

**DEVELOPMENT AND EVALUATION OF A SOCIAL
MEDIA-BASED SUPPORT GROUP FOR CAREGIVERS
OF CHILDREN AND YOUTH WITH COMPLEX CARE
NEEDS IN NEW BRUNSWICK**

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ABSTRACT

Children and youth with complex care needs (CCN) are those with multidimensional health and social care needs who may or may not possess a diagnosis of a recognized condition. Caregivers of children and youth with CCN require timely access to services and resources to ensure the well-being of their families. Online peer-to-peer (P2P) support groups provide an accessible and innovative means of connecting and supporting caregivers and families. Caregivers of children and youth with CCN possess invaluable lived experiences and knowledge around available and effective services and programs; connecting these families together through online P2P support can promote information sharing in a safe and private online environment. Despite widespread use of Facebook groups across various patient and caregiver populations, it is unclear how caregivers of children and youth with CCN use and potentially benefit from these groups. The purpose of this study was to explore the use of a geographic-specific Facebook-based P2P support group by caregivers of children and youth with CCN and its impact on caregivers' perceived knowledge of health services and/or resources and sense of community belonging.

The dissertation is presented in five manuscripts. The first manuscript provides a review of the similarities and differences between patient navigators and case managers; this paper contributed to the development of this research topic by providing insight into the health services navigational support needs of individuals with complex care needs and their caregivers. The second manuscript consists of an environmental scan of Facebook-based P2P support groups that target caregivers of children with youth with CCN in New Brunswick. The third manuscript outlines the development,

implementation, and preliminary findings of a Facebook group, developed for the purposes of this research. The fourth manuscript presents the findings on the use of the Facebook P2P support group by caregivers of children and youth with CCN in NB. The fifth manuscript reports on the experiences and perceived impact of participation in the Facebook group on caregivers' knowledge of programs and services, and sense of community belonging. The dissertation concludes with a summary of the research findings and recommendations for interdisciplinary practice, research, and education.

DEDICATION

To Branden, Emma, Tommy, Alex, and my parents: Dr. Jim and Anne Thompson.

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List of Symbols, Nomenclature or Abbreviations

CCN	complex care needs
CM	case manager
SM	social media
PEI	Prince Edward Island
PFAC	patient and family advisory council
PN	patient navigator
P2P	peer-to-peer
NB	New Brunswick

Introduction

The topic of my dissertation is online peer-to-peer (P2P) support for caregivers of children and youth with complex care needs (CCN) in New Brunswick (NB). The approach for this thesis consists of a papers-based option accepted by the School of Graduate Studies at the University of New Brunswick. The material included in this thesis format is similar to the traditional doctoral thesis; however, the chapters in a papers-based thesis (e.g., literature review, research findings) are written as stand-alone manuscripts that are targeted to specific peer-reviewed journals for publication. The format for a papers-based thesis generally includes an introductory chapter, two-to-three publishable manuscripts that each address a unique objective or question, and a concluding chapter (Morris & Tipples, 1998). Together, these papers form an integrated set of independent projects that have been outlined in the proposal (University of Alberta, 2015). The seven chapters of my dissertation will be presented in the following order: introduction, five publishable manuscripts, and a conclusion.

This doctoral research aims to develop, implement, and evaluate a P2P support group for caregivers of children and youth with CCN in NB using the Facebook social media platform. The current chapter discusses the background and objectives of this research; specifically, the objectives and research questions for the current doctoral research, followed by a detailed review of the literature. The context for this research, including a description of the physical setting and online intervention is then provided. Finally, this chapter concludes by positioning this research in the wider body of interdisciplinary literature and a description of how each chapter (i.e., papers accepted/submitted for publication) contributes to the overall dissertation.

Background and Significance of Research

Children and youth with CCN are those with multidimensional health and social care needs, who may or may not possess a diagnosis of a recognized condition (Brenner et al., 2018a). Children and youth with CCN present across diverse settings, requiring services from multiple care providers, which can result in significant physical, mental, and emotional pressures on caregivers. Caregivers of children and youth with CCN (e.g., parents, guardians, extended family members, etc) face numerous challenges and barriers, such as difficulties accessing needed services and resources and unmet information needs (Roche & Skinner, 2009). The types of barriers typically experienced by caregivers of children and youth with CCN are managing (1) health providers and services; (2) health coverage when uninsured; (3) treatment options; and (4) care received by multiple providers (Sofaer, 2009). Other obstacles faced by patients include communication barriers, lack of information from health care providers, and emotional challenges, such as mistrust of system providers (Pratt-Chapman & Willis, 2013). Caregivers of children and youth with CCN require timely access to services and resources to ensure the well-being of their families (Roche & Skinner, 2009). Accessing this support can be challenging for families that encounter barriers, such as limited availability of primary care services and financial constraints.

Virtual peer-to-peer (P2P) support groups, defined as online communities of individuals with common lived experiences (Naslund et al., 2016), provide an accessible and innovative means of connecting and supporting persons with health-related concerns (Yli-Uotila et al., 2014). Online P2P support has been shown to provide users with valuable informational, emotional, and tangible support (Oh et al., 2013; Rains & Wright, 2016; Zhao & Zhang, 2017), and allows users to receive timely support without

leaving their homes (Cole et al., 2017). Traditionally offered as face-to-face support, online P2P support can result in high quality support messages akin to those offered in person (Rains et al., 2019), due to its focus on the content of the messages in an environment free of in person social pressures (Lim et al., 2011). Moreover, some parents and guardians of children and youth with CCN are beginning to prefer engaging in peer support online rather than in-person (Doty et al., 2016). Finally, some caregivers of children and youth with CCN who participate in online P2P support consider the experience to be more relevant to their needs than information provided by their professional care providers (Niela-Vilen et al., 2014), perhaps owing to an environment consisting of individuals with shared common experiences. Leveraging existing social media platforms where patients and caregivers gather virtually can foster an environment specific to the exchange of social support between caregivers of children and youth with CCN. Social media offers an opportunity to build capacity and better support caregivers through computer-mediated communication for social support (Rains & Wright, 2016); specifically, social media-based peer-to-peer (P2P) support.

Caregivers of children and youth with CCN possess invaluable lived experiences and knowledge around available and effective services and programs; connecting these families together through online P2P support has the potential to promote information sharing in a safe and private online environment (Giustini et al., 2018). Previous research examining how families of children and youth with CCN use social media for social support has suggested that geographic-specific support groups might be especially beneficial in facilitating the exchange of informational and emotional support (Ammari et al., 2014). Facebook, in particular, has been identified as an important gathering place for patients and caregivers to engage in health-related P2P support (Farmer et al., 2009;

Kraut & Fiore, 2014), including families of children and youth with CCN (Ammari et al., 2014). Leveraging this online platform to explore the use of P2P support groups by caregivers of children and youth with CCN can provide important insight into the culture of online information sharing and emotional support and how it can benefit and meet the needs of caregivers.

Objective of the Study

The use of social media for health-related communication has been well documented in the literature over the past three decades (Giustini et al., 2018; Grajales et al., 2014; Moorhead et al., 2013). Despite growing evidence on the beneficial role that social media websites and applications can have in meeting the support needs of patients and caregivers (Moorhead et al., 2013), there has been minimal research exploring the use of these platforms by caregivers of children and youth with CCN. It also remains unclear how these online support communities might impact knowledge of geographically specific services and resources and affect feelings of isolation among caregivers. These gaps in the research literature are a critical oversight, given the significant immediate and long-term informational and emotional needs associated with caring for a child or youth with CCN. Understanding how this population uses social media to engage in online P2P support can provide insight into innovative, cost-effective solutions for connecting patients and caregivers with health and social services and resources to better meet their needs.

The objective of this research is to generate knowledge on the use of social media for health-related communication and support between caregivers of children and youth with CCN. An online, social media group was developed for the purposes of this research to examine the influence of P2P support on knowledge of health-related

services and resources and sense of community belonging among caregivers of children and youth with CCN. Using an exploratory, qualitative descriptive design, this research aimed to 1) develop a geographic-specific P2P support group using the Facebook social media platform to facilitate the exchange of support between caregivers of children and youth with CCN; 2) explore the impact of P2P communications on knowledge of available services and resources, and sense of community belonging; and 3) evaluate the factors that contribute to the group's activity levels and membership. The following research questions formed the basis for the current study:

1. How is the Facebook-based, NB-specific P2P support group used by caregivers of children and youth with CCN to exchange support?
2. Why do caregivers of children and youth with CCN use the Facebook-based P2P support group?
3. What are the experiences of caregivers of children and youth with CCN who use the Facebook group to communicate with other group members?
4. In what ways does participating in the Facebook group affect NB caregivers of children and youth with CCNs' knowledge of services or resources?
5. In what ways does participating in the Facebook group provide caregivers of children and youth with CCN with a sense of community belonging?
6. What factors contribute to the sustained activity level(s) of the Facebook group for caregivers of children and youth with CCN in NB?

Review of the literature

Caregivers of children and youth with CCN require substantial informational knowledge and emotional support to become advocates for their child's care (Dehoff et al., 2016). Increasingly, the Internet has become an important resource for individuals

with health-related concerns to find information and exchange support. Social media, in particular, has become a gathering place to find like-minded individuals with similar experiences. The proceeding section discusses the background literature that led to the development of the current doctoral research. This section begins with a description of children and youth with CCN and their caregivers, followed by discussion on the use of the Internet for seeking information and connecting with peers in the context of social media. Empirical evidence on the benefits of social media for P2P support is then presented, with a specific emphasis on health-related knowledge and sense of community belonging. Finally, the risks and barriers associated with use of social media for P2P support is provided.

Children and Youth with CCN and their Caregivers

Children and youth with complex care needs (CCN) are those with “multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis” (Brenner et al., 2018b, p.3223). They represent a vulnerable population that is served across diverse health and social settings, including (but not limited to): medical care; specialist care (e.g., physical, occupational, or speech therapies); mental health services; and educational services (Newacheck & Kim, 2005). These children and youth often require services from multiple care providers (Luke, Doucet & Azar, 2018), which can result in significant physical, mental, and emotional pressures on caregivers. Approximately 15% of children and youth live with a chronic condition affecting their every day life (Strickland et al., 2015). They face a range of health concerns, including: non-chronic, acute conditions (e.g., pneumonia, trauma); episodic chronic conditions (e.g., asthma, depression, anxiety); lifelong chronic conditions (e.g., Type I diabetes, congenital heart disease); progressive or life-limiting

conditions (e.g., cystic fibrosis; cerebral palsy; Down Syndrome); and malignancies requiring treatment (e.g., Leukemia, tumours) (Children's Hospital Association, 2021). This diversity in the severity and prognosis of the conditions associated with CCN is attributed to the highly individual and contextualized needs of this population (Brenner et al., 2018b). The exact incidence and prevalence rate of children and youth with CCN is not well understood due, in part, to ambiguity in the terms used to define this population (Carnevale et al., 2008), such as medical complexities (Dewan & Cohen, 2013), special needs (Newacheck & Kim, 2005); and medical fragility (Curran et al., 2020).

Despite representing a small subset of the population, children and youth with CCN utilize a significant amount of health services (Malone, 1995). While pressure on the resources needed to provide adequate care for these individuals is challenging the sustainability and effectiveness of the Canadian healthcare system, it also affects the well-being of these persons and their informal caregivers. However, the reliance on health and social services by these patients is in part due to insufficient access to primary care, fragmentation of care, and a lack of continuity of care across health care providers and agencies that support other aspects of the determinants of health, such as housing and employment (Gauvin et al, 2014; Kodner, 2009; Malone, 1995; Rich et al, 2012).

Informal caregivers of children and youth with CCN (e.g., parents, other family members, etc) often take on multiple roles related to the care of their child, including 24/7 medical care to ensure their well-being and survival (Kirk et al., 2005; Woodgate et al., 2015). These caregivers often carry the burden associated with lack of continuity of care and managing health system complexities, including (but not limited to): coordinating care for their child (e.g., assessments, treatments, etc) (Cady & Belew,

2017); monitoring and managing individual care plans across providers (Cady & Belew, 2017); seeking and applying for funding to support care (Sofaer, 2009); and providing routine and/or special at-home medical care to their child (e.g. post-operative care, G-tube feeding, etc) (Woodgate et al., 2015). The pressures associated with carrying out these tasks can be further compounded by work commitments, financial strain, transportation issues, and caring for other children (Pratt-Chapman & Willis, 2013). Moreover, caregivers often face a lack of knowledge about services and programs and other barriers to resources that may be relevant to their child's care (Roche & Skinner, 2009).

Online Health Information Seeking

When confronted with an unfamiliar health concern, many individuals turn to the Internet. The Internet provides a fast, anonymous, and convenient connection to a vast amount of health information unlike anywhere else. In the United States, approximately 82% of Internet users have engaged in online health information seeking (Fox, 2014), such as searching for information related to a diagnosis, course of an illness, symptoms, or treatments (Caiata-Zufferey et al., 2010). Those who engage in online health information seeking perceive more available support to meet their needs than those who do not use the Internet for this purpose (Hampton et al., 2011).

For many individuals, the Internet is a critical resource in searching for and locating services, programs, and resources; also known as self-navigation. The Canadian healthcare system consists of fragmented silos that often result in barriers to optimal healthcare delivery. This is particularly true for children and youth with CCN who, despite only representing 15-20% of the childhood population in North America (Harvey et al., 2006), utilize a substantial portion of healthcare resources (Kaufman & Pinzon,

2007; Pinzon et al., 2006). This reliance on healthcare services is in part due to insufficient access to primary care and fragmentation of care.

Self-navigation can empower patients and caregivers and provide them with confidence when interacting with the Canadian healthcare system (Jackson et al., 2019). Evidence-based tools to support self-navigation through healthcare services can take the form of ever-green web pages listing available resources, services, and programs or more detailed directories of information. For example, the *My Health MaP* virtual health directory describes itself as the only “verified, detailed directory of Canadian specialists by specialty, sub-specialties, expertise and their wait times for consultation and treatment” (Medical Confidence, 2021). These types of directories are becoming increasingly more prevalent, perhaps due to challenges associated with traditional modes of navigation due to the COVID-19 pandemic. Some provincial health authorities have also incorporated self-navigation tools into their strategy to proactively guide certain patients and caregiver populations through the maze of services and programs, such as *Alberta’s Patient Navigation Curriculum* (Watson et al., 2016).

Peer-to-Peer (P2P) Support

Peer-to-peer (P2P) support is defined as “the existence of a community of common interest where people gather (in-person or virtually) to share experiences, ask questions, and provide emotional support and self-help” (Sartore et al., 2013; Schippke et al., 2015). Peer support differs from “natural lay helpers”, who tend to be individuals in a person’s life who might provide support (Dennis, 2003; Embuldeniya et al., 2013); rather, P2P support arises from those with a shared experience (e.g., common diagnosis). There are many models of peer support, including: face-to-face one-on-one; virtual one-on-one (i.e., telephone, internet); face-to-face group; virtual group (i.e., telephone,

internet) (Hoey et al., 2008). Face-to-face support is characterized by the provision of information and emotional support, which has also been shown to be a defining feature of online support (Coulson et al., 2007).

Caregivers of children and youth with CCN require substantial informational knowledge and emotional support to become advocates for their child's care (Dehoff et al., 2016). Providing this support is a major challenge for professional care providers, who are often not able to adequately address barriers (e.g., financial, health literacy) and may not be fully aware of available services and programs. One way that patients and caregivers obtain support for unmet needs is through computer-mediated communication (CMC) with individuals in similar circumstances. CMC refers to "Internet-based technologies that make possible text-based interaction among dyads or groups" (Rains & Wright, 2016, p. 175). These online services connect caregivers with each other (i.e., "peers) through web or mobile-based platforms as a means of exchanging relevant health information (Chandhoke, 2017). Despite differences in the engagement between face-to-face P2P support and online P2P support, both modalities of support have been reported to have a significant positive impact on treatment decision-making (Huber et al., 2018).

Caregivers of children and youth with CCN possess invaluable lived experience and knowledge around available and effective services and programs; connecting these families to each other through peer support has the potential to promote information sharing in a safe and secure online environment. Patients consider these online environments and platforms to be accessible and flexible (Liaw et al., 2017), and they have been demonstrated to empower patients and their caregivers (Lettieri et al., 2015); improve care coordination (Barbabella et al., 2017); improve patient and caregiver self-

efficacy (Mo & Coulson, 2013); and decrease resource utilization (Information and Communications Technology Council, 2009).

Online P2P support offers an accessible and inexpensive source of informational knowledge and emotional support for parents (Rossman, 2007), such as caregivers of children and youth with CCN (Dietrich, 2010). Caregivers of children and youth with CCN who participate in online P2P support can acquire specific advice for their circumstance (Rains & Wright, 2016) and often consider the experience to be more relevant to their needs than information provided by their professional care providers (Niela-Vilen et al., 2014). In some cases, the information exchanged within these groups goes beyond the knowledge of care providers, particularly for conditions that may be rare, not well understood, or beyond the scope of physical health care (e.g., how to dress an infant with a feed tube) (Fox, 2013). For example, online P2P support groups have been reported to supplement information received from a care provider (Bhamrah et al., 2015; Rupert et al., 2014), as well as facilitate shared decision making between patients and caregivers, and their care provider(s) (Rupert et al., 2016) and help patients prepare for medical appointments (Seckin et al., 2016). In a 2014 survey involving parents of children with neurofibromatosis type 1 (NF1), parents indicated that they were very likely to use internet P2P groups to seek research studies (87%), talk to parents with similar diagnoses (67%), and get answers to questions (50%) (Martin et al., 2017).

Physicians are a critical source of support for patients and caregivers with medical-related questions; however, P2P support represents an important source of social support that can complement self-navigation, particularly when connected with patients and caregivers with similar lived experiences. Self-navigation, health information seeking, and P2P communication is not considered a replacement for

professional health care (Caiata-Zufferey et al., 2010); instead, turning to the Internet is often used to complement the support provided by care providers. For example, in a survey of Internet-users, participants considered care providers to be necessary for addressing technical health issues, whereas online peers were more apt to provide information relevant to coping skills or quick relief (Fox, 2011). In this sense, engaging in P2P interactions may be considered a compensation for information or support not generally provided by a healthcare professional (Caiata-Zufferey et al., 2010).

One of the strongest motivations to engage in online P2P support by individuals with health concerns is the desire to connect with other individuals in similar situations (Armstrong & Powell, 2009; Banas et al., 2017; Carter et al., 2018; Chuang & Yang, 2014; des Bordes et al., 2018; Ewing et al., 2009; Henwood et al., 2016; Highton-Williamson et al., 2015; Moorhead et al., 2013; Park et al., 2016; Rupert et al., 2014; Yli-Uotila et al., 2013). However, seeking connections with peers may not apply across all populations and disease types. In a study conducted by van der Vaart and colleagues (2013), participants with systemic sclerosis reported a higher need for online communication with peers than patients with rheumatoid arthritis; researchers explained this finding as possibly being related to the more visible symptoms that systemic sclerosis causes (e.g., deformities). Another study, focusing on adolescents and youth with inflammatory bowel syndrome, reported that participants were not interested in connecting with peers regarding their condition(s), resulting in low retention (Szeto et al., 2018). Individuals with chronic and complex conditions or those with significant caregiving demands may be most likely to seek peer connections online (Carter et al., 2018; Friedman et al., 2018), as well as individuals facing a lack of local resources or support (Yli-Uotila et al., 2013; Zhang et al., 2018). Dumaij and Tijssen (2011) reported

four characteristics that play a role in an individual's decision to use a particular website to connect with peers: (1) whether it is closed access (i.e., private); (2) nature of topics discussed; (3) ease of use; and (4) type of users and structure of discussions.

Defining Social Media in the Context of P2P Support

Social media are “web-based tools that are used for computer-mediated communication” (Grajales et al., 2014). These “web-based tools” broadly encompass websites accessed through a computer (e.g., laptop or desktop monitor) or mobile device (e.g., smartphone). Regardless of means of access (e.g., laptop or smartphone), engagement with social media requires Internet access and is therefore considered to be online communication. Social support, defined as the act of sharing resources that promote well-being (Shumaker & Brownell, 1984) is exchanged between individuals through CMC using various types of Internet-based mediums, including social media, instant messaging, and email (Grajales et al., 2014; Rains & Wright, 2016).

There are many types of social media websites. For example, blogs (e.g., WordPress) and microblogs (e.g., Twitter) allow users to share experiences in a reverse-chronological order of entries, whereas networking websites (e.g., LinkedIn and Facebook) allow users to curate their own virtual environments (Ventola, 2014). When discussing social media, it is imperative to differentiate social media from social networking; social media is broadly conceptualized as any platform that aims to deliver a particular message, whereas social networking is considered to be a type of social media that provides “two-way and direct communication between several parties” (Moorhead et al., 2013). Moreover, social networking websites can be further differentiated between general social networking sites and thematic social networking sites (Grajales et al., 2014). General social networking (e.g., Facebook) may involve P2P

support on a wide range of topics, whereas thematic social networking (e.g., Military and Veteran Caregiver Network) is usually focused on a particular subject. Thematic social networking sites can be hosted by non-profit organizations (e.g., the Canadian Cancer Society) or privately sponsored groups (e.g., PatientsLikeMe) (Gupta & Schapira, 2018).

Through advancements in technology and increased global uptake, social media has become ubiquitous across society. Many of these websites offer a convenient and simple user experience with a minimal learning curve that attracts individuals to the platform; this accessibility is often credited to the “staying power” (i.e., ability to maintain activity despite periods of stagnation) of many large-scale social media websites, such as Facebook. Meaningful and relevant user experiences, curated by these platforms, then aim to retain users over time and encourage them to return frequently (i.e., login).

Social media is characterized by mass communication using the Internet. As a result, social media is not inclusive of limited, one-to-one way communications such as SMS texting, video chat, or the telephone. Email, as a form of social communication, is more difficult to define within the context of social media, as it can involve mass communication. However, the general consensus is that email is not considered to be a form of social media, as it functions primarily as a “distribution mechanism” as opposed to a “collective mechanism” (Bradley, 2010). This collective, en masse communication feature of social media has transformed passive Internet users (e.g., information seekers) into active participants (World Medical Association, 2011).

Internet-based communication through social media facilitates social support between peers by creating an environment that connects support seekers with support providers (Rains & Wright, 2016). Social support is further fostered through the

availability of connection with individuals outside one's personal social network (Rozzell et al., 2014), with whom individuals might share more health-related commonalities and experiences. The most common types of health-related support messages exchanged on social media consist of informational, emotional, and tangible (i.e., instrumental) support (Bender et al., 2011; Farmer et al., 2009; Oh et al., 2013). These categories of support posts can be grouped into action-facilitating (i.e., informational and tangible aid) and nurturant (i.e., emotional) support (Cutrona, 1990; Rains et al., 2015). Tangible support refers to the physical provision of support, whether financial, material, or service related. Action-facilitating support consists of problem solving and instrumental aid messages, whereas nurturant support consists of messages of reassurance, acceptance, and encouragement (Buis, 2008). The most common types of emotional support messages include encouragement themes, where the most common informational support messages are usually medication and treatment-related themes (Pan et al., 2020, p. 112). Tangible support is the most uncommon type of support found in online P2P support groups (Embuldeniya et al., 2013; Mo & Coulson, 2013), and in some cases, not offered at all (Partridge et al., 2018). Importantly, it is not uncommon for messages requesting support to combine different types of support, such as providing an emotionally charged context while also seeking information (Donovan et al., 2014).

The type of support that patients and caregivers seek when using CMC for P2P support differs depending on individual and group-level characteristics. It has been proposed that the degree of controllability that one has on their situation determines the type of support most needed (Cutrona & Suhr, 1992); for example, those with more controllable stress may be more prone to seek action-facilitating support, whereas those with uncontrollable stress seek more emotional-based support. This phenomenon has

been termed the Optimal Matching Model and is supported with empirical evidence in the context of health-related online P2P support seeking (Pan et al., 2020, p. 114). Moreover, caregivers report changes in the type of support needed throughout the trajectory of caring for an individual with a health care need. Specifically, caregivers report a need for practical information in the early stages of a diagnosis, eventually becoming more interested in the experiences of other caregivers once becoming more familiar with the disease/condition (Partridge et al., 2017; Sillence et al., 2016). One study reported that caregivers may eventually find themselves as needing care themselves, due to emotional and physical strain associated with caring for another person, leading to a shift in identity and support needs (Sillence et al., 2016).

Overall, informational and emotional support messages are most common in health-related support groups (Rains et al., 2015). Emotional-type support has been observed to be more common among patient support groups experiencing end-of-life stages and potentially terminal diseases (Rains et al., 2015), such as cancer (Buis & Whitten, 2011), hospice (Buis, 2008), and HIV/AIDS communities (Dahl, 2006). Studies comprised of patients managing chronic diseases (Rains et al., 2015) and caregivers have largely found informational support to be most common (Rupert et al., 2016), such as in forums targeting: parents of children with special needs (Ammari et al., 2014; Cole et al., 2017; S. Park et al., 2016); individuals diagnosed with Cushing's syndrome and Addison disease (Kauw et al., 2015); and caregivers of adults with Alzheimer's disease (Scharett et al., 2017). In one study, members of a social media depression support group in China described the online community as their primary source of information for their condition (Zhang et al., 2018). Caregivers of wounded veterans also view online P2P support groups primarily as a source of information

(Vaughan et al., 2018). Adults with various chronic conditions have reported valuing P2P support on social media as an alternative source of information regarding their specific condition, rather than a source for emotional support (Rupert et al., 2016).

The nature of support requested and provided on P2P support groups depends on the target audience of the particular discussion group. In a study focused on caregivers of patients living with Alzheimer's disease, Scharett and colleagues (2017) observed that the majority of responses to inquiries from caregivers (45.56%) referred to patient well-being. Individuals with arthritis, however, have been observed to seek information related to their medications and potential side effects, as well as disease progression and lifestyle habits (des Bordes et al., 2018). Differences in information needs have also been observed within mental health; specifically, individuals with depression appear to post more messages detailing self-expressed experiences, whereas individuals living with anxiety and post-traumatic stress disorder seek information related to treatment and medication (Park et al., 2018). For example, in a support group for persons with arthritis, researchers noted that many information-based messages containing advice did not consider potential safety issues (e.g., adverse interactions between medications and/or dosages) (Gasteiger et al., 2018); however, individuals receiving these types of messages report evaluating information and advice received from peers using their own personal knowledge gained from years of lived experience (Armstrong & Powell, 2009). Therefore, despite the presence of misinformation in some health-related support groups, individuals do report using critical insight to parse through information received.

The needs of members in P2P support groups have also been observed to change as patients and caregivers transition between various stages of their diagnosis or health condition. In a study examining the support needs of parents of children with chronic

health needs (Pinsk & Nicholas, 2017), parents described an evolution of needs that began with information seeking (following the initial diagnosis), to seeking parental interactions and support, to advocacy. This transition in P2P support needs was also observed in a forum dedicated to individuals living with alcohol abuse related issues (Chuang & Yang, 2014). In this study, researchers noted that members primarily joined the group for information seeking purposes but remained active in the group after gathering needed information due to the relationships that they formed with other members. In another study describing P2P support on social media for breast cancer survivors, Moon and colleagues (2017) noted that messages posted by survivors contained more emotional and informational support than in those who had been recently diagnosed.

Informal P2P support groups are largely based on experiential knowledge from members rather than formal training (Embuldeniya et al., 2013). As a result, posts often involve the sharing of personal experiences through narratives designed to provide updates on personal health or caregiving experiences (Park et al., 2018; Stock et al., 2018), or to share experiences with self-management techniques (des Bordes et al., 2018). These narratives are presented in many ways on social media, whether through written messages (Park et al., 2018; Salzmann-Erikson & Hiadurmaz, 2017) or video blogs (known as “vlogs”) (Carter et al., 2018; Huh et al., 2014). Diefenbeck and colleagues (2017) describe this “storytelling” experience for caregivers of adults with chronic conditions as involving a range of topics, from minor daily events to significant life events. These patient and caregiver experiences provide a lived experience and valuable “actionable advice” to peers facing similar diagnoses or situations (Hartzler &

Pratt, 2011; Mustafa et al., 2015). Importantly, these shared experiences are often intermixed with requests for support (Mustafa et al., 2015; von Rohr, 2015).

Participation in P2P support groups on social media vary between users, with two particular types of users that often appear on these discussion boards: “superusers” (Joglekar et al., 2018) and “lurkers” (Griffiths et al., 2017; McKay et al., 2002). Joglekar and colleagues (2018) describe superusers as individuals who frequently and consistently engage in an online community and play a central role to the sustained activity of the group; they have also been referred to as discussion leaders (Wandrey et al., 2016). Research has shown that when superusers are gradually removed from an active group, the network will begin to collapse. It is possible that contact with peers is particularly reinforcing for these superusers (McKay et al., 2002). Superusers facilitate the spread of information across a group and act as resources to members in need, gradually becoming “experts” in their particular domain. Alternatively, lurkers were individuals who only observed activity, such as by reading messages (McKay et al., 2002), and were considered to be passive participants (Setoyama et al., 2009). Individuals who interact with online communities typically report a great sense of social connectedness with other members and receiving more useful support from the community (Mo & Coulson, 2013). Research regarding lurkers is less clear; some findings suggest that lurkers do not receive needed support (Mo & Coulson, 2010), where other studies found that lurkers can benefit from passively interacting (i.e., reading) with support messages in groups (Ballantine & Stephenson, 2011).

Facebook and P2P support

Social media websites offer multiple means of P2P support, whether unilaterally through digital media sharing (e.g., YouTube) or via two-way communication (e.g.,

Facebook). Today, there are an overwhelming number of social media websites and applications (apps) available at no cost to the general public. Despite the prevalence of websites and apps, Facebook, YouTube, and Twitter are consistently considered to be among the most popular social media websites in the United States (Smith & Anderson, 2018) and Canada (Sherpa Marketing, 2018). As a result, these websites have become natural gathering places for individuals to informally engage with one another. Not surprisingly, Facebook, YouTube, and Twitter are also the most popular websites for health-related P2P support (Giustini et al., 2018).

Studies examining online P2P support groups have noted the wide-spread use of Facebook for health-related communication among different types of patients and caregiver populations (Farmer et al., 2009; Grajales et al., 2014; Meng et al., 2017; Naslund et al., 2016; Oh et al., 2013). Facebook is among the most popular social networking website in the world (Hutt, 2017), particularly in Canada (UFCW, 2017), where 19.6 million users registered on the website in 2018 (Statista, 2018). As of 2010, Facebook was the 4th most popular website for searching information related to health in the United Kingdom (Dawson, 2010), with nearly 2.7 billion active monthly users across the world (Statista, 2020). Available as a browser and mobile application, Facebook allows users to curate their own virtual communities through connections with other profiles and customize visibility to users (Facebook, 2019). Users can create and join discussion groups, with varying levels of privacy from non-members. Caregivers of children and youth with CCN report using the social networking website for personal connections and indicate that it is useful to them (Dehoff et al., 2016). These communities are not meant to replace professional health care (Caiata-Zufferey et al., 2010); however, they do provide a number of important benefits to patients and their

families. As an example, Facebook has been reported as the primary choice to find information and social support by parents of children with special needs (Ammari et al., 2014) and women interested in cancer-prevention (Wright et al., 2019).

Online P2P support, such as those offered through Facebook groups, can connect individuals across large geographic distances. The ability to connect with peers across the world has led to the development of numerous health-related Facebook support groups targeting individuals with health concerns from across the globe (Farmer et al., 2009). One disadvantage to these large- scale, international support groups is the inability of members to provide geographic-specific advice when a member expresses a need for particular services or resources. Caregivers of children and youth with CCN often require substantial support from services and care providers across multiple local settings (Luke et al., 2018), which can result in unmet informational needs that are context specific (Roche & Skinner, 2009). In an exploratory study with 18 families of children with special needs who use social media for P2P support (Ammari et al., 2014), 89% of parents reported using Facebook for geographically based groups as well as case-based groups (i.e., groups targeted to individuals with a specific diagnosis/condition). Geographically based groups (i.e., geographically local to study participants) were used by participants primarily for navigational support and information related to relevant services, programs, and resources. These parents reported a preference for connecting with other parents of children with special needs who live in their geographic area (Ammari et al., 2014); a finding that has been previously reported (Scharer, 2005).

Benefits of Social Media-Based P2P Support

Extensive research has identified a causal link between social support and positive health outcomes over the past 35 years (Uchino, 2006); however, it is important to note that perceived support is considered to be more impactful than actual support on well-being and health outcomes (Cutrona, 1990; McDowell & Serovich, 2007). In other words, for P2P support to impact the well-being and health of patients and caregivers, it must be perceived positively by the recipient; support that is perceived negatively may cause more harm (Wright et al., 2013). When reaching out for support on social media, individuals report messages that demonstrate caring and empathy to be most supportive, followed by those with credible information (e.g., deriving from a health care professional) (Egbert & Bosley, 2020). In contrast, posts considered to be unsupportive are those containing judgement related to personal philosophies, non-conventional medical choices, and sensitive or politically charged topics (Ammari et al., 2014). Lawlor and Kirakowski (2014) propose that benefits of online P2P support groups may arise from a positive attitude towards online groups themselves, resulting in more active participation; in other words, it is the attitude of members that predict perceived benefits (Chung, 2013).

Rains and Young (2009) describe the link between perceived support and subsequent benefits in the context of self-management and self-efficacy. When an individual receives support that directly impacts their perception of a stressor, they are more likely to approach future stressors with the knowledge that these issues can be managed by reaching out to their support group; in other words, stressors become more manageable with the backing of a support group than when that resource does not exist. These findings support evidence for the Buffering Effect Model in the context of online social

support (Rains & Wright, 2016), which suggests that social support can buffer or mitigate against the negative effects of stress (Cohen & Willis, 1985).

The type of social support presented to a receiver is also posited to impact potential benefits. Thoits (2011) argues that action facilitating (i.e., tangible) and emotional support, which she terms active coping assistance and emotional sustenance, respectively, further interact with situational circumstances (i.e., everyday support versus support after a stressful event). Specifically, social support becomes more visible and less reciprocal during particularly stressful times, whereas support is less visible and more reciprocal in everyday support situations. Thoits (2011) further suggests that the source of support impacts how it is perceived. For example, significant others (e.g., spouses, partners) are able to provide better emotional and tangible support than “similar others” (e.g., peers), but are less equipped to provide sufficient informational support. In contrast, “similar others” are better apt to provide informational support due to similar lived experiences. Taken together, this framework suggests the importance of considering factors of stress and the role of significant others versus similar others in providing support.

With regards to online P2P support, many benefits have been identified in relation to using social media for health-related support. Perhaps most importantly, connecting individuals facing similar health concerns can provide an opportunity for the provision and reception of tailored informational and emotional support (Diefenbeck et al., 2017; Partridge et al., 2018; Shavazi et al., 2016); this is achieved through the sharing of personal experiences with others (Henwood et al., 2016; Moorhead et al., 2013), expression of frustrations (Diefenbeck et al., 2017), and inquiries about one’s own care or the care of a family member (Scharett et al., 2017). The relationships formed through

online interactions can result in feelings of community and solidarity (Horter et al., 2014) and improve well-being (Liu & Yu, 2013; Oh et al., 2014). Parents of children and youth with CCN can benefit from P2P support by sharing a common lived experience and receiving timely information and emotional support (Niela-Vilen et al., 2014; Shilling et al., 2013). Recognition of the impact of these groups for facilitating social support was the result of a survey of American adults nearly a decade ago; individuals who used Facebook for health-related P2P support perceived there to be more support available than those who did not use the platform for this purpose (Hampton et al., 2011).

In-person parent-to-parent support has been shown to decrease psychological distress, enhance coping skills, and increase self-efficacy towards problem-solving in parents of children and youth with CCN (Bray et al., 2017; Santelli et al., 1997). Other benefits of offline parent-to-parent support include increased knowledge of services and resources; increased acceptance of care needs; enhanced coping skills; increased self-efficacy, and access to support that may be unavailable from other sources (Santelli et al., 1997). Patients and informal caregivers who participate in online P2P support consider the experience to be more relevant to their needs than information provided by their professional care providers (Niela-Vilen et al., 2014).

Online support can increase feelings of control, reduce isolation, and lower depression and anxiety, and increase self-efficacy to manage one's health (Rains & Young, 2009; Wright et al., 2012); these benefits have been noted among caregivers of children and youth with CCN (Dehoff et al., 2016). Moreover, online support allows those living with a rare disease or in stigmatized conditions to benefit from online discussions with peers (Martin et al., 2017). In a meta-analysis of 31 content analyses,

Yeshua-Katz and colleagues (2019) examined the association between dimensions of stigma and types of online social support messages. The researchers found that physical stigma was associated with more emotional support, whereas concealable stigma was associated with more action-facilitating (i.e., information, network, and tangible) support.

Although the majority of studies on the benefits of P2P support via social media focus on social networking websites, benefits have also been observed on media sharing websites, such as YouTube. In a study examining the benefits of “vlogging” (video blogging) by individuals with self-identified severe mental illnesses, Sangeorzan and colleagues (2019) concluded that the creation and posting of these videos may facilitate recovery by enhancing self-efficacy, encouraging P2P support, and reducing stigma. The unique experience of vlogging can also lead to a sense of community belonging among participating members that may be stronger than text-based websites alone (Huh et al., 2014).

Virtually attending P2P support allows for connections with peers on the family’s own time (Dehoff et al., 2016; Hinton et al., 2010; Malik & Coulson, 2008) and improves access despite geographical isolation (Niela-Vilen et al., 2014). This is particularly relevant for caregivers of children and youth with CCN, who may not have the time or physical resources to attend in-person support or may be living in rural or isolated regions. The ability to connect with peers across the world has led to the development of numerous health-related Facebook support groups that aim to provide informational and emotional support to individuals in similar situations (Farmer et al., 2009).

In a review on the benefits of social media for health communication, Moorhead and colleagues (2013) identified six potential benefits: (1) increased interactions with others; (2) more available, shared, and tailored information; (3) increased accessibility and widening access to health information; (4) peer/social/emotional support; (5) public health surveillance; and (6) potential to influence health policy (p.2). Identified variables that may predict positive outcomes may include the extent to which members actively approach their emotions (Batenburg & Das, 2014a, 2014b) and frequency of participation in groups (Klemm et al., 2014). Participation in online support groups may be particularly beneficial to those at the early stages of a specific condition, during which information seeking is particularly relevant (Magnezi et al., 2014).

Ziebland and Wyke (2012) identified seven domains through which participation in online P2P support groups may benefit users: finding information; feeling supported; maintaining relationships with others; affecting behaviour; experiencing health services; learning to tell a story; and visualizing disease. However, the evidence to support whether engagement in P2P support groups on social media results in these benefits is not clear. Blogging has been reported as a useful intervention to promote adherence in Drug-Resistant Tuberculosis patients (Horter et al., 2014) and to encourage better control of glycemic levels in patients with diabetes (Litchman et al., 2018); however, blogging was not shown to have an effect on duration of breastfeeding in mothers of preterm infants (Niela-Vilén et al., 2016).

There is evidence that P2P support can lead to disease self-management, through a process of learning practical information, experiencing personal growth, as well as supporting others (Shilling et al., 2013). These benefits have been found to be comparable between face-to-face and online P2P groups (Hoey et al., 2008). Although

web-based P2P support on social media appears to result in some benefits related to the information and emotional support messages exchanged on posts, other researchers have posited that online support may need to be supplemented by in-person P2P support for some populations, such as caregivers (Vaughan et al., 2018). Online support, specifically, can increase feelings of control, reduce isolation, and lower depression and anxiety in patients and their caregivers (de Jongh et al., 2012; Dehoff et al., 2016). For example, in a study on Internet support for women with breast cancer (Winzelberg et al., 2003), researchers showed empirical evidence for the psychological benefit of online P2P support groups. Despite these observed benefits, there is a need for more evidence-based research on online P2P support groups (Moorhead et al., 2013; Schippke et al., 2015). Whether P2P support on social media is sufficient to provide the necessary support for all patients and caregivers to self-advocate and become independent from additional emotional support resources needs more research.

Health-Related Knowledge

Health literacy is typically defined as an individual's ability to read and understand health information (Powers et al., 2010); however, the term has evolved to comprise a more comprehensive skill set (Raynor, 2012). Today, health literacy is defined as a "cognitive and social skill that determines the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health" (Harris et al., 2015; Nutbeam, 2008). Health literacy is relevant to the current research as low levels of health literacy is associated with one's knowledge of services and has been identified as a barrier to navigating the healthcare system (Loignon et al., 2018). Health literacy is negatively associated with health inequalities, which are impacted by a person's living and material circumstances, as well as socioeconomic

status (Harris et al., 2015). Low health literacy has been consistently associated with increased hospitalizations; greater reliance on the healthcare system; misuse of medication or treatments; poor health status; and high mortality rates (Berkman et al., 2011). Low health literacy can be particularly problematic when interacting with professional care providers, who often assume a higher level of understanding than a patient might possess (Nielsen-Bohlman et al., 2004).

To improve health literacy, individuals often need information explained in multiple ways (Doak et al., 1996) and the opportunity to interact with health information across diverse settings (Gillis, 2009). The online world, including P2P support, offers an opportunity for individuals to engage with health information in a variety of ways, which can result in the improvement of health literacy (Levin-Zamir & Bertschi, 2018). For example, online P2P support can promote access to information (Kaal et al., 2018) and improve knowledge about a particular condition (Rupert et al., 2016). Social media use is positively related to health literacy, particularly health-related knowledge (Rosenbaum et al., 2018). Thus, P2P support may have a particularly significant impact on individuals with low health literacy levels (Fisher et al., 2015; Moskowitz et al., 2013; Piette et al., 2012).

The impact of online P2P support on health-related information has been evaluated in pregnant women experiencing pelvic girdle pain, a medically unexplained condition referring to pain at the front and/or back of the pelvis that can also affect the hips or thighs (Fredericksen et al., 2016). Participants rated the information received from peers as more valuable than advice from health care providers. The participation in these online P2P support groups led to increases in health-related knowledge and competencies, health promotion activities, and system navigation. This knowledge

gained through online communities can lead patients and caregivers to feeling more equipped to converse with their health care provider(s) (Holbrey & Coulson, 2013). Peer support has the potential to reduce health inequalities and improve health literacy by eliciting a change in the perception of social status (Harris et al., 2015); social media offers a virtual environment devoid of traditional social hierarchies, possibly explaining increases in health literacy due to the exchange of P2P support.

Although health literacy is often attributed to text-based understanding and readability level, visual website design can impact understanding of content (Egbert & Nanna, 2009). For the online world to positively affect health literacy, it must be accessible, easy to navigate, and clear (Egbert & Nanna, 2009). Many web-related features are barriers to content understanding, including format/design, accessibility, graphics, organization, content, audience engagement, and audience sensitivity (Egbert & Reed, 2015). These barriers can be mitigated through simple and accessible design, on both websites and applications, to optimize the success of eHealth interventions to improve health literacy. For example, use of an established and regularly enhanced social media platform for health-related communication, such as Facebook, can reduce potential barriers to content navigation and understanding.

Despite positive associations between P2P support and health literacy, it remains unclear whether social media-based P2P support can affect knowledge of health-related services and programs of caregivers of children and youth with CCN. There is evidence, however, that low caregiver health literacy has been linked to difficulties in navigating the healthcare system, which can result in fragmentation of care (Fields et al., 2018); this link between low health literacy and patient care has also been observed in parents/guardians caring for a child (Lee, 2014). Given the motivation of social media

giants to attract and retain users, advancements are continuously being made to the platforms to improve accessibility and the overall user experience, thus reducing potential accessibility issues associated with new websites designed for P2P communications.

Social Belonging

Belonging to a social group that is valued by contributing members can lead to a shared social identity (Thompson et al., 2019). This sense of social connectedness is an important consideration in P2P support groups that target caregivers of children and youth with CCN. Families in NB report feeling socially disconnected from resources that help them meet their child's care needs (Charlton et al., 2017), which can impact overall well-being (Thompson et al., 2017). A poor sense of community belonging has also been associated with psychological disturbances, such as suicide ideation, independent of mental illness (Thompson et al., 2019).

Social belonging is considered to be one of seven domains for well-being, which also includes: health; employment; finances; life skills; housing; and sociocultural environment (Thompson et al., 2017). According to Thompson and colleagues (2017), these seven domains have a bidirectional causal relationship, meaning that determinants from each domain influence overall well-being across all other domains. In other words, good functioning in one domain (i.e., social belonging) can positively influence overall well-being across the remaining six domains. Previous research has shown that online P2P support groups can influence feelings of connectedness among caregivers of older adults (Anderson & Emmerton, 2016; Colvin et al., 2003); however, the effects of online P2P support on social belonging among caregivers of children and youth with CCN is limited (Shilling et al., 2013).

Risks and Barriers Associated with Social Media-Based P2P Support

A number of potential risks and barriers have been identified with online P2P support forums (Schippke et al., 2015). Individuals who participate in online P2P support forums report concerns related to lack of confidentiality and privacy (des Bordes et al., 2018; Moorhead et al., 2013; Woolford et al., 2013; Y. Zhang, 2012). However, it has been suggested that the ability to share experiences and find validation through online P2P interactions are perceived to outweigh risks around privacy, negativity, and potentially low-quality information (Dumaij & Tijssen, 2011). Reaching out to others online requires a certain level of candidness and honesty that can sometimes prompt negative support; messages perceived by the receiver as being negative or unsupportive is known to lead to poorer overall mental health (McCloskey et al., 2015). Despite the risks associated with sharing personal stories and issues online, parents of children and youth with CCN have reported fewer instances of judgement within Facebook support groups than in offline interactions (Ammari et al., 2014).

Among the most salient of these concerns is the reliability of information posted on P2P groups (Moorhead et al., 2013; Stock et al., 2018) and members' ability to appraise relevant information (Park et al., 2016). This concern may not be as important in groups that primarily exchange emotional support, rather than informational support, as these groups appear to exchange fewer posts related to medical information, which garner inappropriate information related to diagnoses, treatments, and medications (van Uden-Kraan et al., 2008). Moreover, research analyzing content in casual information seeking environments, such as online P2P groups, has shown to self-correct over time, as individuals visiting the group validate or correct the posted information (Esquivel et al., 2006). Wikipedia, a social media database curated by its users, has even been shown

to be comparable in accuracy to Encyclopedia Britannica, likely owing to this internal self-correcting that occurs (Giles, 2005). Moderators can reduce this risk by stopping the spread of misinformation and enforcing membership rules (Ancker et al., 2009; Esquivel et al., 2006; Green et al., 2007). Moderators facilitate and encourage active discussion while ensuring that posts follow posted rules and remain on topic (Sowles et al., 2018).

An important concern with the use of online health-related interventions involves barriers to Internet accessibility, particularly among low-socioeconomic and vulnerable populations (Love et al., 2016). However, improved public accessibility of the Internet and lower costs associated with home-based Internet broadband and Internet-enabled devices has led to a rise in accessibility in recent years (Rideout & Katz, 2016). In 2018, approximately 86% of Canadians had access to the Internet at home and 52% reported having five or more Internet-connected devices (e.g., laptop, mobile phone, tablet, etc.) (CIRA: The Canadian Internet Registration Authority, 2018). Although laptop and desktop computers are used most frequently by Canadians to access the Internet, mobile devices with Internet access are becoming increasingly more popular (CIRA: The Canadian Internet Registration Authority, 2018). The majority (90%) of individuals with home-based Internet access report using the Internet (Sherpa Marketing, 2018), with nearly three quarters spending 3-4 hours online each day; from this number, 61% of Canadian users engaged on social media websites, with Facebook leading in popularity (77%) (CIRA: The Canadian Internet Registration Authority, 2018).

A challenge sometimes associated with P2P support on social media is the organization of information within groups. The chronological presentation of posts (i.e., messages become archived by newer posts) can result in difficulty finding information, which may become lost over time (Kemp et al., 2018; Stock et al., 2018). However, this

temporal aspect to discussion forums results in a process of archiving threads (i.e., posts) that are no longer considered relevant and maintaining current, up-to-date content (Park et al., 2016). The asynchronous nature of online P2P support groups is sometimes considered to be a disadvantage of online support, particularly small groups (Griffiths et al., 2017); however, active groups tend to result in responses to posts within a reasonable amount of time (van Uden-Kraan et al., 2008).

The success of online support groups relies on the recruitment and retention of members, which can be a significant barrier to P2P support. In a study examining the uptake of a P2P support intervention on MXit (popular social networking platform in South Africa) for youth infected with HIV (Henwood et al., 2016), researchers reported a significant decline in the number of regular users despite positive feedback. Users identified three main reasons for the low retention rates: (1) preference for other social media platforms with additional components, (2) loss of password or phone (mobile application), and (3) lack of consistent activity by other users. The intervention in this study did not allow users to view chat histories or posts submitted by other users; this was identified as a significant reason that many members stopped using the website for P2P communication, suggesting that the ability to view the collective discussion of members is an attractive and critical component to P2P support (Ewing et al., 2009). Although users in this study reported leaving due to a lack of activity, other studies have noted that large numbers are not necessarily correlated to greater success of a group; only a small number of active users are needed to ensure the sustainability of some online support communities (Griffiths et al., 2017). A facilitating factor to the curation and success of these smaller online support communities is privacy, or the restriction of content visibility to non-members.

Privacy

One issue with social networking websites is that there is an illusion of privacy when it comes to the content that one shares (McKee, 2013). Although users can often limit content visibility to other users (e.g., sharing only to one's 'friends'), this information is only as secure as the website itself. Moreover, misunderstandings or changes in privacy standards may result in a user believing that their profile is only visible to connected friends, when in fact it may be publicly accessible. This concern is particularly salient in the context of the patient and care provider relationship. For example, personal use of social networking websites may result in patients posting information on their profile that they might not share with a care provider; searching for, or viewing, this information could violate the patient-provider relationship (Lehavot et al., 2012). The World Medical Association (2011) recommends that professionals maintain appropriate patient boundaries online and understand the privacy provisions of social media websites; but these distinctions can be difficult to maintain in practice.

A number of strategies have been developed to protect the privacy of individuals with health concerns and their caregivers who post in online P2P groups. For example, two studies discuss screening members upon entry to the group (Stock et al., 2018; Woolford et al., 2013). Stock and colleagues (2018) report that members prefer when groups are limited in some capacity to maximize the relevance of threads within the group. In a study of adolescents with weight issues and their parents (Woolford et al., 2013), participants agreed that Facebook groups should be set to "secret" privacy, which prevents the group from appearing in the general search engine. To join the group, existing members had to add new members. Membership also reported the necessity of posted rules to encourage positive participation and discussion, and the importance of

enforcing these rules. Some studies have reported negative posts consisting of inappropriate language or terminology (Stock et al., 2018), however these types of messages appear to be limited (van Uden-Kraan et al., 2008).

Another way that privacy has been protected within some online P2P support groups is through anonymous user accounts. While several successful P2P support groups exist on platforms that display personal information of members (e.g., full names and location) (Stock et al., 2018; Woolford et al., 2013), studies show that peer support is possible through public and anonymous forums (Halonen, 2012). This element of anonymity can result in creation of a safe online space where individuals with health care needs and their caregivers can freely share sensitive information (Jaworska, 2018; Miller, 2006).

Facebook Groups

Facebook provides a variety of features to users, one of which is groups. Groups are online gatherings intended to facilitate shared interests between people. As of May 2018, 1.4 billion people used Facebook groups each month; this is more than half of its entire user base (Facebook, 2018). The popularity of Facebook groups compared to other social media websites that offer a similar feature (e.g., LinkedIn, Reddit, WhatsApp) is largely credited to its user friendly design, functionality, and pre-existing “buy-in” by individuals who use social media to communicate (Holmes, 2018). Motivation to use Facebook groups has been attributed to socialization (e.g., peer support and belonging to a community); entertainment; self-status seeking (e.g., to develop one’s career); and information seeking (e.g., on products, services, or health) (Park et al., 2009). The most common uses of groups are to maintain associations with an organization (e.g., team or club) and to keep in touch with family and friends,

respectively (Kraut & Fiore, 2014). Facebook groups are a feature within the website/application that provide an opportunity to compartmentalize personal and support needs. For example, Facebook users are able to curate a profile visible to a wider social network of friends and family, while simultaneously being members of multiple Facebook groups, the content of which may not be visible to their different networks. Maintaining a sense of one's personal identity while building personal relationships and obtaining support is an important aspect of Facebook and other similar social networking websites (Gibson & Hanson, 2013).

The *groups* feature was first launched on Facebook in October 2010 during a major overhaul to the website (Dag, 2020). This primitive version of groups resembled traditional online discussion boards and content was publicly accessible to anyone with a Facebook account; administrators were limited to modifications of the title, description, and multimedia files (see Figure 1). These features were expanded during another major overhaul to the platform nearly a decade later in 2019 during the release of FB5. This version of Facebook highlighted a user experience that went from a primarily open discussion format to more private communities. Group administrators and moderators had access to many new tools to tailor an experience that fit the needs of their curated communities of members (see Figure 2). This new group experience incorporated small updates throughout the decade (e.g., the restriction of group and content visibility and the addition of membership screening questions) and allowed administrators to designate a group *type* (i.e., topic, such as “parenting” or “education”) and monitor membership engagement. Groups now offer a dynamic experience with the ability to organize and track educational content, engage in synchronous discussions through in-app video

conferencing software (i.e., Portal and Messenger), and facilitate mentorship relationships between members.

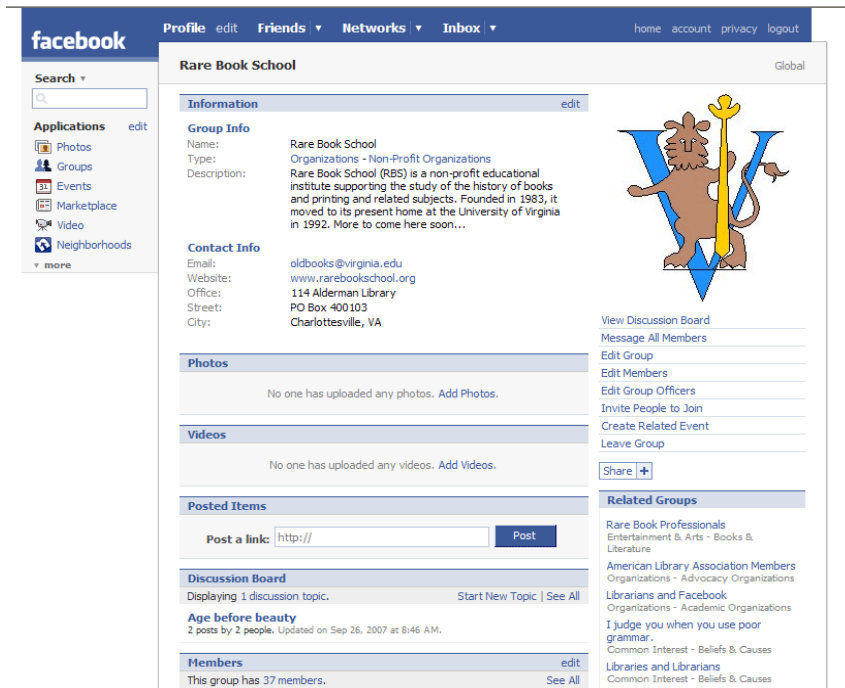


Figure 1. Screenshot of the groups feature in 2006

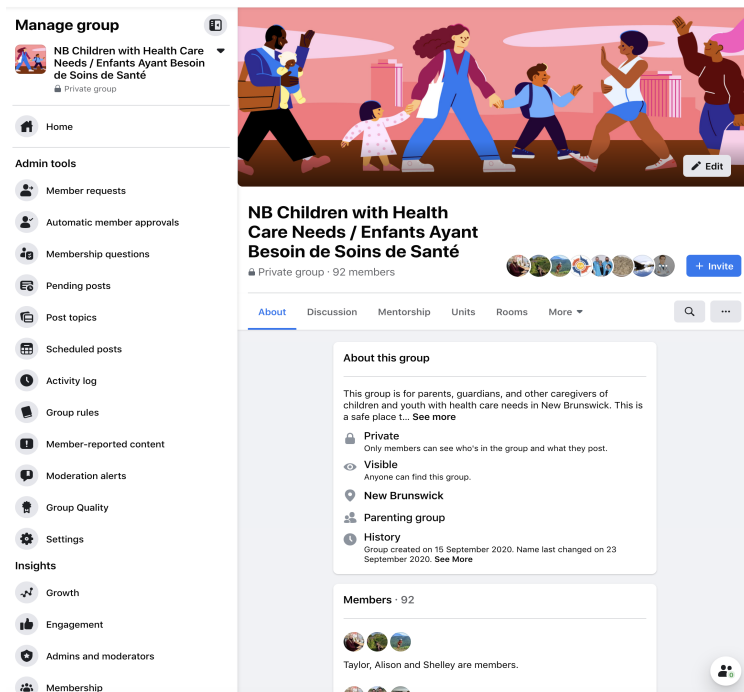


Figure 2. Screenshot of the groups feature in 2021

Maximizing the Success of Facebook Groups for P2P Support

According to internal data from Facebook, approximately 100,000 new groups are created every day; less than half of these groups (43%), however, survive past the first three months (Kraut & Fiore, 2014). The overall success of a group is defined by, and relies on, members contributing to and interacting with content (Kraut & Resnick, 2012). Many variables are associated with the survival of these groups, including group and user-level variables (Kraut & Fiore, 2014) and the level of trust among members (Iyer et al., 2020; Ma et al., 2019).

In a large-scale study conducted by Kraut and Fiore (2014), 472, 231 English-language Facebook groups created over eight days were monitored for a period of three months to better understand the factors that inhibit and promote long term success of groups. Data obtained from Facebook's server logs were used to evaluate group-level variables (e.g., membership size, privacy designation, etc) and variables related to the founders of these groups (e.g., number of friends, visits to the group, etc). In the vast majority of these groups (91%), the founder was the only administrator and moderator; however, researchers found that groups with more than one administrator were 25% more likely to survive than groups with only one administrator.

Initial decisions made by founders of Facebook groups had a direct impact on whether the group was likely to succeed. For example, groups were 36% more likely to survive to three months if they had a cover photo, description, and logo, than if it had none of these. Moreover, groups with founders who posted frequently in the early days of the group's creation were 19% more likely to survive, which is believed to model content publication and encourage engagement with new members (Booth, 2012). Further analysis into this phenomenon revealed that the association between founder-

produced content during the first week of a group's existence and membership-produced content was 0.40, indicating a strong positive correlation. Similarly, groups with founders who frequently visited the group to post and interact with content were 57% more likely to survive. Iyer and colleagues (2020) suggest that trust is established through a cycle by which the contribution of members increases trust and encourages others within the group to contribute.

For a group to survive long term, members must become engaged and willing to produce their own content. This occurs through likes and comments, which are a form of direct communication between members in groups (Ellison et al., 2014; Ma et al., 2019), as well as making posts (i.e., writing, multimedia, or other content published on a social media website). Group membership size and policy are known contributors to intragroup trust; specifically, trust decreases with group size and increases with privacy restriction (La Macchia et al., 2016; Moser et al., 2017). In a study that surveyed 10,000 individuals who used Facebook groups in the United States (Ma et al., 2019), researchers found that group size was the most significant predictor of trust; larger groups, over 150 members, were viewed as less trustworthy than smaller groups. Similarly, public groups were less trusted than private and secret groups, with no difference between the latter two categories. This may be a result of in-group exclusivity, allowing members to develop a shared identity (Moser et al., 2017).

Facebook groups are created by an administrator who is then able to designate other members as discussion moderators and administrators. The presence of administrators and moderators has been identified as an important variable in membership retention and user engagement of P2P support groups (Biagiante et al., 2018). Moderators can be professional individuals (Burns et al., 2009) or informal users

designated with the responsibility (Sowles et al., 2018). Generally, moderators are considered to be a positive addition by group members (Huh et al., 2016). The number of administrators in a Facebook group is positively associated with trust among members, whereby a great number of administrators can lead to increased trust among members (Iyer et al., 2020). Taken together, these findings suggest that ensuring the success of Facebook groups, such as a P2P support group, requires careful consideration and monitoring throughout the development and first few months after implementation.

Context

The present doctoral research aimed to develop a P2P support group on the Facebook platform for caregivers of children and youth with CCN. This P2P support group is limited to caregivers in the Canadian province of New Brunswick. The following section describes the context for this doctoral research, including the physical setting, target population, and rationale for this work. This section concludes with context for the online setting (i.e Facebook groups) of this research.

Setting

The setting for this doctoral research is New Brunswick, Canada. This province is bilingual (English and French) and spans a relatively dispersed (i.e., 72,908km²) geographic region. The intervention took place virtually on Facebook, which is a social networking service that launched to the public in 2006 and is available through a website and mobile application (Facebook, 2019). This website is free to use and accessible through any type of browser or internet-enabled device. More specifically, the intervention was a closed Facebook group, the content of which (e.g., discussion posts) was restricted to screened members. NaviCare/SoinsNavi, based at the University of New Brunswick Saint John, provided the physical location for this study.

Population

The increasingly widespread use of the Internet and smartphones suggests that online P2P support is a more accessible path to P2P support for low-income families, who are often not able to attend in-person support groups due to transportation and work conflicts (Swindle et al., 2014). This issue is an important consideration for NB, where the poverty rate in Saint John was almost 20% higher in 2013 than any other census metropolitan area in the country (Conference Board of Canada, 2017; Statistics Canada, 2013); yet approximately 77% of NB households had access to the Internet as of 2012 (Statistics Canada, 2012). Given recent reports on the quality and speed of Internet use in NB (CIRA: The Canadian Internet Registration Authority, 2018), it is likely that more New Brunswickers have gained access in recent years. Despite this widespread use of the Internet and social media use, few investigations have been made into the use of social media for P2P interactions by New Brunswickers.

NaviCare/SoinsNavi: A Patient Navigation Centre for Children and Youth in NB

The Facebook-based P2P support group in the current doctoral research was developed in collaboration with NaviCare/SoinsNavi, which is a patient navigation centre for children and youth with CCN in NB. The group was conceptualized as one way to explore how caregivers might use and benefit from a P2P support group as one way to maximize and optimize navigational support for this population with limited resources.

Patient navigation offers one solution for overcoming the barriers experienced by caregivers of children and youth with CCN and improving access to healthcare and reducing disparities, as well as empowering patients and caregivers to make choices regarding needed services (Krebs et al., 2013). Patient navigators engage patients and

caregivers as central members of the care team (Martinez-Donate et al., 2014) and work to educate patients and caregivers about the healthcare system, which can have an impact on patient decisions regarding treatment or services (Desimini et al., 2017).

To address the needs of children, youth, and their caregivers in New Brunswick (NB), Drs. Shelley Doucet (University of New Brunswick) and Rima Azar (Mount Allison University) launched NB's first free, bilingual patient navigation centre for children and youth with CCN in January 2017, called NaviCare/SoinsNavi. The centre is currently co-directed by two members of my supervisory committee, Drs. Shelley Doucet and Alison Luke. NaviCare/SoinsNavi's PN supports children, youth, and their families using a personalized family-centred model of care. The mission of NaviCare/SoinsNavi includes: improving access to health, social, and education services; facilitating the integration of services across levels of care and sectors; improving transition in care; promoting self-management; improving the well-being of children/youth and their families; and increasing community capacity in the care of children/youth and their families (NaviCare/SoinsNavi, 2021). Online P2P support provides an opportunity to support the goals of NaviCare/SoinsNavi by creating an opportunity for caregivers to engage with one another and exchange support.

NaviCare/SoinsNavi currently employs one patient navigator who is a registered nurse. This individual became a moderator and administrator for the Facebook P2P support group. Her role is identical to that of other moderators; to ensure that members abide by the group rules, respond to unanswered posts made by members; and approve new members. She also writes weekly discussion posts intended to prompt interaction between members and generate information that might be useful to other members.

Figure 3 represents an example of a discussion post by the patient navigator intended to stimulate activity among group members and provide information.

The screenshot shows a Facebook post from an Admin. The post text is: "Happy Monday everyone! I know a big barrier to care for children with health care needs is lack of funding for different therapies/activities/supplies/etc. I know this is something we have discussed briefly in this group, however, I am wondering if anyone has any further suggestions regarding financial support? Thanks everyone for always answering my questions and participating in the discussion!". Below the post are interaction buttons for "Like" and "Comment", and a notification that "6 comments" have been made, "Seen by 53" people. There are three replies visible. The first reply says: "We've not called yet but it's on my list to call and have a file opened under the Family Supports for Children with Disabilities program. Not sure exactly what we might or might not qualify for." The second reply, from the Author, says: "I have referred many families to this program and it is a great financial resource! Thanks for sharing and I do recommend calling to see if your family meets the eligibility requirements!". The third reply says: "I'm looking for volunteers to help me , and the new Brunswick coalition of persons with disabilities". A fourth reply says: "yes I think the children program will pay for quite a bit but they have limits like someone else said it's on a case by case bases I believe". At the bottom is a comment input field with the text "Write a comment..." and icons for emojis, photos, GIFs, and stickers.

Figure 3. Discussion prompt post made by NaviCare/SoinsNavi’s patient navigator.

Patient and Family Advisory Council

This doctoral research was developed and executed in consultation with NaviCare/SoinsNavis' Patient and Family Advisory Council (PFAC). The PFAC consists of six parents/guardians who have children and/or youth with CCN and one young adult who grew up with CCN. Consultation with the members of PFAC was vital to ensure that the intervention reflected the needs of caregivers of children and youth with CCN in NB. Specifically, a meeting was held with the PFAC in spring 2019 to discuss strategies for optimizing support to caregivers of children and youth with CCN beyond the current scope of NaviCare/SoinsNavi. The idea to curate a P2P support group led to plans to explore different types of social media websites and determine whether any province-wide groups currently existed for this population. PFAC members supported this project through regular meetings, via videoconferencing, and provided insight into recruitment and implementation. The PFAC was consulted twice during the initial development of this project and then monthly, beginning one month prior to the implementation (i.e., launch of the Facebook group). Members of the PFAC who had a Facebook account became members of the group and one member volunteered to be a group moderator; this individual has been particularly instrumental in ensuring the group's success immediately after implementation by posting content and responding to messages posted by new members.

Summary of the Literature

In summary, research supports the notion that patients and caregivers are using social media for health-related communication to exchange informational and emotional support. This online P2P support has many demonstrated benefits, but little is understood about how caregivers of children and youth with CCN might use or benefit

from a geographic-specific online environment. There is currently insufficient research on the use of social media-based P2P support among caregivers of children and youth with CCN and how engagement in these informal interactions might affect knowledge of health services and/or resources and the well-being of these individuals. Given the multidimensional needs of caregivers of children and youth with CCN in NB, an interdisciplinary approach to research is needed to explore the multifaceted complexities of this topic.

Interdisciplinary Focus

Interdisciplinary research is broadly conceptualized as the act of extracting ideas from multiple disciplines and integrating those ideas to form a more global understanding of a topic (National Academy of Sciences et al., 2005, p. 2).

Interdisciplinary study provides an opportunity to learn from multiple disciplines independently and integrate ideas across the boundaries of those disciplines to form a novel perspective (Committee on Facilitating Interdisciplinary Research & Committee on Science, Engineering, and Public Policy, 2004). Interdisciplinary research and collaboration can optimize the knowledge and skills of health professionals to address pragmatic and socially relevant issues that can benefit patients, caregivers, care providers, and the health system. To best answer the research questions of how caregivers of children and youth with CCN use and benefit from social media-based P2P support groups, an interdisciplinary approach was used. The following two sections describe the evolution of this research and how my doctoral education and collaborations with professionals across diverse fields of inquiry were integrated to develop the current project.

Background: Building the Project through Interdisciplinary Study

Prior to starting my doctoral studies, I worked as a Research Assistant for Drs. Shelley Doucet (UNB) and William Montelpare (University of Prince Edward Island) in the Strategy for Patient Oriented Research (SPOR) and the NB and PEI Primary and Integrated Healthcare Innovations (PICH) Networks. I assisted on numerous projects related to individuals with chronic and complex care needs, including a series of reviews on the uses of technology to support patients and caregivers living in rural areas of Atlantic Canada. I became knowledgeable about the siloed nature of the Canadian healthcare system, particularly for vulnerable populations, such as older adults and children and youth. I collaborated with professionals from many sectors, including researchers across diverse disciplines, policy makers, patients, caregivers, health care professionals, and those within the private industry. Through these experiences, I became increasingly interested in the influence that technology could have in reducing barriers and improving patient outcomes.

I started my PhD at the University of New Brunswick Saint John in 2017, which is the same year that NaviCare/SoinsNavi launched their patient navigation services for families of children and youth with CCN. Prior to this time, I was not aware of the concept of patient navigation; however, I immediately recognized its value in supporting patients and caregivers, particularly with regards to improving health service delivery in Canada. I conducted an independent study course on the topic of patient navigation and through this course I completed a scoping review on the roles and functions of patient navigators and case managers; terms that are often used interchangeably in the literature but serve distinctly different purposes in the healthcare system. This study, completed in partial fulfillment of my PhD coursework, spanned across multiple disciplines, including

nursing, social work, education, and policy. Moreover, it directly informed my current direction in the exploration of online social support to help address the unmet support needs of caregivers of children and youth with CCN.

After completing the review on patient navigators and case managers, I became interested in the use of online health portals to support families of children and youth with CCN in NB. The initial direction of my doctoral studies focused on the development of an online portal that would facilitate care coordination using patient navigation services, while keeping patients and caregivers as equal partners on the care team. The portal, which we termed eConnectNB, would allow all members of the care team to easily upload, organize, and access information related to a child or youth's care and work towards improved communication across the team. It was our intention that the portal, available as a mobile application and website, would have the ability to integrate with eHealth records, should they become available province wide. In developing this project, I consulted with professionals in the technology sector and those knowledgeable about ethical considerations related to the construction of a portal that would contain medical information. I discovered the importance of considering the perspectives of those who might ultimately use the portal (e.g., patients, caregivers, and care providers), particularly with regards to hesitations and resistance to its uptake and retention. It was at this time that I realized the missing piece in the research: input from patients and caregivers themselves.

I began collaborating more closely with NaviCare/SoinsNavi's Patient and Family Advisory Council (PFAC), which is composed of parents of children and youth with CCN and a young adult who experienced CCN as a child, as well as a health psychology researcher and NaviCare/SoinsNavi's patient navigator. In addition to being

parents of children and youth with CCN, and a former youth with CCN, members of the PFAC possess expertise in diverse areas, including cardiology, technological development, and medical health research; the development of my research has benefited from their diverse perspectives and backgrounds. The PFAC felt strongly about the impact that navigational services can have on families of children and youth with CCN in NB. The topic of P2P support using social media arose as a possible means to facilitate support to families beyond the services of NaviCare/SoinsNavi, due to their extensive knowledge obtained through lived experiences.

Interdisciplinary Research in the Current Project

The chapters of this dissertation drew on various perspectives, including media and communication sciences; nursing; health and social psychology; and education. Developing this project required insight into the application and use of social media, requiring knowledge of media and communication sciences, as well as insight into the application and use of social media; this line of inquiry shed light on the types of social media available, evolution of these websites and their features, and how users interact with one another. I explored various theories at the intersection of technology and psychology, including the Stress and Coping Social Support theory (Thoits, 1995), Optimal Matching Models (Cutrona, 1990), and Social Cognitive Theory (Bandura, 2002). Developing a P2P support tool led to research in user interface design and its impact on accessibility and health literacy (Egbert & Reed, 2015), which helped to inform the decision to use an existing social media website. My doctoral coursework largely consisted of independent studies that allowed me to focus on and integrate different perspectives towards the development of the current project. Specifically, my first independent study consisted of a scoping review on patient navigation (chapter 1,

published in the *International Journal of Nursing Studies*); and the second focused on components necessary for the successful uptake of eHealth tools and applications.

During my first year of doctoral studies, I took a course on interdisciplinary study where I learned the difference between interdisciplinary and multidisciplinary studies; the former referring to a synthesis of perspectives to solve a problem and the latter referring to a team of individuals with diverse expertise collaborating together (Choi & Pak, 2006). Where many of my collaborations throughout my doctoral studies as a Research Associate have consisted of multidisciplinary teams, the perspectives that I have taken from those experiences have been integrated into an interdisciplinary research project. I have been able to learn from professionals across various disciplines and apply that knowledge to the current project. For example, my supervisory committee was selected for their diverse knowledge and expertise in nursing and health sciences (Dr. Shelley Doucet), sociology (Dr. Alison Luke), and public health (Dr. William Montelpare). Their perspectives have been integral to the development and success of this doctoral research.

Format for Thesis

The approach for this thesis consists of a paper-based thesis. The material included in a paper-based thesis is similar to the traditional thesis; however, the chapters in a paper-based thesis (e.g., literature review, findings) are written as stand-alone manuscripts that are targeted to specific journals for publication. The outline for this manuscript-based thesis includes an introductory chapter, five publishable manuscripts, and a concluding chapter. The concluding chapter provides a general discussion, including the implications of the findings for interdisciplinary practice, research, policy, and education. Together, the papers form an integrated set of independent projects

(University of Alberta, 2015). Traditional dissertations are often lengthy and read only by a handful of people, while paper-based approaches are accessible to a wider audience (Thomas, 2015). The following is a description of the five publishable manuscripts in my dissertation, including how they address the research problem under study. As the first author of the five manuscripts, I played the key role in the development of the manuscripts at all stages, from conception to final approval. The first and third manuscripts have been published, the second has been accepted for publication, and the fourth and fifth manuscripts are in the process of being submitted for publication. The manuscript styles vary to meet the requirements of specific journals.

1. **Manuscript One:** Kelly, K., Doucet, S. & Luke, A. (2019). Exploring the roles, functions, and backgrounds of patient navigators and case managers: A scoping review. *International Journal of Nursing Studies*, 98, 27-47. doi: 10.1016/j.ijnurstu.2019.05.016

Patient navigators and case managers are health care workers who aim to provide individualized assistance to patients facing significant health concerns. Although these roles emerged from distinct historical need, the terms are often used interchangeably in the literature and are described to have overlapping functions. Differences in the way that these roles are conceptualized across countries has led to a lack of clarity regarding the exact functions that each offer to patients, caregivers, and the healthcare system. This paper contributed to the development of my doctoral project by providing insight regarding methods of support for patients and caregivers with complex care needs. Through this research, I became aware of virtual patient navigation services and the idea of “self-navigation”, which occurs when patients and caregivers locate services,

resources, or programs on their own. I was interested in additional ways to support caregivers of children and youth with CCN that stem from patient navigation. This line of inquiry led me down the path of virtual P2P support and, specifically, geographic-specific support groups, as a means to provide informational and navigational support to families.

2. **Manuscript Two:** Kelly, K., Doucet, S., Luke, A., Azar, R. & Montelpare, W. (accepted). Peer-to-peer support groups on Facebook for families of children with complex care needs in New Brunswick: An environmental scan. *Journal of New Brunswick Studies*.

This study consisted of an environmental scan of Facebook-based P2P support groups that target families of children and youth with CCN in New Brunswick. The scan revealed that there are many P2P support groups available to families in NB for a wide range of conditions and targeting individuals from various locations across the province. However, there were no active groups that broadly targeted caregivers of children with any complex care need from across NB. Discussion content analyzed in public P2P support groups revealed valuable information about the use of identified, condition-specific groups by caregivers in NB. Informational posts appeared the most frequently across groups, followed by emotional and inquiry-based posts. This scan also revealed variables that may contribute to the activity level of Facebook-based P2P support groups, including: use of moderators; type of discussion posts; and privacy designation of groups (e.g., public vs. private). Determining the variables that contribute to the success of online P2P support groups can provide important insights into future development of support groups for caregivers of children and youth with CCN.

3. **Manuscript Three:** Kelly, K., Luke, A., Doucet, S. (2021). Development and Implementation of a Facebook-Based Peer-to-Peer Support Group for Caregivers of Children with Complex Care Needs in New Brunswick. *Healthy Populations Journal*, 1(1), 43-54.

This paper presents the development, implementation, and preliminary findings of a Facebook group developed for the purposes of this research. Findings from the previous two manuscripts (Papers 2 and 3) were used to inform the development of this group, in addition to consultations with members of NaviCare/SoinsNavi's Patient and Family Advisory Council (PFAC) and research team. The following factors were taken into consideration: group characteristics, moderators, language, recruitment, and implementation. The Facebook-based peer-to-peer (P2P) support group, launched in October 2020, has been monitored for a period of 10 weeks for its use by caregivers. The group has attracted a total of 81 caregivers of children and youth with health care needs in New Brunswick (NB), including three moderators. Inquiry-based posts are the most common type of posts made by members. The uptake of the Facebook P2P support group by families of children and youth with CCN in NB suggests the need for informational and emotional support by this population. Ongoing monitoring and evaluation will determine how the group is used by members and whether it has any effect on knowledge of services and resources.

4. **Manuscript Four:** Kelly, K., Doucet, S., Luke, A., Azar, R. & Montelpare, W. (in preparation). Exploring the use of a Facebook-based support group for caregivers of children and youth with complex care needs. *Journal of Medical Internet Research*.

This paper presents findings from the implementation of the Facebook-based P2P support group specific to the use of the group by caregivers of children and youth with CCN in NB. Factors related to its sustained use by members are also reported. This study consisted of: (1) a sample of individuals who joined the Facebook group, and (2) content published to the group (e.g., posts, comments, likes, and loves). An online survey was distributed, and semi-structured interviews were conducted with a sub-sample of group members. A total of 108 caregivers joined the Facebook group between October 2020 and March 2021. There were 93 posts with 405 comments and 542 associated interactions (448 likes and 94 loves); 37 of these posts were made by caregivers of children and youth with CCN rather than moderators. The online survey was completed by 39 participants and 13 members participated in interviews. Content analyses of posts and interview data revealed that members primarily used the group for informational support and to engage in altruistic contribution. Although many participants were self-described “lurkers” or moderate contributors, these individuals reported that their support needs were met through the group. These findings demonstrate the use of a geographic-based Facebook-based P2P support groups for informational and social support by caregivers of CCN and provides insights into factors facilitating the group’s longevity.

5. **Manuscript Five:** Kelly, K., Doucet, S., Luke, A., Azar, R. & Montelpare, W. (in preparation). Experiences, motivations, and perceived impact of participation in a Facebook-based support group for caregivers of children and youth with complex care needs. *Journal of Medical Internet Research*.

The previous manuscript reported on the use of the Facebook P2P support group by caregivers of children and youth with CCN specific to: (1) content analyses of posts and related interactions (e.g., comments and likes) published to the group; and (2) survey and interview data related to factors that facilitate the ongoing activity and use of the group by members. This paper reports on the experiences of caregivers of children and youth with CCN in the Facebook group and perceived impact of participation on knowledge of services and resources, and sense of community belonging. Data from surveys (n=39) and interviews (n=14) with a sub-sample of members in the group was analyzed using thematic analysis. Five themes emerged related to the experience of participants and perceived impact: (1) Safe Space; (2) Informational Support and Direction; (3) Virtually Connect with Peers; (4) Impact on Knowledge of Programs and Services; and (5) Degree of Community Belonging. Participants reported joining the group to obtain geographic-specific information support and to connect with peers. Many participants reported an improvement in knowledge of programs and services and felt connected to the community; however, group infancy and diversity among the caregiver population were cited as barriers to social belonging.

6. **Concluding chapter:** This chapter provides a general discussion of research findings and a conclusion. The discussion includes implications for interdisciplinary practice and policy, and recommendations for future research.

Conclusion

Patients and caregivers are increasingly engaging in online P2P communications to seek and provide support. Investigations into the use of these online groups has

demonstrated the importance of these communities in meeting the needs of diverse populations. These internet “hive minds” for health-related information and support represent an important phenomenon for researchers, particularly with regards to how it might be improved.

Exploring how these individuals come together in a private social media environment can reveal important insight into this population’s support needs and the impact of these interactions on caregivers’ knowledge of health-related services and resources, and well-being. Moreover, studying this environment can allow researchers, health care workers, organizations, and clinicians to better understand how to support this population and where their expertise might further benefit this culture of online connections. If the Internet is the way of the future, understanding how health care services can fit into that future is paramount.

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MANUSCRIPT ONE

Exploring the roles, functions, and backgrounds of patient navigators and case managers: A scoping review

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Abstract

Background: Patient navigators and case managers are health care workers who aim to provide individualized assistance to patients facing significant health concerns.

Although these roles emerged from distinct historical need, the terms are often used interchangeably in the literature and are described to have overlapping functions.

Differences in the way that these roles are conceptualized across countries has led to a lack of clarity regarding the exact functions that each offer to patients, caregivers, and the health care system.

Objectives: To differentiate the functions and backgrounds of patient navigators and case managers across settings and disease contexts.

Design: This review was guided based on the PRISMA extension for scoping reviews using a five-step review process: identify the research questions; search and identify relevant studies; select studies based on a priori criterion; chart the data; and collate, summarize and report the results.

Data sources: A search of the literature was undertaken in peer-reviewed databases (Medline, CINAHL, and PubMed) and the grey literature (Google and unpublished articles in online repositories).

Review methods: Extracted data included information on patient navigators and/or case managers related to their reported background, training, and/or knowledge; roles and/or specific functions; clinical setting; and targeted condition or disease type.

Results: The search strategy resulted in 10,523 articles. After applying the eligibility criteria during title and abstract evaluation, 468 full-text articles were reviewed, resulting in a total of 160 articles. Functions of patient navigators and case managers were organized into nine emerging categories: (1) advocacy; (2) care coordination; (3) case monitoring and patient needs assessment; (4) community engagement; (5) education; (6) administration and research activities; (7) psychosocial support; (8) navigation of services; and (9) reduction of barriers. The background and knowledge areas of each role were compared and contrasted, and three categories related to the practice context of each role were identified: (1) typical setting and care trajectory; (2) target patient population; and (3) mode of service delivery.

Conclusions: The current study identified important differences in the functions between patient navigators and case managers. However, there remains significant ambiguity between the functions of these two roles. Standardized definitions detailing scope of practice, and allowing for inherent flexibility across different settings, are needed to improve service delivery.

1. INTRODUCTION

A myriad of services, treatments and programs have led to an intricate and fragmented health care system, making it difficult for patients and their families to obtain timely care¹. The complexity of this system has led to a rise in the popularity of roles aiming to address barriers and improve care coordination to patients facing significant health conditions and diagnoses². The need for such care is evident by the rise in popularity of roles that aim to reduce barriers and improve care coordination through patient-centered initiatives. Some of these roles include case managers, patient navigators, care coordinators, care managers, health coaches, medical home care coordinators, and clinical care coordinators³⁻⁵. Patient navigators and case managers, in particular, have been identified as invaluable members and consultants to patient care teams across the world⁶. Although historically these roles held distinct responsibilities, the terms are now being used interchangeably in the literature and are often described to have overlapping functions between their respective roles. This has led to a lack of clarity regarding the exact functions that each offers to patients, caregivers, and the health care system. The current study seeks to delineate the distinct functions between case managers and patient navigators through the scoping review methodology. The following section outlines a brief history on the background of patient navigation and case management relative to the evolution of each role's functions.

2. BACKGROUND

2.1. Definition of Patient Navigation and Case Management

The current study defines patient navigation according to its functionality for reducing physical or psychological barriers to care. Specifically, patient navigation is defined as a partnership between a patient or caregiver and a navigator (e.g., registered

nurse or peer) that seeks to proactively guide patients through the healthcare continuum to facilitate timely access to care and foster self-management and autonomy through education and emotional support⁷⁻⁹. Case management is defined according to the definition put forth by the Case Management Society of America¹⁰ as “a collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost effective outcomes” (p.11). Both roles aim to reduce barriers to care, including geographic, cultural, socioeconomic, and organizational barriers¹¹. Patient navigators and case managers seek to address gaps in services provided to patients, rather than duplicate existing efforts provided by other health care professionals^{12,13}.

2.2. Patient Navigation History

Patient navigation was coined by Dr. Harold Freeman in a report to the American Cancer Society¹⁴, which led to the first patient navigation program at Harlem Hospital Center in 1990¹⁵. This inaugural patient navigation program aimed to promote access to timely breast cancer diagnosis and treatment, by helping patients navigate through the healthcare system¹⁶. The program targeted a community surrounding Harlem Hospital, which experienced substantial financial concerns and mistrust of healthcare professionals¹⁷. The Harlem patient navigation program was implemented to promote culturally sensitive and timely access to quality cancer care for at-risk patients¹⁶. A significant improvement in survivorship rates in the area (39% pre-implementation to 70% post-implementation), led to the *Patient Navigator and Chronic Disease Prevention Act* signed into US law in 2005¹⁵. This act ensured navigational support to patients across the United States dealing with one or more chronic disease(s)¹⁸.

Initially, these patient navigation programs were targeted at cancer patients from marginalized communities, particularly aiming to reduce barriers during the stages of screening and diagnosis^{15,16}; this eventually expanded to include quality-of-life outcomes¹⁹ and other patient populations and health conditions^{7,20}. The prevalence of patient navigators in the oncology care setting has led some to speculate that patient navigators are simply case managers for the cancer setting²¹; however this role is expanding to include patients with chronic disease (e.g., diabetes, cardiovascular disease, kidney disease, and dementia)²².

Initially, navigators at Harlem Hospital were individuals with lived experience from the target patient community, who embodied cultural knowledge that reflected that population. These individuals, who continue to practice today, are known as peer or lay navigators¹⁶ and do not have clinical experience. In contrast, professional navigators are paid health care workers with a background in clinical care (e.g., registered nurse) or social work^{8,21}. Today, patient navigation programs can involve either type of patient navigator, or be comprised of both professional and lay navigators²³. Moreover, navigators can work individually or within the context of a team²⁴.

There exists significant debate over how patient navigation should be defined in the literature, partly due to variations in work settings and navigator backgrounds. Definitions of a patient navigator depend on three critical components: (1) the type of navigator (e.g., professional vs. lay person), (2) clinical context (e.g., cancer), and (3) organizational setting (e.g., community vs. hospital)⁷. While there is a lack of a common definition, navigation is often defined in terms of its functions.

Patient navigation typically employs an individualized, holistic approach to help patients navigate through a range of health care services²⁵. Navigation is considered to

be a patient-centered method of care coordination, as the decision to pursue a particular service is decided by the patient after receiving information from the navigator⁹. Patient navigation is often considered to comprise two types of interventions: (1) instrumental, involving logistical tasks (e.g., arranging transportation or facilitating care coordination); and (2) relationship-based, involving inter-personal connections and support between patient and navigators^{26,27}. Across the world, patient navigation programs are being implemented to improve health and social services delivery, better support populations with specific needs, and improve the well-being of patients²⁸.

2.2.1. Professional and Lay Patient Navigators

Lay patient navigators are often individuals with lived experience who possess in-depth knowledge of the care system²⁹, and are often supervised by a professional navigator³⁰. Training is usually provided to lay patient navigators^{29,31–33}, even volunteers³⁴; however this training is not well documented or standardized in the literature³⁰. In Canada, lay patient navigation training programs often involve defining scope of practice, while promoting cultural awareness and communication skills³⁵. However there remains controversy regarding the necessary background and qualifications of a lay navigator^{30,36}.

In the United States, patient navigators are often lay persons or peers¹⁹, in those cases, individuals with clinical experience are known as nurse navigators³⁷. In an attempt to delineate the functions of a navigator, Willis and colleagues³⁷ developed a framework in which they describe three types of patient navigators: community health workers, patient navigators, and nurse/social work navigators. The functions of each role were differentiated across 12 domains: professional roles and responsibilities; community resources; patient empowerment; communication; barriers to care/health

disparities; education, prevention, and health promotion; ethics and professional conduct; cultural competency; outreach; care coordination; psychosocial support services/assessment; and advocacy. In general, community health workers were found to play a more supportive role within the community, patient navigators supported individuals at the patient-level (e.g., assisting patients in overcoming barriers to care), and nurse/social work navigators provided care through a clinical lens. This conceptualization of a patient navigator differs from literature that uses these terms interchangeably³⁸ and describes the role of a nurse navigator as being similar, if not identical, to that of a case manager. In Canada, the role of a patient navigator is often filled by nurses or other professionals^{21,39}. As a result, there remains ambiguity regarding the differences in the roles and functions between professional and lay patient navigators.

2.3. Case Management History

Case management arose in the early 1900s in response to a need for more integrated care across health and social services, particularly for those in vulnerable situations (e.g., low socioeconomic populations and immigrants)⁴⁰. Throughout the mid-20th century, case managers became prevalent across multiple settings in response to the deinstitutionalization of those with severe mental illnesses⁴¹ and veterans returning home with complex injuries^{40,42}. These case managers were nurses and social workers who addressed a need for community-based care, as a means to reduce hospital resource use and strain, while enhancing quality of life⁴³. Case management arose through social work and did not become part of the nursing profession until the middle of the 20th century⁴⁴.

The term “case manager” is generally used to describe a care professional that promotes upstream approaches to health care and facilitates individualized care coordination for those with complex and chronic health conditions^{45,46}; however, lack of a standardized definition has led to ambiguity⁴¹ and variations in its interpretation⁴⁷. Case managers are often known to conduct patient assessments; patient identification and outreach; care planning and coordination; and service evaluation^{48,49}. The functions of a case manager depend on a number of variables, including the setting of care, health condition of the patient, and the professional background of the case manager⁴¹.

Today, case management is found across diverse settings and contexts⁵⁰. The case manager position is typically considered to be a specialization fulfilled only by a professional (i.e., an individual with clinical, medical, psychosocial, or rehabilitation expertise)^{51,52}. It has been argued that nurses are particularly suited to the role⁵³ due to their holistic, clinical background, likely explaining why most case managers are nurses with clinical expertise⁵⁴. Case management is considered to be an important opportunity for integration with social services and community-supports due to its use of its role outside of the health care sector (e.g., employment, legal, etc)⁴¹.

2.4. Comparison of Patient Navigation and Case Management

Few studies have directly compared the roles and functions of a patient navigator to a case manager. In a recent study by Schutt and colleagues⁴⁴, the roles of patient navigators and case managers were compared within a state-wide care coordination program that employed individuals in both capacities across 26 health care sites. This program involved lay navigators with no clinical expertise, and, in contrast to the case managers, were mostly bilingual. Functionally, case managers reported a focus on educating patients, whereas patient navigators were concerned with patient needs and

community services and interacted more with outreach workers; however, overlaps in the functions of these two roles did appear. Investigators found that the case managers in this program were more likely to report their work as closer to that of a physician and saw fewer patients than the patient navigators. Investigators concluded that the observed overlaps in functions between the two roles did not negatively affect the delivery of healthcare services to patients. This may be due, in part, to the inherent flexibility of patient navigation; some have argued that a defining characteristic between patient navigators and case managers is that navigation is not restricted to a “predefined set of services” and thus can be more flexible in its approach to supporting patients⁵⁵.

3. PURPOSE AND RESEARCH QUESTION

Few studies have attempted to delineate the functions and responsibilities of patient navigators⁷ and case managers^{41,54}, however no studies (to the authors’ knowledge) have attempted to explicitly distinguish the difference between patient navigators and case managers. The responsibilities for each of these roles overlap in the literature, sometimes blending into one position¹⁸. Some authors have even argued that the role of a navigator undermines the position of case manager on the care team⁵⁶. Others have suggested that case management is a profession within a profession^{57,58}, while a patient navigator is a position filled only by lay persons, with the exception of a nurse navigator³⁷. The purpose of this scoping review is to delineate the differences in the functions and backgrounds of patient navigators and case managers.

As suggested by Arksey and O’Malley⁵⁹, an iterative process was used to develop the research question for the current review. The following research question was identified to address the gap in the literature:

1. How do the roles, functions, and backgrounds differ between patient navigators (professional and lay) and case managers in the context of healthcare delivery?

The current study defines the terms “role” and “function” according to Tahan and Campagna⁵⁴. In their roles and function analysis, role is defined as a “term that refers to a set of behaviors associated with a position in a social structure, such as one’s job title”; Alternatively, function is defined as a “grouping of specific activities that are derived from a role” (p. 247). This study will bring clarity to the specific functions (i.e., activities or responsibilities) and background (i.e., a priori knowledge and previous education) for two roles (patient navigators and case managers).

4. METHODOLOGY

A scoping review was chosen to explore the differences between patient navigators and case managers. The scoping review methodology is used to address broad concepts and is useful for examining ambiguous topics⁵⁹⁻⁶¹. Scoping reviews also provide a structured and rigorous methodology for exploratory research questions^{59,62}. Unlike systematic reviews, which evaluate the rigor and quality of studies⁶³, scoping reviews allow for diversity in methodological scope and quality to identify gaps in particular knowledge areas^{61,64}.

The objectives, inclusion criteria and methods for this scoping review were established in accordance with the recommendations for reporting in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA-ScR) extension for scoping review guidelines⁶⁵. This scoping review used the PRISMA-ScR checklist⁶⁵ to ensure rigor during the planning, organization, and reporting of this review.

4.1. Eligibility Criteria

To be included in this scoping review, the central focus of the article had to be on patient navigation and/or case management in the context of healthcare delivery.

Included articles were also required to contain a discussion on the roles, functions, or responsibilities of patient navigators or case managers. Study methodology was not limited in this review, due to the inclusive nature of scoping reviews⁶¹; therefore the following full-text article types were considered for inclusion: qualitative, quantitative, and mixed methodology studies; literature reviews; and grey literature (e.g., government reports and organizational materials). Only articles published in English were included. Articles that did not use the terms “patient navigation/navigator” or “case management/manager” in the context of health care delivery were not included (e.g., those that focused on “care management” or those with a focus other than health were excluded). Articles were not restricted to a specific span of publication years. Finally, articles in which full-texts were not available (e.g., conference proceedings) were not included. Table 1 illustrates an overview of the inclusion and exclusion criteria. The lead author conducted an initial review of abstracts to determine if articles met inclusion criteria, and that same researcher conducted a full-text review of articles to assess eligibility for data extraction.

Table 1. Inclusion and exclusion criteria

Criterion	Inclusion	Exclusion
Study focus	Patient navigation and/or case management in the context of healthcare delivery; discussion on the role and/or functions of the role	No reference to patient navigation and/or case management, or the presence of these roles outside of healthcare; no discussion on the role and/or functions of the role
Type of article	Any type of publication (e.g., empirical study, government report, etc) where a full text is available	Articles without a full-text publication (e.g., conference proceedings) and/or where the full-text article is not available
Language	English	Non-English
Geographical place of study	Any geographical place of study	No exclusions
Time period	Any date of publication	No exclusions based on date of publication

4.2. Information Sources

4.2.1 Academic Literature Search

Searches were run in October 2017 in academic databases selected for their widespread use by health sciences researchers and potential for retrieving relevant articles. A second search took place in June 2018 to capture publications released between the time of the first search. Three databases (Medline, CINAHL, and PUBMED) were searched, using the following search terms: **Medline:** [patient navi* OR case manag*]; **CINAHL:** [MH “Professional Role+” AND (“case manag*” OR

“patient navi*”); **PUBMED**: [(patient navigation OR patient navigator) OR (case manager OR case management)].

4.2.2. Grey Literature Search

In addition to academic journal articles, the grey literature was also searched due to the likelihood of relevant information in organizational reports and websites (e.g., government documents). Consultations with a health research librarian facilitated a search of the grey literature on Google. An additional search was also conducted according to the Canadian Agency for Drugs and Technologies in Health’s (CADTH) Grey Matters⁶⁶ tool, which consists of various databases. The search strategy in the non-academic literature comprised of the following search terms: patient navigation/navigator and case management/manager. Sources were screened in Google according to titles until the point of saturation (i.e., after 2 pages passed in which a link was not opened).

4.3. Study Selection

Articles identified in the academic database and grey literature searches were exported and organized into Excel for evaluation. The lead author screened titles and abstracts to determine each article’s eligibility for full-text screening based on the broad a priori inclusion criteria (see 2.1). The second stage of study selection consisted of the retrieval of full-text articles, which were extracted and collated in a reference manager (Zotero) for further evaluation. When the lead author was unsure about a particular article (e.g., whether it fit the inclusion criteria), a co-author (SD) was consulted.

4.4. Data Collection and Analysis

Studies were initially coded with respect to whether the article described the functions of patient navigators, case managers, or both. Articles describing these roles

were further coded for four descriptive variables: study type (academic or grey), article type (research study, academic review, report, etc), and country of study. Information related to the characteristics of patient navigators and case managers (e.g., practice setting (e.g., hospital or community); targeted disease type or condition (e.g., cancer); and training and knowledge) were also extracted and coded. Data from included articles were extracted and collected into a data charting form (Table 2), by the lead author. This data form was developed in consultation between the lead author and a co-author and piloted using a sample of articles before being implemented. Extracted data was organized in Excel under appropriate headings for all included sources.

Table 2. Data charting form

Category	Extracted component
General information	Author(s)
	Title
	Publication Year
	Article focus (i.e., patient navigation, case management, or both)
	Study methodology type (e.g., research study, academic review, etc)
	Study location (i.e., country)
	Article type (e.g., research study, academic review, report, etc)
Descriptive information and characteristics	Setting (e.g., hospital, community, etc)
	Targeted condition, health care need, and/or disease type (e.g., cancer)
	Information on background, training, and/or knowledge of patient navigators/case managers
	Definition of case manager/management or patient navigator/navigation (professional versus lay patient navigator)
Definition	Roles and/or functions of case manager or patient navigator (professional versus lay patient navigator)

Coded data were collated according to the emerging functions identified in the literature using the inductive thematic analysis. Themes were created based on the identification of patterns from the coded data. Summary statements regarding patient navigator and case manager functions were created for each domain.

5. RESULTS

5.1. Study Selection

A total of 1145 articles were identified through the search strategy in the academic databases. After the removal of duplicates, 928 academic articles underwent a title and abstract evaluation from which 438 were excluded. The majority of the articles excluded at this stage did not discuss the specific functions of either role and/or were not specific to the health care setting (e.g., case management in law, policing, etc). After full-text screening, another 357 were excluded, resulting in 133 included academic articles. A total of 9595 articles were identified in the grey literature database searches, from which 9568 were excluded after the title/abstract screening. Most of the grey literature articles were excluded due to the inclusive nature of these search engines compared to academic databases, often resulting in articles of little relevance. Moreover, grey literature sources were primarily excluded at the title/abstract stage (as opposed to the full-text evaluation) because screening involves having immediate access to full-text articles (i.e., clicking through to links) (see Figure 1). A total of 160 articles were included in this review (76 on patient navigation, 84 on case manager, and 1 on both). Figure 1 illustrates the number of articles at each stage of the study selection process.

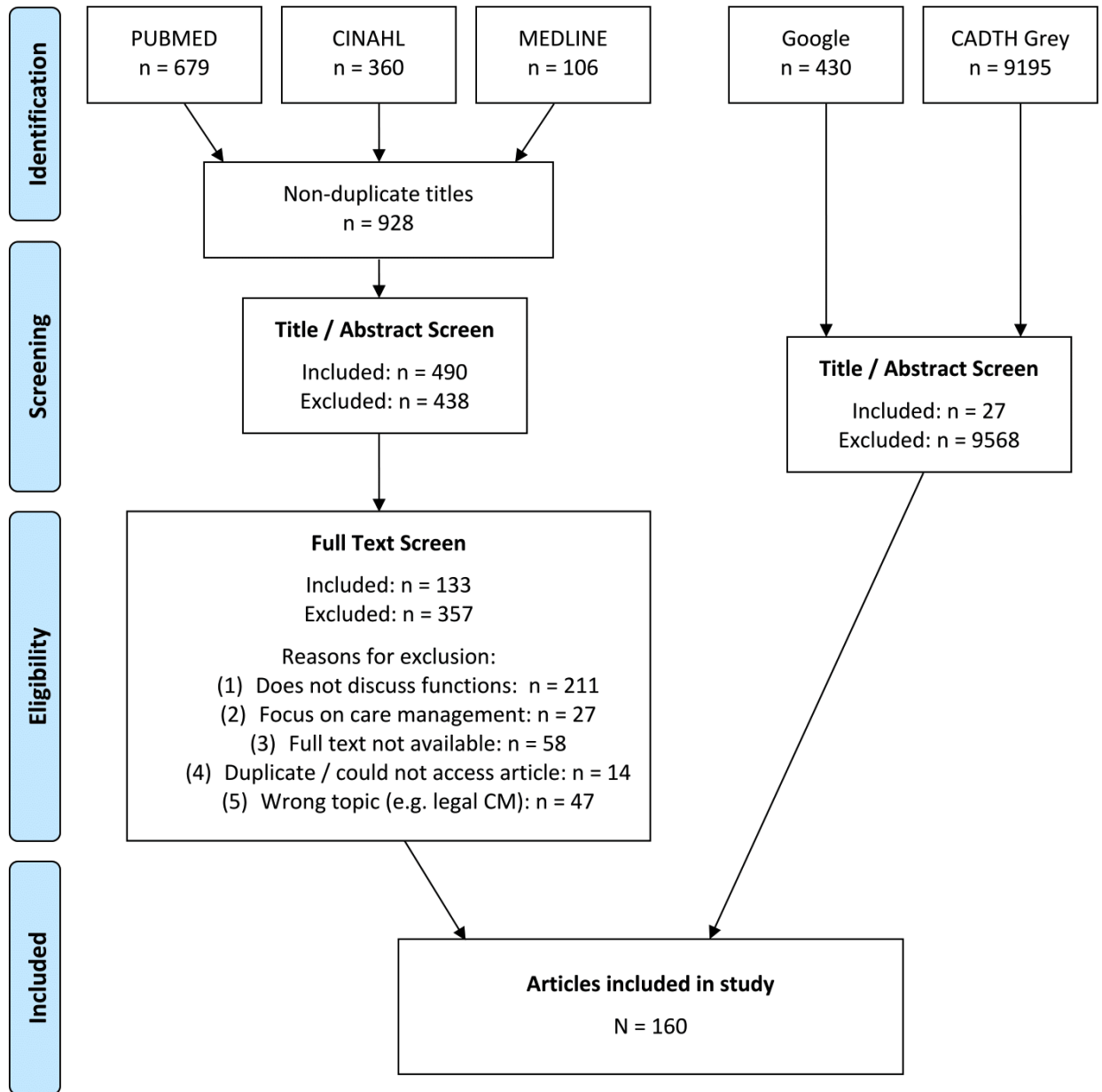


Figure 1. PRISMA⁶⁷ flow chart depicting the number of studies at each step of the selection process

5.2. Descriptive Characteristics of Articles

Descriptive data extracted from the included articles in this study provided information on the diverse settings and targeted health condition(s) of patient navigators and case managers. Included articles derived from 8 different countries, with the majority from the US ($n=120$) and Canada ($n=26$), followed by the United Kingdom

($n=5$), Sweden ($n=3$), Australia ($n=3$), France ($n=1$), Pakistan ($n=1$), and Singapore ($n=1$). The articles on patient navigation most often focused on the hospital setting ($n=19$), followed by the community setting ($n=8$), whereas articles on case management resulted in an approximately equal number of community ($n=16$) and hospital ($n=20$) settings. In remaining articles, the roles of patient navigators and case managers were found across multiple settings (patient navigators, $n=31$; case managers, $n=24$). Remaining articles did not specify a setting. Most of the articles that described patient navigation focused on cancer care ($n=51$), whereas most articles describing case management were not focused on providing services for a specific health care need ($n=60$). A list of the included articles and associated findings can be seen in the corresponding Data in Brief article.

5.3. Theme 1: Characteristics of Patient Navigators and Case Manager Practice Context

Information related to the characteristics and typical practice settings of patient navigators and case managers were collected and collated to better contextualize the identified functions for each role. The following section summarizes these findings under three categories that emerged from the data: (1) typical setting and point of care; (2) target patient population; and (3) delivery of services (i.e., modes of communication).

5.3.1 Typical Setting and Point of Care

The typical setting of patient navigators and case managers vary greatly. Patient navigators may be employed by hospitals^{34,68-71} and other health centers⁷², community-based organizations^{34,71,72}, insurance companies⁹, and as independent consultants⁹. Likewise, case managers can be found across many settings⁷³, such as home care,

hospitals, rehabilitation, and long-term care facilities⁷⁴⁻⁷⁶, but are also found in community-based and independent-care settings⁷⁷. Case managers are also sometimes employed by insurance companies and government agencies⁷⁷.

The point at which patient navigators and case managers become involved in a patient's care needs (e.g., from screening to discharge and beyond) varies across programs. Patient navigation services have been implemented at all stages across the cancer care continuum (e.g., prevention, screening, treatment, and survival)^{4,55,68,69,78-84}, but have also been targeted at defined points of care during which patients need significant support and guidance (e.g., diagnosis)^{78,82,83,85-89}. Likewise, case managers work at different points along the healthcare continuum⁹⁰, such as palliative and terminal phases of illness^{91,92}. Case management services may also be limited to patients with a predetermined criteria, reflected through an initial assessment⁹³. The relationship between case managers and patients tend to be long-term⁹⁴, sometimes spanning several years⁹⁵. Case managers often get involved within the first 24 hours of a critical injury or diagnosis^{96,97}, establishing an initial relationship upon admission^{98,99}. In some models of navigation, patient navigators serve as a constant point of contact for patients throughout their care journey^{17,68,72,86,100}. However, patient navigation has been demonstrated to be most effective at the level of screening^{27,85}.

5.3.2. Target Patient Population

Both patient navigators and case managers tend to work with specific patient populations that require additional support. Navigators usually target individuals diagnosed with particular disease or condition⁴⁴, such as cancer^{17,68,70,79,89,101-103}, mental health^{68,88}, and other chronic disease(s)^{71,104}. Case managers also target specific patient populations that require complex care coordination^{47,105}. For example, case managers are

known to provide services in cardiology^{76,105}, HIV/AIDS¹⁰⁶ and mental health care^{77,107}. Case management is also provided to the chronically ill and acutely injured^{76,107,108}, such as veterans with complex injuries⁷⁴. Typically, patient navigators serve individuals from marginalized or underserved communities^{27,72,81}, but are also known to serve the general population²⁷.

5.3.3. Delivery of Services (e.g., Mode of Communication)

Patients have been known to contact patient navigators by telephone^{4,44,70,100,109–111}, email⁴, or meeting face-to-face^{31,70,109}. Case managers communicate directly with patients and health care professionals⁹⁹ through various modalities, such as face-to-face, telephone, or email^{112,113}. Case managers often remain on-call for their patients¹¹⁴. There is variation in the number of times that a patient or family may contact a patient navigator. Patients and family members may contact patient navigators between one to five times¹¹⁵, or more than 18 times¹¹⁶, from diagnosis to treatment and follow-up¹¹⁵.

There is little information about the typical caseload for patient navigators. The case manager's patient case load can vary, sometimes without limitations on size¹¹⁷. There is some consensus that navigation services should be provided at low- to no-cost^{34,85} to ensure accessibility, particularly to low-income and marginalized individuals^{78,85}.

5.4. Theme 2: Functions of Patient Navigators and Case Managers

Functions identified from the articles included in this study were collated and grouped into nine resulting categories: (1) advocacy; (2) care coordination (including transitions, discharge, and rehabilitation); (3) case monitoring and patient needs assessment; (4) community engagement; (5) education (including self-management and

empowerment); (6) administration and research activities; (7) psychosocial support; (8) navigation of services (including referrals); and (9) reduction of barriers. Specific functions are described in the following section according to each category. An overview of the similarities and differences between each role according to these nine functions can be seen in Table 3, located at the end of this section.

5.4.1 Advocacy

Patient navigation typically involves advocacy^{21,23,44}; but not always⁷. The term patient navigator is sometimes used interchangeably with “patient advocate”⁹. Likewise, advocacy is considered by some authorities to be a primary responsibility of case managers¹¹⁸. Patient navigation programs that involve advocacy usually do so on behalf of the patient^{68,119–121}, such as by advocating for additional services or coverages^{25,34}, or marshalling support for patient navigation services^{105,119}. Similarly, case managers are often required to advocate on behalf of their stakeholders, which include patients^{54,74,107,114,122–130} and their families¹³¹; physicians and staff^{10,118,132}; the community and the payer¹³³. However, when a conflict between these entities arises, case managers usually take the position of the patient¹⁰. Patient advocacy takes place during treatment and sometimes through palliative and terminal phases of illness⁹¹. Case managers strive to promote patient self-advocacy as a means towards independence from health services^{10,134}. Examples of case management advocacy functions include: providing a voice for the patient on the care team¹³⁵; ensuring patient rights¹³⁶; negotiating elements of the care plan (e.g., length of stay and required services)¹³¹ or living situation⁷⁴; reducing costs to patients by avoiding unnecessary tests or procedure¹¹⁸; and justifying expenses and resource allocation to payers¹³⁷.

5.4.2. Care Coordination (Including Transitions, Discharge, and Rehabilitation)

Care coordination is considered to be a central function in both patient navigation^{4,7,19,23,47,69,78,86,101,138–141} and case management^{10,74,90,92,112,114,123,129,136,137,142–148} as a means of better integrating or streamlining healthcare to improve continuity and timeliness of care for patients and their families. Collaboration with multiple care providers across various settings (i.e., working within the context of a multidisciplinary care team) has been observed with both patient navigators^{4,21,29,68,116,119,120,149–151} and case managers^{54,137,143–145}. Promoting open communication between formal and informal care providers was identified as a function for both patient navigators^{17,21,21,23,25,86,109,121,138,141} and case managers^{54,75,76,96,105,124,137,152–156}. Importantly, not all patient navigation programs work within the context of a multidisciplinary team⁷.

Identified care coordination functions performed by patient navigators include: providing transitional support^{21,70,86} and personalized coaching⁸⁶; coordinating and planning medical appointments^{25,70,79,157}; communicating relevant information about a patient's care to appropriate members of the care team (e.g., changes to treatment)^{21,31,110,158}; acting as a liaison between care providers¹⁰⁴; contributing to a patient's multidisciplinary care team^{21,120}; seeking new collaborations (i.e., additional care team members)¹¹⁰; and assisting patients manage care across multiple providers^{109,159}. Patient navigators sometimes interact with nonclinical staff on behalf of the patient, such as receptionists or administrators^{110,138,150}, to book appointments or communicate with physicians⁴. Patient navigators answer questions³⁹ and match unmet needs to resources²¹. Patient navigators may also initiate consultations with individuals in other disciplines⁸⁰ to develop and coordinate new partnerships^{29,34}. Professionals

patient navigators (i.e., those with clinical expertise) have also been known to coordinate multiple procedures to ensure continuity of care across multiple settings¹²⁰.

Care coordination functions carried out by case managers include: establishing relationships with referrals¹⁶⁰; contributing to a multidisciplinary care team to manage a patient's care^{10,73,76,117,131,135,145,161}; and coordinating efforts with all members of the care team¹⁶². Often, case managers are involved in the administrative aspect of care coordination, which involves detailed record-keeping^{10,145,160} and follow-up post-discharge¹¹³. Case managers act as a resource for members of a care team (e.g., physician)^{113,114}, which often results in the case manager becoming a liaison between patients, their families, community organizations, care providers, and other stakeholders (e.g., payers)^{10,76,113,128,137,152}, thus simplifying the point of contact on behalf of a patient⁷⁴ and reducing fragmentation in service delivery¹⁰. In some cases, case managers become responsible for managing a multidisciplinary team^{10,152,163} and delineating specific functions of all parties (e.g., providers) involved in the care plan¹⁵³. However, not all programs involve a centralized case manager; sometimes case management services are delivered in a more team-based approach^{132,164–166}. This is particularly important for the development of an effective care plan, which is often created and executed in collaboration with the care team^{137,155,167,168}.

Patient navigators are sometimes involved in the facilitation and expedition of discharge^{68,104}, creating summary notes and providing next steps to the care team¹¹⁶. In contrast, discharge planning is an important function of case managers^{42,54,73,77,105,114,156,165,166,169,170}, as well as deciding when case management services are no longer needed¹⁵⁵ in collaboration with the primary care provider⁹⁷. Case managers may also be involved in intake planning during admission⁷⁷, and continue to

make modifications and amendments to the discharge plan throughout the patient's care journey¹⁷¹. In some countries with universal healthcare systems (e.g., Canada, Australia), case managers are known as discharge planners¹⁴⁵. When a case is closed, the case manager will discuss next steps with the patient and notify stakeholders (e.g., care providers and payers)¹⁵⁵. Case managers are often involved in the administrative side of case closure, with functions related to data collection, analysis and reporting¹⁵⁵. Although patient navigators are involved in transitional support^{70,86,172}, it does not appear to be a primary goal of patient navigation. Case managers, however, are typically responsible for planning changes in level of care^{105,114} and managing transitions^{10,54,105,107,134,154,161,165,167,173,174}, usually consulting with the patient's primary care provider before significant changes in care interventions¹⁶⁴.

Within the identified articles, patient navigators were not identified as playing a substantial role in rehabilitation services, apart from reducing barriers to services and appropriate care (see sub-theme 5.4.9). However, a key function of case managers is to assist is the “restoration of health following a disease, illness, or injury to the pre-injury or illness state”^{54,162}. Case managers achieve this through many functions, such as: overseeing and arranging rehabilitation activities^{165,167}; communicating with employers regarding job modifications^{54,155}; and identifying a need for specialized services and coordinating any accommodations⁵⁴.

5.4.3. Case Monitoring and Patient Needs Assessment

Both patient navigation^{4,35,68,78,81,140,175,176} and case management^{10,105,145,148,153,177} employ a patient-centered healthcare model based on a goal-oriented intervention (patient navigators²⁷; case managers^{54,117,145}). In other words, helping patients set and prioritize goals is a function for both patient navigators^{21,68,149} and case

managers^{54,105,131,160,178,179}. Patient navigators provide evidenced-based¹⁴¹ and individualized assistance to patients and their families^{22,87,102} using a biopsychosocial approach²⁵. Similarly, case management aims to improve the overall well-being of a patient through individualized and tailored assistance^{94,108,160,162,179}.

Patients may either be approached by^{21,116} or referred to¹¹⁹ a patient navigator; this is in contrast to case management, where patients may be screened to determine their need for services, by using data related to patient's physical, mental and social care needs^{47,54,76,92,99,117,123,155,160,168,169,180}. Patient and risk screening are considered to be among the primary functions of a case manager^{99,166}.

Patient navigators conduct comprehensive screening and needs assessments with patients^{4,29,35,36,80,82,141,159,172}; which involves assessing the patients' medical and social supports^{29,80}. Similarly, case managers provide comprehensive screening and needs assessments of a patient's overall status across the domains of well-being (e.g., emotional, physical, social, and financial status)^{10,42,52,54,90,98,123,127,131,134,137,142,143,145,148,156,160,161,168,168,178,180–182}. Case managers collect this information through chart reviews^{54,75}, and by approaching individuals involved in the patient's care (e.g., family and other care providers)^{52,54,74,98,123,165,166,168,169,178}. This initial assessment leads to the development of an appropriate and personalized care plan (in collaboration with formal and informal care providers) by both patient navigators^{47,80,88,172} and case managers^{10,54,98,125,127,128,134,182}. Patient navigators aim to match unmet needs with services and resources^{116,172}, whereas case managers plan, implement, and evaluate care activities^{42,54,73,76,125,126,142,145,146,148,163,164,178}. Case managers usually perform ongoing assessments and make appropriate changes to the care plan or implementation

process^{54,76,114,168,171,178,180,182}, and help patients and their families make decisions related to treatment¹⁴⁴.

Patient navigation is usually centered on a specific, pre-defined outcome of interest (e.g., screening)²⁷. Patient navigator functions related to case monitoring include: monitoring symptom management in their patients^{21,116,159}; tracking procedures, interventions and outcomes^{157,183}; ensuring that patients follow-up with referrals^{80,138}; providing timely information related to self-management¹⁷²; helping patients maintain lifestyle and social activities during their care journey⁴ and working to reduce barriers to high quality care⁸². Patient navigators aim to deliver services to patients that are proactive and preventative^{35,68,172}.

In contrast, case management can be provided over a long period of time, in order to monitor and assess medical and psychosocial issues throughout an illness⁹¹. Case manager functions related to case monitoring include: documenting progress with the care plan (e.g., through interviews with patients and providers)^{54,114,160}; monitoring for changes throughout the care journey^{42,49,54,75,76,90,113,117,127,144,148,155,160,168,168,171,180,182}; identifying gaps in the care plan^{113,168}; proactively managing complex and long-term conditions^{73,92,94,113,131,161,168,171}; reassessing the care plan on a patient's well-being^{54,112,171}; and following-up on interventions¹⁶⁷. These functions ensure that patients receive timely and appropriate care^{130,131,168,170,179}. Case managers sometimes oversee care pathways through an episode of illness^{99,114,163} and conduct medication procurement and reconciliations¹⁷⁴. Case managers can be responsible for resource allocation and management^{131,137,155}, as well as hospital visits¹³⁷.

5.4.4. Community Engagement

Patient navigators are sometimes known to lead or assist in the development of community supports^{100,184}, such as health care resources¹⁷² and collaborations with community organizations^{109,157} and support groups⁷⁹. Patient navigators have been documented to conduct outreach activities⁷⁹, such as community education³⁴, community-building¹⁸, and fundraising⁸⁰; these types of outreach activities appear to be the primary responsibility of lay patient navigators¹⁸. There is less evidence in the literature of case managers conducting community engagement as part of their functions. Case managers do appear to assist with setting up and mobilizing community resources on behalf of patients^{75,180}, and sometimes educate members of the community about the needs of their patients⁷⁶.

5.4.5. Education (Including Self-Management Skills and Empowerment)

Patient education was identified to be an important function for both patient navigators^{25,34,80,138,151,158,159} and case managers^{47,73,77,105,114,122,130,134,144,161,165}, for example, patient navigators are engaged educating families⁸⁰, helping to demystify the healthcare system⁸⁷, and providing information relevant to their illness(es) and treatment(s)^{4,88,159}. Patient navigators also educate patients and providers about their role as a navigator^{38,103}, and the history, culture, and needs of a particular community to promote cultural appropriateness^{34,138}. Similarly, case managers have been known to educate care teams (e.g., families and caregivers)^{10,134,167} about available services and resource^{98,168} and information related to their illness and treatment(s)¹⁰⁵. Case managers often act as an important resource for patients⁴⁹ and consultants for members of a care team (i.e., informal and formal caregivers)¹³⁴.

More specific patient navigator functions related to education include informing patients on early signs and symptoms of a condition¹⁵⁹ or side effects of a treatment^{25,38,121}; facilitating the understanding of a diagnosis or information provided by other sources (e.g., professional care provider)^{35,86,119,157}; and managing expectations for treatment^{29,87,88}. Patient navigators help patients feel more prepared¹⁸⁴, by advising them about care options^{25,68,89,116,120,157} and assisting with literacy issues and misconceptions⁸⁴. Health promotion and prevention is sometimes conducted by patient navigators^{17,23}.

Case managers also integrate health promotion and preventative information into their services^{10,131,146,155,168,185}. In certain situations, case managers have been documented to provide guidance about a patient's insurance or benefit coverage, or other financial supports available to them⁷⁶. Case managers sometimes work as change agents, encouraging healthcare workers towards new methods or knowledge of care delivery^{131,134,186}.

Patient navigators assist patients with decision making^{18,29,35,100,184} and problem-solving³⁵ by maintaining a library of appropriate materials^{18,34,69,138,157}, and acting as educational⁶⁸ or informational consultants^{100,157,187}. Similarly, case managers help patients make informed decisions about their healthcare needs^{47,54,134,135} and empower them to problem-solve^{10,107,134,154}. For example, case managers might explain multiple options for treatment^{10,134,153} and encourage patients and their families to ask questions as they arise¹⁵³. Case managers also teach pertinent skills to patients¹⁴⁵ to foster self-management^{10,54,92,153,173,180} and promote independence from healthcare services^{92,107,153,173}. For example, case managers might assist patients in self-glucose monitoring¹⁸⁸.

Patient navigators usually aim to provide enough support to patients to empower them to make their own care decisions through self-navigation¹⁵⁹ and learn to self-manage their conditions^{22,121}. This is achieved by directing patients to appropriate sources instead of doing it for them¹⁷². While patient empowerment is sometimes considered an important component of patient navigation^{21,23,31,119,120,172}, not all patient navigation programs emphasize empowerment⁷.

5.4.6. Administration and Research Activities

Significantly more functions related to administrative duties were observed for case managers as compared to patient navigators. Although utilization review (i.e., resource management) was identified as a patient navigation function in one article⁸⁰, it is considered to be central to many case management programs^{10,54,77,90,114,134,148,168,171,186,189–191}. This function includes assessing appropriateness of level of care¹⁵⁵, monitoring and managing resources allocation^{54,155}, and documenting activities¹⁵⁵.

Patient navigators are sometimes known to assist patients with insurance and financial issues^{84,109}, such as helping with health insurance applications^{25,157,159,183}, identifying financial assistance options^{25,79,104,157,159,192}, and determining eligibility for public programs (e.g., Medicare)¹⁵⁹. Case managers are more often known to assist patients and their families with health insurance coverage^{118,166,168,186}, in some cases reviewing eligibility for benefit coverage^{43,76,97,114,118,155,168,189}, providing information to payers about needed resources^{10,97,118,155,168}, and advocating for applicable services or resources (e.g., medical equipment)^{97,114,155,156,167,168}. However, case managers are not always involved in the financial aspect of health care service delivery¹¹⁸.

Patient navigators can be responsible for program evaluations^{34,80,105,119,157} and may assist in the research process (e.g., applying to Research Ethics Boards)¹⁵⁷. Case managers can also be responsible for evaluating the effectiveness of care plans and other outcomes (e.g., cost-effective analysis)^{10,42,54,137,144,153,168,170,178,182} to help improve efficiency¹⁰⁵. Case managers may be involved in research activities, such as writing grant/research proposals related to patient care¹³¹, and collecting and analyzing data^{178,186,189}. Case managers might also conduct predictive modelling and other analyses to determine if a patient would benefit for case management services¹⁰. Maintaining accurate and detailed record of case management services is also an important function of case managers^{166,182}. Case managers are often required to balance high quality care with cost-effectiveness^{10,76,144,152,168,186}. Sometimes case management can involve disease management^{43,77,130,168,191}.

Case managers are sometimes responsible for preparing reports in compliance with applicable regulatory requirements^{54,124,168,186}. To facilitate case management and monitoring, case managers will oversee the management and monitoring of all medical records¹⁶⁹. Case managers are responsible for protecting the patient's privacy, confidentiality, and safety^{54,114,160,168}, adhering to ethical and legal accreditation standards^{54,160,168}. Patient navigators may also help patients^{34,36,110} and employers (e.g., hospital)^{36,68} secure, maintain and transfer health records. Handling test results, reviewing cases, and documenting patient navigator activities have also been identified as patient navigator functions¹¹⁰.

5.4.7. Psychosocial Support

Patient navigators aim to provide emotional^{69,82,86,87,100,109,119,141,151,158,159,183,187} and psychosocial^{23,69,80,87,89,159,183,187} support to patients and their families¹⁷². Patient

navigators often provide a sympathetic ear to patients and their families⁸², by “just being there”³¹. However, the extent to which patient navigators are involved in emotional support varies between navigational programs¹⁹. Likewise, case managers provide emotional support^{49,54,75,126,145}. In some cases, case managers are known to provide crisis intervention and grief counselling¹¹⁴, as well as conflict resolution¹⁵³. Counselling is considered to be a central function of the case management role^{106,128,132}. Case managers assist patients in managing their mental well-being^{42,92}. Importantly, patient navigators provide a supportive, but not psychotherapeutic support¹⁸⁴. In contrast, case managers can provide psychiatric treatment to patients¹²⁷, and support families by acting as an ally and constant presence^{124,132,179}.

Patient navigators strive to build and maintain relationships and trust with patients, their families, and their providers^{71,183}, often acting as a main point of contact for the patient^{69,116,138}. Likewise, case managers build and maintain relationships with patients⁴² and act as a key point of contact on behalf of the patient⁷³. Patient navigators typically initiate and maintain close communication to support and assist patients^{21,183}, including the patient and their families as members of the care team^{74,156}. Alternatively, case managers maintain intimate relationships with patients and their families, which involves regular communication¹⁰⁶, and involvement in many aspects of the patient’s life¹⁰⁶. Case managers usually communicate on an ongoing basis with patients and their care team to ensure that information is transparent¹⁰. Case managers may work to validate a diagnosis with the appropriate stakeholder (e.g., patient, family, other healthcare providers) when deemed necessary¹⁷⁸. In some programs, case managers also seek out and establish appropriate new partnerships^{47,107,171}.

Patient navigators aim to reduce anxiety in patients^{4,70} by building trust and breaking through health literacy barriers²⁵; teaching them how to access needed resources or services⁷⁰ and emotionally preparing them for treatments¹⁸⁴. Patient navigators also provide support for caregivers⁸⁸ by conducting distress screening^{151,172}, resolving caregiver disputes^{72,104}, and offering peer counselling¹⁹². Patient navigators sometimes monitor patient satisfaction with their care experience⁷¹. One study suggested that lay patient navigators are unprepared to provide psychosocial support and barrier assessments³².

Case management functions related to psychosocial support include providing psychosocial assessments and interventions^{52,54,105,155,166,170} to patients and their families; helping patients better understand and cope with various medical or emotional issues¹³⁵; and referring patients to formal and informal community support programs⁵⁴.

5.4.8. Navigation of Services (Including Referrals)

The central premise of patient navigation is to proactively guide, support, and orient patients through the healthcare system^{9,11,69–71,82,85,116,119,121,193}, matching patients' unmet needs to appropriate resources^{35,36,38,150,157,172} to decrease fragmentation, improve access, and promote integration of care^{79,85,176}. In other words, patient navigators link patients and their families to appropriate services and resources^{38,39,68,69,71,100,111}. This is a primary function for both professional⁸⁵ and lay patient navigators³². Importantly, patient navigators do not create new services¹⁵⁰, but they may advocate for services that do not currently exist³⁴. Fundamental to this function is the need to identify medical and community supports (e.g., screening services)^{25,109,159,172,184}, and help patients choose, use and understand services¹⁰⁹. To facilitate this, patient navigators might maintain a directory of services for a particular geographical area^{34,157}. Patient navigators help

patients connect to primary care¹⁹⁴, or identify a “medical home” (model of primary care that provides individualized and patient-centered care delivery¹⁹⁵)^{25,68,159}, and determine eligibility for clinical trials³².

Similarly, case managers help patients navigate the healthcare system^{96,126,177}, ensuring that they receive timely, efficient, and appropriate care^{108,122,177}. Case managers guide patients and their families^{49,124}, by providing a linkage to pertinent resources and services^{49,123,127,135,171,177} and up-to-date information⁹⁸. Case managers have also been identified to evaluate patients for community-based services¹⁶⁸.

Both patient navigators^{7,21,36,36,138,196} and case managers^{10,43,54,128,167,171,180,185} refer patients and their families to appropriate mental and physical healthcare services, including specialty providers and community-based supports across various settings (e.g., domestic violence assistance, legal and financial assistance, etc). In some case management programs, coordinating referrals makes up a large amount (45%) of the case manager’s workload¹⁷⁴. Case managers identify new resources in the community and maintain ongoing relationships with referral sources^{54,174}.

5.4.9. Reduction of Barriers

Patient navigation is often considered to be a “barrier-focused” intervention^{55,78,85,89,193} that aims to identify and reduce physical and psychological barriers to care delivery^{11,17,22,23,31,34–36,81,83,89,102,104,105,110,115,141,151,157,172,176,192,197} and bridge system gaps^{21,89}. Case management also involves proactively reducing barriers for patients and their families^{10,54,105,136,152,182}, as a means towards timely and effective care delivery.

Patient navigators are known to make appointments for patients^{25,34,70,84,109}, during which they might help fill out necessary paperwork and provide language

interpretation^{25,31,34,79,82,149,157}. Patient navigators also assist with transportation (e.g., to appointments)^{25,32,34,70,79,82,84,149,157} and other practical needs (e.g., obtaining child care or financial assistance)^{31,38,82,109,172,184}. Although patient navigators address barriers to care, they do not provide services⁵⁵. An identified function of patient navigation is proactive and flexible problem-solving^{44,55,172}. Patient navigators can help patients manage expectations and prepare for appointments and treatment⁶⁹, sometimes facilitating ancillary care as needed²⁵.

Case managers are known to reduce barriers by helping patients improve their health literacy¹³⁵ and independent living skills (e.g., housing assistance)¹²⁷. Case managers can also assist with complicated forms (e.g., financial services)^{49,105}. A central function of case management is problem solving as a means of providing more integrated care to patients^{49,107,124,132,177}.

5.5. Theme 3: Background and Knowledge Areas of Patient Navigators and Case Managers

Patient navigators can be individuals with or without a professional background in care delivery^{22,23,27,31–33,36,101,104,111}; non-clinician navigators are typically referred to as peer or lay navigators^{27,31,32,36,101}. Whether patient navigation programs should be staffed by a professional or lay patient navigator is controversial³⁶. Many patient navigation programs in the United States employ lay patient navigators¹⁹. Navigation programs are diverse in personnel and practice scope, as this is typically driven by local needs²⁷. Professional patient navigators have backgrounds in various disciplines²⁷ including nursing^{29,32,69,80,86,87,101,103,121,139,151}, social work^{29,70,72,80,87,101,103}, and health education¹⁰¹. Alternatively, case managers typically have a professional clinical background in areas of social work^{77,189}, nursing^{73,77,90,92,99,105,146,189,198}, physiotherapy,

occupational therapy¹¹², pharmacy¹⁶⁴ and other health and human services^{77,125}. In some jurisdictions, case management services are provided by community-care nurses¹¹².

Lay navigators are sometimes individuals from the local community that strive to improve access to care for a particular population^{32,78} or have experience with the healthcare system (e.g., survivors)^{9,29,192}. Individuals in these roles can often address barriers in a more culturally appropriate manner¹⁹². Patient navigators may also be individuals with administrative or legal experience⁹. Typically, lay patient navigators receive some level of training^{32-34,44}; in Canada, this training includes role definition, cultural awareness, communication skills, and scope of practice³⁵. Lay patient navigators usually work under the supervision of a care professional¹⁹⁹, such as a social worker¹⁰³. Professional patient navigators also receive training upon becoming navigators¹¹⁶; this includes learning about relevant community resources and guidelines for services¹¹⁶.

Both case managers and patient navigators understand the healthcare system to varying extents. Patient navigators usually have extensive knowledge of care systems and community supports^{32,36,70,100,103} and understand the culture of care^{32,34}. Professional navigators (i.e., nurses) have knowledge of medical procedures and possible complications¹²⁰. Patient navigators understand applicable professional and legal standards and regulations^{105,119}. Case managers usually have extensive knowledge of complex diseases^{113,161,182} and epidemiology¹⁴⁴. They possess knowledge of available services and treatments¹¹³, as well as the healthcare delivery system^{113,133}. For example, case managers possess the applicable knowledge to identify and use evidence-based clinical pathways^{137,160,180} and how to collect, analyze, and synthesize data¹⁸². Case managers in rural settings are considered to be “expert generalists”¹³⁰ who are able to provide quality and timely care with limited resources and healthcare options¹⁹⁸. They

are sometimes known as disability specialists⁷⁷. Case managers have extensive knowledge of applicable legislation and rules (including ethics)^{131,136,160} to facilitate the creation of a care plan across diverse settings and services¹⁴⁷. They understand emergency care and utilization management^{113,166}.

Patient navigators often collaborate with care professionals to provide culturally-sensitive care^{79,157,183} and competencies²³. For example, patient navigators strive to offer culturally and linguistically appropriate assistance and resources (e.g., assessment tools)^{17,35,192} to assist patients overcome barriers to care²⁵. Patient navigators ensure that information is provided in the patient’s language³⁴ and work within the customs of the surrounding community³⁶. They also work towards system change by encouraging diversity in staff and educating care providers³⁴. Although case managers also strive to provide culturally-appropriate care¹⁰, less information that describe specific functions related to the provision of culturally-appropriate care was described in the included articles. One way that case managers might achieve culturally-appropriate care is by determining the ways in which relevant cultural influences or beliefs might affect delivery systems^{168,182}.

Table 3. Overview of the similarities and differences in functions between patient navigators and case managers

Function	Patient Navigator	Case Manager
Advocacy: Providing public and explicit	Advocates on behalf of patients (e.g., for programs or services) ^{21,68,119,120,183}	Advocates on behalf of patients ^{10,54,76,106,114,122–124,128,131,136,146,152,186,200} in addition to hospitals ^{54,114,118,119,186} and insurance

<p>support on behalf of a particular entity (e.g., patient, organization, program, etc). The process of advocacy includes addressing recognized gaps in the system.</p>	<p>Advocacy is not considered to be a primary function⁷</p>	<p>companies; when conflict arises, however, case managers generally take position of the patient¹⁰</p> <p>Advocacy is considered to be a primary function^{74,118,133}</p>
<p>Care coordination (including transitions, discharge, and rehabilitation):</p> <p>“The deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services”²⁰¹</p>	<p>Networks and coordinates with patients and care providers across diverse settings^{4,69–72,79,89,110,119,138,141,151,159,202,203}.</p> <p>Distributes information across this network^{17,86,183}</p> <p>Provides care coordination^{4,39,79,82,89,101,138,183,193,204} to improve continuity⁴ and timeliness¹³⁹ of care.</p> <p>Sometimes integrated into patient’s care team^{29,183,184}, but not always⁷</p> <p>Supports transitions in care¹³⁹</p> <p>No literature to indicate that patient navigators are involved rehabilitation, apart from reducing barriers to needed care (<i>see sub-theme 5.4.9</i>)</p>	<p>Networks and coordinates with patients, caregivers, care providers, and stakeholders across diverse settings^{10,107,135,137,162,165,171,186}.</p> <p>Distributes information across this network^{10,124,154,165,186}</p> <p>Provides care coordination to improve continuity and timeliness of care^{10,33,92,107,112,114,123,147,148,173}</p> <p>Monitors and oversees the patient’s care pathway^{163,169}</p> <p>Acts as a coordinator of the care team^{74,163}. Regularly consults with members of the patient’s care team^{76,131,144,156}</p> <p>Coordinates care transitions in collaboration with care providers^{10,54,134,154,167,170,186}</p> <p>Rehabilitation is considered to be a key function of case managers^{54,54,162,167}</p>

<p>Case monitoring and patient needs assessment:</p> <p>Case monitoring refers to the process of supervising a patient’s activities as it relates to the maintenance and delivery of health care services. Patient needs assessment is a process of identifying and addressing gaps in patient care needs.</p>	<p>Helps patients and caregivers set and achieve care-related goals^{27,68,172}</p> <p>Conducts patient needs assessments^{4,29,35,172} and tracks interventions/outcomes¹⁸³. Provides patient-centered support¹⁹⁷ using a biopsychosocial model of care²⁵</p> <p>Patients may be approached by^{21,116}, or referred to¹¹⁹, a patient navigator</p> <p>Services are typically centered on a specific, pre-defined outcome of interest (e.g., screening)²⁷</p>	<p>Helps patients and caregivers set and achieve care-related goals^{10,54,94,112,131,134,153,160,167,179,182,186,186}. Organizes, plans, and implements activities according to goals and the care plan^{10,127,142,143,153,154,163,169,178,186}</p> <p>Conducts full initial^{47,134,148,156,160,164,166,178,182,205} and on-going^{91,178,186} patient needs assessments. Monitors, tracks, documents, and evaluates care^{54,75,76,137,155,164,170,182,186,186,200} and makes modifications⁵⁴ through patient-centered care^{146,177}</p> <p>Patients are typically screened to determine their need for case management services^{47,54,76,92,99,117,123,155,160,168,169,180}</p> <p>Services can be provided over a long period of time throughout the course of an illness⁹¹</p>
<p>Community engagement:</p> <p>Collaboration with individuals from various community groups to partner in collective activities (e.g., fundraising, knowledge</p>	<p>Conducts community outreach^{17,79} (e.g., to communicate role of the patient navigator^{34,105}). Sometimes involved in fundraising³²</p>	<p>Sometimes involved in the implementation and mobilization of community resources^{75,143}</p>

<p>dissemination, etc).</p>		
<p>Education (including self-management and empowerment) :</p> <p>Informational support provided to patients, and their caregivers and/or care providers. Includes emphasis on educating patients about the health care system and other information as it pertains to receiving appropriate and timely care.</p>	<p>Provides information and education to patients and their caregivers about treatment options and available resources^{4,25,34-36,68,69,86,89,110,116,157,159,172,206} by acting as a resource^{21,86,116}</p> <p>Promotes self-management^{21,34,35,119,159,202} to foster autonomy; however not all patient navigation programs emphasize empowerment⁷</p>	<p>Educates patients and their care teams about treatment options and possible complications^{10,47,54,76,161,167} and financial support (e.g., insurance) information^{54,76}</p> <p>Offers health promotion and self-management education^{47,54,94,103,106,134,143,146,171,173,179,186,186} to empower patients and foster autonomy^{10,134,153,154,168,179,186}</p> <p>Educates other professionals about treatments, financial supports for patients, and case manager duties^{10,76,131,186}</p>
<p>Administration and Research Activities:</p> <p>Involvement in the management or organization of an organization or research inquiry.</p>	<p>Helps patients and their caregivers find financial support/assistance^{34,79,82,104,157,202}</p> <p>Documents patient care activities^{110,138} and helps patients find and maintain health records³⁴. Aims to standardize processes within and across care settings^{86,105}</p>	<p>Organizes information on behalf of patients and their caregivers for financial support/assistance^{10,54,131,170,186,191}; however case managers are not always involved in the financial side of care¹¹⁸</p> <p>Mobilizes and evaluates appropriate use of resources across settings (e.g., utilization review)^{10,123,156,160,166,171,186}</p>

	Sometimes responsible for program evaluations ^{34,80,105,119,157} and assist in the research process ¹⁵⁷	Involved in cost-effectiveness ^{54,144,186} and quality analysis ^{54,186} . May be involved in research activities, such as writing project proposals ¹³¹ and collecting/analyzing data ^{178,186,189}
<p>Psychosocial support:</p> <p>Support provided to patients that extends across psychological and social needs. Includes, but not limited to: mental health; identity; and community support structures.</p>	<p>Provides emotional support to patients and their caregivers^{32,69,72,82,86,89,100,110,116,119,159,183,202,206}</p> <p>Does not provide counselling¹⁸⁴. Aims to reduce patients' anxiety and distress while interacting with care system^{4,21,68,70,121,172}</p> <p>Build and maintain relationships with patients, caregivers, and their providers^{71,183}</p> <p>Do not create new services¹⁵⁰, but may advocate for services that do not exist³⁴</p>	<p>Provides emotional and informational support for patients and their families^{105,106,124,186,200}</p> <p>Provides counselling^{75,174} (e.g., providing grief counselling and crisis intervention¹¹⁴)</p> <p>Build and maintain relationships with patients, caregivers, and their care team^{21,74,156,183}</p> <p>Sometimes fill a need for a need service (e.g., providing psychosocial care)¹²⁷</p>
<p>Navigation of services (including referrals):</p> <p>Proactive guidance through health care services, programs, and treatments, relevant to the patient's needs. Directing and coordinating a patient to specialized or</p>	<p>Helps patients and their caregivers navigate the healthcare system by connecting them to relevant services across various sectors and settings (e.g., hospital and community)^{69,72,82,100,111,140,176}. Considered to be a primary function for both professional⁸⁵ and lay³² patient navigators</p> <p>Initiates referrals to relevant services and resources^{34,39,71,100,150,159,184,202,207}</p>	<p>Helps patients and their caregivers navigate the healthcare system by connecting them to relevant services across various sectors and settings (e.g., hospital and community)^{43,105,177,186}</p> <p>Initiates referral to relevant services and resources to optimize patient outcomes^{10,54,122,123,128,143,167,171,174,177,185}</p>

professional services.		
<p>Reduction of barriers:</p> <p>Refers to the minimization or elimination of actual or perceived barriers to timely services, programs, or treatments.</p>	<p>Works to proactively reduce barriers to care^{17,34,39,70,79,81,82,84,89,102,105,110,116,141,151,157,159,176,184,203,207} (e.g., health literacy^{25,35})</p> <p>Patient navigation is considered to be a “barrier-focused” intervention^{31,78,89,103,193}. Patient navigators reduce barriers to care instead of providing care⁵⁵</p>	<p>Works to pro-actively reduce barriers to programs, services, and funding^{10,124,186} that could impact or delay care (e.g., transportation)^{105,152,165}</p> <p>Anticipates and solves problems^{10,107,132,137,156,177,182}</p>

Note. Exceptions to these differences have been noted in the literature and are further highlighted in the results section.

6. DISCUSSION

6.1. Principal Findings

This scoping review sought to identify differences in the roles, functions, and backgrounds of patient navigators and case managers. Despite significant overlap within the observed functions for each role, important distinctions did emerge. This research also noted many differences in the background and lens of patient navigation and case management services across varying contexts.

Patient navigators were observed to provide support in lieu of treatment or advice¹⁴⁹, whereas case managers were often reported to provide clinical care (e.g., psychiatric treatment)¹²⁷. In other words, a defining difference between patient navigators and case managers is that navigators provide emotional and informational

support, not clinical care²². This may be due to differences in clinical backgrounds, where the role of patient navigators may be filled by lay persons^{19,27,36,101}.

Across articles, an important goal of patient navigation was to help patients navigate amongst existing services⁹ and advocate for missing services³⁴ rather than create new services¹⁵⁰. However, case managers were able to fill a need by sometimes acting as a care provider (e.g., providing psychosocial care)¹²⁷. This differentiation had implications for the responsibilities of each role on the patient's care team. Specifically, patient navigators were observed to facilitate communication amongst formal and informal care providers^{17,21,23,25,86,109,121,138,141,172}, but were not always members of a wider care team⁷. Case managers, however, were observed to be integral members of the care team^{113,114} that were sometimes responsible for overseeing its management^{10,76,113,128,137,152,163}.

It has been noted in the literature that while patient navigation has become a staple in oncology care delivery, the position is largely unknown outside of that setting^{22,151}. Indeed, the current study found that most studies on navigation focused on the cancer care setting, but the intervention did target other conditions as well (e.g., chronic disease). Case management, on the other hand, is prevalent across many complex disease types and injuries^{47,105}. This distinction is likely owing to the historical origins of each role.

In settings where patients have access to both patient navigators and case managers, the distinction between roles is sometimes based on the length of relationship with patients. Specifically, patient navigators may work with patients for a predetermined amount of time (e.g., from screening to diagnosis), after which patients may transition to the case manager's care⁸³. However, patient navigation services are not

always limited to a certain point; in some cases, they might extend from pre-diagnosis to one year post-diagnosis⁸⁶.

Differences in the way that patient navigation and case management are defined across jurisdictions and countries^{47,136,208} suggests that these roles may depend on the nature of a governing health care system (e.g., United States' Medicare versus universal health care in other countries) and the focus of a particular provider¹⁴⁸. For example, case managers based in the United States appear to conduct more tasks related to utilization management and administration on behalf of patients than those in Canada. In Australia, cancer care coordinators fulfill a similar role to that of a patient navigator^{93,158}. In the past, case management was carried out by social workers to facilitate discharge for patients leaving the hospital²⁰⁹; case managers continue to be involved in discharge planning in countries with universal health care services (e.g., Canada, UK, Australia, etc)¹⁴⁵. Patient navigators, however, were not identified to play a substantial role in patient discharge in this study.

Within the identified articles, case managers conducted more administrative tasks related to administration, such as utilization review. Utilization review is undertaken as a means to lower costs associated with care delivery²¹⁰, thus is often conducted within insurance companies, hospitals, and other care setting²¹¹. Indeed, more studies described case managers in the hospital setting than patient navigators in this study. Historically, utilization review is considered to be an original function of the case managers¹⁷⁰.

As expected, some functions related to the case management role did depend on the context and setting of the intervention (e.g., rural case management¹⁷⁴). However, many functions appeared to be consistent across case management, such as patient

advocacy⁵⁴, care coordination activities¹⁰, rehabilitation⁵⁴, screening and needs assessments^{10,42,168}, administrative tasks (e.g., program/care plan evaluations)^{10,144,153}, and providing clinical care^{10,54}. Evidence from the literature supports core functions to the case manager role. In a recent review, Lukersmith and colleagues⁴¹ determined five core models across case management: (1) Broker (identifies patient needs and helps patient navigate care system); (2) Clinical (provides short-term clinical care in collaboration with care team); (3) Chronic Care (long-term care that is integrated across the social determinants of health); (4) Strengths Based (empowers patient towards self-management of care); and (5) Assertive (case managers provides intensive care that focuses on recovery over cure, such as in mental illness). Findings from the current study support the notion of these five core models across case management.

6.2. Professional Patient Navigator vs. Lay Patient Navigator

Few articles differentiated functions between professional and lay navigators in the current review. Like professional patient navigators, lay navigators were observed to assist patients and their families in overcoming barriers to quality care³³ and will sometimes make appointments on behalf of patients³¹. Where care coordination activities performed by professional navigators often involve transitional support⁴ and follow-ups after appointments¹³⁸, lay navigators have been observed to conduct more administrative tasks to promote integration³¹. For example, lay navigators are sometimes responsible for distributing consultation reports or test results to relevant members of the care team and notifying care providers about new symptoms³¹.

Given that lay navigators usually represent a particular population of patients, they are often responsible for conducting community outreach, such as by educating the public about screening practices and early symptoms of cancer³². Similarly, lay

navigators have been identified to provide emotional support to patients and their families⁸⁷, however they may not be suited to providing psychosocial support³².

6.3. Study Strengths and Limitations

A strength of this synthesis is that it covered a wide range of disease types, allowing for generalizations across settings. This may also be a limitation of this study, as it may be difficult to draw accurate conclusions about the functions of each role from a broad lens. Despite careful and systematic efforts with regards to methodology, articles were evaluated by one author. This may have impacted the reliability of the described method. To be included in this review, articles were required to use the terms patient navigation (/navigator) or case management (/manager). This may have eliminated articles that describe the same role under a different term (e.g., care coordinator). While every effort was made to capture articles that delve into the functions of patient navigators or case managers, it is likely that not every relevant article was identified through the search strategy. Included articles were also limited to those in which full-text papers could be retrieved; therefore, potentially relevant articles may have been excluded due to inaccessibility (e.g., through inter-library loan). The databases used in the current study were chosen due to their wide-spread use across diverse health sectors; however, additional databases relevant to the present inquiry (e.g., Embase) may have additional articles of relevance. Finally, few articles related to lay patient navigators were identified in the present study. This may have been due, in part, to the MeSH term “professional role+” used in the CINAHL keyword search strategy.

Finally, this study was limited to published articles regarding the functions and background of patient navigators and case managers. Given the ubiquity of patient navigation and case management programs, many of which are not formally

documented, current patient navigation and case management practices may not have been captured within this scoping review.

6.4. Implications

This is the first study, to the authors' knowledge, that directly compared the functions and backgrounds of case managers and patient navigators (professional and lay). Differences in the way that patient navigation and case management are defined (both within and across countries) has led to role confusion. For example, in practice, patient navigators encounter cases that sometimes require additional resources that may not be available to the patient. As a result, patients using patient navigation services may require additional support more akin to case management.

The present study offers important distinctions between the roles and functions of patient navigators and case managers, which may be used to inform current practices across multiple health and social settings. The distinctions presented in the current paper provide a basis for advancing future research and practice through more consistent use of language related to these two particular roles.

6.5. Concluding Remarks and Future Research

The current study identified important distinctions on the differences and unique contributions of patient navigators and case managers, regardless of setting or context. However, there remains significant ambiguity between these two roles, particularly with regards to the scope of a patient navigator's responsibilities¹¹⁰. Future research is needed to capture standardized definitions for these roles, and others that deal with individualized, patient-centered care (e.g., care coordinators). Moreover, further work is needed to determine the relationship between these functions and the context (i.e., target condition or diagnosis) and setting (e.g., hospital vs. community) of patient navigators

and case managers. For example, accommodating diversity in both patient navigation at the program level will be critical in the development of standardized definitions.

Standardization in the scope of practice between these roles is necessary to reduce role ambiguity¹⁶ and improve service delivery.

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MANUSCRIPT TWO

Peer-to-peer support groups on Facebook for families of children with complex care needs in New Brunswick: An environmental scan

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Abstract

This environmental scan aimed to describe the purpose, use, and reach of health-related peer-to-peer (P2P) support groups on Facebook for caregivers of children and youth with complex care needs (CCN) in New Brunswick. A total of 3,104 searches on Facebook and consultations with thirty-two stakeholders led to the identification of forty-seven Facebook support groups (21 active). Groups targeted a range of conditions, with autism and related intellectual disabilities appearing most frequently. Content analysis of posts indicated that groups were primarily used to exchange informational support. This study showed that Facebook-based P2P support groups are available to families of children and youth with CCN in NB. This work also lays a foundation for future scans of Facebook-based support groups in other Canadian provinces and beyond.

1. Introduction

Children and youth with complex care needs (CCN) are individuals with multidimensional health and social care needs, who may or may not possess a diagnosis of a recognized medical condition (Brenner et al.). Children and youth with CCN present across diverse settings, requiring services from multiple care providers (Luke, Doucet, and Azar), which can result in significant physical, mental, emotional, and financial pressures on their caregivers. Moreover, families of children and youth with CCN often have multiple unmet informational needs (Roche and Skinner). Reading information on the Internet has been shown to help parents and guardians improve their understanding and gain a vocabulary related to their child's health concern (Ziebland and Wyke); however, conducting relevant searches with a limited understanding of a suspected or confirmed diagnosis and interpreting identified information are known barriers to accessing information and support (Roche and Skinner).

Online peer-to-peer (P2P) support represents an opportunity for families of children and youth with CCN to communicate with peers and receive support without leaving their homes (Cole et al.). P2P support can help families increase their knowledge of available services and resources (Santelli, Turnbull, and Higgins) and promote problem-solving (Bray et al.). Social media websites in particular provide a platform for the exchange of emotional and informational support among users (Shavazi, Morowatisharifabad, and Mellat Ardekani; Setoyama, Nakayama, and Yamazaki). For example, Facebook has been identified as an online environment conducive for P2P support and health-related information seeking (Bender, Jimenez-Marroquin, and Jadad; Farmer et al.). However, the availability and use of P2P support groups for families of children and youth with CCN on Facebook is unclear. The current study aimed to

identify P2P support groups on Facebook that target families of children and youth with CCN in New Brunswick (NB) and characterize the purpose, use, and reach of the identified groups.

2. Background

Meeting the support needs of caregivers of children and youth with CCN can be challenging for care providers due to the complex nature of these conditions.

Approximately 15% of children and youth in Canada live with a chronic condition affecting their every day life (Strickland et al., 2015). They face a range of health concerns, including: non-chronic, acute conditions (e.g., pneumonia, trauma); episodic chronic conditions (e.g., asthma, depression, anxiety); lifelong chronic conditions (e.g., Type I diabetes, congenital heart disease); progressive or life-limiting conditions (e.g., cystic fibrosis; cerebral palsy; down syndrome); and malignancies requiring treatment (e.g., leukemia, tumours) (Children's Hospital Association, 2021). The exact incidence and prevalence rate of children and youth with CCN is not well understood due, in part, to ambiguity in the terms used to define this population (Carnevale et al., 2008).

Increasingly, caregivers are turning to the Internet to connect with individuals in similar circumstances to exchange informational and emotional support (Giustini et al). Social media websites and mobile applications provide virtual spaces for caregivers to engage in health-related communication. In this paper, we define social media as any web-based tool used for “computer-mediated communication” between two or more individuals (Grajales et al.). Social media websites and applications may be a particularly useful means of facilitating P2P support for caregivers of children and youth with CCN, due to their accessibility, ease of use, and prevalence (Moorhead et al.).

Informal caregivers of children and youth with CCN (e.g., parents, other family members, etc) often take on multiple roles related to the care of their child, including 24/7 medical care to ensure their well-being and survival (Kirk et al., 2005; Woodgate et al., 2015). These caregivers often carry the burden associated with lack of continuity of care and managing health system complexities, including coordinating care for their child (e.g., assessments, treatments, etc) (Cady & Belew, 2017) and providing routine and/or special at-home medical care for their child (e.g., post-operative care) (Woodgate et al., 2015). The pressures associated with carrying out these tasks can be further compounded by work commitments, financial strain, transportation issues, and caring for other children (Pratt-Chapman & Willis, 2013), which can lead to increased caregiver stress and loneliness (Vasileiou et al.). Parent-to-parent support has been shown to decrease psychological distress, enhance coping skills, and increase self-efficacy towards problem solving in caregivers of children with CCN (Bray et al.; Santelli, Turnbull, and Higgins).

Online P2P support can promote access to information (Kaal et al.), improve knowledge about a particular condition (Rupert et al.), and facilitate the exchange of tailored informational and emotional support (Shavazi, Morowatisharifabad, and Mellat Ardekani; Diefenbeck, Klemm, and Hayes; Partridge et al.); this occurs through the sharing of personal experiences with others (Henwood et al.; Moorhead et al.), expression of frustrations (Diefenbeck, Klemm, and Hayes), and inquiries about one's own care or the care of a family member (Scharett et al.). Moreover, relationships formed through online interactions can result in feelings of community and solidarity (Horter et al.). Finally, engaging in online P2P support can help fill a gap in support

needs that may have been previously unmet by professional care providers (Niela-Vilén et al.).

P2P support on social media facilitates social support between peers by creating an environment that connects support seekers with support providers (Rains and Wright). Social support is further fostered through the availability of connection with individuals outside one's personal social network (Rozzell et al., 2014), with whom individuals might share more health-related commonalities and experiences. The most common types of health-related support messages exchanged on social media consist of informational, emotional, and tangible (i.e., provision of physical aid or instrumental) support (Bender, Jimenez-Marroquin, and Jadad; Farmer et al.). Where informational and emotional support is often found to be the most common type of support exchange in online P2P support groups (Rains, Peterson, and Wright), tangible support is the least common (Embuldeniya et al.; Mo and Coulson).

Potential risks identified with engagement of health-related online P2P support include the reliability of information posted to groups (Moorhead et al.; Stock, Martindale, and Cunniffe) and members' ability to appraise relevant information (Park et al.). However, an emphasis on emotional support within some support groups has been observed to result in fewer posts related to medical information, suggesting that concerns regarding quality of information may not be a global (Van Uden-Kraan et al.). Individuals who participate in online P2P support have also cited concerns related to lack of confidentiality and privacy (des Bordes et al.; Moorhead et al.; Zhang). Despite these concerns, the ability to share experiences and find validation through online P2P interactions is often perceived by users to outweigh risks around privacy and potentially low quality of information (Dumajj and Tijssen).

Although online health-related interventions have been criticized due to barriers, typically experienced by low-socioeconomic and vulnerable populations (Love et al.), improved public accessibility of the Internet has led to a rise in accessibility in recent years (Rideout and Katz). By 2018, approximately 86% of Canadians had access to the Internet at home, with 61% reporting activity with social media websites (Canadian Internet Registration Authority). Among those available, Facebook led in popularity, with approximately 77% of users registered on the website (Canadian Internet Registration Authority). Today, Facebook communities include a wide diversity of users, including patients, caregivers, health professionals, and researchers, among others (Green et al.). This increasingly widespread use of the Internet suggests that online P2P support is a more accessible path to P2P support for low-income families, who are often not able to attend in-person support groups due to various barriers (e.g., transportation, work, etc.) (Swindle et al.). New Brunswick (NB), in particular, has one of the highest rates of poverty in the country (Conference Board of Canada); yet, approximately 77% of NB households had access to the Internet as of 2012 (Statistics Canada). Given recent reports on the quality and speed of Internet use in NB (Canadian Internet Registration Authority), it is likely that more New Brunswickers have gained access in recent years.

An important advantage of online P2P support rests in its ability to traverse geographical boundaries and time constraints (Naslund et al.). This benefit of online P2P support is particularly relevant for caregivers of children and youth with CCN in NB, who may not have the time or resources to attend in-person support or may be living in rural or isolated regions. The ability to connect with peers across the world has led to the development of numerous health-related Facebook support groups that aim to provide informational and emotional support to individuals in similar situations (Farmer et al.).

Across the numerous social media platforms, Facebook appears to contain the largest number of support groups for caregiver and persons living with chronic diseases (de la Torre-Diez, Diaz-Pernas, Anton-Rodriguez, and Giustini et al) One disadvantage to these large scale, international support groups is the inability of members to provide geographic-specific advice when a member expresses a need for particular services or resources. Caregivers of children and youth with CCN often require substantial support from services and care providers across multiple local settings (Luke, Doucet, and Azar), which can result in unmet informational needs (Roche and Skinner). Locally based P2P support groups on social media platforms, whether provincially or regionally based, represent an opportunity for caregivers to connect and provide navigational support through the provision of information and advice. Despite the widespread use of the Internet and social media, it remains unclear how NB caregivers of children and youth with CCN use social media to engage in P2P support for health-related communication. Moreover, the extent to which these types of P2P support groups are available and used by caregivers of children and youth with CCN in NB, however, has not been previously explored.

3. Objectives and Research Questions

The current study aimed to identify the number of P2P support groups on Facebook for caregivers of children and youth with CCN in NB and describe the purpose, use, and reach of identified groups. Caregivers of children and youth with CCN possess valuable knowledge obtained through lived experiences. Better understanding and awareness of online P2P support groups for caregivers of children and youth with CCN in NB may serve to improve informal support networks and create bidirectional education opportunities between caregivers, health professionals, and community organizations.

As a result, the following three broad research questions were identified and used to guide the environmental scan:

1. What are the available P2P support groups on Facebook for caregivers of children and youth with any CCN in NB?
2. What is the purpose (i.e., intention of the group) and use (i.e., by members) of Facebook-based P2P support groups for caregivers of children and youth with CCN in NB?
3. What are the target audiences, conditions, and geographical reach of P2P support groups for caregivers of children and youth with CCN in NB?

Few studies have attempted to identify and analyze health-related P2P support groups on Facebook. Farmer and colleagues aimed to quantify the number of Facebook groups connected to common medical conditions. These researchers noted that Facebook contains a large number of patient and carer groups (757), with over a quarter of a million individual users. Similarly, Mamun and colleagues examined the objectives, use, and reach of Facebook groups related to hypertension, revealing that the purpose of most identified groups was awareness creation and active communication did not appear to occur between members. Another study examining the use of Facebook groups for persons with diabetes (Stellefson, Michael et al.) found a greater emphasis on the exchange of informational support.

Bender and colleagues aimed to determine the purpose and use of Facebook groups related to breast cancer through content analysis and apply a coding scheme to classify the age and geographical location of group creators. Results also showed a large number of patient and carer groups (620) with over one million total members. Finally, in a study that analyzed user-generated content in a Facebook-based diabetes support group

(Zhang, He, and Sang), researchers found that users' interactions centres on the exchange of emotional and informational support, as well as community building. All of the observed support groups in the described studies focused on an international audience of members across the social media platform, whereas the current study intends to explore geographic-specific Facebook groups. No studies, to the authors' knowledge, have attempted to catalogue Facebook-based P2P support groups for use by caregivers of children and youth with CCN. The purpose of this study is to explore the purpose, use, and reach of P2P support groups on Facebook for caregivers of children and youth with CCN in NB.

4. Methodology

An environmental scan was chosen to identify and describe available P2P support groups for caregivers of children and youth with CCN on Facebook.

Environmental scanning is a process of collecting and organizing data about events or trends from multiple sources (Choo). Environmental scans, sometimes referred to as *needs assessments* (Rowell et al.) or *internal assessments* (Graham, Evitts, and Thomas-MacLean), are used in the healthcare sector to inform decision-making, strategic planning, and evidence-based policies (Charlton et al.; Graham, Evitts, and Thomas-MacLean). Although an agreed upon established methodology does not exist on conducting environmental scans (Rowell et al.), the process typically involves multiple (two or more) methods of data collection (e.g., interviews, surveys, literature searches, etc.) (Society for Human Resource Management).

4.1. Data Collection

For the purposes of this environmental scan, the following data collection methods were used: (1) an online Facebook search of relevant groups; and (2)

consultations with NB stakeholders, including organizations that provide services and resources to caregivers of children and youth with CCN and caregivers themselves.

These methods are described in further detail in the following sections.

4.1.1. Online Facebook Search

Relevant support groups were identified by searching Facebook using the platform's built-in search engine and a predetermined structured keyword search in both English and French. Given that NB is a bilingual province, careful consideration was made to ensure that potentially relevant groups in both languages were captured by the search strategy. Comprehensive keyword searches related to children and youth with CCN, using various synonyms often used by the general public (e.g., "special needs"), were conducted for groups inclusive of various condition types. The list of keywords was developed in English, translated to French, and then vetted by a bilingual co-author (RA). Given the broad range of conditions encompassed by complex care needs, a second keyword search examining specific conditions was conducted in May 2019 and updated in May 2020 using the same protocol. Keywords for this search were derived from a list of conditions that have been encountered by patient navigators employed by NaviCare/SoinsNavi, a province wide patient navigation centre for children/youth (0-25 years of age), families, and health care providers of children and youth with CCN. Since launching in January 2017, this centre has assisted over 200 families and professional care providers, connecting them to needed services, resources, and programs. A full list of keywords can be seen in Supplementary File 1.

Since it is currently not possible to limit search results on Facebook by geographical location, the identification of relevant groups in NB impacted the targeted keyword search by requiring the pairing of keywords with twenty-four geographical

locations in the province. Geographical locations consisted of cities and towns with more than 2,000 inhabitants.

4.1.3. Consultations with Key NB Stakeholders

Various stakeholders (e.g., patient navigators, care providers, and parents or family members of children and youth with CCN) were consulted to inquire about additional Facebook support groups for caregivers of children and youth with CCN in NB that may not have been captured by the keyword search. A total of thirty-two relevant stakeholders across NB were identified by NaviCare/SoinsNavi patient navigators. Stakeholders (initially contacted in May 2019) were informed about the objectives of the current environmental scan by email and asked if they were aware of any Facebook groups that may be of relevance. The participating NB stakeholders included individuals from various government and non-profit health care organizations from across the province.

NaviCare/SoinsNavi's Patient and Family Advisory Council (PFAC) were consulted for additional relevant Facebook groups. The PFAC, which advises the centre's patient navigators and research team, consists of six parents of children and youth with CCN and one young adult who experienced CCN as a child. The PFAC members were invited to provide input on the environmental scan during one of their monthly meetings by providing recommendations during the meeting or sending an email to the lead author.

Finally, a bilingual Facebook post was published to NaviCare/SoinsNavi's Facebook page requesting information about relevant groups from the general public. Approval from the Research Ethics Board was not required as this study met the

exclusive criteria of the Canadian Tri-Council Policy Statement, given that all data requested is considered to be publicly available information.

4.1.4. Inclusion and Exclusion Criteria

Groups identified from the online Facebook search strategy and consultations with stakeholders were screened according to an a priori inclusion and exclusion criteria. Facebook groups were included if they included informal caregivers of children and youth with CCN (e.g., parents, grandparents, relatives, etc) in NB across a broad range of conditions and were categorized as *support* groups (see section 4.3 for more information on this categorization). Given the relatively small population within the province of NB and the rarity of certain conditions in the keyword search, groups were not required to specifically target caregivers of children and youth with CCN; however, groups were required to include informal caregivers within its scope for support. In other words, groups that generally targeted individuals with various CCN, such as adults with CCN or caregivers of adults with CCN, were included if they also included informal caregivers of children and youth with CCN within their membership. This strategy ensured that we cast a wide net across available support groups for caregivers of children and youth with CCN in NB. Included groups were required to primarily target individuals within NB, which impacted the search strategies. Eligible groups were not required to have the name of a NB location in the group title or description, but groups without a geographical designation did require verification from a key stakeholder that it exclusively targets New Brunswickers.

Facebook groups can fit within one of three privacy designations: public (content is publicly accessible and any user can join); closed (discussion content and members are only visible to members; prospective members must be added by a moderator); and

secret (group is not visible in the Facebook search engine; prospective members must be invited by current members). The privacy designation of groups (public vs. closed) is determined by the visibility of discussion posts: public groups are those visible by any user, whereas users must request to join closed groups to see their content. Secret groups were not included in the current study as these groups are not visible to non-members. Groups were included in the current study if they were publicly available; content collected from private (i.e., “closed”) groups, identified by stakeholders, only included publicly available data on its main page (i.e., name, description, number of members, number of recent posts). Private groups were included despite the restriction in content visibility to better understand the extent of support available to caregivers of children and youth with CCN.

4.2. Data Extraction

Keywords were inputted individually into the Facebook search engine and total results were recorded. A total of 3,104 searches took place according to the keyword search strategy (1,552 in English and French, respectively). Groups were screened according to the predetermined inclusion criteria (see section 4.1.4). Data was extracted using a data extraction form developed for the purpose of this study (see Table 1).

Table 1

Data extraction form

External group characteristics	
Characteristic	Description
Group Name	Designated name of the group
	Internet URL of the Facebook group

Group URL	
Target audience(s)	Type of user targeted by group (e.g., patient, parent/guardian, sibling, etc.)
Target condition(s)	Condition(s) that represent the focus of the group (e.g., autism, spina bifida, not condition specific, etc.)
Target geographical location	Location within NB (e.g., NB, Sussex, Saint John, etc.)
Internal group characteristics	
Characteristic	Description
Number of members	Total number of members in the group
Average number of posts	Average number of posts published in group within the past thirty days
Active versus not active	<i>Active</i> is defined as a group with a post published within the past twelve months
Privacy designation	Whether the group is classified as <i>public</i> or <i>closed</i>
Number of administrators or moderators	Total number of group administrators and moderators
Discussion posts	Description and time stamp of posts published to the group, if available
Average number of replies	Average number of replies to the last twenty posts published in the group, if available
Group description	The published description of the group

Other notable findings	Any other information of relevance to the group
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The lead author reviewed eligible groups and extracted information related to each groups’ external and internal group characteristics. Publicly available information on the main page of Facebook groups includes a numerical summary of posts published to the discussion board within the past thirty days but does not show the content of these posts if the group is designed as “closed”. Therefore, some “closed” groups could be classified as active if this section on their main page indicated whether a post had been published within the past thirty days.

4.3. Data Analysis

Thematic analysis was chosen to understand the purpose and use of each group by examining the title of the group, the description of the group, and the twenty most recent discussion or “wall” posts (where available). Thematic analysis aims to provide a comprehensive summary of a phenomenon in the everyday language of those events by remaining close to the “surface” of the words used by participants themselves rather than attempting to interpret meaning (Sandelowski). A pilot analysis of posts within Facebook groups determined that twenty posts would be sufficient for characterizing the use of each group and this number has been used in previous research analyzing content in Facebook groups (Stellefson et al.).

Group content (i.e., title, description, and wall posts) were used to determine categorical group type, as determined by Bender and colleagues. This classification scheme resulted in four different group types: support groups (aims to support the informational or emotional need of caregivers of children and youth with CCN); fundraising or awareness-raising groups (aims to bring awareness/raise financial

resources for a cause); promote-a-site groups (aim to advertise an external website); and others (e.g., research, educational, and social groups designed for knowledge dissemination or health promotion, etc). Two reviewers from our team independently screened each group and classified them according to one of the four categories. Only groups labelled as support groups were included in further analysis. None of the researchers were members of the groups identified in the scan.

Content from Facebook discussion posts were categorized and labelled according to one of 6 categories: *informational*, *emotional*, *inquiry*, *advertising*, *fundraising*, and *other*. Informational posts were those containing information of relevance (e.g., shared news articles). Emotional posts describe posts relating an experience, story, or narrative, often allowing a user to share frustrations or successes. Inquiry posts contained a question or set of inquiries from members (e.g., about seeking resources). This type of post differs from informational posts, in that it is primarily based around a question. Advertising posts include a notice regarding an event or sale of a product, and fundraising posts aim to raise funds for a particular cause. Finally, posts designated as “other” are any posts that do not fit one of the previous five categories with an explanation.

The purpose of included Facebook groups was determined by a content analysis of group descriptions, available regardless of group privacy designation (i.e., public or closed). Content analysis is a qualitative and systematic approach to coding and categorizing text (Mayring) that involves multiple strategies (Vaismoradi, Turunen, and Bondas). The use of Facebook support groups was determined through content analysis of the twenty most recent discussion posts and group descriptions (Stellefson et al.), in addition to a quantitative descriptive analysis of data related to discussion posts and

membership, specifically of the following analytics: the number of posts in the past thirty days; number of group members and moderators; number of discussion post types (i.e., informational, emotional, inquiry, advertising, fundraising, and other); and number of replies to discussion posts). Data related to the use of Facebook groups were collected in public groups only, as discussion post content is not visible to non-members in closed groups. Quantitative data was organized and analyzed using Excel.

5. Results

5.1. Facebook Group Selection

A total of forty-seven support groups were identified through the environmental scan (Table 2). Thirty-seven groups originated from the Facebook keyword search, five from consultations with the NaviCare/SoinsNavi FAC, and five from recommendations from other key stakeholders. The keyword search of groups using Facebook's built-in search engine resulted in 19,883 groups (15,160 in English, 4,723 in French). After applying the inclusion and exclusion criteria for the groups retrieved through the Facebook keyword search, thirty-seven groups were included in the current analysis. Groups were excluded for the following reasons: (1) duplicate/previously identified group; (2) group did not primarily target New Brunswickers; (3) irrelevant group; and (4) not a support group. Due to restrictions of the Facebook search database, results were not collated outside of the platform; therefore, the total number of results yielded from the Facebook search (19,883) includes Facebook groups that appeared multiple times across the 3,104 individual searches. For a complete list of the results from each individual keyword search in both English and French, see Supplementary File 2.

Included groups involved a total of 2,935 members across support groups. Only twenty-one groups were active compared to fourteen not active groups. The remaining twelve groups could not be labelled as either active or inactive due to privacy restrictions (i.e., group discussions were closed to non-members). Groups had an average of 4.0 posts (sd = 9.2) over the past 30 days and demonstrated an average of 1.75 (sd = 2.3) replies for each discussion post. Included groups had a rounded average of one moderator per group; however, the specific number of moderators varied considerably. Eight groups did not have a designated moderator (C, M, O, T, X, LL, SS, and UU) and one group (II) had ten moderators. The earliest support group on Facebook that primarily targeted families of CCN in NB was group E, created on 10 May 2007. The most recent group (Z) was created on 25 April 2019. Most of the groups presented their information in English (n = 44), with two bilingual groups, and one French group.

5.2. Research Question #1: Facebook Support Groups that Target NB Caregivers

Included groups represented a diverse range of available P2P support on Facebook for NB caregivers of individuals with CCN, including children and youth with CCN in NB. Table 2 outlines the complete list of Facebook groups identified through the environmental scan, including related demographic variables. For full descriptions of each identified group, please see Supplementary File 2.

The majority of identified groups (thirty-three total) required Facebook users to request to join the group to see content and participate in discussion posts (i.e., closed groups). Some of these groups required prospective members to answer two to five short questions to assess membership eligibility. Remaining groups (fourteen total) were public groups and did not screen members or restrict content to the public. Four groups

contained only one member; while one could argue that these groups may not be support groups (which would require more than one member to interact), these groups were included to define the breadth of support groups available to NB caregivers.

Table 2

Groups identified through the search strategy

Group identifier	Group Facebook name	# of members	Privacy designation	Activity status
A	ADHD Parent Support Miramichi, NB	1	Closed	Not visible
B	ADHD, ODD, Autism Family Support Group New Brunswick	236	Closed	Active
C	Allergies, Asthma, Eczema Support - Fredericton Area	37	Public	Not active
D	Autism Family Friendship Group	120	Closed	Active
E	Autism New Brunswick*	3	Public	Not active
F	Autism New Brunswick*	12	Public	Active
G	Autism New Brunswick Support Group for Parents	95	Closed	Active
H	Autism Parents Group - New Brunswick, Canada	515	Closed	Active
I	Autism Resource Centre - Moncton	283	Public	Active
J	Bathurst/Orange autism support group for families and caregivers	45	Closed	Active
K	Bedford Sackville Autism Support	1	Public	Not active
L	Brain Injury New Brunswick	302	Closed	Not visible
M	Cerebral Palsy Parent Support Group, Saint John N.B.	2	Closed	Active
N	Charlotte County NB Autism and Intellectual Disability Support Group	31	Closed	Active
O	Child Mental Illness New Brunswick	4	Public	Not active
P	Children with Behavioral Issues support group- New Brunswick	2	Closed	Not active
Q	Complex Children Of The Maritimes	293	Closed	Active
R	Diabetes Sussex & Area Group	61	Public	Active
S	Epilepsy support and Awareness in New Brunswick	11	Closed	Active
T	Family Support Workers of Fredericton and Surrounding Area	1	Public	Not active

U	FASD Support Group Fredericton	3	Closed	Active
V	FAST-NB Food Allergy Support Team-North Bay	6	Closed	Not visible
W	Focus on Youth Mental Health in New Brunswick	38	Closed	Not visible
X	Fredericton ADHD Support	5	Closed	Not visible
Y	Fredericton F.A.S.D Support Group	7	Closed	Active
Z	Friends Who Like CDBA NB Inc. Pat Peterson	1	Closed	Not active
AA	Friends Who Like Learning Disabilities Association of New Brunswick	2	Public	Not active
BB	Life with Type 1 Diabetes	17	Closed	Active
CC	Miramichi Diabetes Support Group	2	Public	Not active
DD	Moncton ADHD Support Group	27	Closed	Active
EE	Moncton Anxiety Support Group	2	Closed	Not active
FF	Moncton Autism Support Group	16	Closed	Not visible
GG	Moncton Diabetes Support Group	33	Closed	Active
HH	Moncton Support Group: Depression & Anxiety	35	Closed	Not visible
II	NBACL-Families United Network/L'ANBIC-Réseau des familles unies	197	Public	Active
JJ	New Brunswick Autism Connection	43	Closed	Active
KK	New Brunswick Families with Complex Special Needs	51	Public	Not active
LL	New Brunswick FASD/special Needs support group	6	Closed	Not active
MM	Oromocto Families of Children with DisABILITIES Support Network	13	Public	Not active
NN	Parents avec enfants déficients visuels - Nouveau Brunswick	18	Closed	Not visible
OO	PSGF - Parent Support Group Fredericton	65	Closed	Active
PP	Saint John Fibromyalgia + Chronic Fatigue Syndrome SUPPORT GROUP	14	Closed	Not visible
QQ	South Western New Brunswick Brain Injury Awareness and Support	75	Public	Active
RR	St John Families support network	50	Closed	Active
SS	Support for struggling families in st johns	6	Closed	Not visible
TT	Supporting Mental Health in New Brunswick	122	Closed	Not visible

UU	Sussex Support for Family Carers	26	Closed	Not visible
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Note. Group descriptions have been transcribed exactly as found in the publicly

available information on the group’s “about” page; grammatical errors have not been corrected.

* These two groups presented with identical names

5.3. Research question #2: Purpose and Use of Facebook P2P Support Groups for NB Caregivers

The purpose and use of Facebook caregiver support groups were determined through an analysis of group titles, descriptions, and discussion posts and quantitative analysis of variables related to the numbers of group members and moderators, types of posts (e.g., informational, emotional, inquiry, etc.), and number of replies to posts. From the forty-seven groups identified from the scan, thirty-nine contained group descriptions.

5.3.1. Purpose of Facebook-based P2P support groups

A total of four themes were compiled based on a thematic analysis of Facebook group descriptions to determine the purpose of Facebook P2P support groups. These themes are summarized in the next section and include examples from the group descriptions.

5.3.1.a. Theme 1: To Facilitate the Exchange of Emotional and Social Support

Statements related to the provision of emotional and/or social support were mentioned in the descriptions of thirty-one groups included in the current scan. Many descriptions alluded to feelings of isolation or difficulty coping as a motivating factor for the creation of the support group:

We all know that getting out of the home to participate in parent support groups is difficult and we all rely on the internet for this support (group MM).

Emotional support was a goal of many included Facebook groups, as expressed through group descriptions. Group creators encouraged members to share personal narratives through the detailing of personal accomplishments or struggles. The purpose of many groups centred around the creation of an online personal network, which sometimes extended into physical meetings and an emphasis on locally provided emotional and social support. Many descriptions alluded to feelings of isolation or difficulty coping as a motivating factor for the creation of the support group:

Every child with autism is unique, but many of our experiences are similar and as a parent we sometimes can feel alone in these experiences. We are here to show you you [sic] are not alone and when you've had a bad day and the meltdowns won't end, we want to be here to say "we get it." Our children our [sic] special, they are amazing and we are on the journey of our lives - but sometimes it can be the most frustrating journey on the face of the planet (group H).

5.3.1.b. Theme 2: To Provide a Platform for the Exchange of Informational Support

The sharing of information, through the exchange of advice and experience, was mentioned as a main purpose of 31 groups included in the current scan. This manifested itself in group descriptions through the encouragement of members to give advice and post any information that could be deemed useful to others.

My wish is that we can support one another, give advice to each other, and new information we come across (group A).

The motivation and purpose of these groups sometimes arose from a personal need to fill a gap in local services or resources:

When I finally accepted it and reach out for support. I realized there wasn't any support/resources designated to ADHD in our community (group A).

The lack of resources leading to the creation of some of these groups directly influenced the purpose of many groups. The provision of navigational support amongst peers was particularly prevalent in many Facebook group descriptions, particularly in the local geographic region:

I also hope that we may be able to share information about resources in the community, as we know that the population of oromocto [sic] fluctuates with the influx and outward movement of the military families. Sharing information here will help those families learn what resources are available to them (group MM).

5.3.1.c. Theme 3: To Create a “Safe” Space Conducive to Sharing Information

Many groups explicitly stated rules in their descriptions, intended to encourage a “safe” space between members for the exchange of emotional, social, and informational support. In some cases, rules were more extensive and required members to review external documents prior to joining. Rules were more often summarized in two to three short statements around respect and politeness:

We would like to keep this group a positive place and protect the dignity and integrity of our members. Please keep posts polite, avoid the use of foul language (group KK).

The privacy of members and confidentiality of information was an implicit goal of many groups, as indicated by the choice to designate thirty five out of the forty-seven support groups as closed groups. However, six groups specifically list privacy in their descriptions in the form of rules or clarification to prospective members about the visibility of information. Within these six groups, four were designated as closed groups and two were public. Moderators attempted to reassure members about their privacy

within the group by reminding them about the visibility of posted information to non-members:

Instead of a 'secret group', this closed group can still have privacy but be something others can find and ask to join. If you want to get personal and want some privacy, choose private messages, please, so you can choose those who will be privy to your information (group N).

The emphasis on creating a “safe space” (i.e., environment where members do not feel that they will become subject to emotional or physical harm based on their contributions) extended to group administrators and moderators, often in the form of disclaimers regarding medical advice and seeking opinions. These disclaimers were often a measure taken by moderators and/or group creators to protect themselves from legal risk. In some cases, groups included local resources for members to consult for primary care needs:

****NOTE:** We are not qualified to diagnose or provide medical advise [sic] related to childhood mental illness. We can however provide information on how to navigate mental health and other agencies for the benefit of your child (group O).

Finally, many groups emphasized that the purpose of their groups was to create a support network based on informal support. In this environment, informal support referred to a community of P2P support led by individuals facing similar situations as members (e.g., parents) rather than involving trained professionals (e.g., as moderators).

5.3.2. Use of Facebook-Based P2P Support Groups

Although forty-seven support groups were identified in the scan, discussion content from only 14 groups was analyzed due to privacy restrictions (i.e., closed

groups). The total number of posts collected from public support groups was 183. These posts were categorized according to one of six post types: informational support (n = 72, 39.3%); emotional support (n = 10, 5.5%); inquiry (n = 17, 9.3%); advertising (n = 17, 9.3%); fundraising (n = 3, 1.6%); and other (n = 64, 35.0%). The posts contained in the “other” category consisted of the following: group meeting announcements (n = 11, 17.2%); notifications about changes made to the group (e.g., name or description) (n = 11, 17.2%); shared content from another source on Facebook (n = 19, 29.7%); shared photos (n = 5, 7.8%); membership announcement (e.g., new member welcome) (n = 11, 17.2%); and event announcements (n = 6, 9.4%).

Despite the high number of informational posts in support groups (n = 72, with 13 total replies or 18% reply rate), more replies were observed on inquiry-based (n = 17 with 52 replies or 305.9% reply rate) and emotional (n = 10 with 28 replies or 280% reply rate) posts. An example of an observed inquiry-based post includes a question regarding locating a five-point car seat harness large enough for an older child with significant physical limitations; this post received twelve replies from other members.

5.4. Research question #3: Target Audiences, Conditions, and Geographical Reach of Facebook Support Groups for NB Caregivers

Identified Facebook groups targeted a wide range of Facebook users applicable to caregivers of individuals with CCN, including children and youth with CCN. Nearly half of the included groups aimed to provide support specifically to parents, guardians, and family caregivers of individuals with CCN (n = 25, 54.3%). An additional 45.7% (n = 21) targeted adults and youth with complex needs as well as caregivers and families.

Groups included in the scan aimed to provide support for many conditions, with autism spectrum disorder and related intellectual disabilities (n = 12, 25.5%) appearing

most frequently, followed by children and youth with CCN (in general) (n = 8, 17.0%); among these eight groups that target caregivers of children and youth with CCN in general, one geographically included all three maritime provinces (NB, Prince Edward Island, and Nova Scotia). This group was included due to its emphasis on NB caregivers. A list of all targeted conditions in the included Facebook groups can be seen in Table 3.

Table 3*Health-related conditions targeted by Facebook groups*

Condition	Number of groups	Percent of total
Autism and related intellectual disabilities	12	25.5%
Children and/or youth with CCN (general)	8	17.0%
Diabetes (general)	4	8.5%
Attention deficit hyperactivity disorder (ADHD)	3	6.4%
Fetal alcohol spectrum disorder	3	6.4%
Anxiety	2	4.3%
Brain injury	2	4.3%
Children and youth with mental health conditions	2	4.3%
Hearing and visual impairments	2	4.3%
Cerebral palsy	1	2.1%
Allergies	1	2.1%
Allergies including asthma and eczema	1	2.1%
Children with behavioral issues	1	2.1%
Epilepsy	1	2.1%
Fibromyalgia and chronic fatigue syndrome	1	2.1%
General with mental health conditions	1	2.1%
Learning disabilities	1	2.1%
Oppositional defiant disorder, ADHD, and autism	1	2.1%

Note. Table contains information from all groups included in the scan (N = 47)

Nearly half of the included Facebook groups aimed to provide P2P support for individuals from across NB (n = 20, 41.6%), regardless of specific place of residence. The most commonly targeted geographical locations within the province included: Moncton (n = 7, 14.9%), Fredericton (n = 6, 12.8%), and Saint John (n = 4, 8.5%); these three cities represent the largest municipalities in NB. Total number of groups categorized by geographical location is outlined in Table 4.

Table 4

Geographic basis of Facebook groups within New Brunswick

Targeted geographical reach	Number of groups	Percent of total
New Brunswick (general)	20	42.6%
Moncton, New Brunswick	7	14.9%
Fredericton, New Brunswick	6	12.8%
Saint John, New Brunswick	4	8.5%
Bathurst, New Brunswick	2	4.3%
Miramichi, NB	2	4.3%
Sussex, New Brunswick	2	4.3%
Charlotte County, New Brunswick	1	2.1%
North Bay, New Brunswick	1	2.1%
Oromocto, New Brunswick	1	2.1%
Woodstock, New Brunswick	1	2.1%

6. Discussion

The current environmental scan sought to better understand the availability and reach of P2P support groups on Facebook for caregivers of children and youth with CCN in NB, as well as their purposes and use, by group members. We identified relevant Facebook groups that primarily target NB caregivers of individuals with CCN, including children and youth with CCN. Our environmental scan included a structured keyword search on the platform and consultations with key stakeholders from across the province. Facebook was selected due to its high rate of use by Canadians (Canadian Internet Registration Authority) and the large number of health-related P2P groups on the platform (Bender, Jimenez-Marroquin, and Jadad; Farmer et al.).

A total of forty-seven Facebook support groups were identified in the current scan with a combined 2,935 members. The purposes of groups were summarized into three overarching themes: (1) to facilitate the exchange of emotional and social support; (2) to provide a platform for the exchange of informational support; and (3) to create a “safe” space community conducive to sharing information.

True to the goal of online social networking in general, Facebook groups in the current study often aimed to develop an online community of peers facing similar situations. The purpose of groups, as created by group administrators (e.g., moderators), was communicated through the group descriptions. Analysis of these descriptions revealed that many groups encouraged members to share personal experiences, through narratives, that could lead to a community of support. Some groups even encouraged members to connect with peers one-on-one through private messaging on the platform or offline in person. Two groups existed to facilitate the organization and planning of

offline meetings that took place in the local community; given the focus on geographic specific groups in the current study (i.e., NB), this was not a surprising finding. These groups provided an online environment for members of the offline group to connect outside of meeting hours and exchange relevant information.

Despite the emphasis on the provision of emotional and social support in the description of Facebook groups, the exchange of informational support (inquiry-based posts or those detailing information or advice) appeared to be the most common use of groups. This finding is consistent with previous research on health-related Facebook P2P support groups (Greene et al.; Stellefson, Michael et al.; Zhang, He, and Sang). These findings also support the notion that caregivers of children and youth with CCN appear to be motivated to use online P2P support groups to supplement information on health-related issues (Martin et al.). Although informational posts (i.e., those providing unsolicited information) were most prevalent in public groups, these types of posts received fewer replies than inquiry-based posts (i.e., those requesting information). The latter result is not surprising, given that these types of posts generally ask a specific question or seek constructive feedback (Zhang et al.).

Previous content analyses of health-related Facebook support groups have noted a high percentage of posts advertising products or services (>25%) (Greene et al.; Mamun, Ibrahim, and Chowdhury). The current study found that only 9.3% of posts in public support groups were related to advertising; this finding is consistent with Stellefson and colleagues who found that only 6% posts in diabetes support groups promoted a product or service. In a similar study, Zhang and colleagues did not find any posts related to advertising. These types of posts can be problematic, particularly those promoting non-Canadian Food and Drug Administration and US Food and Drug

Administration approved treatments (Greene et al.; Mamun, Ibrahim, and Chowdhury) or questioning the authenticity of health care authorities (Greene et al.). However, the current study did not find indications that P2P support groups for caregivers of children and youth with CCN are misleading or risky.

The majority of the groups were closed groups, meaning that the groups' memberships and content are not visible to non-members. Only fourteen groups were public groups, through which any user could view content published to the group. An additional twelve groups could not be categorized as either active or not active due to privacy restrictions. Facebook contains a feature that summarizes the number of posts over the past thirty days, which is visible even when a group is closed. Therefore, it is likely that many of the groups that could not be categorized were not active, as no posts were recorded over the past thirty-day period. Previous studies have limited their analysis of health-related Facebook groups to open groups due to this limited visibility for research purposes (Greene et al.; Mamun, Ibrahim, and Chowdhury; Stellefson et al.; Zhang, He, and Sang); however, the current study aimed to survey available P2P supports for caregivers of children and youth with CCN in NB, thus necessitating the consideration of both open and closed groups.

Previous research (Bender, Jimenez-Marroquin, and Jadad) has found that the majority of available online, health-related P2P support groups that specifically target individuals with breast cancer contained twenty-five wall posts or fewer. Although total wall posts were not counted in the current study, it is possible that this variable is linked to overall group activity level. The exact reasons why some groups are able to maintain sustained activity level ("successful") over a longer period of time than others ("unsuccessful") requires further research. It is possible that it is linked to the groups'

administration, specifically their moderators and administrators. The current study found that active groups had multiple moderators and group administrators, suggesting that perhaps these users influence active discussions in some way. Previous research (Stellefson et al.) has noted that inactive groups appear to have specific individuals (known as “engagement leaders”) publish the majority of posts, which typically include links to relevant resources or information but do not invoke discussions between members. This finding was also observed in the current study. These engagement leaders may contribute to declining participation in groups, perhaps being perceived as intrusive or “annoying” to members, in turn influencing activity in groups (Stellefson et al.).

Groups were included in the current scan if they targeted any NB caregivers of children and youth with CCN. While many general P2P support groups (i.e., not specific to NB) were identified through the keyword search, these groups were not included. It is likely that NB families use these non-geographically specific groups to exchange support and information with caregivers in similar situations (Farmer et al.). However, it is possible that locally based groups may provide families with navigational support relative to their specific needs as it pertains to their child’s care (Ammari and Schoenebeck). Indeed, some groups in the current scan did emphasize navigational support in their descriptions, which were used to determine the purpose of P2P support groups. Creators of groups often expressed feelings of isolation or encountering a lack of resources or support that led to the implementation of these groups on Facebook. Many of these groups emphasized the provision of navigational support as a primary purpose. Posts related to informational support and inquiries were also noted across public groups, which suggest that members use these P2P support groups for navigational

support. It is possible that the emphasis on navigational support observed within the included Facebook groups may be unique to support groups that primarily target individuals in a specific geographic region, as opposed to large, international groups (Zhang, He, and Sang).

The current study included groups targeting caregivers and individuals with complex care needs, a category that involves multiple conditions and comorbidities. Indeed, a diverse range of conditions were targeted by groups in the current scan, with autism and related intellectual disabilities appearing most often. Only eight groups targeted caregivers of children and youth with any CCN (rather than specifying a condition), one of which invited families from the two other nearby Canadian Maritime provinces (i.e., Prince Edward Island and Nova Scotia). This was an important finding, as these three provinces share a regional children's hospital based in Halifax, Nova Scotia. Therefore, caregivers of children and youth with CCN may benefit from the connections with peers in these other two provinces, particularly if they frequently travel to this hospital for services.

The majority of groups identified in the current scan (n=44) were presented in English, despite identical keyword searches in French. Only one exclusively French support group was identified, with an additional two groups presenting information (i.e., title and description) in both English and French. It is unclear whether interactions within those two groups were bilingual due to the private nature of the groups. The province of NB is the only province in Canada that is officially bilingual (Office of the Commissioner of Official Languages). As of 2017, French was identified as the official first language of 32% of the NB population (Statistics Canada). The low number of bilingual and French language support groups identified in this scan suggests that there

could be a lack of informal support available to Francophone caregivers of children and youth with CCN. However, this may also indicate a difference in the support needs of these two populations. For example, Francophone caregivers may preferentially seek support offline rather than online. More research is needed to determine potential cultural differences within this population.

Clarifying the range of available support groups for caregivers of children and youth with CCN has important implications for NB families, health professionals, and community organizations. For example, caregivers of children and youth with CCN may not be aware of the extent of social media-based support communities available from individuals in similar situations. Moreover, improved understanding of these groups can better equip care providers to direct caregivers to potentially useful support networks that optimize collective knowledge, obtained through lived experiences, with limited strain on existing resources.

6.1. Study Strengths and Limitations

This environmental scan was timely as no previous studies, to the authors' knowledge, have attempted to profile the purposes and use of P2P support groups on the Facebook platform for caregivers of children and youth with CCN. Despite this major strength, there were some limitations associated with using the Facebook platform for attempting a structured keyword search of available groups. First, Facebook contains a very primitive search engine that does not allow for advanced search techniques (e.g., specific keyword search). When a keyword is typed into the main search text box, users can limit results to "groups", but must conduct a hand count of all search results (website does not provide a summarized tally of findings). It was noted that search results did not exceed a maximum of 99 results, which may be a function of the software

search engine. Despite this limitation, results appeared to be ordered by relevance to the keywords, and results beyond the first dozen groups were rarely relevant to the current study.

Second, Facebook is known to filter information according to the interests of a particular user (Boyd), suggesting that results in the keyword search may have been altered depending on the user conducting the search. Third, the current scan included groups that were not strictly limited to caregivers of children and youth with CCN. Although this limits the generalizability of some of the findings, particularly with regard to the content analyzed in the current study from discussion posts that may have been from caregivers not in our target population, including these groups could also be considered to be a strength of the study. Limiting our search to groups that only include caregivers of children and youth with CCN would not have considered additional support groups available to this population. For example, although support groups that target those affected by autism may include caregivers of adults and adults living with autism themselves, this group is likely also used by caregivers of children and youth living with the condition; excluding these groups because they include a wider population than our target population would not have provided a comprehensive picture of the Facebook-based P2P support available to caregivers in NB.

Third, a lack of cultural considerations in the search strategy may have impacted the generalizability of findings, specifically to Indigenous populations within NB. No support groups were identified that targeted Indigenous caregivers of children and youth with CCN, which may have reflected the search terms used in the keyword strategy and the types of stakeholders approached during the identification of groups. For example, the inclusion of Jordan's Principle workers, a service that ensures that all First Nation's

children in Canada have access to needed services and programs (Government of Canada), may have revealed additional groups available to Indigenous caregivers within the province. Moreover, there may have been additional keywords specific to this population, such as Jordan's Principle, that may have resulted in the identification of additional support groups.

Finally, many of the observed groups were closed to public access, meaning that content was restricted to those who were current members. These groups often employed screening practices and enforced rules to ensure the privacy and confidentiality of members. As a result, the findings drawn from the use of P2P support groups on Facebook may not be generalizable to closed groups, where members may feel more comfortable to disclose certain types of information. Given the larger proportion of closed groups to public groups observed in the present study, it is possible that privacy may be considered to be important to users and may have an impact on the type of content shared within those groups (Wang et al.).

This study focused on one social media platform (i.e., Facebook), however many social media websites exist for health-related P2P support (Grajales et al.). Facebook was chosen for the current investigation due to its wide use in Canada (UFCW) for health and non-health related purposes, suggesting that Canadians are familiar with its uses, functions, and capabilities. The multiple, available functions on the website allow users to engage with users across a range of different social groups and control the content that is visible to different types of users.

7. Conclusion

NB caregivers of individuals with CCN of all ages, including children and youth with CCN, use Facebook to engage in P2P support. There are many groups available

that aim to provide P2P support, across a broad range of conditions, such as autism, allergies, and brain injury. The purposes of these groups primarily aim to create a safe community of emotional and informational support led by peers in similar situations. While most groups exist to provide this support online, some groups used as a source of support for members between offline meetings in the local community. Groups were often used by members in the exchange of navigational support, likely due to the focus on geographic-specific support groups in NB. Specifically, users were found to inquire about resources or services available to them in their geographic area to other users.

Further research is needed into the culture of closed P2P support groups on Facebook, particularly for health-related support. Future studies should determine potential differences between geographic-specific support groups, such as those described in this scan, and general support groups on Facebook that include international membership. It is unclear whether a large community of members would lead users to feel more or less comfortable when divulging personal information, particularly when considering the increased likelihood of individuals meeting offline in their local communities. Furthermore, it remains unclear whether the interactions between users differ between closed and public support groups on Facebook, where any user can view the content published by members, including the names of members themselves. For example, whether users feel more comfortable divulging more information in private versus public groups or differ in their approach to communicating with other members.

This research provides clarity on the purposes and use of P2P support groups on Facebook for caregivers of children and youth with CCN in NB. The findings from this scan provides information that can inform health-related organizations and care providers about online P2P support groups. This work also lays a foundation for future

scans of Facebook-based support groups in other Canadian provinces and beyond. Better understanding the health-related communication that takes place online between patients and caregivers may impact knowledge dissemination efforts and help to improve discourse between health care professionals and the general public. It may also highlight gaps in the system related to health literacy. Further research is needed to determine the potential impact of these groups on the health and well-being of patients and caregivers across diverse populations.

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MANUSCRIPT THREE

Development and implementation of a Facebook-based peer-to-peer support group for caregivers of children and youth with complex care needs in New Brunswick

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Abstract

Facebook has become an important gathering place for patients and caregivers to exchange health-related information and emotional support, otherwise known as peer-to-peer (P2P) support. Despite the widespread use of Facebook groups across various patient and caregiver populations, the use of these groups by caregivers of children and youth with complex care needs (CCN) has not been previously reported. This paper describes the development and launch of a Facebook group for families of children and youth with CCN in New Brunswick, Canada, as well as the plans for evaluation and preliminary findings. The Facebook group was developed in consultation with various stakeholders, including a patient and family advisory council. The following factors were taken into consideration: group characteristics, moderators, language, recruitment, and implementation. The potential impact of the group on perceived knowledge of health services and/or resources and health literacy will be assessed through conducting semi-structured interviews with group members. The group, launched in October 2020, has been monitored for a period of 10 weeks for its use by caregivers. To date, the group has attracted a total of 81 caregivers of children and youth with CCN, including two moderators. Inquiry-based posts are the most common type of posts made by members. The observed surge in group membership upon implementation suggests the need for P2P support platforms for caregivers of children and youth with CCN in New

Brunswick. Ongoing monitoring and evaluation will determine how the group is used by members and whether it has any effect on health literacy and caregiver knowledge of resources and services.

Keywords: peer-to-peer support, social support, social media, children and youth with complex care needs

Note: The methodology section of this paper is written in future tense as it is a published protocol for the doctoral study.

Introduction

Caregivers of children and youth with complex care needs (CCN) often have multiple unmet informational needs and require timely access to services and resources to ensure the well-being of their families (Roche & Skinner, 2009). Accessing this support can be challenging for families that encounter barriers, such as access to primary care or financial aid (Charlton et al., 2017), particularly during the COVID-19 pandemic. Online peer-to-peer (P2P) support groups, defined as online communities of individuals with common lived experiences (Naslund et al., 2016), provide an innovative means of connecting and supporting families. Caregivers of children and youth with CCN possess invaluable lived experience and knowledge related to available and effective services and programs; connecting these families together through P2P support has the potential to promote information sharing among a community of patients and caregivers in a safe, secure online environment.

Current evidence on the use of social media-based P2P support groups has relied on content analysis of posts from publicly accessible groups, primarily those of patients with various health concerns (Bender et al., 2011; Farmer et al., 2009). This paper describes the development and evaluation plan of a geographic-specific P2P support group for caregivers of children and youth with CCN in New Brunswick (NB), Canada. Facebook will be used as the platform for this group. In this study, children and youth with CCN are defined as those with multi-dimensional health and social care needs, who may or may not possess a diagnosis of a recognized condition (Brenner et al., 2018).

Background and Rationale

Children and youth with CCN present across diverse settings, requiring services from multiple care providers, which can result in significant physical, mental, and

emotional pressures on caregivers. These pressures have been further exacerbated by the COVID-19 pandemic, due to increased strain on health and social services (World Health Organization, 2020). Social distancing measures, for example, have led to unique challenges for caregivers of children and youth with CCN, leading to increased caregiver stress and loneliness (American Psychological Association, 2020).

Online P2P support offers an accessible and inexpensive source of informational knowledge and emotional support (Rossman, 2007). P2P groups have been shown to provide individuals with valuable and timely informational, social, and emotional support without participants leaving their homes (Cole et al., 2017; Diefenbeck et al., 2017; Partridge et al., 2018). These benefits have been observed in groups of individuals with chronic disease (Partridge et al., 2018), multiple sclerosis (Shavazi et al., 2016), and HIV (Henwood et al., 2016), and caregivers of individuals with chronic illnesses (Diefenbeck et al., 2017; Scharett et al., 2017). The relationships formed through online interactions can result in feelings of community and solidarity (Horter et al., 2014), which can influence a sense of belonging (Anderson & Emmerton, 2016). This is an important consideration for caregivers of children and youth with CCN in NB, who have reported feeling socially disconnected from resources that help them meet their child's care needs (Charlton et al., 2017).

Studies focusing on P2P support groups on social media have noted the widespread use of Facebook groups across different types of patient and caregiver populations (Bender et al. 2011, Farmer et al., 2009; Naslund et al., 2016), including families of children and youth with CCN. In an exploratory study on the uses of online groups by 18 parents of children with special needs, Ammari et al. (2014) noted that parents primarily used Facebook for accessing informational and social support. Specifically, parents

accessed geographic-specific groups for locally-based support and case-based groups for support related to specific conditions. These findings suggest that geographic-based communities can meet the support needs of caregivers of children and youth with CCN; however, it remains unclear how caregivers of children and youth with CCN use these geographic-specific support groups and what potential impact that membership might have on meeting the support needs of caregivers. Leveraging existing social media to explore the use of P2P support groups by caregivers of children and youth with CCN can provide important insight into the culture of online information sharing and emotional support and how it can benefit and meet the needs of caregivers.

For many individuals, the internet is a critical resource in searching for and locating services, programs, and resources. P2P support can increase knowledge of health-related resources and services (Santelli et al., 1997), which can, in turn, affect health literacy. Health literacy is typically defined as an individual's ability to read and understand health information (Powers et al., 2010). Health literacy is negatively associated with health inequalities, which are impacted by a person's living and material circumstances, as well as socio-economic status (Harris et al., 2015). Improved access to information about available health and social programs can empower caregivers and provide them with confidence when interacting with the Canadian health care system (Jackson et al., 2019). However, it is unclear whether social media-based P2P support can improve knowledge of health-related services and programs of caregivers of children and youth with CCN. There is evidence, however, that low caregiver health literacy has been linked to difficulties in navigating the health care system, which can result in fragmentation of care (Fields et al., 2018); this link between low health literacy and

patient care has also been observed in parents/guardians caring for a child (Lee et al., 2014).

Despite the benefits that Facebook-based P2P support groups can provide for caregivers, ensuring the retention and success of these groups can be difficult for administrators. According to internal data from Facebook, approximately 100,000 new groups are created every day; however, less than half of these groups (43%) survive past the first three months (Kraut & Fiore, 2014). Research on general Facebook groups has identified specific variables that promote short-term success, such as presence of moderators (Kraut & Fiore, 2014), membership size (La Macchia et al., 2016), privacy (Ma et al., 2019), and established rules (Moser et al., 2017). For example, group administrators can promote the initial success of P2P support groups by posting content and frequently interacting with posts by other members (Booth, 2012; Kraut & Fiore, 2014). However, it is unclear what variables might lead to the overall sustainability of these groups.

Online P2P support groups present an opportunity for caregivers of children and youth with CCN to learn about and make sense of the maze of services, programs, and treatments available to them, as well as the overwhelming amount of information provided to them from various sources (DeHoff et al., 2016). It gives families control and presents a safe environment in which to exchange emotional support with peers (Zhao & Zhang, 2017). Facebook, in particular, has been noted as an important gathering place for individuals with health care needs and their caregivers (Farmer et al., 2009); however, there currently exist no active P2P support groups for caregivers of children and youth with CCN in NB on Facebook (Kelly et al., Submitted). Previous research has suggested that caregivers of children and youth with CCN prefer to connect

with other caregivers who have similar experiences and live in their geographic area (Ammari et al., 2014; Scharer, 2005); however, the use and perceived benefits of such groups by caregivers of children and youth with CCN is currently unknown.

Specifically, it is unclear whether a geographic-specific Facebook P2P support group can improve knowledge of health-related services and resources and increase sense of social belonging in caregivers of children and youth with CCN. This paper describes the development, launch, and preliminary observations of a Facebook P2P support group for caregivers of children and youth with CCN in NB and outlines the plan for evaluation.

Study Objectives and Research Questions

This research project investigates the use of a Facebook-based P2P support group by caregivers of children and youth with CCN in NB. This research consisted of three steps: (a) develop a Facebook P2P support group for caregivers of children and youth with CCN, (b) assess its use by caregivers, and (c) explore potential impacts on knowledge of health services and/or resources and sense of social belonging among caregivers. The first section of this paper will describe the development and launch of the Facebook P2P support group. The second section will outline the protocol for evaluation and outline preliminary observations.

Primary Objective and Corresponding Research Questions

The primary objective in this research was to develop and implement a geographic-specific Facebook P2P support group, in collaboration with a patient and family advisory council, and investigate its use and perceived benefits by caregivers of children and youth with CCN. The following research questions form the basis for this research:

1. How is the P2P support Facebook group used by NB caregivers of children and youth with CCN?

2. What are the experiences of caregivers of children and youth with CCN who use the Facebook group to communicate with other caregivers?
3. In what ways does participating in the Facebook group affect NB caregivers of children and youth with CCNs' perceived knowledge of services or resources and sense of belonging?

Secondary Objective and Corresponding Research Questions

The secondary objective of this research is to better understand factors that relate to the use of the group. Success of the group will be determined by a consistent level of interaction between members of the group. The following research question was used to explore this secondary objective:

4. What factors contribute to the success or failure of the Facebook group for caregivers of children and youth with CCN in NB?

Facebook Group Development

A P2P support group was developed using the Facebook platform, which is a free social media website. The group was developed in response to a needs assessment that found that NB families of children and youth with CCN feel disconnected from local resources (Charlton et al., 2017), and an environmental scan which revealed that there are currently no P2P support groups on Facebook for these caregivers in NB (Kelly et al., Submitted). The Facebook group, developed for the purpose of this research, is restricted to screened members who live in NB. The purpose of this group is to facilitate the exchange of informational and emotional support between caregivers of children and youth with CCN.

The group was developed in consultation with a team composed of stakeholders from NaviCare/SoinsNavi (NB's patient navigation centre for families of children and

youth with CCN), the University of New Brunswick, Mount Allison University, and the University of Prince Edward Island. Focus groups were held with NaviCare/SoinsNavi’s Patient and Family Advisory Council (PFAC), which is composed of six caregivers of children and youth with CCN and one young adult who grew up with CCN. Group components were vetted by the PFAC, including the title, description, and membership requirements. Table 1 below presents the final iteration of details published on the group.

Table 1

Facebook Group Components

Component	Description of Components
Title	NB Children with Health Care Needs*
Description	<p>This group is for parents, guardians, and other caregivers of children and youth with health care needs in New Brunswick.</p> <p>This is a safe place to connect with other NB families and share/learn about local services and resources. It is also a place to find answers to your questions and to help others who are on a similar journey. We welcome anyone who cares for a child/youth with any health care need(s).</p> <p>Please note that this group is developed and managed by NaviCare/SoinsNavi (a research-based patient navigation centre based in New Brunswick) to facilitate the exchange of services</p>

	<p>and resources between caregivers (e.g., parents and guardians) of children and youth with health care needs in NB. This Facebook group serves as a pilot project to better understand online peer-to-peer support. This means that the group is monitored for use and members will be invited to participate in a research interview; however, the information shared within this group will never be made publicly available or shared outside of the group. This project has been approved by the Research Ethics Board at UNB. The letter of information and informed consent is available at the following link: https://bit.ly/3mHPSeY. By participating in this group and answering the third membership question, you are agreeing to participate in this study.</p> <p>The views and opinions expressed in this group are those of the members and do not necessarily reflect the official policy or position of NaviCare/SoinsNavi.</p>
Privacy designation	Closed group
Language	Bilingual
Moderators	NaviCare/SoinsNavi's PFAC member and patient navigator

Note. French translation of the title and description is provided in the group.

Membership Screening

Prospective members are required to undergo a short screening prior to gaining admittance to the Facebook group. This screening consists of two short questions presented to the user when they request to join the group:

1. Do you identify as a caregiver of a child or youth with health care need(s)?
2. Do you live in New Brunswick, Canada?

An additional required question asks prospective members to type “I consent”.

This question provides users with an explanation of the purpose of the group from a research perspective and provides links to the letter of information and informed consent form:

3. CONSENT REQUIRED: Please read the page at the following link and type “I consent” after reading: <https://bit.ly/3mHPSeY>

Moderators

The use of moderators is posited to be an important contribution to the activity levels (i.e., success) and long-term sustainability of online P2P support groups (Biagianti et al., 2018). Group moderators currently consist of the NaviCare/SoinsNavi patient navigator, who is a Registered Nurse, and a member of the PFAC. Moderators conduct the following tasks on a daily basis: screen prospective members, monitor ongoing discussions, and provide responses to posts without replies.

The patient navigator provides a novel contribution as a health professional in a P2P support group; however, their role within the group is simply to offer one perspective. The lived experiences of other caregivers provide a rich dialogue and exchange of social support that is only available from someone on a similar journey.

Implementation and Recruitment Strategy

After details related to the group were vetted and approved by NaviCare/SoinsNavi's PFAC, the Facebook group was officially launched on October 5, 2020. Members of the PFAC and research team were invited to review the final version of the group to provide feedback before launching. Recruitment of group members started on October 13, 2020, using the following strategies:

- invitation to caregivers enrolled in NaviCare/SoinsNavi, sent by their patient navigator;
- media release to 35 community organizations that support families of children and youth with CCN in NB;
- posts made on existing Facebook groups and pages used by families in NB (e.g., car seat safety group, etc); and
- media releases to various digital newsletters and online boards off the Facebook platform.

This recruitment strategy was completed on October 20, 2020. Ongoing recruitment primarily consists of word-of-mouth from group members and advertisement of the group on NaviCare/SoinsNavi's public Facebook page.

Evaluation Plan

Study Design

The Facebook group will be evaluated using a qualitative descriptive design to understand the perceived impact and use of a Facebook-based P2P support group for caregivers of children and youth with CCN. Qualitative description is a pragmatic qualitative approach that facilitates obtaining straightforward answers to questions in

applied health research (Sandelowski, 2000). A qualitative model was chosen to explore the uses and benefits of a Facebook-based P2P support group absent of preconceived models or restrictions.

Study Population

All members of the Facebook group represent the study population. An online survey and semi-structured interviews will take place with a subset of volunteers from within the group. A survey will be distributed to members through a post on the group's discussion board; participants will be asked at the conclusion of the survey if they are interested in being contacted for an interview. Interview participants are required to have been in the group for a minimum of three months; this length of time is specified to ensure that members have had time to interact with content and members within the group. A total of 50 survey participants and 20–25 individual interviews will be sought beginning in January 2021. These numbers were chosen to ensure membership representation and information saturation.

Data Collection

Group members will be invited to take part in an online survey and interview about their use and experience as a member of the group (Research Questions #1 and #2) and perceived knowledge of health services and resources (Research Question #3). The online survey consists of 15 closed-ended questions (e.g., "Have you learned about any services or resources for children/youth with health care needs in New Brunswick as a result of your membership in *NB Children with Health Care Needs*?") and three open-ended questions (e.g., "In what ways has the *NB Children with Health Care Needs* Facebook group helped you, or can help you, address some of your needs in your role as a caregiver?"). Interview questions were structured based on users' experience of the

P2P support group (e.g., “In what ways did you or did you not find that the Facebook group was able to meet your needs or provide needed support?”) and its effect on accessibility and knowledge of the health care system (e.g., “How did the P2P support group affect your knowledge of existing health-related resources or services?”).

The online survey was created using Qualtrics XM, an online survey tool. Interviews will take place using Zoom video conferencing software, using the steps outlined by Lobe et al. (2020) regarding social distancing interview measures, given the current pandemic situation. Zoom was chosen due to previous empirical support for its ease of qualitative data collection, data management features, and security options (Archibald et al., 2019). Content published to the group (e.g., posts, replies, etc) will be regularly collected and organized into Excel to better understand the use of the group by members and moderators (Research Question #1). Specifically, Facebook posts will be labelled according to one of six categories based on the information provided in the post: *information*, *emotional*, *inquiry*, *advertising*, *fundraising*, and *other* (Bender et al., 2011; Farmer et al., 2009). Information posts are those containing information of relevance (e.g., shared academic article or news post). Emotional posts describe posts relating an experience, story, or narrative, often allowing a user to share frustrations or successes. Inquiry posts contain a question or set of inquiries from members; this type of post differs from information posts, in that it is primarily based around a question. Advertising posts include a notice regarding an event or sale of a product, and fundraising posts aim to raise funds for a particular cause. Finally, posts designated as “other” are any posts that do not fit one of the previous five categories.

Factors related to the success or failure of the proposed P2P support group, as determined by membership activity, will be regularly collected throughout the

evaluation period (Research Question #4). Specifically, the type of posts (as described above) and associated interactions (i.e., likes and comments by members), as well as date and time of post will be counted and kept in an Excel file on a weekly basis. Other indicators suggested in the literature to promote or hinder activity by members, such as number of administrators, involvement of moderators in discussions, and membership size (Biagianti et al., 2018; Kraut & Fiore, 2014), will be recorded throughout the course of the study period. These factors will be compared to the number of published posts, and corresponding interactions, to determine whether there is an association between changes to the group and higher or lower activity levels. Outcomes will be collected throughout the study period (Fall 2020–Spring 2021) and will be analyzed at the conclusion of the study (Spring 2021).

Data Analysis

Survey results from closed-ended questions will be analyzed in Microsoft Excel. Interviews will be recorded using a digital voice recorder and then transcribed verbatim and managed using NVivo software (version 1.0). Open-ended survey questions and interview transcripts will be analyzed using thematic analysis (Braun & Clarke, 2006; Willis et al., 2016). Content collected from the P2P support group (i.e., posts and replies) will be analyzed using content analysis. Content analysis differs from thematic analysis in that it aims to provide a mixed methods approach to describing a phenomenon (i.e., qualitative coding and use of quantitative counts), whereas thematic analysis provides a detailed and in-depth description of qualitative data (Braun & Clarke, 2006; Vaismoradi et al., 2013).

Risk Mitigation

A variety of risk mitigation strategies associated with the use of online P2P support forums have been identified within the literature. These include monitoring discussion posts to prevent the spread of misinformation, lack of replies, technical problems, and data security (Niela-Vilén et al., 2014). Discussion moderators monitor discussion boards to respond to posts and ensure the validity of information on a regular basis. Moderators are trained using best practice protocols (Schippke et al., 2015), adhering to a guide developed specifically for this project. Specifically, all members are provided with clear rules for participating in the P2P support group, which are enforced by moderators. Members who fail to adhere to rules are asked by a moderator to review the group rules and warned that if they continue to break the rules, their membership will be revoked. Misinformation is clarified in a timely manner by moderators, by providing correct information with appropriate source(s).

Preliminary Observations

At the time of writing this paper (December 2020), the Facebook group (*NB Children with Health Care Needs*) has been live for a period of 10 weeks. The group has a total of 81 members, two of whom act as discussion moderators. Prior to the development and launch of this group, there were no P2P support groups available on the platform for NB caregivers of children and youth with CCN (Kelly et al., Submitted). However, it has become clear that there is a need for such a group by the immediate surge in membership after the launch of the group.

The first six weeks of the group represented a period of intense growth in membership, but little interaction between members on the discussion board. A social media plan was put together by moderators to encourage interaction by members; this

resulted in weekly discussion posts that prompt members to answer various questions. Moderators posited that members might have been uncomfortable being the first to post; therefore, they reached out to a member of the group to ask if she might be comfortable posting a question. This led to a surge in novel posts by members, predominately inquiry-type posts related to caring for a child during the COVID-19 pandemic and locating resources to support their child. Other types of posts published in the group have largely consisted of shared resources from other pages, such as information about children and youth with CCN webinars or information about developmental assessments or therapy. The increase in membership activity levels (i.e., posting and interaction) observed in response to weekly discussion posts by the moderators suggests that pre-existing posts may encourage content publication from existing and new members (Booth, 2012), in turn promoting group success.

At this time, a total of 45 posts have been made in the Facebook group. A total of 17 (37.7%) of these posts were categorized as inquiry-based posts. A further 14 were classified as “other” (e.g., administration update); 11 were information-based posts (e.g., post on an upcoming webinar of relevance); and two were fundraising-based posts.

The moderating team meets on a weekly basis to discuss activity within the group and any concerns that arise. The lead researcher (KK) meets with NaviCare/SoinsNavi’s PFAC on a monthly basis to present updates on the group and receive feedback. This feedback consists of ways to promote group interaction and content, as well as input on the research methods and analysis of the project.

Determining the factors that affect interaction between members and ensure the longevity of the group continues to be a challenge in the infancy stage of this group due to lack of data; however, the increase in membership activity level is expected to provide

further insight into these factors over time. The online survey will be distributed to members in early January 2021, and interviews will begin in February 2021.

Conclusion

This research aims to explore the use of a Facebook-based P2P support group by caregivers of children and youth with CCN in NB. The positive response to the group, as indicated by a surge in membership within only four weeks, suggests a possible need for better support and interaction among caregivers of children and youth with CCN in NB. Ongoing monitoring and evaluation will determine how the group is used by members and whether it has any effect on health literacy and knowledge of resources and services.

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MANUSCRIPT FOUR

Exploring the use of a Facebook-based support group for caregivers of children and youth with complex care needs

(In Preparation). Journal of Medical Internet Research

Abstract

Background: Caregivers of children and youth with complex care needs (CCN) require substantial support to ensure the well-being of their families. Online peer-to-peer (P2P) support groups present an opportunity for caregivers to seek and provide timely informational and emotional support. Despite the widespread use of social media for health-related support across diverse patient and caregiver populations, it is unclear how caregivers of CCN use and potentially benefit from these groups.

Objective: The aim of this study was to explore the use of an online P2P support group for caregivers of children and youth with CCN and investigate factors related to its sustained use by members.

Methods: The study sample consisted of individuals who joined a closed Facebook group and analysis of content published to the group. In Phase 1, a Facebook group was developed in consultation with a patient and family advisory council and members were recruited to the group. Phase 2 of this research consisted of an observation period during which posts and related interactions (i.e., likes, loves, and comments) by members were collected. In Phase 3, an online survey was distributed, and semi-structured interviews were conducted with a sub-sample of group members; survey and interview data were analyzed using thematic analysis.

Results: A total of 108 caregivers joined the Facebook group between October 2020 and March 2021. There were 93 posts with 405 comments and 542 associated interactions (448 likes and 94 loves); 37 of these posts were made by group members and 56 by moderators. An online survey was completed by a sub-sample of 39 members and 14 members participated in interviews. Content analyses of posts by members revealed inquiry (46%), informational (40%), and emotional posts (11%) to be most common. Emotional posts received the greatest number of interactions (\bar{x} =24.5). Five themes emerged from interviews related to the use of the group and mediating factors of interactions between group members: 1) resource for information; 2) altruistic contribution; 3) varying level of engagement; 4) growing activity in the group; and 5) moderators as contributing members.

Conclusions: These findings demonstrate that caregivers of children and youth with CCN seek geographic-specific P2P support groups to meet informational and social support needs. This study contributes to the knowledge of how caregivers use Facebook groups to meet their support needs through moderate and passive engagement.

Keywords: peer-to-peer support; children and youth with complex care needs; social media; social support

Introduction

Children and youth with complex care needs (CCN) are those with multidimensional health and social care needs, who may or may not possess a diagnosis of a recognized condition. Children and youth with CCN present across diverse settings, requiring services from multiple care providers, which can result in significant physical, mental, and emotional pressures on their caregivers. Meeting the support needs of caregivers of children and youth with CCN can be difficult for care providers, particularly during the COVID-19 pandemic due to increased strain on health and social services [1]. Online peer-to-peer (P2P) support presents an opportunity to connect caregivers in a safe and accessible online environment to promote information and the exchange of timely support. Previous research has demonstrated the prevalence and use of Facebook for health-related P2P support [2], including by parents of children with CCN [3]; however, it is unclear how caregivers of children and youth with CCN use these groups. Moreover, the factors that facilitate the success of these support groups have not been investigated with this population. Understanding the content and interactions between caregivers of children and youth with CCN can inform our understanding of these groups and how they may be leveraged to better support this population. This paper describes the use of a geographic-specific, Facebook-based P2P support group for caregivers of children and youth with CCN in NB and explores the factors that contribute to its use by group members.

Background

Caregivers of children and youth with CCN face many unique challenges due to their complicated and multi-faceted care needs. Barriers related to financial resources, continuity of care, and service navigation make accessing timely support challenging for

these caregivers [4–6]. Caregivers of children and youth with CCN possess invaluable experiential knowledge related to available services and programs; how to access to resources; and effective professional support; connecting these caregivers with each other through online P2P support is one way to meet their informational and emotional support needs. Social media websites, in particular, provide an accessible and inexpensive space for the exchange of support between individuals with similar lived experiences.

Online P2P support has been shown to provide users with valuable informational, social, and emotional support [7] and allows users to communicate with peers and receive timely support without leaving their homes [8]. Virtual P2P support allows for connections with peers on the caregivers' own time [9–11] and improves access despite geographical isolation [12]. P2P support groups present an opportunity for caregivers of children and youth with CCN to learn about and make sense of the maze of services, programs, and treatments available to them, as well as the overwhelming amount of information provided to them from various sources [9]. Finally, online support allows those facing rare or stigmatized conditions to benefit from online discussions with peers [13].

Concerns related to lack of confidentiality and privacy have been identified as barriers to online health-related P2P support [14–17]. However, the opportunity to share experiences and connect with peers in similar situations have been reported to outweigh risks related to privacy, as well as concerns about online negativity and potentially low-quality information [18]. Reaching out to others online requires a certain level of candidness and honesty that can sometimes prompt negative support; messages perceived by the receiver as being negative or unsupportive is known to lead to poorer

overall mental health [19]. Despite the risks associated with sharing personal stories and issues online, parents of children and youth with CCN have reported fewer instances of judgement within Facebook support groups than in offline interactions [3].

Many social media websites and applications exist for use by the general public to connect and share content. Facebook, in particular, has been noted for its use in health-related communication among diverse types of patients and caregiver populations [20–24]. Facebook is among the most popular social networking website in the world [25], particularly in Canada [26], where 19.6 million users registered on the website in 2018 [27]. Despite evidence that caregivers of children and youth with CCN use Facebook for personal connections and P2P support [3,9], how these caregivers communicate in this setting has not been previously investigated.

Objectives and Research Questions

The current research aimed to explore the use of a Facebook-based P2P support group by caregivers of children and youth with CCN in the semi-rural the Canadian province of New Brunswick (NB). Despite previous research demonstrating the use of Facebook groups by caregivers of children and youth with CCN [3], the way that caregivers use these groups is unclear. Moreover, previous literature has not assessed the factors that contribute to its use by caregivers. In a preceding environmental scan of Facebook groups for caregivers of children and youth with CCN [28], we determined that there were no province-wide support groups for this population in NB. Therefore, the current study aimed to develop, implement, and examine the use of a Facebook-based P2P support group for caregivers of children and youth with CCN in NB, developed for the purposes of this research.

This research consisted of three phases: (a) develop a Facebook P2P support group for caregivers of children and youth with CCN in NB; (b) assess its use by caregivers through analysis of posts and interactions (i.e., likes, loves, and comments), and (c) explore the factors that contribute to the group's activity levels and perceived success or failure by members. The following research questions guided this research:

1. How is the Facebook-based P2P support group used by NB caregivers of children and youth with CCN?
2. What factors impact the activity levels (i.e., interactions between members) and perceived success or failure of the Facebook-based support group by caregivers of children and youth with CCN in NB?

Methods

Design and Sample

A qualitative descriptive design was used to explore how caregivers of children and youth with CCN use a Facebook-based P2P support group to communicate and to examine factors related to ongoing activity levels within the group. Our sample consists of caregivers of children and youth with CCN in NB who joined and interacted with the Facebook group and a sub-sample of these participants who agree to participate in the survey and interviews. This research was approved by the University of New Brunswick Research Ethics Board.

Phase 1: Development and implementation of the Facebook group

A bilingual (English and French) Facebook P2P support group was developed in consultation with NaviCare/SoinsNavi, a patient navigation centre for children and youth with CCN in NB. Focus groups and meetings were held with members of NaviCare/SoinsNavi's Family and Patient Advisory Council (PFAC) to delineate an

implementation strategy and determine appropriate content of the intervention. The PFAC consists of six parents/guardians who have children and youth with CCN and one young adult who grew up with CCN in NB. Investigators met with the PFAC three times during the development of the group and then monthly after its implementation until the conclusion of the research. Specifically, the PFAC informed our team on the development of group characteristics (e.g., title, description, membership screening, and rules); plan for discussion moderation and recruitment; and evaluation.

The Facebook group, which has been described in detail elsewhere [29], was designed to facilitate the exchange of support between caregivers of children and youth with CCN. The group was closed to members, meaning that information posted within the group was not visible to non-members; this was to protect the confidentiality of those within the group and create a space conducive to the exchange of support. All prospective members underwent a screening process prior to gaining approval to join the private group by the group moderators, which included providing informed consent to participation in this research. The group was moderated by one member of NaviCare/SoinNavi's PFAC and NaviCare/SoinNavi's patient navigator. These moderators monitored the discussion page to respond to unanswered posts, ensure the validity of information, and enforce group rules. While the patient navigator represented a unique contribution to the support group as a health professional, this individual's role within the group was simply to offer one perspective in addition to those of the caregivers within the group. The patient navigator's role was to ensure that posts received a timely response (i.e., respond to posts that did not receive a prompt reply from peers).

The Facebook support group was launched on October 5, 2020. Members were recruited to the group using four strategies: (1) email blast to past and present NaviCare/SoinsNavi clients; (2) media release sent to 35 community organizations that support families of children and youth with CCN in NB; (3) messages sent to moderators of Facebook groups and pages used by caregivers in NB (e.g., general parent support groups); and, (4) media releases on other social media platforms and websites.

Upon implementation of the Facebook group, moderators created a social media plan for ensuring that the group remained active and relevant while it began to grow. Previous research has noted the importance of the first three months for group success, demonstrating that less than half of Facebook groups survive past this trial period [30]. For example, groups with moderators who post frequently immediately after the launch of a group were 19% more likely to survive, as it is believed to model content publication (i.e., provide an example to members for how to interact or solicit support) and encourage engagement with new members [31]. The social media plan involved a weekly structure of planned posts that included: a welcome post each Friday (tagging all new members that week); a discussion post that prompted members to answer a question or share their experience; and ongoing interaction with posts made by members to ensure that content was not left unacknowledged.

Phase 2: Observation of Facebook Group

Phase 2 of the study consisted of an observation period, during which participants joined and began to use the group; this phase took place over six months (October 2020 to March 2021). Content published within the group (i.e., posts, comments, likes, and loves) were collected and organized into Excel to examine how members and moderators use the group. Additional factors observed to potentially

influence ongoing activity levels within the group (e.g., time and date of posts) were also noted throughout the research period.

Analysis Strategy: Group Posts and Interactions

A qualitative descriptive design was used to investigate the use of the group by members and factors related to the success or failure of the Facebook-based P2P support group. Specifically, qualitative content analyses were used to analyze posts published to the group. Content analysis is a qualitative and systematic approach to coding and categorizing text [32] that aims to describe a phenomenon [33]. Posts were categorized according to one of six labels based on its content: informational, emotional, inquiry, advertising, fundraising, and other [20,34]. Posts categorized as informational were those containing information of relevance (e.g., shared article or details on a program). These differed from inquiry-based posts, which were centred around a question. Emotional posts described experiences, story, or narratives. Advertising posts comprised the promotion or sale of a product or service, and posts labelled as "other" were those that did not fit the previous categories.

Observed numerical data related to the factors of membership activity (e.g., number of interactions) were analyzed using Microsoft Excel. Specifically, descriptive statistics and comparisons related to the frequency of posts types (e.g., informational, emotional, inquiry, etc.); interactions (e.g., likes, loves, and comments); time and date of publication; and source (i.e., moderator or group member) were conducted to explore possible associations.

Phase 3: Online Survey and Interviews

In Phase 3 of the study, an online survey was distributed to members within the group and interviews were conducted. The online survey was developed using Qualtrics

XM and consisted of sixteen closed-ended questions and three open-ended questions related to participants' use of the group and perception of its success or failure. A group administrator posted the survey, available in both English and French, as a link in the Facebook group.

Interviews consisted of 15 of open-ended questions based on participants' use of the P2P support group. Interviews were conducted in both English and French. Interviews took place using Zoom video conferencing software due to its ease of qualitative data collection, data management features, and security options [35]. Videoconferencing was also chosen due to restrictions to in-person contact during the COVID-19 pandemic. All interview participants received an Amazon gift card as remuneration. The University of New Brunswick's Research Ethics Board approved this research.

Analysis Strategy: Survey Responses and Interviews

Survey results from closed-ended questions were collated in Qualtrics XM and exported to Microsoft Excel for analysis. Interviews were audio recorded using Zoom and then transcribed verbatim into Microsoft Word by the lead author. Interview transcripts were analyzed using thematic analysis to identify themes related to the use of the group and its perceived success or failure by members, as well as any factors that facilitate or hinder activities levels within the group. Thematic analysis differs from content analysis, which was used to analyze posts from the Facebook group, as thematic analysis aims to provide a comprehensive summary of a phenomenon in the everyday language of those events by remaining close to the “surface” of the words used by participants themselves rather than attempting to interpret meaning [36]. Previous investigations of online P2P support that have employed the use of content analyses

often focus on received support rather than perceived support [37]; interviews and survey data provide an opportunity to better understand findings from content analyses [37].

Results

A total of 108 caregivers of children and youth with CCN joined the Facebook group during the study period. Between October 5, 2020 and March 26, 2021, there were 93 posts with 405 comments, 255 likes, and 81 loves from the participants and moderators on the Facebook P2P support group; 37 of these posts were made by group members (i.e. caregivers of children and youth with CCN) and 56 by moderators. Date of post publication indicated an increase in the total number of posts each month throughout the data collection period (Figure 1). A breakdown of interactions on posts revealed that the majority of comments, likes, and loves came from group members (n=537) rather than moderators (n=204); specifically, group members made 318 comments, 156 likes, and 63 loves on posts.

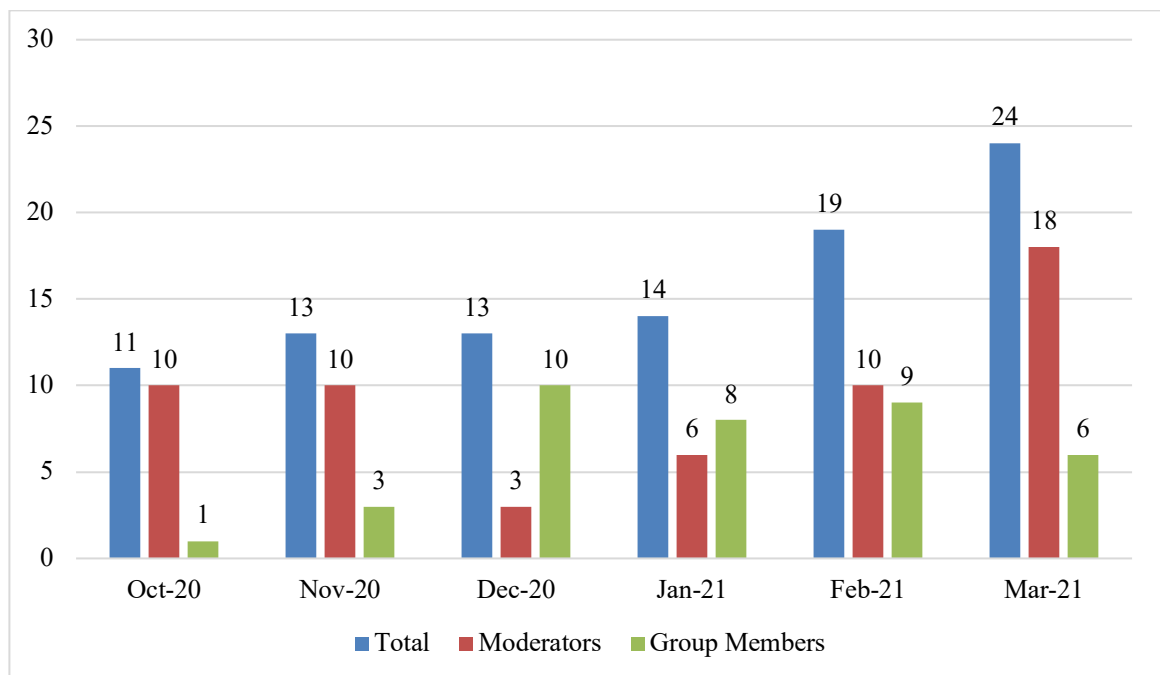


Figure 1. Number of posts published during data collection period by month and member type.

From the 108 members of the Facebook group, a sub-sample of 39 participants completed the online survey (all English). The majority of the survey participants were female (n=29) and the remaining ten preferred not to answer. Survey participants were primarily between the ages of 25-34 years (N=16) and 35-44 years (N=9). Only four participants were between 45-54 years of age and one over 55 years. Remaining participants (n=9) preferred not to respond. Participants represented a wide geographical range across the province of NB, with nearly a third reporting the province's capital (Fredericton) as their place of residence (n=11).

Fourteen interviews (13 in English, one in French) were completed with members of the Facebook support group. Just over half of the interview participants reported caring for young children under the age of five years (n=8) and most had been members of the group for at least three months (n=12). Similarly, the majority of survey participants reported belonging to the group as a member for longer than three months (n=20). Three participants reported a length in membership between 2-3 months and five between 1-2 months. Three participants reported belonging to the group for less than one month.

Most participants reported seeing content from the Facebook group appear on their main timeline a few times per month (n=12), once a week (n=8), and once a month (n=7). Only two participants reported that they never saw content from the group appear on their main timeline. The majority of survey participants reported logging into Facebook daily (n=29).

Of the 39 survey respondents, 23 indicated that they had never published a post within the group; however, when asked about their approximate number of interactions on posts within the group, the majority of participants indicated that they have had 1-2 interactions with posts (n=15), followed by 3-5 interactions (n=8). Only five participants indicated that they had never interacted with a post within the group (Figure 2). When prompted about their perceived comfort with posting in the group, 25 participants indicated that they felt "comfortable" posting or commenting in the group; those who indicated that they did not feel comfortable indicated that their hesitations was due to the research focus of the group (n=2) and concern that information would become available to personal connections (n=1).

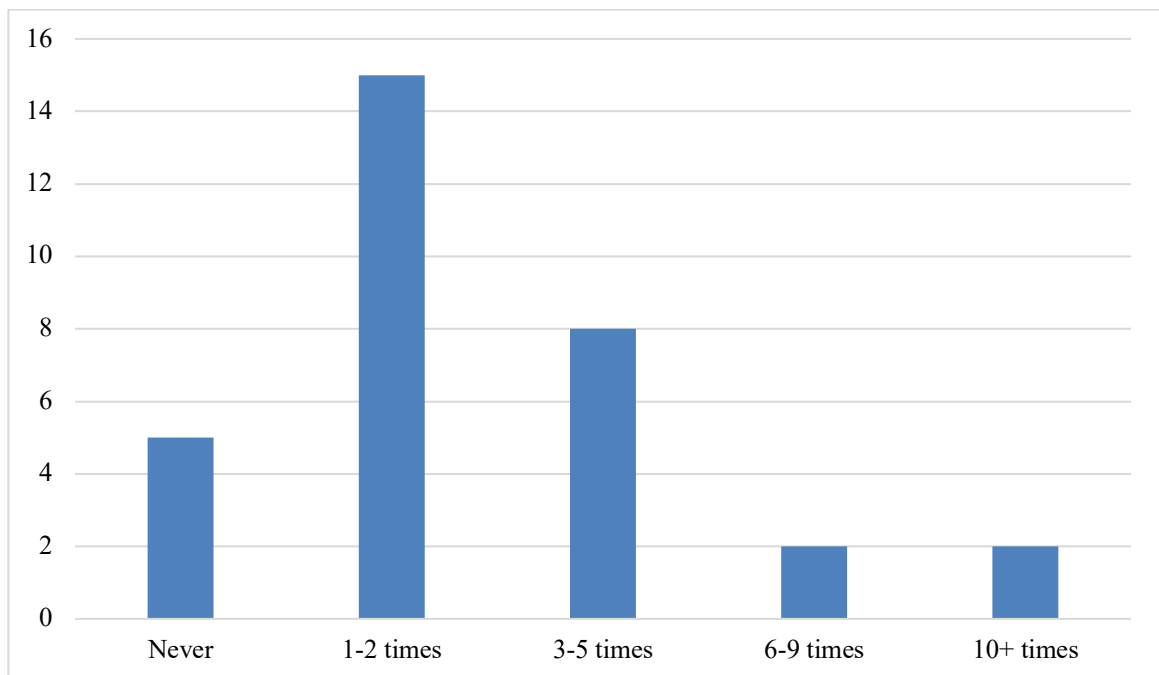


Figure 2. Reported number of interactions on group posts by survey participants

Nearly two thirds of survey respondents (n=23) reported belonging to at least one other Facebook-based P2P support group related to their role as a caregiver of a child or

youth with CCN. Most of these participants (n=14) reported belonging to three or more other Facebook support groups. Many survey participants (n=18) reported using Facebook support groups when they have questions or support needs related to the care of their child.

Content Analysis of Posts

Posts published to the Facebook group's wall represented five of the six categories of post types (informational, emotional, inquiry, fundraising, and other); no advertising posts were observed during the data collection period. Combining posts made by both moderators/administrators and group members, inquiry posts were the most commonly observed (n=38), followed by other posts (n=28), and informational posts (n=23). In group members alone, inquiry posts were the most common (n=17), followed by informational posts (n=15), and emotional posts (n=4). Fundraising (n=1) posts were the least commonly observed type of post (Figure 3).

Posts in the other category were published exclusively by moderators and administrators (n=28). This category consisted of posts welcoming new members (n=14), invitations for members to introduce themselves or share photos (n=8), and research gathering posts (n=6). The one remaining post consisted of an update made to the group description during the data collection period.

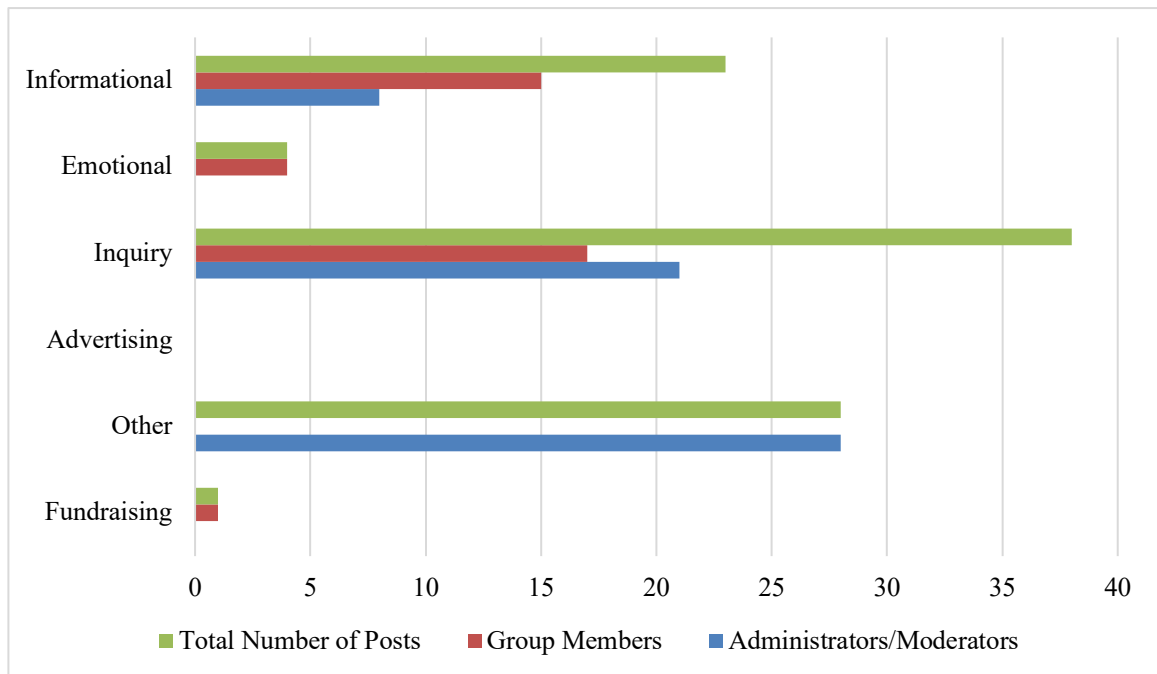


Figure 3. Number of posts according to categorization (Bender et al., 2011).

Emotional posts received the greatest number of interactions, including comments, likes, and loves ($\bar{x} = 24.5$, range 18-35), followed by other ($\bar{x} = 9.0$, range 2-20), inquiry ($\bar{x} = 7.2$, range 0-29), and informational ($\bar{x} = 5.1$, range 0-33). Fundraising and advertising received no interactions.

The type of interactions elicited by each type of post varied, with emotional posts ($n=4$) having received the greatest number of comments ($\bar{x} = 10$), followed by inquiry posts ($\bar{x} = 5.5$) and others posts ($\bar{x} = 4.0$). Emotional posts ($n=4$) also received the greatest number of likes ($n=5.3$) and loves ($n=9.8$), followed by other posts (likes, $\bar{x} = 4.1$; loves, $\bar{x} = 1.0$), and informational posts (likes, $\bar{x} = 2.7$; loves, $\bar{x} = 0.4$).

The time that posts were made to the group and the number of corresponding interactions indicated a positive, but weak correlation between the two variables, $r(97)=0.20$, *ns*. No correlation was observed between the number of views that a post received and corresponding interactions, $r(97)=0.02$, *ns*.

Thematic Analysis of Interviews

The use of the Facebook-based P2P support group and factors that impact its perceived success or failure was further explored through thematic analysis of interviews with group members (i.e., caregivers of children and youth with CCN). Five themes emerged from these interviews: (1) resource for information; (2) altruistic contribution; (3) varying level of engagement; (4) growing activity in the group; and (5) moderators as contributing members. Each of these themes are described in further detail in the following section.

Theme 1: Resource for Information

Interview participants reported using the group as a resource for informational support. Participants described other caregivers within the group to be a knowledgeable source of information that could assist them in the care of their child(ren) by providing information gained through lived experience:

And the fact that there is a Facebook group... cause at my age, that's what they use for information, right? To know that it is from a source that is knowledgeable and they've done their homework and those things, or that they'll point you in the right direction, uh, helps.

Facebook groups for anything related to her would definitely be where we probably would start, and then go from there. But just getting that advice from others parents is huge and it kind of helps you direct yourself. When it's very overwhelming, that kind of gives your brain a place to like, settle on, and then

“OK how do we approach this” and then it usually spirals, you can get a lot more information.

Some participants described joining the group in anticipation of support that they will need as their child(ren) transition to new stages, thus using it as a resource for future informational support needs:

I find, for myself, I read comments a lot, or I read the post, and then I get a lot of information out of what people are commenting back. I find that is extremely helpful because, even if I don't, if it's not directly related to me yet, it might be something I encounter later on. So it's helpful to have, like, “oh, I can go back to this and read it”.

...what kind of resources are available for parents and kids that are going into the school system, you know, at different phases it changes like the transition from being a baby to going to school, the transition from being in elementary school, to going to high school, the transition from high school to adulthood. So those are important transitions, where you're going to need to change a service. You're going to need more resources; you're going to need different resources. Um, and I think this, this page could be really a good resource for parents that, you know, can see like, oh, this is what's going on. You know what I mean?

Many participants identified the geographic-specific aspect of the group as an important resource for navigational support. The majority of interview participants

indicated that they were members of other Facebook-based support groups that were not specific to NB that aid in their role as a caregiver of a child or youth with CCN. These participants described using the NB group to complement support received from their other Facebook support groups; specifically, the NB support group is used for local informational and navigational support needs, whereas many described using condition-specific groups for support related to their child(ren)'s medical care:

The other [condition-specific] groups, I tend to go more for, like, medical things. So for instance, like on my [condition] group, I'll post like, you know, "what medications are you guys being given for seizures and sleep, because we're struggling right now". And then I can get the support from that. So the other groups, I tend to use more of like a medical piece. [...] But this one here, I see more as like a resource piece, looking for resources and things like that.

I find, yeah, every group has their own kind of thing. But I find your group in particular is good for looking for resources and things like that.

So, say if I were looking for a new, um, pediatrician or something like that, I would ask into that group [NB group]. Kind of what people's experience[s] were.

Some participants discussed the impact of the COVID-19 pandemic on their role as a caregiver of a child or youth with CCN, and specifically how it has affected their use of Facebook support groups. Participants described experiencing barriers related to the pandemic and using the support group to fill gaps left in their information resources:

I'm so new here and because of the pandemic, it hasn't really allowed me to go out and explore and find these things for [my daughter]. And all these questions that I've asked, everyone's been very helpful and very kind, and yeah.

Participants noted an increase in their use of Facebook for informational support, due to additional pressures faced by having a child or youth who is immunocompromised:

Sometimes it's hard to meet with parents, that's another... thing to, um, to think about is that when you have children that have complex needs, it looks very different when our children get sick, even when a basic cold with an ear infection, things like that. So sometimes our interactions are limited because of that too .

You know with the pandemic, you can't meet anyone else, you can't get support anywhere.

Theme 2: Altruistic Contribution

Many participants described using the group to share the knowledge that they have gained through lived experience as a caregiver of a child or youth with CCN. Participants described a desire to help other individuals going through similar situations by sharing the knowledge that they obtained.

So like, now I don't feel like I'm an expert at all, but I have so many, like, things in my backpack, like that I can reach out to and go to. I wish that I could give that backpack to me eight years ago. Like, other people that I know now that are starting to go through it. And that's why it's really awesome that this Facebook group happened, because it's a way for other people to share with me what's in their backpack and for me to share with those people.

I find that experienced parents kind of pass that knowledge on, which is the nice thing about that group. They can pass that knowledge on, and then the next parent will learn it, and then they'll pass that when they meet someone or they become connected with somebody who has another child with complex needs. So that's, that's been huge.

And that's why I feel, and that's why I felt this was important because I do say that if I can help a family, one family not have to go through everything we've gone through, uh and the system's learned or that family what we've learned and I can share that knowledge, I would.

Theme 3: Varying Level of Engagement

Interview participants described a range of engagement with the Facebook group. Although many participants described themselves as “lurkers” and “stalkers” within the group, many still felt that they benefited from participation:

I'm a Facebook stalker, I'm a group stalker, so I just wait for other people to [laughs] post stuff and people have posted exactly what's on my mind all of the time so I don't even have to post, which is really nice. Just being on the group.

Even, even if you don't post a lot, it feels like, if you're reading even, it just feels like you're part of something

A lot these I don't like, you know, post in or do a lot with, but I do read through some of the posts just to see if there is anything relevant that I can learn.

One participant described using a search bar within the group to find information and chose not to post or interact with any of the content:

That little search button. That is super helpful. And then I don't even have to ask my own questions. Um, cause someone else has probably asked already.

Participants who reported making contributions to the group, through posts and related interactions, described using the group infrequently or inconsistently:

I'm not on Facebook a ton. Um, um, so I 'like' things and sometimes I'll share things that I think are relevant to the group. Um, and I have made a post, a post or two and commented on a post.

I haven't actually made any posts myself. Um, just a commenter.

Participants who reported feeling comfortable posting in the group when they had a question or concern attributed it to the geographic-specific nature of the group and observing other members model interactions with content:

I think that it being, like, a private, like New Brunswick group, um, makes it feel more comfortable.

I think just personally I still have a hard time putting myself out there. Like, to ask a question. But when I see someone else, like I feel comfortable commenting on someone else, or like, liking and things like that.

I do, I feel like if I had a question, I could post it there, it's a safe space for it, so

Theme 4: Growing Activity in the Group Perceived Barriers and Facilitators of Activity

Some participants described a lack or low incidence of activity within the Facebook group compared to other Facebook support groups in which they are members. These participants felt that part of the reason for this lack of activity may be due to the diversity in conditions experienced by caregivers and their children within the group:

I think the only way that it's not [active] is because it's just so diverse.

My little boy's disease is extremely rare. So rare that this is the only case in New Brunswick. He's the only one with that disease.

Her condition is so rare. I only know of one other family here whose son has [it], like I said so I don't expect, yeah, I don't expect to learn too much more about her condition and a lot of the times, her condition isn't black and white either.

Despite the diversity in conditions, participants felt that the similarities between the journeys of individual caregivers, due to the geographic-specific nature of the group may promote long-term success of the group:

I feel pretty good, like everybody fits in really well together.

I think, so far it's been successful in terms of like, being welcoming and, um, I think maybe, more interaction, um, in terms of, like, posting, obviously what I want from the group is obviously resources. You know, we're all here together, you know this is our lives, let's all just bask in it together kind of thing [laughs].

Having [a group based] in New Brunswick has been very helpful, just to know that we can connect to people who are close by. And even just knowing someone is, even if they're in Moncton, or they're anywhere else, like just knowing they're in New Brunswick is helpful, and they're kind of on a similar journey.

Some participants identified the research focus of the group as a potential reason for a lack of activity, though these individuals did not feel uncomfortable with posting or interacting with posts themselves:

I mean I don't have a problem with it, some people maybe are worried to share things because there's administrators or moderators in there, you know what I mean? I wouldn't, but maybe some people wouldn't complain about services in New Brunswick if they're worried it would get back to the service provider, I don't know. I personally don't think that it makes a difference, knowledge is power, and I think that if people hear what we go through or what our struggles are or what's lacking or where it's lacking, that it's going to help our kids in the long run.

The private nature of the group and restricting content to members was considered to be a facilitator of activity within the group:

I think that it being, like, a private, like New Brunswick group, um, makes it feel more comfortable.

However, a lack of clarity in exactly what content is visible to non-members was identified as the barrier to participation by one participant:

Overall, uh, we haven't really used it a lot. That's more because, uh, there's not the comfort level there, knowing who's in it and who's in charge of it, and who can be looking in.

There was a sense that the community within the Facebook group was growing.

Participants reported feeling that a larger community would lead to increases in group activity, such as more posts and interactions:

So as people are joining and maybe feeling more comfortable posting, and asking questions, and just seeing that this is a place where they can connect. So it seems to be, seems to be growing in my mind.

Even in like the mom, like, there's a mom chat group for New Brunswick that's quite, it's daily, like, people are constantly posting in it. I think once this group grows like that, it will have the same effect, I think, that people will look to that first and they'll get the support from there.

And it seems like more people are comfortable asking questions or putting things out there. Um, the more members the more people probably post things.

Some of the parents haven't said too, too much yet. I think that once it starts to evolve, there is going to be a lot more, um, questions asked, and, um, I think it's still, still needs more time.

Many participants described referring prospective members to the group as a means to continue building the online community:

I think that the more people, I think that's why I'm trying to add people to it that I meet, that have complex needs, cause I feel the more people that are in New Brunswick that add themselves to it, it'll become that much more, um, that'll be the first place people look to, cause it's local.

Anyone I meet that's new, I try to add them, either, if know they're in New Brunswick, I add them to the, to your group, which has been nice, or I direct them to it.

Theme 5: Moderators as Contributing Members

Many participants described the influence of group administrators and moderators. Most participants felt that the moderators were the primary contributors to the group:

I think they're the primary contributors right now [laughs], um, to the group and therefore to the community in the group. Um, so I just, I feel like they're the only contributors right now. I think they're doing a good job, yeah, I don't know.

When asked about the contributions of the moderators, participants reported seeing weekly discussion posts intended to maintain activity within the group and interactions

with members' posts. These participants viewed the moderators as active members of the group who interacted with and facilitated discussions:

I think they do a great job because I think see them comment on almost every comment. And, uh, I see that they, they put posts on there, you know trying to facilitate discussion or whatever, which I think is nice too.

I find it really great just to have a check-up kind of thing happen. I mean you guys seem to sometimes just ask questions or kind of encourage people to share things.

Discussion

Principal Results

The current study aimed to investigate how caregivers of children and youth with CCN use a Facebook-based P2P support group and explore factors related to its ongoing activity levels. The group attracted a total of 108 caregivers of children and youth with CCN over a period of six months upon implementation. There were approximately 10 times more interactions with posts (e.g., likes, loves, and comments) than posts themselves; an observation that is consistent with previous studies on the use of Facebook groups [38].

Survey respondents were mostly female; although ten participants did not disclose their gender, no participants reported being male. This is consistent with previous research suggesting that white, female, and college-educated users are more likely to use social media for health-related support than men [39].

Nearly two-thirds of the survey and interview participants reported belonging to multiple P2P support groups related to their role as a caregiver of a child or youth with CCN. Many of these participants described using each of those groups for a specific purpose. For example, groups centred around a specific condition or set of symptoms often involved members from all over the world. These groups were considered to be helpful for informational support related to medical concerns and specific emotional support, due to the often-rare nature of a condition.

The Facebook group, developed for the purpose of this research, was viewed as an important source of informational support, specifically navigational support for local programs, services, resources, and activities. The majority of survey participants in the current study reported using Facebook daily. Previous studies posit that the more intensely an individual uses social media, the more perceived support that they receive [40]. Participants in the current study reported using the group for these informational support purposes and gaining insight from individuals whom they considered to be knowledgeable experts. It appeared that interview participants valued the knowledge available from their peers, which they specifically attributed to the experiential knowledge of their peers [41]. The information obtained from peers within the group included their experience with various services, resources, programs, and activities, as well as their opinions and suggestions, which were highly trusted by participants; this trust in knowledge obtained from peers in similar situations has been previously observed [42].

Content analyses of the posts published to the group showed that inquiry-based posts (i.e., those centred around a question) were the most common among group members, followed by informational posts and emotional posts. Most of the posts

published to the group originated from group moderators as a means to promote activity within the group and prevent it from becoming stagnant. However, over the course of the research period, the total number of posts published to the group was observed to increase each month. Despite the short timeframe between the implementation and evaluation of the Facebook group, many interview participants also felt that the group was growing in membership and activity levels. Initial recruitment efforts to the group resulted in a corresponding surge in membership, yet membership continued to grow despite the conclusion of the recruitment period; this can be explained by an increase in word-of-mouth referrals made by participants who had joined the group and then shared to other relevant groups on the Facebook platform.

Emotional posts received the most comments, likes, and loves from group members, specifically receiving the most comments; these posts also received the greatest number of likes and loves, suggesting that group members respond the most to posts based around an emotional support need. As expected, inquiry posts received the next highest number of comments, as these posts are generally centred around a question requiring insight from other members and usually develop into a discussion in the comment section.

Use of the Facebook group by caregivers for social support can be explained by the Strength of Weak Ties theory [43]. This theory suggests that social support is exchanged within a social network through strong ties (e.g., family and close friends) and weak ties (e.g., acquaintances), but that weak ties may be particularly important for eliciting benefits. Where online communities with strong ties often result in information saturation, those with weak ties tend to be more heterogeneous and can result in greater access to diverse and stronger information support [44]. Moreover, weak ties can

encourage individuals to disclose more personal or sensitive information due to the perception of less judgement [45,46]. Finally, weak ties can be perceived as helpful to individuals seeking informational support to deal with a health issue [47].

The administrators and moderators may have indirectly influenced how caregivers of children and youth with CCN used the group. Previous content analyses of P2P support groups have shown that members seek more emotional support on informal support groups, whereas they tend to seek more informational support on formal support groups led by professionals [48]. One of the explanations for this is that messages posted by trained health care workers are distinctly different from those posted by group members; specifically, messages from trained peer counsellors tend to be more structured and detailed than those from peer members [49]. Given the research emphasis and professional experience of one of the moderators, caregivers in the present investigation may have viewed the group as a formal support group. However, in a previous investigation on parents of children with special needs, Ammari and colleagues [3] found that parents used geographic-specific P2P support groups primarily for informational support needs over emotional support needs, due to the collective knowledge on locally-available services, resources, and programs amongst members. Therefore, while it is possible that the moderators influenced the type of support that members sought in the present study, previous research supports the notion that geographic-specific groups result in the exchange of more informational support.

Many participants expressed a desire to support other caregivers of children and youth with CCN by sharing their own knowledge and experiences. One participant described this lived experience as a collection of knowledge, their "backpack", which could be shared with those who might be lacking information. Some of these

participants expressed feeling compelled to help others, specifically with regards to informational and navigational support. Previous investigations suggest that this reciprocity and sharing of knowledge and experiences can help foster friendships and promote positive health behaviors in persons that engage in health-related, online P2P support [50]. In the current study, sharing one's experiences was considered to be an important catalyst to social support.

Interview participants described varying levels of engagement with the Facebook group. Despite previous literature suggesting that superusers (i.e., users that consistently and actively engage with content on social media) are the foundation of activity within P2P support groups [51,52], most of the participants in the current study described themselves as either moderate contributors or lurkers. This was supported by survey findings, which revealed that most participants had never published a post to the group but had interacted with at least one to two posts within the group. Although many of the interview participants did not actively interact with content in the group, many described using the group as a source of informational support. Specifically, participants were often able to find answers to their questions through previous posts and/or comments, sometimes even using the search bar in the group to see if a topic had been previously discussed. These findings are contrary to previous research suggesting that lurkers do not gain as much from participation in groups as superusers [53], but support the notion that lurkers can benefit from passive interaction with support groups [54].

Factors identified by participants that contribute to their use of the group included the closed privacy designation of the group (i.e., content was restricted to members) and the focus on NB caregivers. The geographic specificity of the group appeared to counteract the diversity found between the conditions experienced by

caregivers within the group, which was identified as one potential barrier to activity and interactions. Most participants in the survey and interviews reported feeling comfortable posting within the group if they felt the need; those who reported feeling uncomfortable cited concerns related to the research focus. Importantly, only two participants within the study described this as a concern.

The private designation of the Facebook group was an important consideration for attempting to protect the confidentiality of caregivers. Maintaining confidentiality is particularly important in the current Facebook group, which consisted of members from a small geographic community. Concerns related to privacy have been identified as a concern by patients and caregivers who participate in online support [14,15]; however, the benefits associated with sharing such information are considered greater than potential risks [18]. Privacy concerns related to use of P2P support forums on social media do not appear to be consistent across all users and may depend on contextual factors [56].

Participants in the current study perceived the group to be successful as a place for gathering caregivers of children and youth with CCN and providing a space for the exchange of support. Developing a group that can maintain active interactions between members over a period of time requires creating a space that is trusted by its members [38,57]. Variables identified in the literature to facilitate trust in Facebook groups include: smaller and more homogenous membership; long group tenure; identity-based groups; and age and gender homogeneity [38]. International diversity, for example, has been negatively associated with trust in Facebook groups [57]. Smaller group sizes with exclusive membership is a known facilitator of trust among online communities that increases opportunities for new connections within the group [38]; specifically, groups

with over 150 members are considered to be less trustworthy than smaller groups. Apart from the short group tenure, each of these factors were observed in the current study of 108 caregivers, suggesting the potential for longevity.

Findings indicate that moderators were viewed by group members to be active contributors to the group which, in turn, encouraged members to use the group; this supports earlier findings about the importance of moderators for network engagement [58]. Although moderators were perceived as the primary contributors to the group, this interaction by moderators appeared to facilitate group activity. Support groups are moderated by professionals (e.g., care providers) [59,60] or peers (e.g., other patients/users) [61,62]; the present Facebook group was moderated by a patient navigator (care professional) and a member of NaviCare/SoinsNavi's PFAC, who has experience with being a caregiver of a youth with CCN. A limitation of moderators identified in the literature rests in their ability to answer certain questions from members [55]; although moderators aimed to respond to posts by group members to ensure posts were never ignored, other group members often provided their unique insight into questions raised. Therefore, while the Facebook group was not a solely a P2P support group, as the moderators did not represent the target population, responses from both the moderators and other caregivers integrated to form a unique perspective on raised issues from group members.

Limitations

Limitations of this research include a time constraint between the implementation and evaluation of the Facebook group and small interview and survey sample sizes. This research may have oversampled caregivers who are more engaged in the needs of their children, as survey and interview participants came from a sample of

the population who chose to become members of the Facebook group. Moreover, there was overlap between the participants who completed the online survey and interviews; specifically, twelve out of fourteen interview participants also completed the online survey. However, survey and interview questions were different; specifically, interviews aimed to provide greater context to questions within the survey.

Demographic information was not obtained about members of the Facebook group due to privacy restrictions imposed by the Facebook platform. However, as the focus of the study was on the use of the support group by caregivers of children and youth with complex care needs, this information was not central to the goals of the study. Survey data suggested that the participants were primarily female; therefore, the male perspective is missing from the current study. Another potential concern is that the research focus of the Facebook group may have impacted the way that prospective members approached it and used by group members. Specifically, concerns regarding privacy may have prevented members from posting content. Moreover, one of the moderators was a patient navigator who does not identify as a caregiver of a child or youth with CCN. It is possible that the presence of a health professional within the group affected the dynamic of P2P interactions.

Data was not obtained on a user-level regarding the number of posts and/or interactions made by each group member. This was partly due to the short time span (six months) of the study period, where the group experienced a surge in membership. Although prospective members were required to undergo a screening to ensure that the population was restricted to caregivers of children and youth with CCN in NB, this information was self-reported by users and could not be verified by group

administrators. As a result, it was not possible to confirm that every member of the group was a caregiver of a child or youth with CCN and lived in the province of NB.

Although the group was developed prior to the COVID-19 pandemic, the Facebook-based P2P support group was implemented and examined through periods of stay-at-home orders and provincial restrictions. Caregivers of children and youth with CCN were particularly impacted by social distancing measures, which led to increased caregiver stress and loneliness [58]. The unique circumstances presented by the pandemic may impact the generalizability of the findings in the current study. For example, it is unclear whether caregivers would have used the group to the same extent outside the parameters of such extreme circumstances. Many of the interview participants expressed concern about interacting with individuals from outside of their household due to their child(ren)'s immunocompromised conditions; it is possible that these participants may have leaned on support from groups like the one studied to fill in missing support. It is also possible that the COVID-19 pandemic will change the future use of P2P support groups for health-related communication on social media.

Future Work

The Facebook group was identified as an important source of information, as well as for social interactions, by caregivers in the present study. Given the close proximity in geographical location between the caregivers in the Facebook group intervention, it is possible that some members of the Facebook group may express a desire to meet face-to-face at the conclusion of COVID-19 social distancing measures. While the caregivers in the present study served as a source of information for members of the Facebook group, future research might examine differences between online and offline social support when individuals initially connect online. For example, offline

social support may result in additional instrumental or tangible support to complement the action-facilitating support exchanged online [64]. Moreover, future work might examine how online and offline social support networks may influence one another.

Despite the initial uptake of the Facebook group by caregivers of children and youth with CCN, few members reported regularly posting and engaging with content in the group. Previous work on the participation of online community members has noted a 1-10-90 pattern wherein 1% of members create 90% of the posts and 10% of members interact with those posts [53]. Although there appeared to be greater participation with content by caregivers in the current study, the sample size was small. More research is needed into the presence of lurkers in online P2P support groups to better understand their experiences and possible barriers to participation.

Future research is needed to better understand the differences in use between geographic-specific Facebook support groups and condition-specific groups with more specific subject matter, but diverse caregiver populations. Moreover, previous literature has suggested that patient and caregiver level characteristics might influence the type of contributions made to groups. For example, individuals facing a new diagnosis versus those with more experience might use online support groups differently [65]. The current study found that some caregivers intended to use the group as they face transitions (e.g., school or respite care). Future research might consider examining the experience of caregivers at various points in their care journeys; moreover, these differences in contributions may point to distinct needs between patient and caregiver populations. Finally, future work may also consider determining the role that health professionals can provide in Facebook-based groups to promote access to information and resources or programs.

Conclusions

Patients and caregivers are increasingly engaging in online P2P communications to seek and provide support. Investigations into the use of these online groups have demonstrated the importance of these communities in meeting the support needs of diverse populations, such as caregivers of children and youth with CCN. P2P support through social media presents a low-cost and accessible avenue for caregivers of children and youth with CCN to obtain needed and timely support. Determining the potential role that health professionals can have in these communities may improve information sharing and improve the well-being of families of children and youth with CCN.

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MANUSCRIPT FIVE

Experiences, motivations, and perceived impact of participation in a Facebook-based support group for caregivers of children and youth with complex care needs

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Abstract

Background: Caregivers of children and youth with complex care needs (CCN) often require considerable support to ensure the well-being of their families. Social media presents an opportunity to better support caregivers through computer-mediated communication for social support. Peer-to-peer (P2P) support groups are one way that caregivers are accessing needed support; however, the impact that participation in these groups has on caregivers of children and youth with CCN is not known.

Objective: This study aimed to: (1) explore the experiences of caregivers of children and youth with CCN who use a Facebook-based P2P support group to communicate; (2) understand their motivations to use the group; and (3) investigate its perceived impact on knowledge of programs and services and sense of community belonging in caregivers.

Methods: A qualitative descriptive design was used to explore the experiences and perceived impact of a Facebook-based P2P support group for caregivers of children and youth with CCN in NB. The group was launched in October 2020 and resulted in 108 caregivers joining the group. An online survey was distributed, and semi-structured interviews were conducted with a sub-sample of members. Thematic analysis was used to identify, and report patterns related to caregiver experiences and perceived impacts of participation.

Results: A sub-sample of members in the Facebook group completed the online survey (n=39) and interviews (n=14). Five themes emerged from interviews: (1) Safe Space; (2) Informational Support and Direction; (3) Virtually Connect with Peers; (4) Impact on Knowledge of Programs and Services; and (5) Degree of Community Belonging. Participants reported joining the group to obtain geographic-specific information support and to connect with peers. Many participants reported an improvement in knowledge of programs and services and felt connected to the community; however, group infancy and diversity among the caregiver population were cited as barriers to community belonging.

Conclusions: Online P2P support groups hold significant promise for supporting caregivers in ways that traditional methods have not been able to achieve. Findings from this study suggest that involvement in online, geographic-specific P2P support groups can influence perceived knowledge of services and resources and sense of community belonging among caregivers of children and youth with CCN. This work further provides insight into the experiences and motivations of caregivers of children and youth with CCN who participate in a private social media environment.

Keywords: caregiver experiences; peer-to-peer support; social support; social media; children with complex care needs; Facebook group

Introduction

Despite representing only 15-18% of the childhood population, children and youth with CCN account for a substantial portion of health care costs and resource use in Canada [1]. While pressure on the resources needed to treat these conditions is challenging the sustainability and effectiveness of Canadian health care systems, it also affects the well-being of children and youth with CCN and their caregivers. Caregivers of children and youth with CCN (e.g. parents, guardians, extended family members, etc) face numerous challenges and barriers [2]. Obstacles faced by caregivers of children and youth with CCN include: managing care from multiple providers and services; lack of information and access to resources; and emotional challenges [3,4]. These challenges have been exacerbated by the COVID-19 pandemic, leading to increased caregiver stress and loneliness [5]. Online P2P support groups through social media is one way that caregivers of children and youth with CCN are accessing needed support [6]. However, the impact that participation in these groups has on caregivers of children and youth with CCN is not known. The current study aimed to explore the experiences of caregivers of children and youth with CCN who use a geographic-specific Facebook-based P2P support group and investigate its perceived impact on knowledge of programs and services and sense of community belonging.

Background

Caregivers of children and youth with CCN often require considerable support to ensure the well-being of their families. Additional pressures on these caregivers can result in significant stress and isolation, particularly when attempting to navigate the healthcare system [3]. Social media websites and applications offer an opportunity to

better support caregivers through computer-mediated communication for social support [7]; specifically, social media-based peer-to-peer (P2P) support. Online support groups provide an environment for the exchange of informational, emotional, and instrumental support [7–9]; however, caregivers of children and youth with CCN report primarily using these groups as a source of informational support [10].

While these communities are not meant to replace professional health care [11], they do provide a number of important benefits to caregivers and their families. P2P support groups can promote access to information and create a sense of community belonging [12,13]. Online support can increase feelings of control, reduce isolation, and lower depression and anxiety in caregivers of children and youth with CCN [14]. Health-related communication is often associated with risks including the privacy and reliability of information [15,16] as well as members' ability to appraise relevant information [17]. Observations of P2P support groups, however, suggest that misinformation is often self-corrected over time by members who validate or correct posted information [18]. Moderators have also been identified to play an important role in decreasing the spread of misinformation in groups [19].

One of the strongest motivations to engage in health-related P2P support is the desire to connect with individuals in similar situations [15]. Dumaij and Tijssen [20] report four characteristics that play a role in an individual's decision to use a particular website to connect with peers: (1) whether it is closed access (i.e., private); (2) nature of topics discussed; (3) ease of use; and (4) type of users and structure of discussions. Engagement with these groups can differ depending on various factors, including the target population of groups. For example, parents of children with CCN report using geographic-specific groups for locally based informational or navigational support, and

condition-specific groups (e.g., autism) for support specific to their child's symptoms and/or diagnosis [6].

Belonging to a social group that is valued by contributing members can lead to a shared social identity [21]. This sense of social connectedness is an important consideration in P2P support groups that target caregivers of children and youth with CCN. A poor sense of belonging has been associated with low caregiver well-being which can affect health outcomes of their child or children [22]. A lack of social belonging, or social isolation, can be defined as "a state in which the individual lacks a sense of belonging socially, lacks engagement with others, and has a minimal number of social contacts" [23]. Online platforms used for P2P support can promote a sense of social inclusion and belonging among informal caregivers [24], such as in older adults [25,26]. Although the impact of these groups on caregivers of children and youth with CCN is unclear, face-to-face parent support groups have been shown to increase a sense of community belonging among these caregivers [27].

Health literacy, broadly known as the ability to read and understand health information [28], is associated with knowledge of health-related services and has been identified as a barrier to navigating the healthcare system [29]. Low health literacy presents additional barriers when interacting with professional care providers, who often assume a higher level of understanding than an individual might possess [30]; this can be problematic for caregivers of children and youth with CCN who often manage the care of their child [31]. Online P2P support offers an opportunity for individuals to engage with health information in a variety of ways, which can promote access to information [12] and improve knowledge of health-related resources [32,33].

Associations between online P2P support and health-related knowledge have been

observed in breastfeeding mothers of preterm infants [34] and caregivers of persons with Type II diabetes [35]; however, it has not been previously explored among caregivers of children and youth with CCN.

Objectives and Research Questions

The primary objective of this research was to explore the experiences, motivations, and perceived impact of involvement in a geographic-specific P2P support group on Facebook, as well as the motivations to use these groups, for caregivers of children and youth with CCN. More specifically, this research aimed to investigate the impact of participation in the group on perceived knowledge of resources and programs, and sense of community belonging. The following research questions formed the basis for this research:

1. What are the experiences of caregivers of children and youth with CCN who use the Facebook group to communicate with other caregivers?
2. Why do caregivers of children and youth with CCN use the Facebook-based P2P support group?
3. In what ways does participating in the Facebook group affect NB caregivers of children and youth with CCNs' perceived knowledge of services or resources?
4. In what ways does participating in the Facebook group affect NB caregivers of children and youth with CCNs' perceived sense of community belonging?

Methods

Design and Sample

A qualitative descriptive design was used to explore the use and perceived impact of a Facebook-based P2P support group for caregivers of children and youth with CCN in NB. Qualitative description is a pragmatic qualitative approach that facilitates

obtaining simple, straight-forward answers to questions in applied health research [36], while offering a comprehensive summary of an event or experience in everyday language [37].

A Facebook group, created for the purpose of this research, was launched in October 2020. The development of this group has been previously described [38]. The group was designed in collaboration with NaviCare/SoinsNavi's Family and Patient Advisory Council (PFAC), who provided insight into the following variables: language; group description and title; moderators; recruitment strategy; research observation; and evaluation. Group content is available in English and French and closed to members (i.e. private). Caregivers of children and youth with CCN were recruited through advertisements on other relevant Facebook groups (e.g. NB-specific groups for parents), media releases to relevant community organizations (e.g. NaviCare/SoinsNavi), and word of mouth. The group attracted a total of 108 caregivers over the six months of the research period and has primarily been used by members to find answers to inquiries related to their child's care and for the exchange of informational support, such as navigational support [10].

Data Collection and Analysis

An online survey was distributed to members of the Facebook group in February 2021, consisting of nineteen questions related to their experience in the group. The bilingual survey was developed using Qualtrics XM and distributed to members through a link posted to the group. Semi-structured interviews were conducted with a sub-sample of members in the group in February and March 2021 using Zoom video-conferencing software. All interview participants received compensation. This research was approved by the University of New Brunswick's Research Ethics Board.

Open-ended survey questions and interview transcripts were analyzed using thematic analysis [39], as a means of identifying, analyzing, and reporting patterns across the data set, as well as organizing and describing the data in rich detail [40]. Specifically, the lead author read through transcripts and assigned initial codes to content. Codes and associated quotes were collected in Microsoft Excel to produce a summary table [40] and grouped into broader themes using an iterative process to ensure that the original context of quotes were preserved. Close-ended survey questions, including demographic information, were numerically summarized in Microsoft Excel.

Results

A total of 39 individuals who were members of the Facebook group completed the online survey and 14 completed interviews. Most of the survey (n=20) and interview (n=12) participants reported being a member of the Facebook group for a minimum of three months. The majority of survey participants were female (n=29), with the remaining participants (n=10) opting not to answer. All of the participants were over the age of 25 years, with 41% reporting their age between 25-44 years. Only one participant was over the age of 55 years.

Most survey participants reported caring for one child or youth with CCN (n=21) and an additional nine reported caring for two; remaining participants did not provide a response. Most of the participants reported caring for children between the ages of 6-12 years (n=13), followed by children 4-5 years of age (n=11). Participants reported caring for four young children between 2-3 years of age and four youth between 13-18 years (Figure 1). Similarly, most interview participants reported caring for young children between the ages of three and five (n=8). Only one interview participant reported caring for a school-aged child, and two reported caring for adolescent youths.

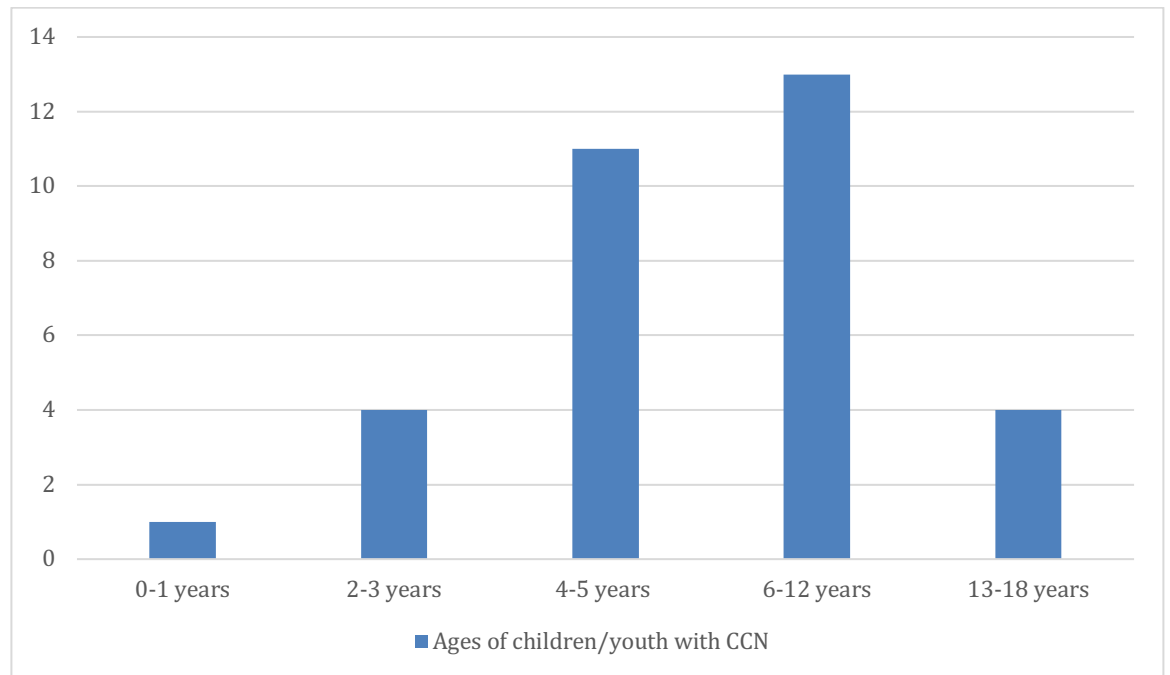


Figure 1. Age of children/youth under the care of survey participants.

Note. Participants were able to select multiple responses if caring for more than one child or youth.

Conditions identified by caregivers were grouped according to six categorizations of disorders: mental health disorders (n=8); developmental disorders (n=16); neurological and genetic disorders (n=9); movement and motor disorders (n=8); cancer (n=1); and undiagnosed CCN (n=7). The most common type of mental health disorder included anxiety (n=3) and attention deficit hyperactivity disorder (n=2). Autism (n=9) was the most common reported developmental disorder, followed by global development delay (n=4). Neurological and genetic disorders consisted of nine different very rare conditions; these are not reported to protect the anonymity of participants in the study. Finally, cerebral palsy (n=7) was the most common movement disorder. The total number of conditions reported exceed the number of survey

participants (n=39) as nearly a third of participants (n=12) reported caring for a child with multiple diagnosed conditions.

Online Survey: Motivation to Participate and Perceived Impact of Participation

Most survey participants reported becoming aware of the group from a friend or acquaintance (n=11) or through NaviCare/SoinsNavi (n=7). Four participants reported learning about the group through another support group on the platform. When asked about their motivations for joining the Facebook group, survey participants reported the topic to be relevant to their needs (n=23), the need for information and/or support (n=16), and the desire to make connections with others (n=13), among other reasons (Figure 2). Among the "other" reasons included the foresight to use the group as a resource for future support needs.

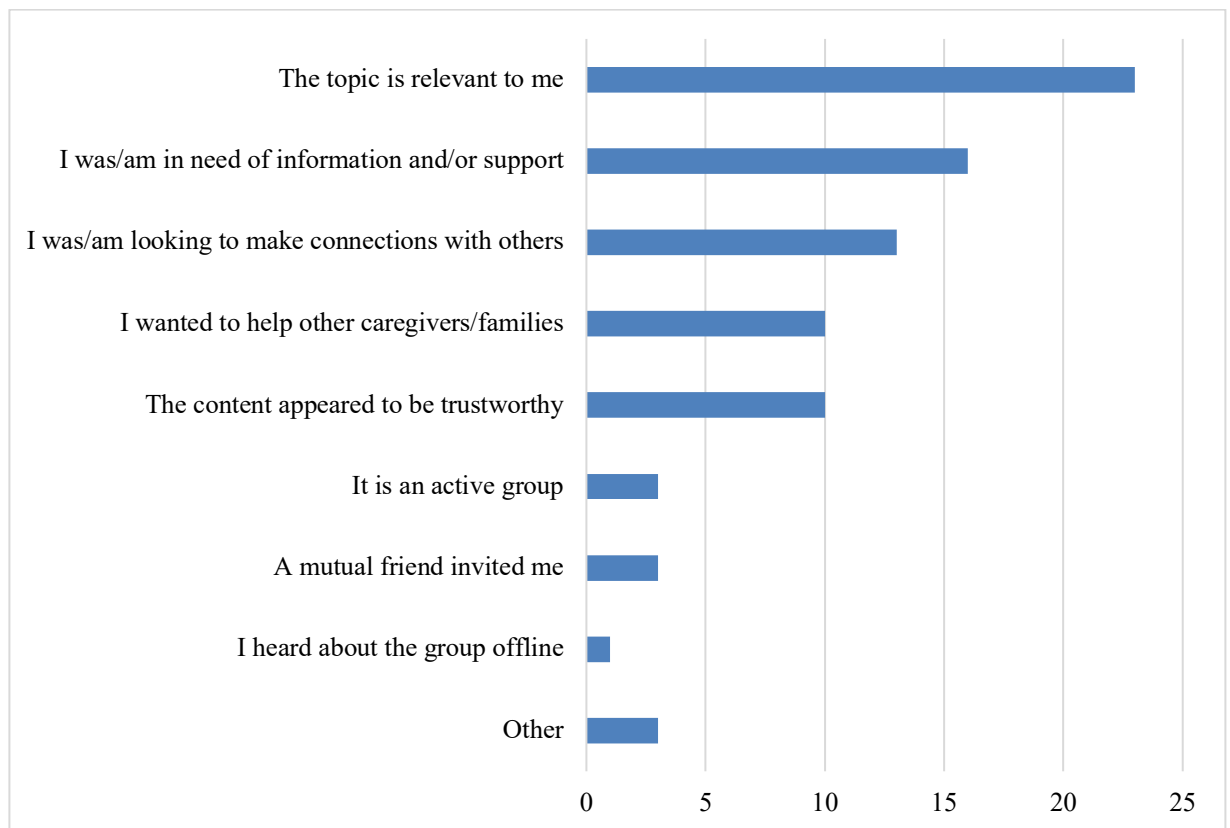


Figure 2. Motivation for joining the Facebook group

Approximately one third of respondents (n=14) indicated that they had learned about new services and/or resources relevant to their child(ren)'s care from participation in the Facebook group. An additional twelve indicated that they did not learn anything new. Four participants responded that they did not know if they had learned anything new. When asked about the impact of the group on caregivers' role in caring for their child(ren) using an open-ended question, two participants stated that the group improved their sense of community belonging. No participants in either the surveys or interviews reported that the group negatively impacted their knowledge of services or resources, or sense of community belonging.

Thematic Analysis of Interviews

A total of five themes emerged from interviews when exploring the experiences of caregivers who used the Facebook group and the perceived impact being a member of the group had on their knowledge of services and resources and sense of community belonging. The themes are as follows: (1) Safe Space; (2) Informational Support and Direction; (3) Virtually Connect with Peers; (4) Impact on Knowledge of Programs and Services; and (5) Degree of Community Belonging. These themes are described in further detail below.

Theme 1: Safe Space

Participants described their experience in the Facebook group as a positive environment for the exchange of P2P support. Many participants characterized the group as a safe space that was inclusive of all caregivers regardless of conditions or diagnoses:

I do, I feel like if I had a question, I could post it there, it's a safe space for it.

I feel like this space is inclusive to everyone at different levels, in their diagnosis and in their journey.

Compared to other Facebook support groups, this group was considered by some members to feel safe due to its specificity to caregivers of children and youth with CCN and the culture in NB:

I find sometimes with like, for instance, my [condition specific] group and things like that it's people all over the world. So, you know, I understand that sometimes things aren't translated the same? [laughs] Or the intentions are not the same, or sometimes, you know, people can comment on something and it meant to be good, but you read it, you're kind of like, "oh, okay, that was saucy, or that was like", you know what I mean? But I find this Facebook group, I don't see any of that, we're all kind of, at the same, you know what I mean? Like, it's just it's, it's local, it's in New Brunswick. It's here. Yeah, I could bump into you at Costco or [...] I could meet them for coffee somewhere. They, our kids could meet our you know what I mean?

Some members characterized the Facebook group as a positive space for the exchange of informational support, rather than a reminder of emotional difficulties associated with being a caregiver of a child or youth with CCN:

Sometimes, you know, like, as a caregiver, these groups, sometimes I have to be super vigilant of what I'm reading, because sometimes certain posts can trigger

stuff in it. And it's just like now with, with technology, you have to be your own kind of gatekeeper? So, like, for instance, if I'm going to bed and then right before I looked at that group, and I'm like, "oh, somebody posted like", you know what I mean? It's just, I find this group has been light and positive and informative.

When initially joining the group, some members reported feeling inadequate or doubtful about their place within the group, which they referred to as imposter syndrome.

However, these participants explained that this quickly dissipated after spending time in the group:

[My friend] messaged me [that] this group actually just started, you should join it [laughs]. So, I did and then I immediately got, I think it's called, is it imposter syndrome or something? Cause I just, like to me cancer is no big deal anymore and all these children that are, like, to me, are "real special needs", which I know is not, like, the right way to look at it, but it's just the way that I, the brain works. So I definitely feel, not intimidated, not the right word, but I just felt like, oh like, we don't belong in this group, right away. But I'm over that now [laughs].

Theme 2: Informational Support and Direction

Many participants described significant gaps in their support needs, particularly related to informational needs and navigational support to relevant programs, services, and resources. In some cases, participants reported being provided with an overwhelming amount of information upon recognition of a condition or diagnosis and were left to determine the next course of action:

I think the thing is that once you get your child's diagnosis, for me, I felt like I was given pamphlets, I was given appointments, like you're being pulled, like your life just was just turned upside down. And you're given all this information and sometimes you just don't know what to do with it. It slips through the cracks, you're grieving, you're processing, you're trying to figure out all of a sudden, you know, you thought your life was going one way with a child and all of a sudden, it's like, whoa, now it's brand new. [...] So you're trying to figure it out, um, and it took a lot of my husband and I have, you know, like figuring it out calling and asking questions and making sure that we weren't missing something, and it's exhausting. [...] We all have children with disabilities that we are trying to get the best care for, um, and offer them the best quality of life. And I feel like that the [NB] group is set up to support [us] in that.

It's very difficult to get answers to questions, to get help, because nobody knows where to line us up.

Participants detailed the mental load associated with being a caregiver of a child or youth with CCN, and explained that the Facebook group has been an important informational resource to help ease some of the pressure:

So going to that Facebook page and then there's people coming to it with questions and right away someone says "well I did this" "I did that" and I think, wow, that's, that's, you know. Those are the hours and hours that I spent looking

for information where now I can go and look and see someone's experience.

That narrows my search into "I'll try this first, if it works, great. If it doesn't, I can at least, you know". Where I didn't even know where to start [laughs].

Specifically, the group was viewed as an important source of informational support; one that could provide a starting place and direction forward in the overwhelming amount of information provided to caregivers when their child(ren) experiences a new diagnosis or crisis:

Um, mind you, I don't have the brain power to seek [the resources] out either [laughs] right now, dealing with two kids, and the pandemic, and the whole business. But, um, that, that's kind of the point, I guess to me, that when you're confronted with a diagnosis of any kind for your child, you don't have the time or brain power to go seek out the resources that may not even be there or are there but are so hidden or rarely used that they're just not talked out.

Just getting that advice from other parents is huge and it kind of helps you direct yourself. When it's very overwhelming, that kind of gives your brain a place to like, settle on, and then "OK how do we approach this" and then it usually spirals, you can get a lot more information.

Having the Facebook group is helpful, where it's like, "Oh, I didn't realize that". Maybe we were given the information at first, but we don't, like you forgot about it, or you misplaced it, or you just don't know, you didn't think that that was

applicable to you at that time and, um, or you're just so heavy in the grief, where it's like, you're just like, how do I just get through today and get through now.

Many members described a need for informational support due to an expressed lack of control that is associated with caring for a child or youth with CCN. More specifically, seeking informational support was described to elicit a sense of empowerment:

There's a lot of lack of control when you have a kid with special needs. I'm a control freak, [my husband] will say that. So I feel some sense of control and some power in her diagnosis if I have more knowledge of it. So if I know this is what we need to do or this treatment might help or whatever, whatever, it makes you feel like you have a little power in a very powerless situation. [The group] is a nice avenue to have if I have questions.

So if I know this is what we need to do or this treatment might help or whatever, whatever, it makes you feel like you have a little power in a very powerless situation.

Participants described feeling reassured by their membership in the group, knowing that it was a place that they could turn to for support if/when needed:

I find that even just having the Facebook group, just having it there is helpful. Just knowing that you can comment or post if you need to post. Like, just having it there.

Theme 3: Virtually Connect with Peers

Participants described a desire for a group specific to caregivers of children and youth with CCN in NB prior to the implementation of the study group. One participant explained having attempted to start a support group in the past, which was not successful:

I have been searching for this type of support for the last 6 years, even to the point of trying to start my own group, which was a super flop. I very much appreciate confidentiality of medical situations, but I think that was the biggest barrier. The therapists and doctors that everyone saw were unable to connect people together and there is no place to put up a poster or advertise really just to look for other real people, not just professionals who help, who are going through similar circumstances. I love the fact that it is a small, provincial group. I never would have guessed there were so many people here! I really felt like we were the only ones for a long time. The only people who even knew someone who had a complex need that is. And that is real lonely.

This is something that I've wanted from like the very beginning and to finally have something like that is such a relief, it's awesome, such a big deal.

Many participants were motivated to join the Facebook support group to engage in communication with individuals who were experiencing similar situations and understood their challenges:

You know, something could happen with a child that morning and they get through it with the doctor, blah, blah, blah, and then they want to talk about it. And there's someone to talk about it, because, before you just go along, well I know in my experience, "oh well we got through that one, what's next?" you know? [laughs] And then you can't talk to anyone but your own family members, and friends, but that's the huge, that's the biggest thing I find. They haven't lived your life. [...] I think this group is able to say, I need some help. And people are doing that, so that's good.

I remember there was one person who wrote about their child not being diagnosed. And I feel like that was something, like I would never have written a post like that. But to see that was like "oh my goodness! They are other people in New Brunswick who are the same!" and then there's like another person, I was just like "oh my goodness". It was really nice [laughs].

More specifically, the solidarity associated with membership to a group of peers facing similar challenges in the same province was identified as an important reason why some participants used the group:

Which is helpful, because you have your support of your family and friends and that's always valuable, but the support that you get from people who are going through a similar journey is just a different, you just feel heard, and you feel

valued, and you feel understood, which is just, it has, even if it's online, it's very, very helpful. I don't think anything could replace that, especially when you have children that have, like, any type of rare syndrome, you might not meet anyone that has that syndrome. So it's been a benefit [...] just having the [NB Facebook group] community, a huge support

When my daughter first got her chair, I wish we could have talked with other people too! I think there is a lot to gain from talking with people who are living the experience and not just professionals who support you. Not just about the facts of wheelchair life, but just knowing that there are other people going through the same challenges and success as you and connecting with them.

Some participants pointed to the virtual aspect of the support group as an important factor in why they use it. The availability and accessibility of the group was perceived as a particularly important facet by caregivers, many of whom felt overwhelmed by the daily pressures associated with raising a child or youth with CCN:

As a caregiver, it's completely different. You're burnt out, you're tired at the end of the day, you don't want to go to a support group. You don't even want to get you just want to sit [laughs] if you can, you know, we're talking parents that are, you know, like doing heavy lifting still with their four or five, seven, like teenage kids, you're talking parents that are doing diaper changes that are, you know, anything that's in, in a routine for kids is more complex for us.

Theme 4: Impact on Knowledge of Programs and Services

Participants described engaging in online research of resources and information, which often occurred during the early stages of a condition or diagnosis. Participants reported feeling that they had a good sense of available programs and resources for their child(ren). However, most participants explained thinking that there were additional resources and programs beyond their knowledge, due, in part, to the difficulties of initially finding the programs in which they are aware:

I feel like I know about a lot of them, but I also don't know about a lot of them. Like, even through the Facebook group and just, and through other, um, doctors or um, people, I'm still learning about things. Or maybe something that's available in another province that's just starting in New Brunswick or should be available in New Brunswick too and like, things like that.

I think I have a pretty good knowledge. I mean I'm sure there's things I don't know about, there's always things, can't know everything, right?

When asked about their perceived impact of membership in the group on their knowledge of programs and resources, many participants reported feeling that it had improved their awareness of available supports:

It's only been five months [in the group], but in our case we've already searched for resources. We managed to find some but I imagine that parents who have just

learned that their child is sick with disabilities, it will help them. [French translation]

There has been definitely a couple questions or a couple comments that has expanded my research and my knowledge on resources that are available.

Participants described learning about programs and services through reading posts made by other members and directly making inquiries to the group. Some participants reported learning about programs and services that might be relevant to their child's needs but were located in other parts of the province. However, learning about programs or services that may not be applicable to their specific geographic location was described as providing an opening to ask if anyone knew about similar services in their region:

I definitely learned about more. Um, not all of them in my area, but just knowing that other parts of the province makes me feel like, I could still maybe ask of some. Um, yeah, I've definitely been more aware of different programs.

Some participants reported no increase in their knowledge of available programs and services through participation in the group, but instead reported perceiving the group as a place where they could go if they had specific questions related to programs or services:

I wouldn't say it's increased my knowledge a whole lot, but it does, again, feel like a place I could go and answer if I felt I had an unmet need, it's a place that I could go and ask and see.

I haven't hit a groove yet that this has improved it, or I've felt supported, but I also wouldn't say that I'm not going to follow this page anymore cause I'm not interested. So I would say that I'm middle of the road on that.

In some cases, these individuals felt that they did not know what support they even needed and lacked the language to ask for informational support about available services and programs. In other words, participants described feeling uncertain about the types of services or programs that might exist and/or benefit them in the care of their child(ren):

We haven't found any resources. And to say that, I couldn't even tell you an example of what we're looking for because I don't, I'm a first-time cancer mom, so I actually don't know what resources I am seeking out.

Theme 5: Degree of Community Belonging

The extent to which caregivers of children and youth with CCN felt that they belonged to a community within the P2P support group varied. Despite the short length of time since the inception of the Facebook group, most participants reported feeling a sense of community belonging within the group.

It's definitely just helped me to see that there's a lot of families in New Brunswick, a lot more than you think, before you enter this world [laughs]. Um, that are in the same-ish boat that you are in. Um, I just, I thrive off of community now that we're in this situation. I just, I love to just talk to other parents who are feeling the same thing, it reassures me, it makes me think that I'm not alone in this crazy ordeal. Um, so to me, I just like to be a part of this group.

I think that [my sense of community belonging] could be more, but I definitely feel it.

Some members attributed this reported sense of community belonging to the group's membership exclusivity. More specifically, that the group was private and only permitted caregivers of children and youth with CCN who reside in NB:

But I know just having, um, children with complex needs, I think you feel that community right away when you join a support group.

It's made me feel more connected to our province, knowing that there are other parents out there going through, you know, similar experiences. Cause a lot of the networks that I'm a part of are either like, Canada wide, or you know, different countries, so it's nice to be in a group that's just New Brunswickers.

More specifically, the shared experiences between caregivers, despite differences in the ages and conditions of their children, was reported to facilitate a sense of community belonging within the group:

Even, even if you don't post a lot, it feels like, if you're reading even, it just feels like you're a part of something that, that someone else is going through something similar, even if it's not even the same, um, thing, it's similar enough that people understand the medical stays, the hospital stays, they understand the day to day, how much extra you do in a day. So, I think that, just that, initially creates an initial sense of community support.

I feel like I've, um, just knowing that other people are going through the same thing is like, so big. Sorry, I'm probably going to cry but that's because I'm a crier, so [laughs]

Four participants reported that they did not feel a sense of community belonging within the group. These individuals attributed this lack of community belonging to the short time since the group has been implemented. Some members described the short duration of time since the group was implemented as a reason for experiencing fewer social ties to other members within the group. However, these individuals reported a sense that they might benefit from a sense of community belonging in time:

I think that the relationship is still very new and very fresh. Uh, yeah. I think that it's, I think that it's something that will, that has benefitted me and will continue to benefit me and my family, so yeah.

[...] maybe some people already feel like it is, right, that they've found somebody that relates to them and they can, I haven't.

One participant who reported feeling disconnected from the online group explained that they did not identify with other members, many of whom are caring for younger children:

I'd be more interested if something came across my Facebook page from somebody who might be 55 with a 30-year-old and what they're doing for care and support and as you age as a parent and caregiver what your plan, what their plans are, that would interest me and I haven't seen a lot of that.

Discussion

Principal Results

Consistent with previous studies, most participants reported using the group as an important source of informational support in the care of their child(ren) [41]. Findings indicate that participants felt reassured by their membership in the group, describing it as a resource that could help ease pressures, or "mental load" associated with being a caregiver of a child or youth with CCN. The emphasis on informational support rather than emotional support, which was reported to be more predominant in condition-specific Facebook groups, resulted in caregivers reporting the group to be a

positive space, rather than a reminder of emotional difficulties outside of their control. Other Facebook groups were frequently described as "triggering" negative emotions, whereas the geographic-specificity and inclusive nature of this group was perceived by caregivers to be more conducive to the exchange of informational and navigational support.

That the majority of participants in the online survey were female and between the ages of 25-44 years is consistent with previous investigations, which find that women are more likely to engage in P2P support on social media for health-related concerns [42]. Most of the survey and interview participants reported caring for one or two children under the age of twelve years. Although there was a wide variety of ages and conditions experienced by caregivers, participants felt that the inclusive nature of the group contributed to it feeling like a "safe space" for the exchange of P2P support.

Participants reported joining the Facebook group because it was relevant, supported their unmet informational needs, and connected them with peers. As supported by the interviews, participants were primarily motivated to join the group to meet previously unmet informational needs, specific to the province of NB. Some participants described a lack of control associated with being a caregiver of a child or youth with a CCN. This lack of control was described as a particularly important motivation for seeking out Facebook-based P2P support. These findings support previous investigations suggesting an association between participation in P2P support groups and knowledge of health-related resources in caregivers of children with disabilities [43]. The availability and accessibility of the Facebook group was also identified as a reason why participants used the group; many participants described feeling overwhelmed in their role as a caregiver, with very little time.

Some participants described valuing the group for its exclusivity to caregivers in NB, due, in part, to their shared cultural norms. Using Facebook support groups to find like-minded others that share similar health practices has been previously observed. For example, Zhang and colleagues [44] noted that members of a Chinese depression support group began using the group to connect with others that shared Chinese health beliefs and practices, which differ from traditional medical practices. The geographic-specificity of the group was identified by many participants in the current study as a motivating reason for joining, as it offered a notably different experience than condition-specific support groups on the platform with international members.

Nearly all of the participants in this study reported difficulties navigating services and resources related to their child's care due to a lack of knowledge of relevant services and programs; this was described as one reason for joining the Facebook group. Some interview participants disclosed that they had directly asked for informational support in the group which, in turn, increased their knowledge of programs or other resources. Others learned about locally available supports by passively reading comments or posts by other members. Participants who expressed not feeling that they had learned anything new in the group cited the short duration of time since the group had started (six months) and small membership size. Many participants who reported not experiencing an increase in knowledge of programs and services felt that the group could still be a source of informational support for them in the future. For example, one participant facing a recent diagnosis in her child explained that she did not know what type of programs or services she should be seeking; this individual felt that she lacked the language to ask for support but hoped that it may evolve through further participation in the group. Considerable research has demonstrated an association

between offline support groups and increased knowledge in caregivers [45]. The impact of online groups is less clear, however a recent systematic review on the impact of online P2P support for caregivers of stroke survivors [46] supports the finding that participation is associated with increased caregiver knowledge.

Despite the short time since the group's inception, most participants reported feeling a sense of community belonging within the group. The immediate sense of community reported by some members was attributed to the group's exclusivity, specifically to caregivers of children and youth with CCN in NB, despite diversity in reported ages and conditions. Four participants did not feel a sense of community belonging with the group cited, in part, to the short time since the group's creation. One of these individuals was caring for an older youth and did not identify with other members, most of which were raising children under the age of 12 years. This finding corroborates previous observations that a sense of community in online groups is facilitated by more homogenous membership [47].

The finding that social belonging was facilitated by group membership may have been due to the exclusivity of the group. Caregivers reported feeling a sense of solidarity with other members knowing that, despite differences in conditions, each faced similar challenges. The use of online groups for coping resources have been attributed to a lower risk of threat to one's personal social ties, compared to the mobilization of offline resources [48]. In other words, although participants in the Facebook group shared many of the same characteristics, such as geographic location, engagement with the group for social support could be obtained even without social interaction (e.g., passive interaction). Moreover, the closed (i.e. private) nature of the group may have resulted in greater relational intimacy between members that led to a shared sense of community

than if the group had been public [49]. However, this perceived relational intimacy may pose a risk to online communities of this nature, whereby reduced nonverbal cues, facilitated by the computer-mediated environment, may result in misplaced credibility or “hyperpersonal” interaction [50]. Specifically, the social information processing theory posits that individuals enter into a loop of intense interpersonal interactions that can lead to the perception that others may be more trustworthy or credible than in actual fact [51]. However, more research is needed to better understand the effects of hyperpersonal interactions on perception of support providers [52].

Social Comparison Theory can be used to contextualize some of the findings in the present study. Social Comparison Theory suggests that individuals compare their situations to similar others to make assessments about their own health and well-being [53]. Although evaluation of this theory is limited in the study of online support groups [52], it may be applicable to understanding why caregivers may have experienced perceived benefits from participation in the current study. Many caregivers reported perceived benefits of participation, specifically on their knowledge of services and resources and sense of community. Social Comparison Theory suggests that individuals make lateral, upward, and downward comparisons to others within their social network. Lateral comparisons to similar others may have led to a sense of normalization and comradery between caregivers, thus impacting perceived sense of community. Upward comparisons occur when individuals compare themselves to others who appear to have more experience or better coping skills; this can lead to inspiration to improve one's situation and learn from their experiences. Conversely, upward comparisons can result in feelings of frustration. Downward comparisons occur when an individual compares themselves to another who appears to be struggling, which can result in an altruistic desire

to share one's knowledge and experiences. These social comparisons may explain why caregivers experienced perceived benefits as a function of participation in the Facebook group.

Limitations

Limitations of this research include the small sample size of caregivers of children and youth with CCN who participated in the Facebook group, particularly in the interviews. The survey and interviews may have oversampled caregivers who are more involved in the care of their child or children. There were no participants in the current study that identified as male, which would affect the generalizability of present findings to male caregivers. Participants who participated in the survey and interviews were not independent samples; there was overlap between these two sub-samples from the Facebook group participation. More specifically, twelve of the fourteen participants who completed the survey also took part in an interview to elaborate on their experiences. It is possible that the explicit emphasis of research within the group (e.g. requiring consent to join the group) may have influenced the sample of individuals who joined the group and their subsequent experiences. Individuals who joined the Facebook group were required to undergo screening to ensure that they identified as a caregiver of a child or youth with CCN and resided in NB; this information, however, was self-reported and could not be verified. Therefore, it is possible that some of the members in the group did not fit the target population of the study. However, all participants in the survey and interviews reported information on their role as caregivers of child(ren) or youth(s) with CCN. Finally, the study intervention and investigation took place during the COVID-19 pandemic, which has been identified to particularly affect caregivers of persons with CCN [5]. It is unclear to what extent the pandemic may have impacted the behaviors of

caregivers in the current study and whether these individuals would have used the group to the same extent. As a result, the pandemic may have affected the generalizability of these findings.

Future Work

Many of the participants in the current study were caregivers of younger children with CCN; future research is needed to explore how caregivers at different stages of their caregiving journeys experience and benefit from online P2P support groups. Previous work has suggested that caregivers of younger children CCN look to caregivers with older children and youth with CCN to see where their own children may end up [6]; however, findings from the current study suggest that some caregivers view this longitudinal perspective as "triggering" and become overwhelmed. More research is needed to understand this distinction between caregivers of children and youth with CCN.

While beyond the scope of the current project, future research might explore the impact that participation in online P2P support groups might have on offline relationships between caregivers of children and youth with CCN. More specifically, future work might consider how knowledge gained from these online P2P interactions influence offline conversations, such as with care providers; this may provide further context into why caregivers use online support groups [54].

Conclusions

Online P2P support groups hold significant promise for supporting caregivers in ways that traditional methods have not been able to achieve. Caregivers of children and youth with CCN engage in online P2P support to connect with peers who possess invaluable knowledge gained through lived experience and exchange support.

Involvement in these online support groups can influence perceived knowledge of services and resources and sense of community belonging, thus helping to meet previously unmet support needs. This work provides insight into the experiences, motivations, and perceived impact of participation in a private social media environment by caregivers of children and youth with CCN.

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DISCUSSION

The purpose of this doctoral research was to explore how caregivers of children and youth with complex care needs (CCN) in New Brunswick (NB) use and experience social media for peer-to-peer (P2P) support. The aim was to explore how online P2P support can influence knowledge of services and resources through a social media platform and whether it affects perceived sense of community belonging between caregivers of children and youth with CCN. The main objective of this research was to generate knowledge on how a geographic-specific social media support group is used by caregivers of children and youth with CCN to meet their support needs. These objectives have been achieved by the current research. The following two sections summarize the development of this doctoral research project and contextualize main findings within the broader academic literature.

Development of the Research Project

This research began with a scoping review exploring the role of patient navigators in contrast to case managers. Patient navigation offers an important opportunity to support caregivers of children and youth with CCN, particularly in NB, where caregivers have identified difficulties with system navigation (Charlton et al. 2017). However, similarities between the role of patient navigators and case managers has led to ambiguity in both the academic and practice contexts (Lukersmith et al., 2016). Findings from this review included the identification of nine functions of a patient navigator and further provide contrasts along those functions to that of a case manager. These findings provide an important contribution to the fields of nursing and public health, and have further implications across diverse practice contexts, including in the community and hospital settings. Specifically, this paper delineates differences

between the roles of patient navigators and case managers for patients, caregivers, care providers, policy makers, and other health care professionals. Within the scope of the current doctoral research, this review led to the identification of low-cost means to support navigation programs; specifically, online P2P support. Patient navigation programs, such as NaviCare/SoinsNavi, provide important support to patients and caregivers, particularly those facing complex health and social care needs (e.g., children and youth with CCN). Patient navigators provide individualized support to clients while acknowledging the important role of the patient and/or caregiver in their care journey (Natale-Pereira et al., 2011). Manuscript one revealed important functions of patient navigators that include acting as a reliable source of information and reducing barriers to services and programs. Online P2P groups can support patient navigation programs by leveraging the knowledge gained through lived experience between patients and caregivers and facilitate the exchange of information, particularly about relevant programs, services, and resources. Importantly, these groups do not replace patient navigation programs, as navigators are often more integrated with health and social organizations to help reduce barriers to care (Shockney, 2016). The extent to which online P2P support groups can act as a source of informational (e.g., navigational) support between caregivers of children and youth with CCN, however, had not been thoroughly investigated. In other words, online P2P support is an opportunity to optimize and maximize the exchange of knowledge between patients and caregivers in a geographic-specific context.

During my first doctoral comprehensive exam, I conducted a scoping review to explore how patients and caregivers use social media to engage in health-related communication. This work led to the identification of ten types of social media websites

used by patients and caregivers: blogs (e.g., Tumblr); microblogs (e.g., Twitter); social networking sites (e.g., Facebook); professional networking sites (e.g., LinkedIn); thematic networking sites (e.g., PatientsLikeMe); wikies (e.g., Wikipedia); mashups (e.g., HealthMap); collaborative filtering sites (e.g. Digg); media sharing sites (e.g. YouTube); and other/misc sites (e.g., virtual reality environments) (Grajales et al., 2014). Social networking sites are the most popular social media website used among patients and caregivers (Giuistini et al., 2018; Hamm et al., 2013), followed by blogs and microblogs (Hamm et al., 2013). Previous literature has demonstrated the use of these websites by patients and caregivers to exchange informational and social support, such as in patients diagnosed with cancer (Gage-Bouchard et al., 2017); patients in obstetrics and gynecology (Antheunis, Tates & Nieboer, 2013); and caregivers of adults with Alzheimer's disease (Scharett et al., 2017). Given the widespread use of social media environments by patients and caregivers for health-related concerns, it seemed likely that caregivers of children and youth with CCN could also benefit from these social media interactions.

The scoping review on social media-based P2P support groups revealed that only one previous study has investigated the use of social media by caregivers of children and youth with CCN. In an exploratory, mixed methods study, Ammari and colleagues (2014) aimed to determine what social media websites parents in the United States use for informational and social support and how parents navigate feelings of judgement from online connections. Researchers found that participants primarily used Facebook to connect with peers and, more specifically, used both geographic-specific and condition-specific private groups on the platform. These findings are not surprising, given the popularity of Facebook by patients and caregivers dealing with other health concerns,

including diabetes (Abedin et al., 2017); hypertension (Al Mamun et al, 2015), and other chronic conditions (Partridge et al., 2018).

The use of Facebook by parents of children with special needs in Ammari et al (2014) led to the development of the second manuscript in this dissertation. This paper consisted of an environmental scan of Facebook groups that provide support to caregivers of children and youth with CCN in NB. In other words, I wanted to know two things: 1) what support groups exist on the Facebook platform for this population, and 2) how these groups are used by caregivers of children and youth with CCN, including the status of their activity levels and membership involvement. Potentially relevant groups were identified through a structured search strategy on the Facebook platform, consisting of a pairing of various chronic health conditions faced by caregivers of children and youth with CCN (e.g., autism, cerebral palsy, etc) and synonyms of CCN (e.g. “special needs”) with geographical locations in NB. Additional groups were identified by contacting key stakeholders, consisting of organizations that serve families in NB. This study used similar methods to Bender et al (2011) and Farmer et al (2009) in the categorization of identified Facebook groups; however, only groups categorized as “support groups” were included in the final analysis. This strategy led to the identification of 47 condition-specific groups or groups targeting CCN in a specific geographical location in New Brunswick (33 private groups and 14 public groups); however no P2P support groups were identified that target caregivers of children or youth with CCN with *any* condition for the entire province of NB. This was an important finding. Many of the groups targeted specific diagnoses or health concerns, which may have been perceived as exclusionary by caregivers caring for a child or youth without a recognized diagnosis, despite clear CCN. The lack of a province-wide,

inclusionary group for anyone that identifies as a caregiver of a child or youth with CCN provided an opportunity to develop, implement, and evaluate such a group.

Doctoral Project: Main Findings and Contributions

The intervention of the current doctoral research comprised of a private Facebook P2P support group that was developed in collaboration with NaviCare/SoinsNavis' Patient and Family Advisory Council (PFAC). The Facebook P2P support group was designed to facilitate the exchange of support between caregivers of children and youth with CCN in NB. Manuscript three described the development and implementation of the Facebook group and a protocol for the evaluation of the group. Manuscripts four and five describe the evaluation of the group; specifically, manuscript four explored how the group was used by caregivers of children and youth with CCN and factors associated with its activity levels (i.e., "success), and manuscript five reported the perceived impact of participation in the group on caregivers' knowledge of services and programs and sense of community belonging. The following section provides an overview of the development and implementation of the Facebook group (manuscript three) and contextualizes the main findings from the evaluation within the broadened academic literature (manuscripts four and five).

The development, implementation, and evaluation protocol of the Facebook group (manuscript one) was informed by the PFAC and models from previous investigations exploring use of social media by caregivers (Ammari et al., 2014). A recruitment strategy led to the recruitment of 81 caregivers of children and youth with CCN within the first three months, to a total of 108 caregivers by the conclusion of the study period (after six months). The Facebook group was evaluated beginning after a period of five months post-implementation (i.e., launch of the group to the Facebook

platform) through an online survey and semi-structured interviews with group members (i.e., caregivers). Posts published to the group, including relevant interactions (i.e., likes, loves, comments) were collected until six months post-implementation. Survey data and posts made by group members were analyzed using content analysis and interviews were analyzed using thematic analysis.

Content analysis of posts (manuscript four) revealed that the group was primarily used by caregivers of children and youth with CCN for informational support. More specifically, caregivers reported using the group as a resource for information and to share their knowledge gained through lived experience. These findings support the previous study on the use of Facebook by parents of children with special needs (Ammari et al., 2014), which found that caregivers used geographic-specific support groups primarily for informational support (e.g. system navigation) and condition-specific groups for emotional support and more specific support related to their child's needs. Indeed, many participants in the current study reported also using condition-specific groups and benefited from interactions with other caregivers facing often rare or stigmatized conditions. These findings suggest that caregivers of children and youth with CCN use and benefit from membership in multiple online P2P support groups for different purposes.

Varying levels of engagement with the Facebook group in the current study (manuscript four) led to many participants describing themselves as “lurkers” or reported moderate or inconsistent engagement with the group. In other words, these participants passively used the group by reading posts and comments rather than interacting directly. These varying levels of engagement were not reported by participants to impact their use of the group for informational support. Previous research

on lurkers has suggested that these individuals do not received needed support from online groups (Mo & Coulson, 2010); however, many of the self-described lurkers in the current study reported learning about new programs and services through posts made by other members and moderators and developing a sense of community within the group. These findings are in line with Ballantine and Stephenson (2011) who found that individuals classified as lurkers seeking informational and emotional support in an online weight loss benefited from passive engagement. Overall, findings from the current study suggest that while activity levels within a group are important towards the long-term survival of P2P support groups on Facebook (Kraut & Resnick, 2012; Ma et al., 2019), direct interaction with posts may not be a requirement for members to benefit.

Many participants in the P2P Facebook support group study reported feeling empowered by participation in the group, as it provided a resource for informational support that supported unmet navigational needs (manuscript five). These findings support previous research identifying a need for increased navigational support among this population (Charlton et al., 2017) and suggest that caregivers regularly engage in self-navigation as a means to fill this gap. It appears that caregivers of children and youth with CCN in NB used the group as a way to contribute towards their self-navigation of services, programs, and resources relevant to the care of their child(ren).

Importantly, the group was reported by participants to be a “safe space” for the exchange of support among caregivers (manuscript five). The perception of the group as a safe space was attributed by members to three specific reasons: privacy designation; inclusivity, regardless of diagnosis or condition-type; and involvement of moderators. The privacy designation of the group was set to “closed”, which restricted the visibility of content to members only and required a screening process for prospective members

(i.e., prospective members were subject to approval by moderators). The private nature of the group may have also facilitated the recruitment and retention of members in the current study (Dumaij & Tijssen, 2011) and might have fostered a sense of community (Moser et al., 2017) as these types of groups are often more trusted by members (Ma et al., 2019). To join the group, prospective members were required to identify as a caregiver of a child or youth with CCN and live in NB. Many of the caregivers that took part in the Facebook group reported a lack of diagnosis for their child(ren) or a lengthy process for obtaining a diagnosis, despite obvious CCN. One of the reasons for the lack of diagnosis included very rare, genetic issues that are either not well understood by their care provider(s) or unknown in general. In contrast to condition-specific groups, the Facebook group intervention provided a place for caregivers of children or youth without a recognized diagnosis. Finally, moderators further contributed to the perception of the group as a safe space. Moderators have been previously noted to facilitate a safe space online by reducing the spread of misinformation and enforcing membership rules (Ancker et al., 2009; Esquivel et al., 2006; Green et al., 2007); this may have explained the positive reaction to moderators in the current study by caregivers. Group moderators were observed in this study to be the primary contributors to the Facebook group; however, members also described moderators as valued contributors to the group. This is in line with previous investigations of the role of moderators, which has described these individuals as pertinent to active discussions and engagement between members (Sowles et al., 2018).

One of the main aims of this study was to determine the perceived impact of participation in the group on caregivers' knowledge of programs and services, and sense of community belonging (manuscript five). Most participants felt part of a community

within the group, facilitated by the exclusivity of the group to NB caregivers and inclusion of caregivers facing diverse conditions, including undiagnosed conditions. Less clear, however, was the impact of the group on caregivers' knowledge of programs and services. Some participants reported learning new knowledge that helped them in their role as a caregiver and others reported passively monitoring the group for information that may help them in the future. The few participants who reported a lack of belonging or did not perceive an increase in their knowledge of programs or services attributed it to group infancy, low membership numbers, and diversity among the caregiver population. Few studies have explored the perceived impact of participation in online P2P support groups on caregivers. In this study, we explored perceived support rather than measuring actual support or benefits from involvement in the group. While this might be considered a limitation of the study, previous literature has noted the importance of perceived support rather than actual support on well-being and health outcomes (Cutrona, 1990; McDowell & Serovich, 2007). Specifically, support that is positively perceived by the recipient has a greater impact on individuals than the objective measurement of the quality or quantity of the support received (McDowell & Serovich, 2007). One of the important contributions of the current study is that short-term participation in a new P2P support group can result in support that is perceived by caregivers of children and youth with CCN to improve their knowledge of services and resources and sense of community belonging.

It is unclear how many caregivers of children and youth with CCN in NB could have benefitted from the intervention in the current study. Differences in the way that CCN is conceptualized and defined across the literature makes it difficult to determine the exact prevalence of children and youth with CCN; however, it is generally estimated in North

America to be somewhere between 13-18% and rising (Perrin et al., 2014; United States Census Bureau, 2018). In a 2020 report by the Canadian Institute for Health Information (2020), it was estimated that there are 738 per 100,000 children and youth with medical complexities in NB, which was demonstrated as the second lowest incidence across the Canadian provinces. However, this low rate was partially attributed to missing data including the exclusion of newborns who shared their mother's health care number during their first hospital stay. Moreover, this report defined children and youth with medical complexities as those with neurological impairment or diagnosed conditions significant enough to have required hospitalization. The current study defined CCN as inclusive of those with and without a recognized diagnosis, resulting in broader inclusivity of children and youth with CCN. The conceptualization of CCN that I deal with in my study is much more inclusive of any child or youth with perceived complex care needs. Therefore, if we consider the incidence of children and youth with CCN to consist of approximately 18% of the population, that results in approximately 27,503 children and youth in NB (StatsCan, 2020). The intervention in the current study, therefore, impacted 0.3% of children and youth with CCN in NB; however, it is difficult to know how many caregivers are associated with this number of children.

Strengths, Limitations, and Future Directions

This doctoral research had many strengths. The Facebook group intervention was developed, implemented, and monitored by a PFAC to ensure its relevance to the target population. This may have also been a limitation to the research, however, as many of the members of this council are caregivers of former children and youth, meaning that these children and youth are now adults. Moreover, some of them were not registered to the Facebook platform and therefore did not join or visit the Facebook support group.

Future research should consider engaging a patient and caregiver advisory board is composed of the specific population of interest to ensure relevance of the intervention, particularly where technology is involved.

An environmental scan of Facebook groups available to caregivers of children and youth with CCN in NB ensured that our intervention did not duplicate existing groups. Although we did not find any support groups for our target population, there was one large support group that included other provinces in the Atlantic Canadian region. This group was specifically centred around the region's children's hospital, which was reported by almost all of the caregivers in the current study as a primary source of care for their child(ren). It is unclear how many of the members in our intervention were also members of the regional support group. A strength of our intervention is that it was limited to NB, which facilitated the exchange of information related to NB specific programs, services, and resources. However the existence of the other support group with a similar purpose may impact the generalizability of findings from the current study related to the use of the geographic-specific Facebook group to other patient and caregiver populations. In other words, caregivers that used the Facebook support group in the current project may have received complementary and/or additional support from the other Facebook group that may not be available to other populations. Further research is needed to determine the nuanced differences in the use and impact of membership in multiple Facebook groups by patients and caregivers.

The Facebook group intervention in the current study was designed as a P2P support group between caregivers of children and youth with CCN. Although one of the moderators cannot be described as a peer, due to her professional role as a patient navigator, this individual provided a valued perspective to members, as reported by

participants, that was reported to complement the perspective of other members (i.e. caregivers). This finding that a patient navigator can be trusted and valued by caregivers in a P2P support group is a novel contribution of this study. However, further investigation into how this role might impact the nature of discussions and use of the group by caregivers is needed.

An important limitation to the current study is the timeframe; specifically, the duration of time between the implementation (i.e., launch) of the Facebook support group and evaluation. The decision to begin evaluation of the group five months post-implementation was made due to practical limitations. Future research might consider extending this time frame to gain a better understanding of the longevity and impact of the group on members. Moreover, future work may benefit from the inclusion of baseline surveys and addition of standardized assessments related to health literacy and/or mental health measurements.

Current Status of the Facebook Group

After the conclusion of data collection and analysis, members were informed that the group would no longer be under research observation. Findings from the study were made available to participants and group members in the form of abstracts and individual papers (i.e., chapters). An announcement post was made to the group inviting members to become moderators of the group. I am currently the main administrator of the group and will continue to manage the group until it is fully passed over to the members. Since the conclusion of the study, the group has continued to grow in membership and now has 125 members. It continues to be a source of support for caregivers of children and youth with CCN in NB.

Implications for Practice, Research, and Education

Interdisciplinary Practice

1. Care providers and community organizations can work with families to strengthen community support networks and connect them with informal and formal online P2P support networks.
2. It is necessary that health care providers recognize and acknowledge the ubiquitous use of social media and its important role in the exchange of informational and emotional support between caregivers of children and youth with CCN.
3. Health professionals from a range of disciplines (e.g., patient navigators, community care workers, physicians, social workers, educational assistants) all have important and unique contributions to support caregivers of children and youth with CCN in NB.
4. Health professionals can reach a broader audience of patients and caregivers using social media, specifically private discussion communities, and provide a unique contribution in a P2P support environment.
5. Health professionals can develop, facilitate, and monitor P2P support groups for caregivers of children and youth with CCN using social media, provided patients and caregivers are involved and engaged throughout the process to ensure a patient-centric community.

Research

- The findings from this study can be used as a guide for future research on geographic-specific social media-based P2P support interventions for caregivers of children and youth with CCN and other patient and caregiver populations.

- Research is needed to systematically examine the effectiveness of social media-based P2P support groups on improving knowledge of services and programs, and sense of community belonging.
- It is vital that future research examining the use and outcomes associated with social media-based P2P support groups include the perspectives of caregivers of children and youth with CCN and children and youth with CCN themselves.
- Future research should examine the role that care providers can play in reducing the spread of misinformation and improving access to current clinical practices and recommendations.

Education

- Patient navigators and other care professionals should be trained in the use of social media websites and applications to improve access to navigational and emotional support.
- Care providers need to be aware of informal and formal P2P support discussion groups on social media, in order to suggest support for caregivers of children and youth with CCN.
- Caregivers of children and youth with CCN possess invaluable knowledge gained through lived experience; care professionals can learn from these individuals and leverage their knowledge to better support the population both online and offline.

Conclusion

It is clear that patients and caregivers use online support groups for informational and emotional support, and that this support has some mental and physical benefits for

certain groups of people. This doctoral research demonstrated that informal support groups, specifically closed, geographically-specific groups, can impact knowledge of services and resources and sense of community belonging in caregivers of children and youth with CCN. Caregivers of children and youth with CCN require substantial support to ensure the care of their children and maintain their own well-being. The level of support required by this population is difficult to meet through care providers alone, due to practical issues associated with providers' time and resources limitations, as well as a lack of knowledge in some cases. For example, these caregivers often experience isolation and stress while caring for a child with life-long complicated medical and social issues; or trying to fulfil their child's daily and sometimes overwhelming needs. It is through the management of these situations that many of these caregivers become incredibly knowledgeable about available services, programs, and resources through their own lived experiences.

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APPENDICES

Appendix A: Email Recruitment to NaviCare/SoinsNavi clients

Dear NaviCare/SoinsNavi client,

We recently launched a peer-to-peer group on Facebook to help families with children and youth with complex care needs in the province to connect and exchange support. The group, called **New Brunswick Support Group for Caregivers of Children and Youth with Complex Care Needs**, is moderated by NaviCare/SoinNavis's patient navigators, and members of our Family Advisory Council and research team. You can find the group by clicking the link below:

[LINK](#)

We invite you to join this group and would like to encourage you to share it with anyone else that you think would benefit from it. It is our hope that this group will grow to form a supportive and helpful community.

As part of our journey to better serve families, this Facebook group is part of a research project led by one of our doctoral students at the University of New Brunswick, Kate Kelly. She will be observing the use of the group and will strive to ensure that it is relevant and useful for families in NB. Specifically, content posted to the group, such as discussion posts and replies, will be collected and analyzed to better understand how participation in peer-led discussion groups might influence knowledge of the health care system and family well-being. Importantly, your privacy and confidentiality will always be maintained; no identifying data will be collected during this process.

For more information, please do not hesitate to contact Kate at kj.kelly@unb.ca, or any members of our NaviCare team (<https://www.navicarenb.ca/our-team>). Thank you!

Appendix B: Media Release for Facebook Group Recruitment

Are you a caregiver of a child or youth with complex care needs? NaviCare/SoinsNavi, the New Brunswick patient navigation centre for children and youth with complex care needs, has recently launched a Facebook peer support group to help families connect and exchange support. The group, called the **New Brunswick Support Group for Parents, Guardians, and Caregivers of Children and Youth with Complex Care Needs (TAG IN POST)**, is moderated by NaviCare's patient navigators and members of our Family Advisory Council. The group can be found by visiting the following link:

LINK

We invite you to join this group and would like to encourage you to share it with anyone else who you think would benefit from it. It is our hope that this group will grow to form a supportive and helpful community. If you are interested in joining, please read the group description carefully and feel free to share the group with anyone who you think would benefit from participation! Please note that this Facebook group is developed and monitored by researchers at the University of New Brunswick. This means that content posted to the group, such as discussion posts and replies, will be observed to better understand the use of online peer support groups by families. Your privacy and confidentiality will always be maintained through this process, and no identifying information will be recorded. Members of the Facebook group will be invited to take part in further research (i.e., interview) through a post that will be pinned to the top of the discussion board. For information about this study, please visit the following link: ***LINK***.

Appendix C: Interview and Survey Recruitment Letters (Facebook Posts)

Survey Recruitment:

CALL FOR SURVEY PARTICIPANTS

Hi everyone! My name is Kate, and I am one of the moderators for this group. As you may recall when you became a member, this group was created, in part, to better understand how social media can help meet the needs of caregivers of children/youth with health care needs in NB. It has now been 5 months since we launched the group, and we're hoping to learn more from you about your experiences through the survey below.

This survey takes approximately 5 minutes to complete. All participants will be entered into a draw to win a \$100 Amazon gift card. All members of this group are invited to participate.

The results from this survey will be used to help inform organizations, health care workers, and researchers about how they can better support caregivers of children and youth with health care needs in NB. All submissions will be completely anonymous and will not be tied back to you. More information about this research can be found on the first page of this survey.

Please let me know if you have any questions or concerns.

Thank you!! We sincerely appreciate your valuable insight and time.
https://unbcric.ca/qualtrics.com/.../SV_1NDbq62D6sZRht3

APPEL À DES PARTICIPANTS À L'ENQUÊTE

Salut à tous! Je m'appelle Kate, et je suis l'un des modérateurs de ce groupe. Comme vous vous en souvenez peut-être lorsque vous êtes devenu membre, ce groupe a été créé pour mieux comprendre comment les médias sociaux peuvent aider à répondre aux besoins de soutien des aidants naturels des enfants / adolescents ayant des besoins en matière de soins de santé au Nouveau-Brunswick. Cela fait maintenant 5 mois que nous avons lancé le groupe et nous espérons en savoir plus sur vos expériences grâce à l'enquête ci-dessous.

Ce sondage dure environ 5 minutes. Tous les participants participeront à un tirage au sort pour gagner une carte-cadeau Amazon de 100 \$. Seuls les membres actuels de ce groupe sont invités à participer. Les chances de gagner la carte-cadeau Amazon dépendront du nombre de membres qui y participeront.

Les résultats de cette enquête seront utilisés pour aider à informer les organisations, les travailleurs de la santé et les chercheurs sur la façon dont ils peuvent mieux soutenir les aidants naturels des enfants et des jeunes ayant des besoins en soins de santé au Nouveau-Brunswick. Toutes les soumissions seront totalement anonymes et ne vous

seront pas liées. Vous trouverez plus d'informations sur cette recherche sur la première page de cette enquête.

Veillez me faire savoir si vous avez des questions ou des préoccupations. Merci!

https://unbcric.ca1.qualtrics.com/.../SV_73BC905LU5Qde4d

Interview Recruitment:

CALL FOR INTERVIEW PARTICIPANTS!

We are currently looking for members to participate in a research study that will explore your experiences as a caregiver of a child/youth with health care needs and your experiences as a member of this group. You will be asked to participate in an interview (using Zoom), which lasts approximately 45 minutes. To compensate you for this time, all participants will receive a \$25 Amazon gift card. Les entretiens sont également disponibles en français. To learn more about this study, or to participate, please feel free to send me a direct message here or send me an email (kj.kelly@unb.ca)! I look forward to hearing from you

This study is supervised by Dr. Shelley Doucet (sdoucet@unb.ca, (506) 654-3419) and has been reviewed and approved by the University of New Brunswick Research Ethics Board.

Appendix D: Interview Guide (English)

I. Introduction, Consent and Confidentiality (5 minutes)

Hello, my name is Kate Kelly. I am the doctoral student researcher for this study entitled *Development and evaluation of a peer-to-peer support group on Facebook for caregivers of children and youth with complex care needs in New Brunswick*. I would like to thank you for agreeing to participate in this interview.

Before we begin with the interview questions, I would like to walk you through the consent form. This is the same form that you have seen and returned to me to indicate your consent to participate. If you have any questions about the form, please do not hesitate to ask.

[REVIEW INFORMED CONSENT FORM AND ANSWER ANY QUESTIONS]

Before we begin our discussion on peer-to-peer support groups on Facebook, I would like to point out a few details about our conversation today.

- We may use quotes collected during our discussion, but these quotes will not be attributable or identifiable.
- You can expect this interview to last approximately 30-60 minutes.
- I would like to remind you that our conversation today will be audio recorded to increase accuracy and to reduce the chance of misinterpreting your comments.
- I will be transcribing these audio recordings. As soon as they have been transcribed, the audio files will be deleted. Data will be password protected and only the research team will have access to it.
- Your name will be removed from the data and replaced with a study code. Your name will be linked to that study code in a separate document, which again, only the research team will have access to.

Unless you have any questions, we can begin. I am now turning on the audio recording device.

[START THE AUDIO RECORDING DEVICE]

1. Tell me about your experience as a caregiver of a child or youth with complex care needs here in New Brunswick.
2. What has been your experience with finding services or resources in New Brunswick that help you provide care for your son or daughter?
3. How would you describe your knowledge about the relevant services, programs, and/or resources for your child?
4. To what extent do you feel supported (e.g., by care providers, community organizations, family or friends, etc) as a caregiver of a child with complex care

needs?

5. Tell me about your experience with the Facebook peer-to-peer support group?
 - a. Approximately how long have you been a member of the group?
 - b. Have you engaged in any other groups for children and youth with complex care needs?
 - c. If yes, what have been your experiences?
6. In what ways did you or did you not find that the Facebook group was able to meet your needs or provide needed support?
7. To what extent do you feel that the Facebook group was successful in creating a community of caregivers facing similar challenges? Why or why not?
8. How did the P2P support group affect your knowledge of existing health-related resources or services?
9. To what extent do you feel comfortable reading medical or health-related information on the Internet?
 - a. Did you find that the Facebook group helped you understand more about your child's condition? If so, in what ways?
10. Do you have any other insights into how the Facebook group helped you, or perhaps made things more difficult, as a caregiver of a child or youth with complex care needs?
11. In what ways do you feel the moderators or administrators of the Facebook group contributed to the discussions and online community?
 - a. Were you aware that one of the moderators is a patient navigator?
12. Have you heard of NaviCare/SoinsNavi? If so, in what capacity?

[WHEN QUESTIONS HAVE BEEN COMPLETED, ASK PARTICIPANT WHETHER THEY FEEL ANYTHING HAS BEEN FORGOTTEN OR IF THEY WISH TO MAKE ANY ADDITIONAL COMMENTS]

III. Wrap up (2 minutes)

That concludes our discussion for today. The results of this study will be available on the NaviCare/SoinsNavi website following completion of my project, or alternatively you may contact me via e-mail or telephone to receive a summary report of the results.

[THANK PARTICIPANT]

Appendix E: Interview Guide (French)

I. Introduction, consentement et confidentialité (5 minutes)

Bonjour, je m'appelle Kate Kelly. Je suis le chercheur au doctorat pour cette étude intitulée *Développement et évaluation d'un groupe de soutien entre pairs sur Facebook pour les soignants d'enfants et de jeunes ayant des besoins de soins complexes au Nouveau-Brunswick*. Je tiens à vous remercier d'avoir accepté de participer à cette interview.

Avant de commencer avec les questions d'entrevue, j'aimerais vous expliquer le formulaire de consentement. C'est le même formulaire que vous m'avez vu et renvoyé pour indiquer votre consentement à participer. Si vous avez des questions sur le formulaire, n'hésitez pas à les poser.

[LIRE LE FORMULAIRE DE CONSENTEMENT ÉCLAIRÉ ET RÉPONDRE À TOUTES LES QUESTIONS]

Avant de commencer notre discussion sur les groupes de soutien peer-to-peer sur Facebook, je voudrais souligner quelques détails sur notre conversation d'aujourd'hui.

- Nous pouvons utiliser des citations recueillies au cours de notre discussion, mais ces citations seront attribuables ou identifiables.
- Vous pouvez vous attendre à ce que cet entretien dure environ 30 à 60 minutes.
- Je voudrais vous rappeler que notre conversation d'aujourd'hui sera enregistrée en audio pour accroître la précision et réduire le risque de mal interpréter vos commentaires.
- Je vais transcrire ces enregistrements audio. Dès qu'ils auront été transcrits, les fichiers audio seront supprimés. Les données seront protégées par mot de passe et seule l'équipe de recherche y aura accès.
- Votre nom sera supprimé des données et remplacé par un code d'étude. Votre nom sera lié à ce code d'étude dans un document séparé, auquel, encore une fois, seule l'équipe de recherche aura accès.

Sauf si vous avez des questions, nous pouvons commencer. J'allume maintenant le périphérique d'enregistrement audio.

[DEMARRER L'APPAREIL D'ENREGISTREMENT AUDIO]

1. Parlez-moi de votre expérience en tant que soignant d'un enfant ou d'un jeune ayant des besoins de soins complexes ici au Nouveau-Brunswick.
2. Quelle a été votre expérience en matière de recherche de services ou de ressources au Nouveau-Brunswick qui vous aident à prodiguer des soins à votre fils ou à votre fille?
3. Comment décririez-vous vos connaissances sur les services, programmes et / ou ressources pertinents pour votre enfant?

4. Dans quelle mesure vous sentez-vous soutenu (par exemple par les prestataires de soins, les organisations communautaires, la famille ou les amis, etc.) en tant que soignant d'un enfant ayant des besoins de soins complexes?
5. Parlez-moi de votre expérience avec le groupe de soutien Facebook peer-to-peer? une. Depuis combien de temps environ êtes-vous membre du groupe? b. Avez-vous participé à d'autres groupes pour les enfants et les jeunes ayant des besoins de soins complexes? c. Si oui, quelles ont été vos expériences?
6. De quelle manière avez-vous ou n'avez-vous pas trouvé que le groupe Facebook était en mesure de répondre à vos besoins ou de fournir le soutien nécessaire?
7. Dans quelle mesure pensez-vous que le groupe Facebook a réussi à créer une communauté de soignants confrontés à des défis similaires? Pourquoi ou pourquoi pas? 8. Comment le groupe de soutien P2P a-t-il affecté votre connaissance des ressources ou services existants liés à la santé?
8. Dans quelle mesure vous sentez-vous à l'aise de lire des informations médicales ou liées à la santé sur Internet? une. Avez-vous trouvé que le groupe Facebook vous a aidé à mieux comprendre l'état de santé de votre enfant? Si oui, de quelle manière?
9. Avez-vous d'autres idées sur la façon dont le groupe Facebook vous a aidé, ou a peut-être rendu les choses plus difficiles, en tant que soignant d'un enfant ou d'un jeune ayant des besoins de soins complexes?
10. De quelle manière pensez-vous que les modérateurs ou administrateurs du groupe Facebook ont contribué aux discussions et à la communauté en ligne? une. Saviez-vous que l'un des modérateurs est un navigateur de patients?
11. Avez-vous entendu parler de NaviCare / SoinsNavi? Si oui, dans quel capacité?

[LORSQUE LES QUESTIONS ONT ÉTÉ REMPLIES, DEMANDEZ AU PARTICIPANT SI ILS SENTENT QUE QUELQUE CHOSE A ÉTÉ OUBLIÉ OU S'IL SOUHAITE FAIRE DES COMMENTAIRES SUPPLÉMENTAIRES]

III. Récapitulation (2 minutes) Cela met fin à notre discussion d'aujourd'hui. Les résultats de cette étude seront disponibles sur le site Web de NaviCare / SoinsNavi après l'achèvement de mon projet, ou vous pouvez me contacter par e-mail ou par téléphone pour recevoir un rapport récapitulatif des résultats.

[MERCİ PARTICIPANT]

Appendix F: Letter of Information and Consent: Participation in Group (English)

Exploring and evaluating a Facebook-based peer-to-peer support group for caregivers of children and youth with health care needs in New Brunswick

Principal Investigator: Katherine Kelly, University of New Brunswick (kj.kelly@unb.ca)

Note that by participating in the Facebook group entitled “**Support for New Brunswick caregivers of children with health care needs**” you are agreeing to the terms outlined in this letter of information and informed consent.

INTRODUCTION

We invite you to participate in our study, which aims to develop, implement, and evaluate a peer-to-peer support group on Facebook for caregivers of children and youth with health care needs in New Brunswick. This research will assess the potential impact of participating in the group on perceived access to services; health literacy; and social connectedness of caregivers of children and youth with health care needs. The results will help inform future supports for families of children with health care needs in the province. No identifiable information is reported. For the purposes of ongoing research, **the research team is seeking your consent to include all information posted in the Facebook group in our research database, and to be contacted for future research.**

VOLUNTARY PARTICIPATION

Your participation in this research is voluntary. You are free to refuse to participate or discontinue your participation at any time without explanation. However, where this is a research centre, if you choose not to participate, or if you discontinue your participation, you will also be withdrawn from the Facebook group entitled “**Support for New Brunswick caregivers of children with health care needs**” as we require access to the data posted in this group for ongoing research.

RESEARCH AIMS

The objectives of the study are to: 1) determine the experiences of caregivers of children and youth with health care needs who use the Facebook group to communicate with other caregivers; 2) determine the factors that contribute to the success or failure of the Facebook group; 3) evaluate whether involvement in the Facebook group has an effect on health literacy and/or knowledge of health services or resources; 4) assess whether involvement in the Facebook group affects family well-being; and 5) explore how caregivers of children and youth with health care needs use the Facebook support group.

WHAT IS COLLECTED FROM THE FACEBOOK GROUP?

The research database will include content published to the Facebook group, including: posts and replies (i.e., “comments”), as well as numerical counts of posts and members in the group. Names or any other identifiable information posted by FB members will never be recorded with posted content.

HOW WILL YOUR INFORMATION BE PROTECTED?

All of your information will be kept strictly confidential by not recording names or other identifiable information with posted content. Your privacy will be protected at all times. All data will be collected and stored on a secure server located at the University of New Brunswick Saint John. Electronic data will be stored on the research team's password protected secure Sharepoint site. Paper data will be stored in a locked office. Any information used to disseminate research findings will not include any identifiable information. Findings related to this research project can be requested any time.

FUTURE ACCESS AND USE

Any research conducted with data from this research database must be approved by the University of New Brunswick Research Ethics Board before the research begins.

Your information will be accessible by:

- The project research team
- Members of the University of New Brunswick Research Ethics Board for the purposes of ensuring the proper monitoring of the research database.
- You, as you maintain the right to view your personal information and ask to have appropriate corrections made.

I agree to participate in the study entitled "**Exploring and evaluating a Facebook-based peer-to-peer support group for caregivers of children with health care needs in New Brunswick**", led by researcher Katherine Kelly at the University of New Brunswick Saint John (kj.kelly@unb.ca).

I have read the information about the study and I understand it.

I participate in this study of my own free will and without constraint.

I agree to be quoted directly if my name is not published (I remain anonymous with a made-up name).

I understand that the confidentiality of the data will be respected. At no time and in any way data relating to my program effectiveness cannot be disclosed.

I understand that I may withdraw at any time from the study by notifying Katherine Kelly at kj.kelly@unb.ca at any time.

If you agree to these terms, please type "I consent" in the last screening question to join the Facebook group. Note that this step is required to join the Facebook group.

By consenting to this research, you are indicating that you fully understand the information I have shared and agree to participate in this study.

QUESTIONS AND CONTACT INFORMATION

If you have any questions about this research database or your involvement in the research, please contact the lead investigators Katherine Kelly [kj.kelly@unb.ca] or Dr. Shelley Doucet [sdoucet@unb.ca; (506) 654- 3419].

This research has been reviewed and approved by the University of New Brunswick Research Ethics Board. If you have any questions or concerns about this study, you may contact Dr. Beth Keyes, Chair of the UNB Research Ethics Board (reb@unbsj.ca; (506) 648-5908).

Appendix G: Letter of Information and Consent: Participation in Group (French)

Explorer et évaluer un groupe de soutien entre pairs basé sur Facebook pour les soignants d'enfants et de jeunes ayant des besoins en matière de soins de santé au Nouveau-Brunswick

Chercheuse principale: Katherine Kelly, Université du Nouveau-Brunswick
(kj.kelly@unb.ca)

Veillez noter qu'en participant au groupe Facebook intitulé «**Soutien aux aidants naturels du Nouveau-Brunswick d'enfants ayant des besoins en matière de soins de santé**», vous acceptez les conditions décrites dans cette lettre d'information et de consentement éclairé.

INTRODUCTION

Nous vous invitons à participer à notre étude, qui vise à développer, mettre en œuvre et évaluer un groupe de soutien entre pairs sur Facebook pour les soignants d'enfants et de jeunes ayant des besoins en soins de santé au Nouveau-Brunswick. Cette recherche évaluera l'impact potentiel de la participation au groupe sur l'accès perçu aux services; littératie en santé; et le lien social des soignants des enfants et des jeunes ayant des besoins en matière de soins de santé. Les résultats aideront à éclairer les soutiens futurs pour les familles d'enfants ayant des besoins en matière de soins de santé dans la province. Aucune information identifiable n'est rapportée. Aux fins de la recherche en cours, **l'équipe de recherche sollicite votre consentement pour inclure toutes les informations publiées dans le groupe Facebook dans notre base de données de recherche et pour être contactée pour de futures recherches.**

PARTICIPATION VOLONTAIRE

Votre participation à cette recherche est volontaire. Vous êtes libre de refuser de participer ou d'interrompre votre participation à tout moment sans explication. Cependant, s'il s'agit d'un centre de recherche, si vous choisissez de ne pas participer ou si vous interrompez votre participation, vous serez également retiré du groupe Facebook intitulé «**Soutien aux aidants naturels du Nouveau-Brunswick d'enfants ayant des besoins en matière de soins de santé**» car nous avons besoin d'un accès aux données affichées dans ce groupe pour des recherches en cours.

OBJECTIFS DE RECHERCHE

Les objectifs de l'étude sont les suivants: 1) déterminer les expériences des soignants d'enfants et de jeunes ayant des besoins en matière de soins de santé qui utilisent le groupe Facebook pour communiquer avec d'autres soignants; 2) déterminer les facteurs qui contribuent au succès ou à l'échec du groupe Facebook; 3) évaluer si la participation au groupe Facebook a un effet sur la littératie en santé et / ou la connaissance des services ou des ressources de santé; 4) évaluer si la participation au groupe Facebook affecte le bien-être de la famille; et 5) explorer comment les soignants d'enfants et de jeunes ayant des besoins de santé utilisent le groupe de soutien Facebook.

QU'EST-CE QUI EST COLLECTÉ AUPRÈS DU GROUPE FACEBOOK?

La base de données de recherche comprendra le contenu publié sur le groupe Facebook, y compris: les publications et les réponses (c'est-à-dire les «commentaires»), ainsi que le décompte numérique des publications et des membres du groupe. Les noms ou toute autre information identifiable publiée par les membres FB ne seront jamais enregistrés avec le contenu affiché.

COMMENT VOS INFORMATIONS SERONT-ELLES PROTÉGÉES?

Toutes vos informations resteront strictement confidentielles en ne notant pas les noms ou autres informations identifiables avec le contenu affiché. Votre vie privée sera protégée à tout moment. Toutes les données seront collectées et stockées sur un serveur sécurisé situé à l'Université du Nouveau-Brunswick à Saint John. Les données électroniques seront stockées sur un disque dur protégé par mot de passe dans un bureau sécurisé. Toute information utilisée pour diffuser les résultats de la recherche ne comprendra aucune information identifiable. Les résultats liés à ce projet de recherche peuvent être demandés à tout moment.

ACCÈS ET UTILISATION FUTURS

Toute recherche menée avec les données de cette base de données de recherche doit être approuvée par le Comité d'éthique de la recherche de l'Université du Nouveau-Brunswick avant le début de la recherche.

Vos informations seront accessibles par:

- L'équipe de recherche du projet
- Membres du comité d'éthique de la recherche de l'Université du Nouveau-Brunswick dans le but d'assurer un suivi adéquat de la base de données de recherche.
- Vous, car vous conservez le droit de consulter vos informations personnelles et de demander que les corrections appropriées soient apportées.

J'accepte de participer à l'étude intitulée «**Explorer et évaluer un groupe de soutien entre pairs basé sur Facebook pour les soignants d'enfants ayant des besoins en soins de santé au Nouveau-Brunswick**», dirigée par la chercheuse Katherine Kelly à l'Université du Nouveau-Brunswick à Saint John (kj.kelly@unb.ca).

J'ai lu les informations sur l'étude et je les comprends.

Je participe à cette étude de mon plein gré et sans contrainte.

J'accepte d'être cité directement si mon nom n'est pas publié (je reste anonyme avec un nom inventé).

Je comprends que la confidentialité des données sera respectée. À aucun moment et en aucune façon les données relatives à l'efficacité de mon programme ne peuvent être divulguées.

Je comprends que je peux me retirer à tout moment de l'étude en avisant Katherine Kelly à kj.kelly@unb.ca à tout moment.

Si vous acceptez ces conditions, veuillez saisir «J'accepte» dans la dernière question de sélection pour rejoindre le groupe Facebook. Notez que cette étape est nécessaire pour rejoindre le groupe Facebook.

En consentant à cette recherche, vous indiquez que vous comprenez parfaitement les informations que j'ai partagées et acceptez de participer à cette étude.

QUESTIONS ET COORDONNÉES

Si vous avez des questions concernant cette base de données de recherche ou votre participation à la recherche, veuillez communiquer avec les chercheurs principaux Katherine Kelly [kj.kelly@unb.ca] ou Dr Shelley Doucet [sdoucet@unb.ca; (506) 654-3419].

Cette recherche a été examinée et approuvée par le Comité d'éthique de la recherche de l'Université du Nouveau-Brunswick. Si vous avez des questions ou des préoccupations au sujet de cette étude, vous pouvez communiquer avec la Dr Beth Keyes, présidente du Comité d'éthique de la recherche de l'UNB (reb@unbsj.ca; (506) 648-5908).

Appendix H: Letter of Information and Informed Consent: Interview (English)

Exploring and evaluating a Facebook-based peer-to-peer support group for caregivers of children and youth with complex care needs in New Brunswick

Principal Investigator: Katherine Kelly, University of New Brunswick (kj.kelly@unb.ca)

INTRODUCTION

We invite you to participate in an interview on the experiences of caregivers of children and youth with complex care needs on the use of the Facebook support group entitled “**New Brunswick Support Group for Caregivers of Children and Youth with Complex Care Needs**”. This research will assess the potential impact of participating in the group on perceived access to services; health literacy; and social connectedness of caregivers of children and youth with complex care needs. The results will help inform future supports for families of children with complex care needs in the province. No identifiable information is reported.

RESEARCH AIMS

The objectives of the study are to: 1) determine the experiences of caregivers of children and youth with complex care needs who use the Facebook group to communicate with other caregivers; 2) determine the factors that contribute to the success or failure of the Facebook group; 3) evaluate whether involvement in the Facebook group has an effect on health literacy and/or knowledge of health services or resources; 4) assess whether involvement in the Facebook group affects family well-being; and 5) explore how caregivers of children and youth with complex care needs use the Facebook support group.

PARTICIPATION AND INVOLVEMENT

We are seeking approximately 30 participants who have been members of the Facebook group entitled: “**New Brunswick Support Group for Parents, Guardians, and Caregivers of Children and Youth with Complex Care Needs**” for a minimum of three months to participate in a semi-structure interview. During this interview, you will be asked to provide information about your experience in the Facebook-based support group, knowledge of existing services and programs that target families of children or youth with complex care needs, and your perception of support available to you and your family. This interview will take place either in person or over videoconferencing (e.g., Skype) at your convenience and will last for approximately 45 minutes.

VOLUNTARY PARTICIPATION

Your participation in this research is voluntary. You are free to refuse to participate or discontinue your participation at any time (including after the conclusion of the interview) without explanation.

BENEFITS AND RISKS TO PARTICIPATING

If you are participating in the study, our research results will be shared with you. This is the only direct benefit that can be derived from your participation. At the very least, you will have contributed to the advancement of knowledge related to providing better support to families of children with complex care needs in New Brunswick. The direct disadvantages associated with your involvement are the time taken to complete the surveys and/or semi-structured interview. We will do our best to facilitate this process.

HOW WILL YOUR INFORMATION BE PROTECTED?

All information obtained from you as part of this study will be treated confidentially. To do this, we will assign you an identification number. However, the Principle Investigator will maintain a registry containing the names of participating key informants for administrative purposes. She alone will have access to this register. Data from this registry will be destroyed at the end of the study. Researchers conducting this study will not publish any information about you on an individual basis and will not make this information available to anyone outside the study team. Under no circumstances will researchers disclose individual information to your organizations or institutions associated with the researchers.

FUTURE ACCESS AND USE

Any research conducted with data from this research database must be approved by the University of New Brunswick Research Ethics Board before the research begins.

Your information will be accessible by:

- The NaviCare research team, including members of the research team who have been approved to access your records as part of the program.
- Members of the University of New Brunswick Research Ethics Board for the purposes of ensuring the proper monitoring of the research database.
- You, as you maintain the right to view your personal information and ask to have appropriate corrections made.

I agree to participate in the study entitled "**Exploring and evaluating a Facebook-based peer-to-peer support group for caregivers of children with complex care needs in New Brunswick**", led by researcher Katherine Kelly at the University of New Brunswick Saint John (kj.kelly@unb.ca).

I have read the information about the study and I understand it.

I participate in this study of my own free will and without constraint.

I agree to be quoted directly if my name is not published (I remain anonymous with a made-up name).

I understand that the confidentiality of the data will be respected. At no time and in any way data relating to my program effectiveness cannot be disclosed.

I understand that I may withdraw at any time from the study by notifying Katherine Kelly at kj.kelly@unb.ca at any time.

Participant Name: *(ELECTRONIC INPUT)*
Participant Email: *(ELECTRONIC INPUT)*

Please click the submit button below after entering your responses to the questions. By submitting this consent form, you are indicating that you fully understand the information presented and you agree to participate in this study. Thank you.

If you have any questions about this study, please contact Principle Investigator Katherine Kelly (kj.kelly@unb.ca) or her supervisors: Dr. Shelley Doucet (sdoucet@unb.ca; (506) 654-3419), Dr. Alison Luke (aluke1@unb.ca), Dr. William Montelpare (wmontelpare@upei.ca; 902-620-5186), or Dr. Rima Azar (razar@mta.ca; (506) 227-3932). This research has been reviewed and approved by the University of New Brunswick Research Ethics Board. If you have any questions or concerns about this study, you may contact Dr. Beth Keyes, Chair of the UNB Research Ethics Board (reb@unbsj.ca; (506) 648-5908).

Do you have any questions?

By consenting to this research, you are indicating that you fully understand the information I have shared and agree to participate in this study.

QUESTIONS AND CONTACT INFORMATION

If you have any questions about this research database or your involvement in the research, please contact the lead investigators Katherine Kelly [kj.kelly@unb.ca]; Dr. Shelley Doucet [sdoucet@unb.ca; (506) 654- 3419]; or Dr. Alison Luke [aluke1@unb.ca; (506) 648-5704].

This research has been reviewed and approved by the University of New Brunswick Research Ethics Board. If you have any questions or concerns about this study, you may contact Dr. Beth Keyes, Chair of the UNB Research Ethics Board (reb@unbsj.ca; (506) 648-5908).

Appendix I: Letter of Information and Informed Consent: Interview (French)

Explorer et évaluer un groupe de soutien entre pairs basé sur Facebook pour les soignants d'enfants et de jeunes ayant des besoins de soins complexes au Nouveau- Brunswick

Chercheuse principale: Katherine Kelly, Université du Nouveau-Brunswick
(kj.kelly@unb.ca)

INTRODUCTION

Nous vous invitons à participer à une entrevue à propos des expériences des soignants d'enfants et de jeunes ayant des besoins de soins complexes lors de l'utilisation du groupe de soutien Facebook intitulé «**NB Children with Health Care Needs**». Cette recherche évaluera l'impact potentiel de la participation au groupe sur l'accès perçu aux services, littératie en santé et le lien social des soignants d'enfants et de jeunes ayant des besoins de soins complexes. Les résultats permettront d'éclairer les soutiens futurs pour les familles d'enfants ayant des besoins de soins complexes dans la province. Aucune information identifiable n'est rapportée.

OBJECTIFS DE RECHERCHE

Les objectifs de l'étude sont les suivants: 1) déterminer les expériences des soignants d'enfants et de jeunes ayant des besoins de soins complexes qui utilisent le groupe Facebook pour communiquer avec d'autres soignants; 2) déterminer les facteurs qui contribuent au succès ou à l'échec du groupe Facebook; 3) évaluer si la participation au groupe Facebook a un effet sur la littératie en santé et / ou la connaissance des services ou des ressources de santé; 4) évaluer si la participation au groupe Facebook affecte le bien-être de la famille; et 5) explorer comment les soignants d'enfants et de jeunes ayant des besoins de soins complexes utilisent le groupe de soutien Facebook.

PARTICIPATION ET IMPLICATION

Nous recherchons environ 30 participants qui ont été membres du groupe Facebook intitulé: «**NB Children with Health Care Needs**» pour participer à une entrevue semi-structurée. Au cours de cet entretien, il vous sera demandé de fournir des informations sur votre expérience dans le groupe de soutien basé sur Facebook, votre connaissance des services et programmes existants qui ciblent les familles d'enfants ou de jeunes ayant des besoins de soins complexes et votre perception du soutien disponible pour vous et votre famille. Cet entretien aura lieu en personne ou par vidéoconférence (par exemple Skype) à votre convenance et durera environ 45 minutes.

PARTICIPATION VOLONTAIRE

Votre participation à cette recherche est volontaire. Vous êtes libre de refuser de participer ou d'interrompre votre participation à tout moment (y compris après la conclusion de l'entretien) sans explication.

AVANTAGES ET RISQUES LIÉS À LA PARTICIPATION

Si vous participez à l'étude, nos résultats de recherche seront partagés avec vous. C'est le seul avantage direct qui peut découler de votre participation. À tout le moins, vous aurez contribué à l'avancement des connaissances liées à un meilleur soutien aux familles d'enfants ayant des besoins de soins complexes au Nouveau-Brunswick. Les inconvénients directs associés à votre implication sont le temps nécessaire pour répondre aux sondages et / ou aux entretiens semi-structurés. Nous ferons de notre mieux pour faciliter ce processus.

COMMENT VOS INFORMATIONS SERONT-ELLES PROTÉGÉES?

Toutes les informations obtenues de votre part dans le cadre de cette étude seront traitées de manière confidentielle. Pour ce faire, nous vous attribuerons un numéro d'identification. Cependant, l'enquêteur principal tiendra un registre contenant les noms des informateurs clés participants à des fins administratives. Elle seule aura accès à ce registre. Les données de ce registre seront détruites à la fin de l'étude. Les chercheurs qui mènent cette étude ne publieront aucune information à votre sujet sur une base individuelle et ne mettront pas ces informations à la disposition de quiconque en dehors de l'équipe d'étude. En aucun cas, les chercheurs ne divulgueront des informations individuelles à vos organisations ou institutions associées aux chercheurs.

ACCÈS ET UTILISATION FUTURS

Toute recherche menée avec les données de cette base de données de recherche doit être approuvée par le Comité d'éthique de la recherche de l'Université du Nouveau-Brunswick avant le début de la recherche.

Vos informations seront accessibles par:

- L'équipe de recherche NaviCare, y compris les membres de l'équipe de recherche qui ont été autorisés à accéder à vos dossiers dans le cadre du programme.
- Les membres du comité d'éthique de la recherche de l'Université du Nouveau-Brunswick afin d'assurer un suivi adéquat de la base de données de recherche.
- Vous, car vous conservez le droit de consulter vos informations personnelles et de demander que des corrections appropriées soient apportées

J'accepte de participer à l'étude intitulée «**Explorer et évaluer un groupe de soutien entre pairs basé sur Facebook pour les soignants d'enfants ayant des besoins de soins complexes au Nouveau-Brunswick**», dirigée par la chercheuse Katherine Kelly à l'Université du Nouveau-Brunswick à Saint John (kj.kelly@unb.ca).

J'ai lu les informations sur l'étude et je les comprends.

Je participe à cette étude de mon plein gré et sans contrainte.

J'accepte d'être cité directement si mon nom n'est pas publié (je reste anonyme avec un nom inventé).

Je comprends que la confidentialité des données sera respectée. À aucun moment et de quelque manière que ce soit, les données relatives à l'efficacité de mon programme ne peuvent être divulguées.

Je comprends que je peux me retirer à tout moment de l'étude en avisant Katherine Kelly à kj.kelly@unb.ca à tout moment.

Nom du participant:

Courriel du participant:

Veillez cliquer sur le bouton Soumettre ci-dessous après avoir saisi vos réponses aux questions. En soumettant ce formulaire de consentement, vous indiquez que vous comprenez parfaitement les informations présentées et que vous acceptez de participer à cette étude. Merci.

Si vous avez des questions sur cette étude, veuillez contacter la chercheuse principale Katherine Kelly (kj.kelly@unb.ca) ou ses superviseurs: Dre Shelley Doucet (sdoucet@unb.ca; (506) 654-3419), Dre Alison Luke (aluke1@unb.ca), Dr William Montelpare (wmontelpare@upeu.ca; 902-620-5186), ou Dr Rima Azar (razar@mta.ca; (506) 227-3932). Cette recherche a été examinée et approuvée par le Comité d'éthique de la recherche de l'Université du Nouveau-Brunswick. Si vous avez des questions ou des préoccupations au sujet de cette étude, vous pouvez communiquer avec la Dre Beth Keyes, présidente du Comité d'éthique de la recherche de l'UNB (reb@unbsj.ca; (506) 648-5908).

En consentant à cette recherche, vous indiquez que vous comprenez parfaitement les informations partagées et acceptez de participer à cette étude.

Avez-vous des questions?

QUESTIONS ET COORDONNÉES

Si vous avez des questions concernant cette base de données de recherche ou votre participation à la recherche, veuillez communiquer avec les chercheurs principaux Katherine Kelly [kj.kelly@unb.ca]; Dre Shelley Doucet [sdoucet@unb.ca; (506) 654-3419]; ou Dre Alison Luke [aluke1@unb.ca; (506) 648-5704].

Cette recherche a été examinée et approuvée par le Comité d'éthique de la recherche de l'Université du Nouveau-Brunswick. Si vous avez des questions ou des préoccupations au sujet de cette étude, vous pouvez communiquer avec la Dre Beth Keyes, présidente du Comité d'éthique de la recherche de l'UNB (reb@unbsj.ca; (506) 648-5908).

Appendix J: Copyright Permission from Journals

Journal of New Brunswick Studies/Revue d'études sur le Nouveau-Brunswick

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Email: editorjnbs@stu.ca

28 June 2021

Katherine J. Kelly
PhD Candidate
University of New Brunswick

Re: Permission to use a *JNBS/RÉNB* article

Dear Katherine Kelly,

As Editor of the *Journal of New Brunswick Studies/Revue d'études sur le Nouveau-Brunswick (JNBS/RÉNB)*, I hereby grant you permission to use in your doctoral dissertation at the University of New Brunswick your multi-authored article (with Dr. Shelley Doucet, Dr. Alison Luke, Dr. Rima Azar, and Dr. William Montepare) "Peer-to-peer support on Facebook for caregivers of children and youth with complex care needs in New Brunswick: An environmental scan," which has been formally accepted for publication in Volume 13, No. 2 (Fall 2021) of *JNBS/RÉNB*.

Yours sincerely,

Michael Boudreau

Michael Boudreau, PhD
Editor/Éditeur, *JNBS/RÉNB*

Development and implementation of a Facebook-based peer-to-peer support group for caregivers of children with health care needs in New Brunswick

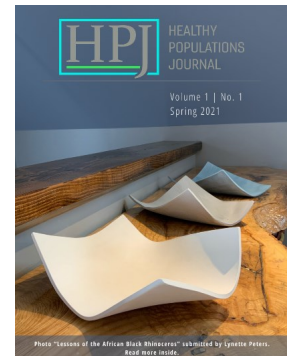
Authors: Katherine J Kelly, Alison Luke, Shelley Doucet

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Curriculum Vitae

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Katherine Jennifer Kelly (nee Thompson)

Universities attended (with dates and degrees obtained):

University of Toronto, Master of Arts (Psychology), 2015

University of Prince Edward Island, Bachelor of Arts (Psychology), 2014

University of Prince Edward Island, Bachelor of Arts (Psychology), 2014

Publications:

Kelly, K., Doucet, S., Luke, A., Azar, R. & Montelpare, W. (in preparation).

Experiences and perceived benefits of participation in a Facebook-based support group for caregivers of children and youth with complex care needs *Journal of Medical Internet Research*.

Kelly, K., Doucet, S., Luke, A., Azar, R. & Montelpare, W. (in preparation). Exploring the use of a Facebook-based support group for caregivers of children and youth with complex care needs. *Journal of Medical Internet Research*.

Doucet, S., Luke, A., Anthonisen, G., MacNeill, A.L., MacNeill, L., **Kelly, K.** & Fearon, T. (in review). Hospital-based patient navigation programs for injury-related trauma patients and their caregivers: A scoping review protocol. *JBIM Evidence Synthesis*.

Kelly, K., Doucet, S., Luke, A., Azar, R. & Montelpare, W. (accepted). Peer-to-peer support on Facebook for families of children with complex care needs in New Brunswick: an environmental scan. *Journal of New Brunswick Studies*.

Doucet, S., Luke, A., Anthonisen, G., **Kelly, K.**, Goudreau, A., MacNeill, A.L. & MacNeil, L. (accepted). Patient navigation programs for people with dementia, their caregivers and members of the care team: A scoping review protocol. *JBIM Evidence Synthesis*.

Kelly, K., Luke, A. & Doucet, S. (2021). Development and implementation of a Facebook-based peer-to-peer support group for caregivers of children and youth with complex care needs in New Brunswick. *Healthy Populations Journal*, 1(1), 43-54.

Kelly, K., Doucet, S. & Luke, A. (2019). Exploring the roles, functions, and background of patient navigators and case managers: A scoping review. *International Journal of Nursing Studies*, 98(October), 27-47.

Kelly, K. (2019). Home visiting programs for vulnerable families of young children. CHANCES Family Centre (internal report). CHANCES Research Board.

Charlton, P., Azar, R., Doucet, S., Montelpare, W., Nagel, D., Boulous, L., **Kelly, K.** & Landry, M. (2019). Use of Environmental Scans in the Context of Health Service Delivery: A Scoping Review Protocol. *BMC Journal*, 9(9), doi: 10.1136/bmjopen-2019-029805

Charlton, P., Azar, R., Luke, A., Doucet, S., Montelpare, W., Nagel, D., Hyndman, N., & **Thompson, K.** (2017). Falling through the cracks: Barriers to accessing services for children with complex health conditions and their families in New Brunswick. *Journal of New Brunswick Studies*, 8, 133-158. Published online: <https://journals.lib.unb.ca/index.php/JNBS/article/view/25883/30037>

Conference Presentations:

- Kelly, K.**, Doucet, S., Luke, A., Azar, R. & Montelpare, W. (2021, May). Development and evaluation of a social media-based support group using patient navigation for caregivers of children and youth with health care needs in New Brunswick. Canadian Association for Health Services and Policy Research (CAHSPR), virtual conference.
- Kelly, K.**, Doucet, S. & Luke, A. (2021, April). Exploring the roles, functions, and background of patient navigators and case managers: A scoping review. Canadian Healthcare Navigation Conference (CHNC), virtual conference.
- Kelly, K.**, Doucet, S., Luke, A., Azar, R. & Montelpare, W. (2019, May). Social media and peer-to-peer support for individuals with health care needs: a scoping review. Canadian Association for Health Services and Policy Research (CAHSPR), Halifax, NS.
- Thompson, K.**, Doucet, S., Luke, A., Splane, J. & Montelpare, W. (2018, August). eConnectNB: Supporting care coordination for children with complex care needs in New Brunswick. UPEI Multidisciplinary Graduate Research Conference (UMGRC), Charlottetown, PEI.
- Thompson, K.**, Doucet, S. & Montelpare, W. (2018, May). Differentiating patient navigators from case managers: A scoping review. Canadian Association for Health Services and Policy Research (CAHSPR), Montreal, QC.
- Thompson, K.**, Malinski, P., Doucet, S. & Montelpare, W. (2018, May). Adopting a nurse practitioner clinic into an existing community organization to support unaffiliated patients: A case study. Canadian Association for Health Services and Policy Research (CAHSPR), Montreal, QC.
- Dionne, E., **Thompson, K.** & Zinnck, S. (2018, May). Multi-service integration of care in Primary Health Care in Canada: Identifying Priority Services and Programs for children and youth with high functional needs and community-dwelling older adults experiencing functional decline. Canadian Association for Health Services and Policy Research (CAHSPR), Montreal, QC.
- Riveroll, A., **Thompson, K.**, Robertson, K., Salijevec, A. & Montelpare, W. (2018, May). Precision health: A personalized approach to active health management. The 41st Conference of the Canadian Medical and Biological Engineering (CMBES), Charlottetown, PEI.
- Thompson, K.**, Harper, T., Doucet, S. & Montelpare, W. (2018, March). Towards the development of an asynchronous e-health patient navigation system: A scoping review. Interprofessional Health Research Day, Saint John Regional Hospital, NB.

- Thompson, K.**, Schmuckler, M. & Zakzanis, K. (2016, July). Examining the cognitive and perceptual differences between musicians and non-musicians: A meta-analysis. Poster presented at the International Conference for Music Perception and Cognition (ICMPC), Hyatt Regency, San Francisco, CA, USA.
- Thompson, K.**, Schmuckler, M. & Zakzanis, K. (2015, October). Examining the influence of music training on cognitive and perceptual transference: A quantitative meta-analysis. Poster presented at the International Laboratory for Brain, Music, and Sound Research (BRAMS) Symposium, Universite de Montreal, Montreal, Quebec.
- Thompson, K.** & Cohen, A. (2014, July). The effects of complexity and music training in a rhythm discrimination task in younger and older adults. Paper presented at the Canadian Society for Brain Behavior and Cognitive Sciences (CSBBCS) conference, Ryerson University, Toronto, Ontario.
- Countryman, J., Gabriel, M. & **Thompson, K.** (2013, August). Spontaneous Musicking and Early Literacy. Poster presented at the Advanced Interdisciplinary Research in Singing (AIRS) Annual Meeting, Ryerson University, Toronto, Ontario.