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"They may cry, they may get angry, they may not say the right thing": A Case Study Examining the Role of Peer Support When Navigating Services for Children with Neurodisabilities

« Ils peuvent pleurer, ils peuvent se mettre en colère, ils peuvent ne pas dire la bonne chose » : une étude de cas examinant le rôle des pairs aidant lors de l'accompagnement au sein des services pour les enfants avec des troubles neurodéveloppementales

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Abstract

Background: *Peer support for parents as a form of service and system navigation for families of children with neurodisabilities facilitates family resilience through their shared lived experience. However, there is little research available describing the experience of the key stakeholders engaged in this type of peer support.*

Methods: *Through thematic analysis of qualitative interviews, the present case study examined the experience of three mothers of children with neurodisabilities engaged in a parent-to-parent peer support network.*

Results: *Peers offer a unique form of support for navigating resources and experiences through shared lived experience. Our study revealed complex aspects of the emotional processes of peer support that have not previously been described. A unique finding was that the peers combined self-reflection and emotional expression in order to simultaneously provide empathy and bridge communication between a parent and service providers. Benefits associated with peer support included further development of knowledge and skills applicable to the peers' own families; however, the emotional weight of the volunteer work was noted as a challenge for peer supporters. The network coordinator played a dual role, providing support to both the parent and peer. Our report on the structure and function of* *this peer support network contributes to a description of the current landscape of navigation support for families of children with disabilities.*

Conclusions: *Findings suggest that peer support can play a complementary role to professional services in helping parents feel understood and access services that are meaningful to them. Peers can benefit from developing navigation skills; however, their role demands significant self-reflection and emotional investment. An additional layer of support for peers may contribute to the sustainability of peer support networks.*

> Note: This article is supplemented by information about the Family Support Program of the Family Support Institute of British Columbia and a vignette based on the study findings that illustrates how the peer support network helped one mother to navigate resources and policies on behalf of her autistic teenaged daughter whose behaviour had become unmanageable.

Résumé

Contexte : Les parents d'enfants ayant des conditions neurodéveloppementales peuvent bénéficier d'un soutien par les pairs, à la fois comme une forme de service et comme une forme de navigation dans le système. De cette façon, le soutien des pairs peut favoriser la résilience de la famille par le partage de leurs expériences. Cependant, il existe peu de d'études portant sur l'expérience des parties prenantes engagées dans ce type de soutien entre pairs.

Méthodes : Par le biais d'une analyse thématique d'entretiens qualitatifs, la présente étude de cas a examiné l'expérience de trois mères d'enfants ayant des conditions neurodéveloppementales, impliquées au sein d'un réseau d'entraide de soutien par les pairs.

Résultats : Les pairs offrent une forme unique de soutien pour naviguer à travers des ressources et des expériences grâce au partage de l'expérience vécue. Notre étude a mis en évidence des aspects complexes des processus émotionnels du soutien par les pairs qui n'ont pas été décrits auparavant. Un résultat unique est que le pair combine l'autoréflexion et l'expression émotionnelle afin de faire preuve d'empathie et d'établir une passerelle de communication entre un parent et les prestataires de services. Les bénéfices associés au soutien par les pairs, pour les parents, sont le développement des connaissances et des compétences pouvant être appliquées à sa propre famille. Cependant, le poids émotionnel du travail bénévole a été noté comme un défi pour les pairs aidants. Le coordinateur du réseau a joué un double rôle, en apportant son soutien à la fois au parent et au pair aidant. Notre rapport sur la structure et la fonction de ce réseau de soutien par les pairs contribue à une description du contexte actuel pour les familles nécessitant un soutien à la navigation dans les systèmes de santé et de services sociaux.

Conclusions : Les résultats de cette étude corroborent l'idée que le soutien par les pairs peut jouer un rôle complémentaire aux services professionnels pour aider les parents à se sentir compris et à accéder aux services significatifs pour leurs familles. En outre, les pairs aidants peuvent également bénéficier de leur rôle en termes d'acquisition de connaissances supplémentaires sur la navigation au sein du réseau. Cependant, ce rôle exige également des investissements personnels et émotionnels importants. Les implications tirées de cette étude indiquent l'importance de développer une strate supplémentaire de soutien pour assurer à la pérennité des réseaux de soutien par les pairs.

Mots clés : troubles neurodéveloppementaux, trouble du spectre de l'autisme, pairs aidants, navigation, soutien à la famille, émotions exprimées.

Introduction

Children living with neurodisabilities such as autism spectrum disorder (ASD), cerebral palsy, Down syndrome, or other brain-based disability (Morris et al., 2013) often experience limitations in adaptive functioning (e.g., social and communication skills; self-care) and cognition, and exhibit behaviours that require a range of health and social services and informal support across their lifetime (Gardiner et al., 2018). Such services are often siloed and untailored to the specific needs of each family (Lindeke et al., 2002; Luke et al., 2018). These needs may vary significantly not only across but also within disabilities (Gardiner et al., 2021). Furthermore, in addition to a range of other barriers to accessing care (Walker et al., 2016), the sheer volume of knowledge required to access the right services at the right time can feel overwhelming for families (Corcoran et al., 2015; Depape & Lindsay, 2015). This creates a need for family support in navigating meaningful resources.

Expecting families to navigate, prioritize and coordinate services without support, whether or not they have the skills or emotional capacity to wade through the high volume of information required of them, can result in poor uptake of services (Majnemer et al., 2020). Alternatively, families may be able to navigate services but struggle to negotiate for them to be delivered in a meaningful and culturally appropriate manner (Banks, 2003). These two concepts and skillsets of *navigation* and *negotiation* are key characteristics of many navigation services but are also important aspects of resilience (Ungar, 2010). Individuals and families need not only an abundance of resources in order to thrive in the face of hardship, but they also need the skills and knowledge to access those resources and the skills to advocate for service delivery that adequately meet their needs (Ungar, 2010).

The use of the term navigation in healthcare has its roots in cancer care in the 1990s (Freeman, 2012). While the term lacks a singular definition, generally, navigation refers to a service, program, or provider that aims to facilitate interactions between service users, families, and/or service providers with the ultimate goal of improving access to care (Carter et al., 2017; Luke et al., 2018). Navigation also often includes a component of emotional support to the service user and/or family (Luke et al., 2018). Formal navigation services may be delivered by a range of professionals, namely social workers and nurses, or by lay persons such as family members or volunteers (Carter et al., 2017; Luke et al., 2018; Reid et al., 2020).

Applying family resilience theory (McCubbin & Patterson, 1983; Ungar, 2010; Walsh, 2021) to navigation focuses the lens on how facilitating access to care and providing emotional support empowers families to shift their perception or belief systems around stressors. Doing so allows them to capitalize on available resources, improve their perception of their capacity to cope, and ultimately adapt to new circumstances. Furthermore, navigation facilitates maintaining or reestablishing access to existing resources both internal and external to the family system as connections to these supports may have been weakened or cut-off following a crisis.

There is a growing interest in the delivery of navigation and other support delivered by peer caregivers (Markoulakis et al., 2021). This support offered by peers is thought to complement rather than replace professional supports (Markoulakis et al., 2018; Reid et al., 2020). Peer support is facilitated by the peer's capacity to draw on shared lived experience to build trust and provide genuine empathy (Shilling et al., 2015). Perceptions and family belief systems can be influenced by peers sharing personal stories and providing alternative narratives to parents that may be feeling stuck or hopeless (Shilling et al., 2013). For instance, a study of a caregiver peer support program within a youth mental health and addictions service found that caregivers who accessed peer support had more positive perceptions regarding their caregiving than those who accessed only professional navigation supports (Markoulakis et al., 2021). Moreover, peers can identify and facilitate access to resources that are likely to be highly meaningful to families given their shared lived experiences (Myers et al., 2015). However, the role of peer support and navigation for caregivers of children with neurodisabilities has not been widely explored in the literature, providing little direction for the development of meaningful programs across Canadian communities.

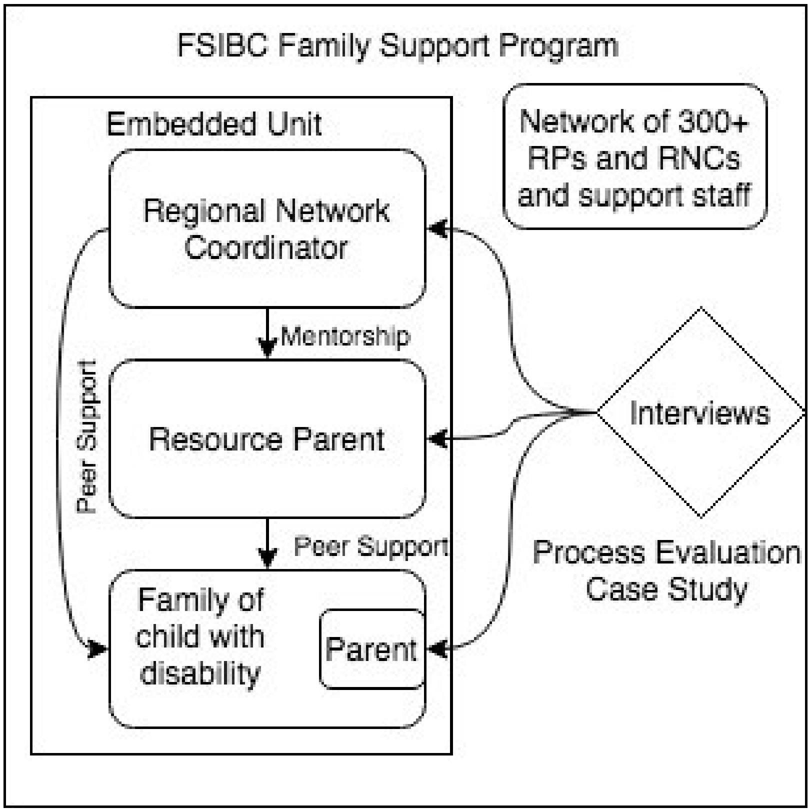
The present manuscript is the first stage of an effort to provide a rich description of the Family Support Program coordinated by the Family Support Institute of British Columbia (FSIBC; 2020), a Canadian volunteer-based organization offering a range of supports and programs for persons with disabilities and their families, including but not limited to peer support and navigation. Qualitative case study methodology (Yin, 2018) with multilevel input, is used to describe the experience of taking part in a parent-to-parent network from the perspective of a service user (parent), volunteer parent (Resource Parent, RP), and staff coordinator (Regional Network Coordinator, RNC) (see Supplementary file for a description of the program). A case vignette is also included in the present paper as an adjunct to bring to life the findings of our research. We believe this case will be of interest to families, clinicians, and policymakers as it highlights how peer support operates as a component of care for families of children with neurodisabilities.

Materials and Methods

The present case study followed a single descriptive instrumental case study design using an embedded unit (Figure 1) (Baxter & Jack, 2008; Yin, 2018).

Figure 1

Case Study Design with Embedded Unit



This design was chosen because it provided an in-depth understanding of the phenomenon (peer support and navigation) within a real-life context (the FSIBC Family Support Program) despite the boundaries between the phenomenon and the context being unclear (Yin, 2018). Studying peer support outside of the context of the program would not be possible given that the support operates within a network of volunteers and staff. This study is *instrumental* in that the context of the case plays a supportive role in facilitating a deeper understanding of peer support and navigation as a phenomenon.

The present study is also a process evaluation case study (Yin, 2018), whereby the process of implementing the initiative (i.e., the Family Support Program) is the focus of the case, rather than the objective success of the initiative. Compared with other methods of evaluation such as experiments and quasi-experiments, the case study captures the complexity of the case and its changes over time, attends fully to the context of the case, and explains how the intervention or initiative works (Yin, 2018). As such, interview guidelines were designed to develop a better understanding of roles and relationships between key stakeholders (i.e., parent, RP, RNC) within the Family Support Program in order to describe how they contribute to and experience the peer support and navigation initiative. In addition to interviews with the embedded unit of key stakeholders, FSIBC's webpage for their Family Support Program (FSIBC, 2020) as well as onboarding documents were included as sources of data for thematic analysis and triangulation to support trustworthiness of the findings. Lastly, memos and fieldnotes were reviewed to support the identification of themes for analysis and contribute to the rigor of the analytic process.

Ethics Statement

Ethics for this pilot project was obtained through the McGill University Research Ethics Board. Informed consent with each participant was obtained by the first author at the beginning of each interview. Participants had the right to withdraw from the study and to decline to answer questions if they felt uncomfortable answering. Participants consented to anonymized data from the interviews being used for the purpose of furthering research on the concept of navigation and to provide feedback to FSIBC to improve the Family Support Program. The first, second and fifth authors have no affiliation with FSIBC outside of the context of research and declare no conflicts of interest. Authors affiliated with FSIBC were not given access to raw data collected during the interview process.

Recruitment

Convenience sampling was used to facilitate ease and comprehensiveness of data collection (Yin, 2018). The participants – a parent, an RP, and an RNC – were identified by management at FSIBC. The participants were chosen purposefully as they were known to have worked well together as a unit within the network. Participants were invited by a manager at FSIBC to participate in interviews with an affiliated research partner (first author) who then contacted the interested participants directly to obtain informed consent prior to conducting interviews.

Participants

The participants were all mothers between the ages of 40 and 59. All three had an adolescent with a neurodisability and resided in the same rural region in western Canada. Reported gross family income varied significantly among the participants, ranging between $25,000 and $199,000 per year.

Interview Procedure

The primary source of data was interviews conducted using video conference software. Demographic information was collected verbally from each participant by survey during the interview. Interview guidelines were used to elicit details of their experience within the network and were tailored to each role as parent (service user), RP, and RNC. For example, questions for parents aimed to gather data on what they found useful or missing from their experience in seeking support and whether they would consider becoming RPs themselves. Questions for RPs explored the motivation for becoming and continuing to volunteer as an RP, and experience in receiving training and support from the organization. Questions for the RNCs explored how they have executed their duties to support and expand the network, including successes and challenges they faced. Participants were also provided with opportunities to provide general feedback not otherwise gathered from the questions posed as a part of the guidelines. Interviews lasted between 1 and 2 hours. The first author was the sole interviewer.

Analysis

Interviews were transcribed and coded using Dedoose mixed methods software (Salmona et al., 2020). Codes were compared and adjusted through an interrater exercise with a student colleague. De-identified sections of each interview transcript were coded independently by the first author and student, with any disagreements resolved through discussion. Thematic analysis of codes was used to identify content and concepts highlighted by participants during the interviews.

Results

Two main themes emerged from the analysis. The first related to how support is offered through shared lived experience, while the second theme highlights the emotional complexity of providing peer support.

How Support is Offered Through Shared Lived Experience

The five subsections below describe the type of support offered by the RP and RNC and how the support was experienced by the participants.

Drawing on Shared Lived Experience to Support Parents. Shared lived experience supported the efforts of the RP and RNC. All participants perceived parental expertise to be highly valuable and reported that support from parents with lived experience is distinct from professional support. The parent reported she felt genuinely understood, knowing that both the RP and RNC had an experience of parenting similar to hers. The RNC noted that the support person does not need to know exactly what the parent is experiencing given that each family follows their own unique developmental trajectory. However, peers can tune into and draw on their own experience to demonstrate empathy and validate the emotions experienced by other parents.

Box 1. *Sharing Lived Experience*

"They [are] in the same boat. They know exactly what we're going through […] [O]ther people with normal kids, they think they know and they understand but they never live like that 24/7" (Parent).

"Well then there was a hope. They cheer us up they tell us to call them anytime" (Parent).

"So, I think it helps me in my own work too–to know that other families know I'm an *autism* parent. They know I get it. You know, I don't live in a perfect world. Um, so days are tough" (RP).

Navigating Systems and Accessing Resources. Consistent with commonly described tasks of navigators, the RP and RNC provided practical support by guiding the parent through co-developing plans, connecting to resources, and attending meetings with parents. The parent participant noted that the RP and RNC knew about resources she had not heard of, and they knew how to access them.

All three participants reported extensive collaboration with various community and government organizations including advocacy groups, funders, housing supports, care coordinators, and ASD networks. The parent participant indicated that the support received from these various sources was not just for her child but supported her directly as a parent as well.

Box 2. *Navigating Systems and Accessing Resources*

"[A]s a family member that has their son or daughter with a diverse ability you live in systems. So, you become a bit of a ninja navigator" (RNC).

"[The RNC] went [to a mental health intake appointment] with me. She's kind of always chill and relax and it's what I needed… I start to get more relaxed and more alive" (Parent).

"She [RP] is the heart of [her community]. If you're newly diagnosed, people always say, 'you need to reach out to [RP].' […] She doesn't operate in the silo. She's very inclusive" (RNC).

Support for Resource Parents. The RP and RNC participants reported appreciation for supports offered by FSIBC in order to carry out their role in navigating systems and resources, highlighting tools like a transition timeline template, webinars, the RP network Facebook group, as well as collaboration with colleagues for training and mentorship. Participants also noted that the RNC provided mentorship and emotional support to the RP in relation to the peer support being provided.

Box 3. *Support for Resource Parents*

"[T]hat experience supported her [the RP]. Like, that's the ripple effect of this peer support […] [S]he has a great skillset and she just needed a little bit of information or she needed reassurance or she just needed to, you know, call me and cry on the phone and just cry and just say, 'hey I'm overwhelmed I can't… I don't even know how this family is doing it' […] And so just being there through that journey and then to come out with such a… such a successful outcome for your family […] [T]hey were able to able to advocate for themselves to get the support that they needed and more importantly for their [child] and for their family" (RNC).

Empowering Parents to Navigate Systems. The participants commented on how parents can be supported by their peers through learning how to navigate the steps and systems to get the support they need. While the RP and RNC were at times available as a supportive presence when accessing resources, it is worth noting that they did not view direct advocacy as a part of their role. Instead, they described supporting the development of self-advocacy skills by sharing their own stories and those of others they knew through their networks who experienced similar circumstances, thereby sharing knowledge of relevant resources available as well as pathways to successfully accessing them. Related to this, the RP noted that she was able to build on knowledge gained through each experience she had volunteering with families, which allowed her to better support other families including her own (see below for more discussion of the benefits, and challenges, of being an RP).

Box 4. *Empowering Parents to Navigate Systems*

"And one day we [were] at the coffee group and we [told] them that we are just done. Done, done. Don't know what to do next […] [T]hey [the RP and RNC] have knowledge. They know where to start and know people. They have connections" (Parent).

"I've seen what they've said to [the families I have supported]: 'how are you using your respite, what are you doing with it, what services have you used?' […] What I know now is that they're going to try to do family conference, where they rally everyone to find out if there's any extended family that can help out with the situation. So, in that instance, I knew that when we're dealing with this with our own [child] there isn't any other family [...] So we've kind of curtailed that. I think we've streamlined it a lot. I learned about becoming efficient" (RP).

Informal Social and Emotional Support. The RP and RNC provided informal and emotional support by tapping into their lived experience and recognizing the expertise of parents. The participants described informal supports as meeting for coffee, giving space for parents to express themselves, and intentionally taking a non-professional stance. As a person with both a professional identity and lived experience as a parent, the RNC noted that peers are not subject to the same constraints as professionals, allowing peers to focus on relational support without time limitations (see Box 5). Informal emotional support was provided by connecting as parents with similar concerns and being present without an agenda to assess or gather information.

Box 5. *Informal and Emotional Support*

"[I]t's that lived experience which is very different […] I can say […] as a navigator with my professional hat on versus my parent hat, it is very different […] I think you can just give families the space that they need to just kind of digest stuff. You're not just checking off boxes […] It's a journey. You may need help today or some support and then you don't need it for another two years and then you hit a wall or– but it's that social emotional support, too, that professionals can't really give you. Right? I mean they can't be everything to everybody, right?" (RNC).

Revealing Emotional Complexity: The Benefits and Challenges of Providing Peer Support

The three remaining subsections describe the benefits and challenges of providing peer support.

Emotional Processing at Meetings with Professionals. The task of attending meetings with parents, such as those with government agencies responsible for providing care, was highlighted as an important part of the roles of the RP and RNC. The RP and RNC indicated that they had developed expertise in knowing what questions might be asked in these meetings, who would be there, what services could be accessed, and how to present themselves in order to increase the odds of getting the support requested (e.g., providing evidence of exhausting all currently available resources).

The RP participant recounted her experience of becoming emotional in a meeting and how it connected to a reflection of her own family's experience. The RNC normalized the RP's expression of emotions in meetings with government agencies. She also indicated a need to go against the prevailing culture of such meetings and make room for parents' emotions, including those of RPs.

Box 6. *Emotional Processing at Meetings with Professionals*

"I was in, like, tears in that meeting, and, like, I'm supposed to be there to support parents, right? So, you know, I left it and I was so emotionally drained from it. I phoned the regional coordinator and I was like, I'm exhausted from that meeting, right? […] I think part of it was because I knew that was what we are going to go through with our son. So, I think there might have been some foreshadowing there" (RP).

"I guess the wild card that you're dealing with always when you're dealing with volunteers and parents is […] you don't have control over how they're going to react all the time. They may cry, they may get angry, they may not say the right thing. They're not professionals, right? They're family members. They're… they're different. So, you and I might go into a meeting and that would be our inside voice, we would never say that. But a family member might […] call you out on that, right? […] And then all of a sudden… people get uncomfortable with that, right? Because that's not the culture of attending meetings. That's not how we behave" (RNC).

Emotional Weight of Being a Peer Supporter. The participants all reported perspectives on the challenges of being or becoming an RP. The RP described how working with other families made her reflect on the circumstances of her own family. Furthermore, the type of requests for support the RP received were emotionally heavy. However, she noted that the network was responsive to her needs by respecting self-set limitations around taking on new families to support.

Not all parents are in a position to become an RP. In relation to the recruitment of new RPs, the RNC noted the importance of being able to reflect on one's own personal experience and how it relates to that of the parent being supported. However, the RP must also be emotionally available without projecting their experience on others. The parent participant was clear that she could not envision taking on the role of an RP, recognizing the toll of being a parent of a child with a neurodisability and the emotional exhaustion from her own experience that would impede her from having the desire to find herself navigating those systems again.

Box 7. *Emotional Weight of Being a Peer Supporter*

"[W]hen I first started this with the first family, I was like, this could be me 3 years from now, right? And I remember saying that to the family, right? And the mom would– and you know because there's stigma involved with giving up your child and stuff and I remember saying, you know what? This might be me. This could happen to any of us, right?" (RP).

"I think that my own personal life has kind of sorted itself out a bit. At the point like, in the summer if anyone asks anything more of me, I was just going to break, right? So, now I think I've gotten to the point where, yeah, I've sort of filled up my bucket again so to speak…" (RP).

"They're always the right fit. Families are the fit. They are who we are. Sometimes it's just not the right time for you to do this. Because you just have some unpacking to do or you need to settle down in your anger. I don't want families going into meetings where, you know […] of course your own stuff is going to come into it. Absolutely. You're not going to be able to separate that, but […] how do you bring your own experience in with […] honouring the family that you're supporting. You have to learn how to do that" (RNC).

"I just don't want to be in that anymore. Yeah, I know it's too much even if I'm done. I just want to relax and have normal life" (Parent on her decision to not become an RP).

Benefit to the RP. Both the RP and RNC reported the benefits of volunteering as an RP. The primary benefit reported was gaining valuable knowledge and skills from the experiences in supporting families. The RP was able to directly use skills, knowledge, and relationships she built in the context of volunteering in order to then support her own family. The RNC facilitated this benefit through being available to provide the RP with instrumental and emotional support.

Box 8. ***Benefit to the RP***

"A lot of what I learned through sitting through those meetings [with other families] and taking minutes for a family member have come in handy with my own family" (RP).

"I did a lot of mentoring with her [RP] because she didn't understand how that particular system worked […] I used to do child protection, so I understand that system. She and I spent a lot of time – we probably talked once a week around this family – and I was there to listen and she could debrief with me" (RNC).

"… I didn't really know the ins-and-outs of the system and now I know it a lot better and I feel comfortable enough to advocate for ourselves" (RP).

Discussion

Parents of children with neurodisabilities often find themselves in survival mode, making it difficult to know who to go to, what to ask for, and where to start to access support (Majnemer et al., 2020; Thomson et al., 2017). While much of the available research on navigation services involves professionals, this case study reports on the experience of non-professional peer support for parents of children with neurodisabilities. Similar to what has been described in the literature, the navigation support received through peers in this study was distinct from that of professionals in that it operated through shared lived experience (Reid et al., 2020; Shilling et al., 2013). In reviewing prior studies, findings related to emotional processes involved in the provision of peer support were limited to the triggering of difficult memories of past experiences (Shilling et al., 2013) or questioning one's emotional capacity to provide peer support (Shilling et al., 2015). In addition to corroborating these findings, our study revealed complex aspects of the emotional processes of peer supporters that have not previously been described. These processes are reflected by the two themes captured in our results, namely drawing on shared lived experience and the emotional complexity of providing peer support.

Connecting to resources and navigating through systems is a skill that parents develop with lived experience (Shilling et al., 2013). We can turn to family resilience theory to understand how lived experience operates in the context of peer support (McCubbin & Patterson, 1983; Walsh, 2021): when peer supporters share their story, they facilitate access to new or existing resources by providing a vision or belief system for how these supports could be accessed. Furthermore, through sharing their experience, they also facilitate hope, optimism, and positive appraisal of the balance between family stressors and available resources (Walsh, 2021). When parents know that their peer supporters have had similar experiences as parents, they may feel they can be well understood. While feeling understood is a potential benefit to parents on its own, there are other cascading benefits. For example, when resources and pathways for managing stressors are shared through peer support, there exists a mutual understanding that those resources and pathways will be meaningful and attainable for someone in the parent's position. This process of sharing lived experiences has the potential as an approach to navigation and support to increase access to services and improve outcomes for families of persons with disabilities, as similar findings have been found for caregiver peer support in the field of child and youth mental health (Markoulakis et al., 2021).

Indeed, shared lived experience can allow for a profound level of empathy for others. Professionals may be knowledgeable and sensitive to the needs of these families, however without lived experience their empathic capacity may be limited. Our findings were consistent with the literature in recognizing that peers operationalize their shared lived experience by telling their stories (Shilling et al., 2013), which in addition to providing practice advice also communicates authenticity of empathy. However, as elaborated below, the present study uniquely highlights another emotional pathway through which peers can leverage their lived experience in order to provide support.

The RP demonstrated that peers can convey emotions on behalf of the parents they support. This is a particularly unique finding as it explains that peers can go beyond sharing raw stories of their past experiences to processing reflections of their experience in order to respond authentically to the needs of parents they aim to support. Parents behave and express themselves differently in front of professionals compared to peers. Parents of children with neurodisabilities often, justifiably, feel the need to maintain the appearance of being strong in front of professionals (Bray et al., 2017). In our experience, we have come to understand that parents may worry that if they express heavy emotions such as sadness, grief, or anger, they may not be able to stop crying, may upset other family members, or may not be taken seriously by professionals. However, these emotions carry important feedback for professionals that can change the course of the services they provide in response to their perception of the needs of families. For example, in our study the RP tuned into the emotional experience of the parent that may not have been perceived by the service provider. After integrating a reflection on her own family's experience and the situation unfolding in front of her, the RP expressed the emotion she was feeling and drew attention to the unmet needs of the parent. In this case, the RP effectively acted as a conduit through which the parent's concerns were expressed. Even skilled and well-meaning professionals are at risk of overlooking or misinterpreting these emotional experiences. While the expression of intense emotion is often not a part of the culture embedded in meetings with professionals, as noted by the RNC, peers are not bound by this framework thereby sharing what might be uncomfortable or otherwise unsaid. The RP and RNC saw the RP's emotional expression as a powerful message of the human impact of discussions that parents have with health and social care professionals. A peer's presence can contribute valuable data to meetings such as this, thereby increasing the odds that the parent will be well understood, and appropriate and meaningful resources can be made available. However, these findings also have support and training implications for peers.

As demonstrated above, there is significant emotional complexity to the RP's role. Peer support requires extensive self-reflection. Experiencing this deep sense of empathy and expressing it can weigh on the emotional experience of peer supporters. Consistent with the literature, the participants in our study highlighted a caveat that a perceived sense of limited emotional capacity can be a potential barrier to peer support (Shilling et al., 2013). The parent participant could not imagine herself becoming an RP, suggesting that the weight of her own experience as a parent would not be something she would want to amplify through regular self-reflection. Similarly, the RP reported regularly reflecting on her own family's experience and trajectory, giving rise to confronting emotional experiences. However, while self-reflection and foreshadowing brought about heavy emotions, the RP also reported these processes as personally beneficial. We have found in our experience, as has been reported by others, parents often seek out the opportunity to provide peer support, citing benefits associated with giving back to the community, recognition of their expertise and validation of personal progress (Schwartz & Sendor, 1999; Shilling et al., 2013). This raises an important question of how to mitigate risk associated with challenging emotional experiences while maximizing potential benefits of providing peer support. In our study, these emotional challenges were managed again, in part, through shared lived experience. The RP received emotional and instrumental support from the RNC who understood challenges she was facing. The RP relied on debriefing and setting boundaries to process her experience and care for herself.

An additional layer of support in the peer-to-peer relationship may facilitate access to benefits of being an RP. The RNC provided knowledge, emotional validation, mentorship, and helped to share the load of direct navigation support to the parent participant. Moreover, the RNC was available to provide support as a witness to the RP's "foreshadowing" experience. With all participants being parents experiencing parallel processes, findings are indicative of a circular relationship between the parent, RP, and RNC, rather than one that is hierarchical. In this case, the RP benefited from honing her skills and knowledge in navigating systems that were meaningful to her own family's circumstances. The provision of peer support was not seen by participants as selfless volunteerism, but rather as a process of reciprocal benefit. Both the parent and the RP benefitted from the relationship. The additional layer of support provided by the RNC to this unit of peer support may have, in part, facilitated this benefit. The RP was able to receive support from the RNC in terms of reassurance, information relevant to navigating systems, and debriefing particularly emotionally challenging moments. Importantly, this supportive relationship is offered in the context of FSIBC's infrastructure facilitating the broader parent-to-parent networking and training opportunities.

In this case study, peer support was experienced as unique and distinct from that of professional support (see Box 5). First, the relationships were developed in an explicitly non-professional and non-hierarchical fashion. The shared lived experience that bound these three mothers together facilitated empathy and understanding that could be leveraged to bridge communication with service providers and increase access to resources for the parent and her family. However, much like clinical supervision for professional health and social care providers, an additional layer of support is likely to protect the well-being of the peer supporter and facilitate the benefits of this role. Little guidance is available for developing parent-to-parent support networks for families of children with neurodisabilities (Schippke et al., 2015), though a best practice toolkit has been devised based on the limited research available in related fields (Schippke et al., 2017). As such, our report on the structure and function of this peer support network also contributes to describing the landscape of navigation support for children with neurodisabilities in Canada (Carter et al., 2017; Luke et al., 2018).

Limitations

There were a number of limitations of the study. While qualitative case studies of an embedded unit such as this are not intended to be generalizable, we acknowledge that our study was limited to the perspectives of only three mothers given practical restraints in the context of our research. Still, we feel their individual and collective stories demonstrate a valuable example of how a cohesive unit of a peer support network can contribute to facilitating service navigation and supports for families. It should still be noted that the experience in other regions and with other parents, RPs, and RNCs, as well as other peer support networks, could be significantly different. A broader sample of participants from the network is likely to yield additional perspectives and experiences of peer support.

While there may be some similarities across needs of families of children with neurodisabilities, we acknowledge that families are all unique. As such, the way navigation supports are implemented may vary based on family needs, issues such as gender, race, and culture and the extent to which caregivers and families experience oppression. Applying a family resilience framework, opportunities to engage in social discourses relevant to care is an essential component of resilience (Ungar, 2010). For instance, families that experience less oppression may have more significant opportunities to contribute to these social discourses (e.g., in the development of social supports such as peer support networks) and therefore a more open pathway to resilience. Furthermore, the availability of resources to match a family's needs could have an impact on how this model of navigation works, as the absence of resources for families is likely to affect their expression of resilience (Ungar, 2016).

Future Research

Future efforts to describe and understand the experience and stories of key stakeholders in peer support and navigation programs can help in the uptake, modification, and future design of services for families of children living with neurodisabilities. While the literature suggests that peer support functions via shared lived experience, to the authors' knowledge, theory bridging peer support for these families and family resilience has not been explored (Schwartz & Sendor, 1999; Walsh, 2021). Such connections could provide a framework for greater understanding of the function and value of peer support for families and service providers and will be a focus of our ongoing research agenda as we continue to explore the diverse experiences of this population.

Key Messages from this Article

People with Disabilities and their Families. Peer supporters can help you learn about what resources might be useful to your family, how to access them, and where to start to get support. They can also be someone to talk to that understands what you and your family are experiencing.

Professionals. Peer support is a valuable resource for parents and families that can facilitate meaningful access to services.

Policymakers. Peer support is not a replacement for professional support. Instead, it can complement the support from professionals and facilitate access to resources, thereby potentially improving the outcomes for families and communities.

Messages clés de cette étude

Personnes ayant une incapacité et leurs familles. Les pairs aidants peuvent vous accompagner et vous renseigner sur les services et les ressources pour votre famille, sur la manière d'y accéder et sur les points de départ pour obtenir un soutien. Ils peuvent également être une personne à qui parler et qui comprend ce que vous et votre famille vivez.

Professionnels. Le soutien par les pairs est une ressource précieuse pour les parents et les familles qui peut faciliter de manière significative l’accès aux services.

Décideurs. Le soutien par les pairs ne remplace pas le soutien professionnel. Il est complémentaire au soutien professionnel et facilite l’accès aux ressources, améliorant ainsi potentiellement les retombées de l’intervention pour les familles et les communautés.

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Supplementary File

Case Description: The Family Support Program of the Family Support Institute of British Columbia

The Family Support Institute of British Columbia (FSIBC) was established in 1985 and has developed into a key resource for families of persons living with a disability. The Family Support Program is a central component of the organization which provides no-cost peer support and resource navigation to any family or individual living with a disability (FSIBC, 2020). This support is provided by nearly 300 Resource Parents (RPs) across the province who share experience and expertise, and guide and support families in their own communities. The network is informed by principles and codes of volunteer engagement ("*Bridging the gap*," 2010; "*Canadian code for volunteer involvement*," 2006). Tasks of RPs may include attending meetings and taking notes, increasing awareness of FSIBC through presentations, and providing an attentive and non-judgmental ear to families. All RPs have lived experience caring for a child or other family member with a disability. Notably, FSIBC is not an advocacy group but rather a charitable organization that aims to “strengthen, connect, and build community resources with families of people with disabilities in BC” (FSIBC, 2020). In line with a resilience theoretical framework, the organization’s mission, vision, and philosophy emphasize the value of expertise of parents and families and the capacities of families to negotiate for their needs to be met when supported with the right information and adequate resources.

Recently, 12 Regional Network Coordinators (RNCs) were hired in regions across the province of British Columbia to support this network of volunteer RPs. RNCs support RPs in their volunteer work through mentorship. They also support the development of relationships between FSIBC and the communities they serve and are responsible for recruiting new volunteers with a particular focus on filling gaps in the network in relation to cultural diversity.

Both RPs and RNCs receive training in topics relevant to their position through an onboarding and orientation process. FSIBC has traditionally provided yearly training retreats, however, since the COVID-19 pandemic, trainings have moved online and are delivered on a more regular basis. Additionally, informal online support groups have been developed for regular check-ins for both volunteers and parents seeking support. The volunteers and staff seek peer consultation and mentorship through online messaging or other forms of communications within the network for up-to-date information on resources, policies, and processes relevant to the parents they support. FSIBC also offers funding for volunteers and staff to access other training opportunities beyond those coordinated by the organization.

FSIBC has not had their services formally studied or evaluated and so are currently seeking to better understand how the program is functioning from the perspective of parents, volunteers, and staff, and how they could continue to improve and expand their program to meet the needs of the communities they serve. Furthermore, with the recent addition of the RNC role, FSIBC is seeking to understand how the addition of these staff members has been experienced within the program.

Case Report

Parents Supporting Parents: A Story from a Parent-to-Parent Network

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Abstract

This complementary narrative is meant to accompany the research article above. This creative piece was born out of interviews with mothers of children with neurodisabilities to provide readers with a brief cohesive story of parent-to-parent support from multiple perspectives.

Introduction

Anna was at her wit's end. She told the group of mothers of children with autism spectrum disorder (ASD) with whom she regularly met for coffee, that she and her husband were "done," and feared they could no longer care for their teenage daughter on their own. They felt trapped by the advice they received from their social worker: either wait until their daughter turned 19 in order to explore supportive housing options or abandon their child to the care and custody of the province.

The organizer of the coffee group was Julia, also mother of a child with ASD and a volunteer Resource Parent with the Family Support Institute of British Columbia (FSIBC;). The organization includes a large peer support network of family members of persons with disabilities. Anna knew that Julia was in the same boat as her, so she didn’t need to explain what it was like to deal with her daughter’s challenging behaviour on a full-time basis. With Julia’s daughter being a few years younger, Anna was faced with decisions around her daughter's care that Julia and her family haven't yet had to make. Julia, however, had the support, knowledge, and resources to help Anna and her family figure out what step to take next.

Julia sought the mentorship of Sandra, a Regional Network Coordinator with FSIBC. Sandra, with her background as a social service professional and as a mother of a child with a neurodisability, knew what resources were available, knew what questions to ask, and could anticipate how meetings with government agencies would go. Sandra and Julia supported Anna that same day to make a phone call that would launch a cascade of meetings with several agencies that would eventually lead to greater government support for her daughter’s daily care. Julia was a supportive presence throughout those meetings and provided practical support as well as empathy for what Anna and her family must have been going through. Over the course of the next weeks and months to come, Sandra and Julia continued to meet with Anna and her husband over coffee to plan the next steps, provide information, make new connections to resources, and make difficult decisions regarding their daughter’s care. Anna received support for her daughter, but also for her own mental health. Sandra accompanied Anna to an intake appointment with a mental health counsellor, but what Anna found most helpful was the solidarity of the mothers that understood her experience, stood with her, and renewed her hope, energy, and life.

Being a Resource Parent

Before Julia became a Resource Parent she was already known as someone to turn to for knowledge and support in the disability community. Her involvement with FSIBC was sparked organically by her prior connection with Anna and her compassion for the situation in which that family found themselves. Julia was already employed with another community organization as a support navigator directing families to resources, but she didn't have the expertise needed to fully accompany with Anna and her family through their challenging circumstances. Sandra, the Regional Network Coordinator, was able to mentor and collaborate with Julia by drawing on her professional experience and knowledge of health and social systems, and by facilitating Julia's integration into the network of nearly 300 volunteer parents who carry a wealth of knowledge and lived experience.

Julia volunteered with other parents experiencing similar situations as Anna, building a certain expertise in a niche area over the course of several years of attending meetings, providing instrumental and emotional support, and navigating systems with these families. With each family she met, she gained new insight into navigating the resources and policies surrounding support for families who were struggling to care for their children due to unmanageable behaviour.

Now, Julia is navigating these resources and policies on behalf of her own family. After years of volunteer work, she was able to refer back to her notes. When Julia was faced with the crisis of no longer feeling able to manage her daughter's challenging behaviour, she knew where to start, what she could and could not ask for, what to expect during the meetings with government agencies, and what her emotional experience would be.

Note: All names and some identifying details in this story have been altered to protect the anonymity of participants.