bigger, so often I feel like I can do better research on it than my phone because it's smaller. I feel like, and this is really in my head, that I would have more options on my computer, which is bigger, and it would be easier to find certain information than on my phone. My phone, it's just going to be quick little things.” - Sarah
OHI sources	“Since I have a degree in health sciences, when I need very, very specific information, I go to PubMed. Otherwise, I go to the website of the College of Dietitians and Nutritionists, which is my professional order, in terms of nutrition. Otherwise, I go to Google, and I look on Doctissimo.” -Nathalie
Social circle	“I live in a big generational house with my son's family. I'm in this situation because I lost my spouse [recently]… and I have another son who lives a little further away from here, who also has children.” -Nathalie
2. Reasons for searching	

Code	Excerpt
Caregiving	“I think it's directed more for the toddlers. But in relation to my own toddlers that I get, very regularly. Basically, as I say, it allows... I have an example here. I had concerns with a little coconut, and my first springboard for concerns was to share an article from Naître et grandir.” -Florence
Curiosity	“Like to understand how things work in these children's brains, and sometimes there are those who say... At one point, a teacher told me: "I think that what is taught in math in Grade 2 is too hot for the development of the child's brain. "That sent me to go... I'm curious. I'll read about it, then one case leads to another all the time. There are questions that come with that. How does it work, memorization? How does it work, mathematics?” - Alisson
Explicit request	“Actually, it was to reassure a friend about the COVID vaccination, the interval between the vaccine received during pregnancy and the COVID vaccine. I sent her a screenshot of the article to reassure her that it was correct.” - Norma
To be reassured	“I was clearly overwhelmed by the situation. It was one of the few times that it was pretty clear that I was overwhelmed by the situation. The calls to the family didn't inform me well enough, in my opinion, about the situation, which was still pretty sharp and pretty specific, so I went looking for very specific information on a specialized and credible site that I knew and came straight to it.” - Mark
3. OHI seeking behaviour	
Information needs	“Either a particular issue, let's say I want to know... He's sick, he has something, he has a fever, I can look around, related to that. Or a particular event, like my grandson who experienced bereavement, I tried to read about it and understand what it meant for a child. It's also about the development of children, developmental charts.” - Joelle
OHI assessment	“There's a bit of intuition, there's a bit of experience. I have a little trouble believing anything too. There's a lot of quackery on the Internet, and I'm wary of sites that aren't officially licensed.” -Mary
Other information sources	“The first place I would go would be the book... because I have a lot of books too. I read a lot, so the internet is not my only source of information. During [my daughter-in-law’s] pregnancy and since the baby was born, I've been buying books about children.” -Nadia
Searching strategies	“I look for the name, for example, of a disease that I think he might have. That's it. If he has an injury, I search for "injury", "how to", I don't know, "how to put a bandage on properly".” -Mathilde
4. Cognitive impact	
Confirmation of what I knew	“Usually, it helps me confirm that I was on the right track…” -Mary

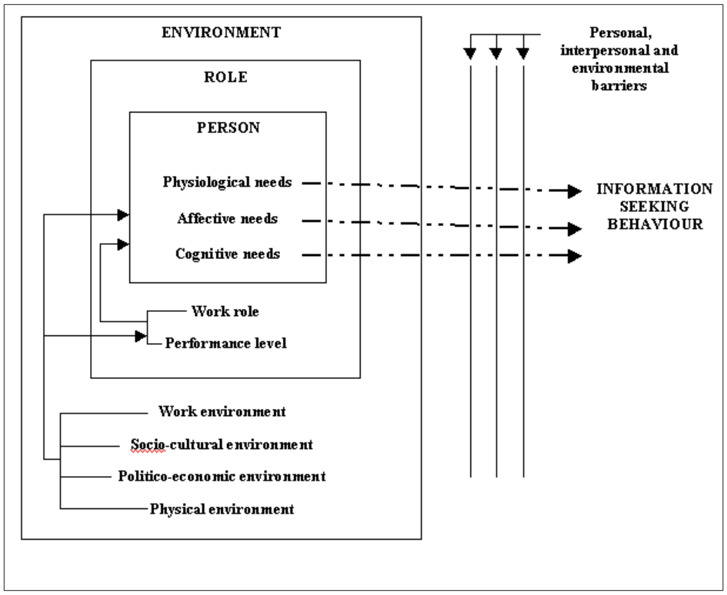
Code	**Excerpt**
Learn something new	“Basically, yes, to pass on information to the mother, and then I realized that the vaccination schedule had changed...” - Florence
Personal satisfaction	“A personal satisfaction of knowledge. The more things you know, the more satisfied you are. We have contentment, in fact. For me, it has... in terms of personal satisfaction.” -Sophie
5. OHI use	
Did not share with someone	"I don't want to give them the impression that I'm watching how they are. I find that everyone gives so much advice when you're a parent. Everyone has their idea of what's best and what not to do and all that, so I try to gauge that, not put too much on it. It's more that I keep it in mind for if they ever bring it up or something like that.” -Nadia (grandmother)
Doing something	“It helped me to be able to guide my brother in his learning at school, to know how to help him more, what I should do.” -Mathilde
Shared with someone else	“I shared that information first with my son and his girlfriend. I sent them the link. There are things that I photocopied and showed to my son.” -Joelle
To discuss with HCPs	“I am lucky enough to work with professionals in speech therapy, special education, and psychology, so at work it's fun to have a credible second opinion, to confirm or specially to refute.” -Mark
To discuss with others	“I usually print the page out or email it to the parents to read. It depends. Sometimes they read more when it's paper because I email it and it gets lost with all the other emails. But I give, and afterwards, at my meeting after: "What did you understand? Did you get a chance to read it? Do we read it together?" and so on.” -Alice
To make decisions	“I'm going to go back and read it again to confirm, actually, that the approach that I want to implement is really in line with the information that I've had, because I wouldn't want to go on and just like stay within my capabilities and it's like just motivated me, but not really being applied.” -Mark
To provide emotional support	“It was more with my son that I talked about it, but really, him, it wasn't so much about where I found the information as it was about discussing the grief.” -Joelle
6. Outcomes of use	
Improved relationships	“Yes. In the relationship, it's clearer when we talk. They already know what we're talking about, how, and they know.” -Alice
Less worried	“Not necessarily, but it reassured me. Going to see that information really reassured me. I was kind of full of questions and stuff and I wasn't sure about everything, so I was like, "Okay. At the same time, I don't necessarily want to call a doctor and ask him a little bit... probably bother him for nothing. "When I saw that, I was like, "Okay, that's good. Okay, that explains some things. "It put some answers to my questions, and I was better with myself after reading that and I felt much better.” -Sarah

Code	Excerpt
More confident in decision-making	“Yes, it gives me more confidence that I'm doing it the right way and that it's okay to do it, let's say. I guess it gives me more confidence in how I'm intervening with her.” -Nadia
Tension	“I have to be careful because she didn't take it very well. She, she thought I was doubting her... I was curious, and at the same time I told her about it, but she wasn't too keen on me telling her about it after all. "You don't mind your own business, old girl.””- Alisson
7. COVID	
Less access to entourage	“If I look at past years, we would see each other almost every week, I would go for a little walk, but that hasn't been the case since March 2020.” -Nathalie
Not relevant	“I don't believe in this pandemic. I don't believe in it at all. No, I think it's a big scam and there's a specific purpose that we're going to know and that we've started to know with the restrictions. I think that's what it is, actually, so I try to have as normal a life as possible. With the people around me, I'm happy because we share a lot of... I would say, 99%, we share the same ideas. I would say that 99% of the people around me share the same ideas in the sense that it's a big scam, so we try to live as normal a life as possible, which normally makes me forget. Sometimes I forget that I have to put on a mask, I forget the restrictions that they put on us.” -Sophie
8. Feelings about N&G	
Newsletter	“It was my daughter who subscribed me, who told me about N&G. I was really interested in having the information to follow up on the development of my grandchildren.” -Sophie
Reasons for completing IAM	“I fill it out a lot. Let's say I'm reading a topic, at some point there's a place where there's a little tab that opens up, "What did you think of this article? Would you be willing to be contacted? "And I fill that out on a regular basis.” - Joelle
9. General comments	
Other forms of social support	“It gives them a chance, while we are on the phone or on Zoom with my granddaughter, while Mario is sleeping, mom and dad are able to do something else. It gives them a little breathing space too.” -Sophie
Parenting philosophies	“I've also noticed that over time, whatever games we have for our kids, the simplest games are cardboard boxes, plastic bowls, glasses and spoons. No matter how much money we spend on toys, I would often say it's useless. That's okay, it's notable. My daughter-in-law is in the recovery mode, so she buys everything, everything, everything second hand. Whether it's toys or clothes, everything is second hand. It's very, very rare.” -Mary

Appendix 6. Relevant Models of OHI Seeking Behaviour

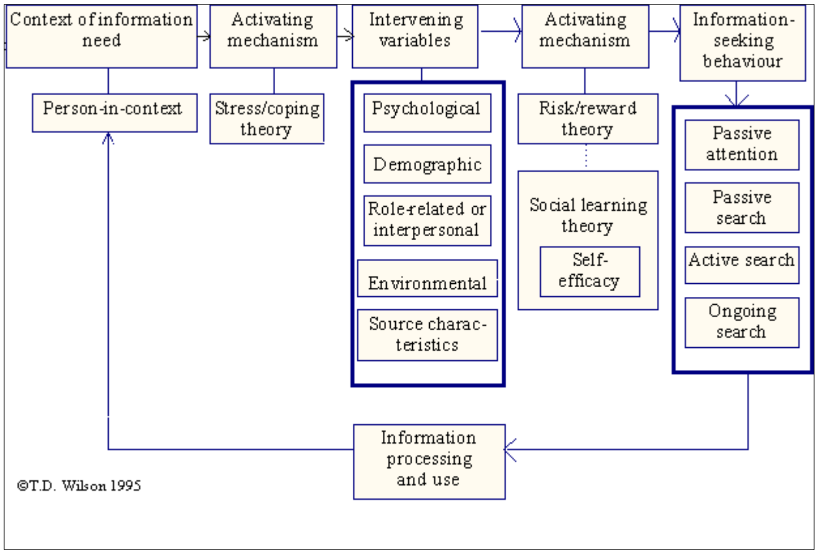
In this Appendix I present the figures for the Models referenced in the Discussion section.

Figure 30. Wilson's 1981 model of information-seeking behaviour



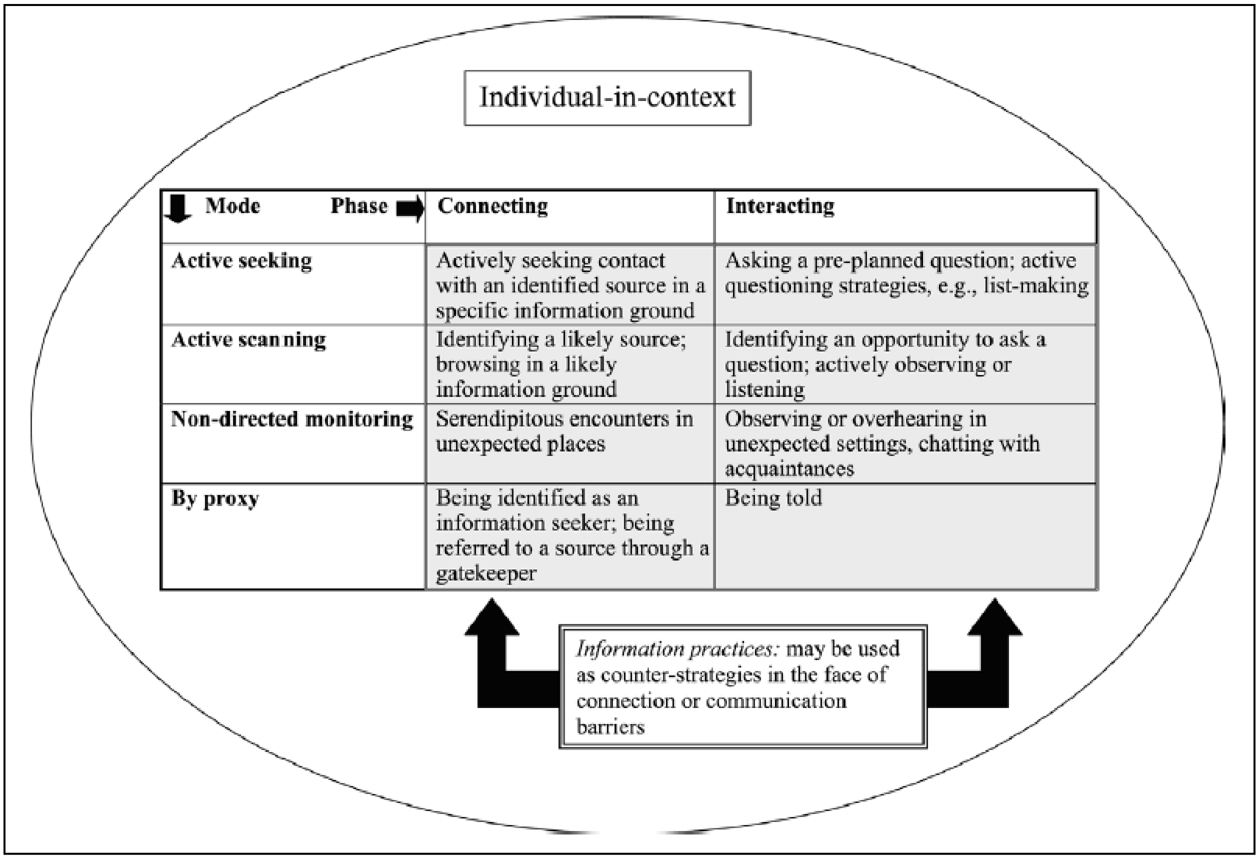
Source: Wilson TD. On user studies and information needs. Journal of documentation. 1981;37(1):3-15.

Figure 31. Wilson's 1996 model of information behaviour



Source: Wilson TD. Information behaviour: an interdisciplinary perspective. Information processing & management. 1997;33(4):551-72.

Figure 32: Two-dimensional model of information practices



Mode / Phase	Connecting	Interacting
Active seeking	Actively seeking contact with an identified source in a specific information ground	Asking a pre-planned question; active questioning strategies, e.g., list-making
Active scanning	Identifying a likely source; browsing in a likely information ground	Identifying an opportunity to ask a question; actively observing or listening
Non-directed monitoring	Serendipitous encounters in unexpected places	Observing or overhearing in unexpected settings, chatting with acquaintances
By proxy	Being identified as an information seeker; being referred to a source through a gatekeeper	Being told

Information practices: may be used as counter-strategies in the face of connection or communication barriers

Source: McKenzie PJ. A model of information practices in accounts of everyday-life information seeking. Journal of documentation. 2003.