PEER-TO-PEER SUPPORT ON FACEBOOK FOR CAREGIVERS OF CHILDREN AND YOUTH WITH COMPLEX CARE NEEDS IN NEW BRUNSWICK: AN ENVIRONMENTAL SCAN

Katherine J. Kelly, Shelley Doucet, Alison Luke, Rima Azar, and William Montelpare

Abstract

This environmental scan aimed to describe the purpose, use, and reach of health-related peer-to-peer support groups on Facebook for caregivers of children and youth with complex care needs 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 (twenty-one 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 peer-to-peer support groups are available to families of children and youth with complex care needs in the province. This work also lays a foundation for future scans of Facebook-based support groups in other Canadian provinces and beyond.

Résumé

La présente analyse du milieu visait à décrire l'objectif, l'utilisation et la portée des groupes de soutien entre pairs liés à la santé sur Facebook pour les personnes qui s'occupent d'enfants et de jeunes ayant des besoins de soins complexes au Nouveau-Brunswick. En tout, 3 104 recherches sur Facebook et des consultations auprès de 32 intervenants ont permis de repérer 47 groupes de soutien sur Facebook, dont 21 groupes actifs. Des groupes ciblaient un éventail de troubles; l'autisme et les déficiences intellectuelles connexes étaient ceux qui étaient les plus fréquents. Les analyses de contenu des messages ont révélé que les groupes étaient principalement utilisés pour échanger des informations de soutien. Selon cette étude, des groupes de soutien entre pairs sur Facebook sont offerts aux familles d'enfants et de jeunes ayant des besoins de soins complexes dans la province. De plus, ce travail jette les bases de futures analyses de groupes de soutien sur Facebook d'autres provinces canadiennes et d'ailleurs.

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 concerns (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 to 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 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 everyday 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) 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) (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 toward 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 support (i.e., provision of physical or instrumental aid) (Bender, Jimenez-Marroquin, and Jadad; Farmer et al.). 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 universal concern (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 (Dumaij 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 (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) (Swindle et al.). New Brunswick, in particular, has one of the highest rates of poverty in the country (Conference Board of Canada); even so, 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 is 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 groups 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 caregivers and persons living with chronic diseases (de la Torre-Diez, Diaz-Pernas, Anton-Rodriguez, and Giustini et al). One disadvantage of 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 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 may 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 the creation awareness; 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. Using content analysis, they applied a coding scheme to classify the age and geographical location of group creators. Results showed a large number of patient and carer groups (620) with over 1 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 centre on the exchange of emotional and informational support and community building. All the observed support groups in these 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 investigated Facebook-based P2P support groups that target 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 health care 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 methods of data collection (e.g., interviews, surveys, literature searches) (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 CCN, 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 (up to 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 two hundred 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, they keywords were paired with twenty-four geographical locations in the province. Locations consisted of cities and towns with more than two thousand inhabitants.

4.1.2. 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 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.

4.1.3. Inclusion and Exclusion Criteria

Groups identified from the online Facebook search strategy and consultations with stakeholders were screened according to 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) in NB across a broad range of conditions; they were categorized as *support* groups (see section 4.3 for more information on this categorization). Given the relatively small population within 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 an 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 (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 (half in English, half in French). Groups were screened according to the inclusion criteria (see section 4.1.4). Data were 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
Group URL	Internet URL of the Facebook group
Target audience(s)	Type of user targeted by group (e.g., patient, parent/guardian, sibling)
Target condition(s)	Condition(s) that represent the focus of the group (e.g., autism, spina bifida, not condition specific)
Target geographical location	Location within NB (e.g., NB, Sussex, Saint John)
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	Active is defined as a group with a post published within the past twelve months
Privacy designation	Whether the group is classified as public or closed
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

The lead author reviewed eligible groups and extracted information related to each group's 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 needs 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 (aims to advertise an external website); and others (e.g., research, educational, and social groups designed for knowledge dissemination or health promotion). 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 six 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 they are 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.

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 thirty 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. The 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 NB	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

Note. Group descriptions have been transcribed exactly as found in the publicly available information on the group's "about" page; grammatical and factual errors (e.g., st johns) 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) 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 thirty-one 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 among peers was particularly prevalent in many Facebook group descriptions, particularly in the local geographic region:

> This group was created to act as a gateway for parents and/or guardians in their search for finding suitable respite/relief/family support/mentor personnel in their area (group T).
>
> 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 fourteen 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 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 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 behavioural 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 were 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	7	14.9%
Fredericton	6	12.8%
Saint John	4	8.5%
Bathurst	2	4.3%
Miramichi	2	4.3%
Sussex	2	4.3%
Charlotte County	1	2.1%
North Bay	1	2.1%
Oromocto	1	2.1%
Woodstock	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 U.S. 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' membership 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 or fewer wall posts. 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 evoke 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—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 CCN, 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. 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 ninety-nine 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 Nations' 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. 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, it remains to be seen 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 provide 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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Katherine J. Kelly is a recent doctoral graduate from the Interdisciplinary Studies program at the University of New Brunswick Saint John.

Shelley Doucet is a Professor of Nursing and Health Sciences and the Jarislowsky Chair in Interprofessional Patient-Centred Care at the University of New Brunswick in Saint John.

Alison Luke is a Research Associate in the Department of Nursing and Health Sciences at the University of New Brunswick in Saint John.

Rima Azar is an Associate Professor of Health Psychology at Mount Alison University and an Adjunct Professor at Dalhousie Medicine New Brunswick.

William Montelpare is a Professor of Applied Human Sciences and the Margaret and Wallace McCain Chair in Human Development and Health at the University of Prince Edward Island.

Acknowledgements

Funding for this research was provided by the New Brunswick Health Research Foundation. The authors would also like to thank Hailey Arsenault for providing support in the categorization of included Facebook groups.

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