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Help-Seeking in Mothers and Fathers who Co-Parent their Child with Neurodisabilities: The Journey of Ladders and Snakes

La recherche d'accompagnement chez les mères et les pères qui sont co-parent d'un enfant vivant avec de troubles neurodéveloppementaux : Un parcours de serpents et échelles

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Abstract

Help-seeking to assist with the care of their child is common for parents who co-parent their child with neurodisabilities (ND), yet little is known about how such a journey unfolds. This article presents the Journey of Ladders and Snakes, a theoretical representation of the help-seeking experience of mothers and fathers, living together or apart, who co-parent their child with ND. Mothers and fathers from 6 co-parenting dyads each participated in individual, semi-structured interviews about their process of help-seeking for their child and for themselves within informal (e.g., family, friends) and formal (e.g., health and social service organizations) networks of support. Designed, conducted, and analyzed according to Constructive Grounded Theory principles, the study's results describe: (i) a highly emotive help-seeking journey that stems from a place of grief, encompassing complementary parent roles that were experienced as both exhaustingly demanding and connecting; (ii) ladders and snakes that aided and/or challenged help-seeking; (iii) gendered differences in their experience of the help-seeking process; (iv) gaps in the availability of meaningful supports. This study takes into account the voices of both mothers and fathers, highlighting the importance of understanding the experiences of both parents, individually and as co-seekers, in order to provide optimum support.

Résumé

Les parents qui co-parentent un enfant vivant avec de troubles neurodéveloppementaux (TD) sont souvent à la recherche d'accompagnement pour naviguer divers systèmes et services d'aide. Pourtant on connait à ce jour peu de choses sur le déroulement d'un tel parcours. Cet article présente le parcours de serpents et échelles, une représentation théorique de l'expérience de recherche d'aide des mères et des pères, vivant ensemble ou séparément, qui co-parentent leur enfant. Les mères et les pères de six dyades co-parentales ont participé à des entretiens individuels semi-structurés pour discuter de leur processus de recherche d'aide pour leur enfant et pour eux-mêmes au sein de réseaux de soutien informels (par exemple, famille, amis) et formels (par exemple, des organisations de santé et de services sociaux). Conçus, menés et analysés selon les principes de la théorie constructive ancrée, les résultats de l'étude décrivent : (i) un parcours de recherche d'aide très émotif qui découle d'un lieu de deuil, englobant des rôles parentaux complémentaires qui ont été vécus à la fois comme épuisants et exigeants ; (ii) des échelles et des serpents qui ont aidé et/ou défié la recherche d'aide ; (iii) des différences entre les mères et les pères dans leur expérience du processus de recherche d'aide ; (iv) des lacunes dans la disponibilité de soutiens significatifs. Cette étude prend en compte les voix des mères et des pères, soulignant l'importance de comprendre les expériences des deux parents, individuellement et en tant que codemandeurs, afin de fournir un soutien optimal à l'enfant concerné.

Mots-clés : recherche d'aide, coparentalité, mères et pères, enfants vivant avec de troubles neurodéveloppementaux, soutien

Introduction

Mothers and fathers who co-parent children with neurodisabilities (ND) regularly seek help to assist them in the daily care of their child, yet little is known about what that help-seeking process is like, or how engaging in that process unfolds. In the context of this study, help-seeking refers to the process mothers and fathers undertake to find support for their child and for themselves related to needs that arise from the child's neurodisability. The concept of help-seeking behaviour is not original to this study but has become topical in recent years (Cornally & McCarthy, 2011). We adopted the term *help-seeking* following a parent advisory committee, gathered in the context of a study[1] conducted in the School of Social Work at McGill University. Parents used the word *help* to describe their overarching need for support (e.g., "Please *help* me."), and *seeking* to describe the active role they undertook to reach the help they needed.

The term neurodisability refers to: " ... a group of congenital or acquired long-term conditions ... that may impact ... movement, cognition, hearing and vision, communication, emotion, and

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[1] 'Support Matters' is a Kids Brain Health Network funded project co-led by Drs David Nicholas (University of Calgary and Lucyna Lach (McGill University). More information about the project can be found here: https://kidsbrainhealth.ca/portfolio-items/support-matters-project/

behaviour" (Morris et al., 2013, pp. 1105-1106). In the legal sense, it refers to a post-divorce or post-separation parenting arrangement in which both parents continue to jointly participate in their children's upbringing and activities (Government of Canada, 2023). In our study we use the term co-parenting to describe mothers and fathers who collaborate in making decisions about, and caring for their child (Hock & Mooradian, 2013). This definition is inclusive of adults who are not the child's birth parent and is not restricted to parents who are currently in a spousal relationship together or living together.

Parents seek help from *informal* (e.g., friends, family, other parents) and *formal* (e.g., therapists, healthcare practitioners) sources of support primarily led by their quest to first and foremost address their child's needs (Thomson et al., 2017). When help-seeking for themselves, mothers seem to do so with more ease than do fathers (Pelchat et al., 2003). Parents seek for help that will increase their child's functioning and that will help them increase their own ability to manage the extra layers of complexity that arise from parenting a child with ND, for example, clear information to help them better understand the diagnosis and anticipated impacts (Gibson et al., 2017), financial support that will offset the expenses related to raising a child with ND (Gilmore, 2018; Stabile & Allin, 2012), respite to have some time away from their caring responsibilities (Thomson et al., 2017) as well as information about education (Thomson et al., 2017), therapies (Gibson et al., 2017), and behaviour management (Rosenblum & Yom-Tov, 2017).

Parents of children with ND experience greater levels of stress, anxiety, and depression (Gilmore, 2018) than do parents of children who develop according to typical norms. They may also experience grief from the sense of loss that comes from not receiving the healthy child they had anticipated (Frye, 2016; Thomson et al., 2017). Thus, for mothers and fathers, engaging in help-seeking is preceded by, and transpires through, a deeply personal and emotive beginning. Acquiring support, when it is experienced as helpful, alleviates some of these negative impacts (Al-Gamal & Long, 2013; Kilic et al., 2013; Wang et al., 2013). However, parents are not always aware of where to locate help (Bussing et al., 2003), and often find it is unavailable, inaccessible and/or lacking the proper fit and feel (Boulter & Rickwood, 2013). Furthermore, help received from professionals is often felt as uncaring and non-empathetic (Nowak et al., 2013), and parents fear stigma (Sahu et al., 2017) from professionals who, they feel, lack knowledge (Gilmore, 2018).

Mothers and fathers of children with ND may experience similarities in being partners in their co-parenting (Mueller & Buckley, 2014). However, the manner in which they co-parent may vary based on individual, complementary roles (McNeill et al., 2014); thus each parent contributes to help-seeking differently. Current scholarship regarding parents of children with ND overwhelmingly comprises studies that utilize samples of mothers (Bogossian et al., 2017; Willingham-Storr, 2014), thus reflecting mothering rather than parenting. Including the voices of fathers in the current study adds to a burgeoning scholarship that highlights their important contribution (Hannon & Hannon, 2017; Meadan et al., 2015; Paynter et al., 2017). Current literature also provides a clear understanding of elements that propel parents' help-seeking journeys (Kilic et al., 2013; Lach et al., 2009; Singh et al., 2017; Thomson et al., 2017); yet what remains unclear is how parents of children with ND move towards help-seeking in the first place: how they decide who seeks, for what, and how? The purpose of the present study, which is based on the PhD thesis of the first author (Glidden, 2019), was to shed light on that exact process in order to bridge the gap in knowledge about how mothers and fathers who co-parent their child with ND engage in a help-seeking journey.

Methods

Methodological Approach

The study was designed utilizing a Constructivist Grounded Theory (CGT) approach (Charmaz, 2006, 2014) to answer: *How do mothers and fathers who co-parent their child with ND seek help for their child and for themselves from within their informal and formal networks?* CGT is a qualitative research method that focuses on generating new theories through analysis of data gathered from participants. In contrast, Grounded Theory (GT) tests hypotheses based on pre-existing theoretical frameworks (see Data Analysis section for more information). In our case, the application of CGT was appropriate because a theoretical framework to answer the study question did not exist.

Ethical approval was received from the McGill University Research Ethics Board.

Recruitment

A purposive sample of mothers and fathers was recruited from four different sources. These were: i) existing databases; ii) snowball sampling; iii) Facebook advertising; and iv) word of mouth. Eligibility was based on the following criteria: (1) they were a mother or father of a child with ND; (2) they actively co-parented with their child's other parent, (whether or not they lived together); (3) their child with ND was between 5 and17 years of age; (4) they could communicate in English or French. Recruitment proceeded incrementally based on CGT principles (Charmaz, 2006, 2014), moving from initial sampling (the starting point of data collection with the first participant) to theoretical sampling, the circular process of constant comparison "... data and data, data with code, code with code, code with category, category with category, and category with concept..." (Charmaz, 2014, p. 342). Thus, as long as interviews added new layers and depth to the understanding of help-seeking, new participants were interviewed to gain further perspectives about these new ideas. Recruitment ended once *theoretical sufficiency* (Dey, 1999, p. 117) had been reached. Theoretical sufficiency challenges the exhaustive nature of data saturation by suggesting that it is impossible to, "... predict accurately whether the very next round of data collection... might throw up something that suggests an important modification or even a new perspective" (Dey, 1999, p. 117). Rather, the *notion of sufficiency* was utilized, "... the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications" (Dey, 1999, p. 117). See Glidden (2019) for further details about recruitment.

Data Collection

Data were collected between November 2016 and February 2018. Information from parents was obtained through in-depth, semi-structured, individual interviews following signed consent. The preliminary interview guide consisted of open-ended questions about family context; types of help needed/sought; characteristics/relationships of help-seeking; decision-making; and help-seeking over time. In line with CGT guidelines (Charmaz, 2006, 2014), the interview guide evolved as the study unfolded to reflect the new ideas about help-seeking that emerged from one interview to another. This allowed for the testing of these ideas by asking new participants, "I have heard from other parents that ... can you help me understand this?". Descriptive data about mothers and fathers and their child (age, family composition, income, employment status, child diagnosis, school, types/location of help sought), were collected through a 26-question demographic questionnaire created for this study. Refer to Glidden (2019) for details about the interviews and demographic questionnaire.

Descriptive data about child functioning were collected using *About my Child* (AMC) (Ritzema et al., 2016), a 26-item measure about child functioning and its impact on child's participation within eight domains: (1) physical function; (2) activities of daily living (eating, toileting, dressing, sleeping); (3) communication; (4) behaviour; (5) mood; (6) cognitive abilities; (7) social skills (with peers and adults); (8) participation in activities outside of school. AMC provides a complexity score that reveals how many functional indicators a parent is concerned about, as well as an impact score that highlights their perception of the degree their child's functioning is impacted. About my Child has a high level of internal consistency (Cronbach's alpha = .84).

Data Analysis

Audio-recorded interviews were transcribed verbatim, de-identified by the first author, verified against the audio for accuracy, and then uploaded into Dedoose, version 9.0.17, a web application for managing, analyzing, and presenting qualitative and mixed method research data (2021). Descriptive and child functional data were analyzed using Microsoft Excel for Mac, version 14.5.7. Parents were contacted to fill in any missing data.

Interviews were analyzed according to CGT guidelines (Charmaz, 2006, 2014) beginning immediately following the first interview. Iterative in nature, CGT analysis loops back and forth, comparing data within and between past and new interviews (Charmaz, 2014; Corbin & Strauss, 2015) to develop and then further define theoretical categories. As such, the analysis of one interview built onto what was known from the previous interview and also guided the next. Following line-by-line coding and focused coding, over 700 codes were reviewed, refined and reorganized based on their relationships to each other, leading to the theoretical understanding of help-seeking described in this article. See Glidden (2019) for detail about the analysis.

Results

Description of the Study Population

The final sample consisted of 6 mothers and 6 fathers from 6 co-parenting dyads, with each parent participating in 1 individual, semi-structured interview. Parent's ages ranged from 39 to54 years. (*M* = 46.11 yrs.). Most parents worked full-time (*n* = 9), and individually, parent's reported annual incomes ranged from $30,000-$39,999 to $80,000+ (Table 1).

Table 1

Individual Parent Characteristics (n = 12)

Parent Code	Parent Name *	Child's Name	Age (Years)	Annual Income	Education
02-Fa	Marc	Annabelle	39	$80,000 +	High school
02-Mo	Nathalie	Annabelle	40	$80,000 +	Technical school
03-Fa	Victor	Connor	44	$30,000-$39,000	Technical school
03-Mo	Helene	Connor	42	$70,000-$79,999	University
05-Fa	Charles	Paul	51	$50,000-$59,999	University
05-Mo	Simone	Paul	53	$80,000 +	Some university
07-Fa	Alex	Charlotte	42	$70,000-$79,999	Technical school
07-Mo	Bridgette	Charlotte	40	$70,000-$79,999	Some university
10-Fa	Trevor	Mike	48	$50,000-$59,999	University
10-Mo	Nicole	Mike	48	$50,000-$59,999	University
11-Fa	George	Mathew	53	$80,000 +	University
11-Mo	Anne	Mathew	54	$80,000 +	University

Note. * Parent and child names are pseudonyms.

Mothers and fathers were parents of boys (n = 4) or girls (n = 2) between the ages of 8 and 15 years (M = 10.66 years) who attended specialized classes within regular schools (n = 4) or specialized schools (n = 2) (Table 2).

Table 2

Child Characteristics (n = 6)

Name *	Age (Years)	Domains of concerns ** (0-9)	# of Concerns (0-26) ***	Impact score (0-3) ****
Annabelle	9	Physical function; daily activities; communication; mood; cognition; social skills; participation	17	1.7
Connor	10	Daily activities; communication; behaviour; mood; cognition; social skills; participation	14	2.03
Paul	10	Physical function; daily activities; communication; behaviour; mood; cognition); social skills; participation	19	2.3
Charlotte	8	Communication; behaviour; mood; social skills	6	.65
Mike	12	Daily activities; communication; behaviour; mood; cognition; social skills	10	1.3
Mathew	15	Physical function; daily activities; communication; behaviour; mood; cognition; social skills; participation	20	2.57

Notes. *Child names are pseudonyms. * **About My Child* (Ritzema et al., 2016) is a 26-item measure about child functioning and its impact on child's participation within eight domains: (1) physical function; (2) activities of daily living (eating, toileting, dressing, sleeping); (3) communication; (4) behaviour; (5) mood;

> (6) cognitive abilities; (7) social skills (with peers and adults); (8) participation in activities outside of school. ***A *complexity score* determines the number of functional indicators that a parent is concerned about. For this score, parents are first asked to indicate whether they are concerned about the 26 functional items by indicating yes/no. The number of *yeses* is totalled. For each *yes* item, parents are then asked to indicate to what degree they perceive the item impacts their child's ability to participate in everyday activities (not at all, a little, somewhat, or a lot). ****A numerical value ranging from 0-3 is assigned to each impact answer. The mean of the total score is then calculated for the *impact score.* Higher scores indicate greater complexity. *About my Child* has a high level of internal consistency (Cronbach's alpha = .84). It is estimated that the completion of both measures requires approximately 10-15 minutes, combined.

The following results section begins with a description of parents' *Journey* of help-seeking through the metaphor of *Ladders and Snakes".* Then, the categories that make up the substantive CGT are presented: Starting from a Place of Grief and Loss; "I'm OK if She's OK"; Help-Seeking Through Informal and Formal Networks; Ladders and Snakes. The parent quotes presented throughout were carefully selected from category excerpts imported through Dedoose during the analysis process.

The Metaphor

The *Journey of Ladders and Snakes* represents the help-seeking of co-parenting mothers and fathers of children with ND, both as individuals, and as co-parents. The *journey* describes mothers' and fathers' experience of trying to locate "*...resources for him, for his path*" (Helene), as well as "*the information that you need that can come to your aid..."* (Marc), from *"...someone who is helping me find what I need"* (Bridgette). Their journey was described as ongoing, continuous, and interconnected; a path with a clear starting point yet lacking a clear ending. "*It's a continuous battle. So you, you think about it, that it's going to go off, but it's continuous. With these conditions, it will never disappear*" (Charles). The ladders and snakes describe steps forward and backwards, halts and setbacks, twists and turns, representing elements that made their journey easier or more difficult. The *metaphor* thus mirrors the popular board game Snakes and Ladders, where unpredictable trajectories, and ups and downs that are represented by ladders and snakes, and it stems from Simone's description of trying to access respite. *"So there you tell yourself, ok. You, you do this, and then I'm going to go there, and I'm going to ask to go here, and then I'm going to go there. And when that's done, I have to call here, and then take him there. It's like a game of snakes and ladders*" (Simone).

The visual image of Simone's dice toss, of her moving tentatively forward, unknowing of the ladders and/or snakes ahead, very clearly characterized her personal journey, and that of the other parents in the study.

The Journey

Whether living together or apart, mothers and fathers illustrated their journey as one that played out through specific roles that each adopted within their help-seeking dyads. These occurred naturally, without discussion, often reflecting their personalities (e.g., quieter, more contemplative parents sought help through researching and gathering information at a distance; parents with more outgoing personalities engaged more directly through telephone calls, information sessions, parent groups), concrete skills (e.g., one's focus, problem-solving, organization) or interpersonal skills (e.g., communication, being person oriented, talking through things):

> *I always say, I do the macro and Charles does the micro. So, I'm the one who, and he would agree, I'm pretty sure, I'm the one who found the school. I got the dog. I found the money. I get this. I fight for that. I do that. And he keeps Paul on track as much as he can. So really, it works a lot like that. Like, it's always, uh, partly because I'm so impulsive, not exactly impulsive, but I need to have results fast, so I'll pick up the phone and start, you know, complain and complain and find this and that. And my husband is a little more methodical and takes his time to make decisions (laughs). So, I think that's part of the reason. Like, I'm always off uh, off the starting gate right away to find solutions about this or that, for better or worse (laughs), and he takes his time.* (Helene)

Sometimes roles were determined by life situations and circumstantial conveniences (e.g., health, employment, timing), with parents doing what needed to be done based on who was available at the time, "*When things need to be addressed, you need to address them*" (Charles). Typically, mothers identified the initial concern(s) and set the help-seeking journey in motion, "*At the beginning, she, she recognized, something's wrong, there's something not right with Charlotte, the way she behaves, you know, reacting to situations and all that*" (Alex). They also anchored the journey, overseeing its evolution (e.g., planning/scheduling appointments, ensuring follow-ups). Importantly, parents reported that the roles they adopted early on in their help-seeking remained constant over time: "*I'd say that, yes, it's um, it's funny eh, it's been, let's say, it's been about twelve years and, um, yes, it was like that, I'd say, it's always been like that*" (George).

While roles remained constant through time, where and how parents journeyed changed as their child aged and developed, and as their own experience and knowledge about help-seeking increased, helping them better anticipate what lay ahead. Their help-seeking journeyed from pediatric, to youth and young adult settings, focusing on current and future concerns. Their journey also took into consideration the quantity and frequency of help they sought from their informal helpers who also aged through the passage of time. Mothers and fathers portrayed the journey as both a partnered experience of sharing and discussing with each other, and a solo undertaking with each engaging in their specific roles, independently of the other.

Starting from a Place of Grief and Loss

The sense of help-seeking as a solo undertaking was also reflected in mothers' and fathers' description of their experience as a very personal process, weighted by the heaviness of mourning and grieving the child they had hoped for but had not gotten. The arrival of a child with a non-typical development launched them into a visceral and private experience, challenging their expectations of what being a parent would look like, how parenting would unfold, and where their anticipation of what family life would lead them:

> *Definitely not the child I was expecting... I look at friends' children and all that, and you get sensitized through TV as well, thinking of what growing up is supposed to be like. So I had this mental image of, of, a happy- go-lucky family and all that, But then ... your vision of what's a childhood supposed to be, in your head, it's not the same anymore. And ... it's sort of disappointing to not be the father that I was hoping to be.* (Victor)

The sense of loss often unfolded simultaneously along-side other responsibilities, and for many, help-seeking for a child with ND meant losing their sense of being an independent being, plunging them instead into the unfamiliarity of vulnerability and neediness, and a realm of unknown and uncertainty:

> *Under normal circumstances, I am someone who is independent, ah, goal oriented, I know how to get from point A to point B, I can figure out what the steps are. But when it came to the circumstances surrounding my son, I'm not in the same water. I'm not in the same comfort zone as how I typically go about doing things.* (Simone)

Help-seeking is thus, not only a journey that mothers and fathers navigate together; it is a toss of the dice that is preceded by a personal sense of loss. As mothers and fathers engage in help-seeking, they do so with the added complexity of sadness, grief and loss.

"I'm OK if She's OK"

Despite the personal, emotional heaviness that accompanied their help-seeking, mothers and fathers in this study focused their help-seeking predominantly on their child; getting a diagnosis, understanding its impact on their child's functioning (currently and in the future), acquiring the therapies and interventions that would expand their child's abilities (e.g., communication, socialization), and planning for the future (e.g., where their child will live, work, engage in relationships). Placing their child's needs first did not imply they were not unaware that they, too, had needs. Rather, it reflected a sense of their own needs being met through their child's needs being met. Thus, in helping their child they were also helping themselves: "*I always figured that if Charlotte is doing well, then I'm doing well... you know, once she's okay, then I'll be okay:* (Bridgette).

When they did seek help for themselves, mothers and fathers were less demanding, expecting less from helpers: "*I would be more demanding of the person I was asking for help if it was for Mike. Um, for myself... if I only got 80% of whatever I needed, I'd be okay with that. If it was for Mike, no, I would push*" (Trevor). Older parents, while still reluctant to seek for themselves, recognized the link between how taking care of themselves impacted their capacity to be helpful to their child: "*I have to think of myself if I want to be there for him"* (George).

Fathers were less decisive seekers, more weary or exhausted of the process, and laden with the sense that help-seeking somehow weakened them as fathers. Thus, help-seeking was a last resort, taken only once they had tried every possible option they could manage on their own. The help they sought focused on concrete activities (e.g., going to movies, going hiking) that assisted them to escape their difficulties, and they shared a sense of needing to justify that any help they received was accepted only so they could be well enough to care for their child: *"... you're doing it because it's going to benefit your child. You have more respite time for yourself, which I feel guilty doing but, you got to. You got to, but it always has to be in the child's interest*" (Marc).

Contrastingly, mothers spoke of help-seeking for themselves with normalcy, as something natural. They sought emotional support from professionals (e.g., social workers, psychologists, counsellors), "... *without any hesitation if I feel I need it*" (Ann). Additionally, mothers created reciprocal bonds with family and friends and thus became both supporters and supported, simultaneously.

Help-Seeking Through Informal and Formal Networks

Whether focusing their help-seeking on their child's needs or on their own, mothers and fathers expressed that their help-seeking journeys transpired with helpers from both informal (e.g., mothers' and fathers' own parents, siblings, friends), and formal (e.g., health and social services organizations, community organizations, alternative treatments) networks, differentiated not only by the manner in which help was sought, but also by the types of help that each could provide:

> *I'm not asking for the same help though... when I'm asking for help from organizations ... I need techniques, ... insight on what works for my child ... But my family and friends, I need emotional help. I need a shoulder to cry on. I need someone to listen to me.* (Bridgette)

Help-seeking from family and friends was most often directly related to the child (e.g., babysitting, transportation) and was experienced somewhat seamlessly and as almost always available. In their help-seeking, parents carefully weighed their requests, being considerate of their helpers' personal capacities and mindful of not being too intrusive. They also often contemplated about accepting help from friends they thought might have silently preferred not to help:

> *But you, you are always in your head, trying to think of, like, you're trying to get into their head like, Ah, they're doing this because you're a good friend to them but they don't really want to but, uh, just take the help and run with it. But I can't. I'm always thinking, 'what are they really thinking.' I mean, you're forcing someone to do something. You ask them, 'oh, my son is sick at the hospital, would you like to help?' They're not going to say 'no.' They're going to say 'yes, because if they say 'no,' what does that look like?* (Victor)

Parents also sought help from other parents of children with disabilities, differentiating it from the support they got from friends with typically developing children, stressing a unique quality of caring that could only stem from their shared parenting experience:

> *I have a lot of friends. And my friends all have typical kids. And it, it's not the same (laughs). They provide support in a certain way but it's, it's not the same because they, I don't think they understand the same way. So it's different getting support from somebody that understands it more. For me, anyway. So I appreciate my friends with the typical kids but, if their greatest worry is that their kid didn't cut their meat properly, and on that particular morning my son had a complete meltdown because his sock didn't go on perfectly, we're not on, it's not the same.* (Nicole)

As well, support sought through parent social media groups provided parents with the convenience of time to take in the written support that appeared on the screen, whether they participated engagingly or in silence.

Parents' journey of help-seeking from formal networks left them exhausted and weighted down by the sense of having to compete with other parents in a system they felt was understaffed and under-resourced. Parents were frustrated and exasperated by the little support they received from professionals they perceived as not always properly equipped or knowledgeable. Help-seeking from formal networks required that parents proceed strategically, learning the fine balance between following versus altering/challenging the rules of the game, being nice to those from whom they sought, and playing the game to avoid being seen as non-compliant:

> *So... I guess... if we weren't compliant parents, you know, following her instructions and giving her that, uh, feedback that she, she requested and needed, would she have been so willing to, you know, make those phone calls to the (names hospital) for us? Maybe not....* (Alex)

Ladders and Snakes

As mothers' and fathers' help-seeking journeys unfolded, they encountered elements that rendered their journey easier (ladders) or more difficult (snakes). At times these were more personal in nature, at other times more systemic, reflecting the policies and practices established within formal support systems.

Ladders of Transformation, Privilege, Complementarity, and Relationships

Retrospectively, parents reported having gained knowledge through their help-seeking that transformed their sense of being. Fighting for supports for their child transformed them from being more laid back and accepting of what was offered to them, to becoming more of an empowered and self-assured fighter, who pushed and persevered to obtain the help they sought:

> *...my personality tends to be more timid if it's about anything other (emphasis) than my son. So, if I had received a report on myself that I felt was wrong, I think I would probably have been more shy to question it. Whereas for him, I don't even think. I just, like, out it comes!* (Anne)

They also recognized that certain life privileges (e.g., education, socioeconomic status, access to computers, employment, life insurance) lead to more expedient location of, and access to support in the private sector:

> *Ah, so... (name of organization), introduced me with the (other organization) and the lady there ... introduced me to the (another organization), which is where they do, ah, psychological tests for (name of diagnosis), all kinds of things. And she said 'but its private so you'll have to pay.' So I said 'I don't mind paying. I mean uh, let's do it!'* (Simone)

Having financial ease meant parents thus gained access to crucial evaluations, treatment and interventions for their child more rapidly than did less privileged parents whose only means of support was from the private sector.

> Parents spoke about complementarity, and about the help-seeking journey being one that connected them to each other, balancing each other's strengths and bridging each other's difficulties. This sense of complementarity rendered help-seeking more efficient, with parents being supportive of one another and sharing the responsibilities: *"Yeah, yeah. We definitely each have pros and cons that, you know, uh, that balance each other out. Work off each other. No, it's good team-work"* (Alex).

Parents also observed that having relationships with the right people to guide them within formal and informal networks was more efficient than if they journeyed alone: "*So yes. I called because they know people, who know people, who know people. So yes, if you have a social network or you know, friends or family that know people, uh, yeah, that helps"* (Simone).

Meeting “une bonne personne” (George: Translation: a good person) within a system that parents described as impersonal and cold, made parents feel cared for, important, and validated. Positive relationships improved the effectiveness of parents’ current help-seeking and encouraged future help-seeking ventures as well. Relationships that felt less personal led parents to anticipate future help-seeking more tentatively and cautiously.

Snakes of Power, Navigation, Consistency, and Gender

While the heaviness of parents’ help-seeking journey was alleviated by personal and relational circumstances, their journey was nonetheless challenged by elements for which they had little control. Many of the snakes encountered stemmed from within formal networks of support, where parents encountered professionals who they reported did not always grasp the intricacies that fully captured their child’s actual functional state. Through their perspective, parents felt that professionals did not always take their own knowledge about their child into consideration, and so when recommendations were made, they did not always seem to fit with their own experience of their child. Parents felt dependent on professionals, and constantly needed to prove the legitimacy of their child’s needs, and thus they proceeded cautiously and with a sense of vulnerability. Bridgette expressed it this way:

> *So, right now we know, and I think, like I said to Alex, not like I'm not listening to anyone any more, I listen, but, I'm really going much more on my own instinct, on how I feel and what I feel is good for Charlotte. I listen. I'll take points where I agree, but uh, I'm to the point where I am the expert on Charlotte! I know her more than anyone. And I know what works and doesn't work. So, I'm willing to try things and yes, I listen but I'm, it's been so long now that now I know, I know what works for her.... Because, I know they're professionals. But they're not the professionals of Charlotte. I am!* (Bridgette)

Parents’ journeys were rendered difficult by the great complexity of the public systems that were challenging to understand, making locating and accessing help difficult. Encountering long wait lists for evaluations/interventions, feeling the need to be in a crisis in order to be prioritized, and then being ping-ponged from one professional/organization to another due to restrictive inclusion criteria added complexity to a journey that was already experienced as stressful and unpredictable:

An element that added a personal heaviness to their help-seeking experience was a continuous turnover of professionals from the public sector who provided direct care to their child in their homes, making consistency and daily routines difficult to establish. For parents, staff turnover meant they were constantly engaging in training and retraining new staff and readjusting to entrusting their child into their care. For children, the impact was felt on a very personal level, because of the nature of some types of help they received (e.g., personal hygiene, bathing). Staff turnover reflected a systemic difficulty that did not, at all, consider the very private relationships children established with workers. Frequently unexpectedly, and unbeknownst to them, children’s intimate/personal care was often transferred from the familiar, into the hands of strangers with no guarantee that they would return: *“So someone came in, we trained them and told them what they had to do. They would wash Annabelle and get her ready for bed. And that worked, until the next appointment, when it was somebody new*”(Marc).

For fathers, help-seeking from formal networks was also experienced as gendered. While they were able to identify situations in which they needed help, they reflected that contrastingly to their child's mother, they, themselves, were rarely invited to share their difficulties with professionals. On the rare occasion when sharing was encouraged, fathers were offered the same types of support that mothers reported as helpful (e.g., individual counselling, support groups). These were less impactful to fathers, adding a layer of complexity to their already reluctant help-seeking nature, and leaving their needs largely unmet.

Discussion

The *Journey of Ladders and Snakes* describes the embodied help-seeking experience of six co-parenting mother/father dyads, reflecting not only what parents do as seekers, but who they are as help-seekers in co-parenting contexts. Mothers and fathers' help-seeking journeys highlight the interconnected relationships that transpire between them, their child, and formal/informal support networks within the larger socio-political environment, connecting them to Bronfenbrenner (1979) ecosystems framework. By including the voices of both mothers and fathers, this study offers a joint perspective about a co-help-seeking process that is truly representative of parents. This contrasts with current studies about parents of children with ND that mainly stem from studies comprised of samples of mothers (Bogossian et al., 2017), and thus offer perspectives more closely related to mothering than parenting. Providing help that is meaningful to parents requires knowledge about the needs of both mothers and fathers (Derguy et al., 2015).

Mothers' and fathers' journey often stemmed from a place of grief, aligning with Pelchat, Levert, and Bourgeois-Guérin (2009), as they struggled to comprehend the sense of loss that replaced their joyful anticipation of the child they never received. Living with their unexpected child closely links to the concept of psychological ambiguous loss (Boss, 2000, 2016), wherein parents "...construct their own meaning" (Boss, 2016, p. 270) of their child, of themselves as parents and co-parents, and of their concept of family "... within a paradox of absence and presence" (Boss, 2016, p 270). Their grief aligns to some current literature about parent's experience of lost dreams (Mulligan et al., 2012) altered relationships, (Fernandez-Alcántara et al., 2016), and feelings of sadness and anger at having been "thrown a curveball" (Lutz et al., 2012, p. 316).

Parent's experience of the support they received from informal and formal networks is congruant with current literature: family and friends appear to be reliable and consistant and are experienced as having positive impacts on well-being (Hsiao, 2014; Jeong et al., 2013; Manor-Binyamini, 2014); online peer support allows parents to provide/receive support within convenient, flexible timeframes (Mohd Roffeei et al., 2015; Reinke & Solheim, 2014; Wong et al., 2015); formal networks are bureaucratic and difficult to navigate (Nowak et al., 2013; Olsson & Roll-Pettersson, 2012; Whitehurst, 2012), impose long wait times for access (Ben-Cheikh & Rousseau, 2013; Connolly & Gersch, 2013), and lack meaningful supports (Kirk et al., 2015; Ryan & Quinlan, 2018; Samadi et al., 2012).

Mothers and fathers in this study described a highly complementary and collaborative help-seeking process that unfolded through the individual roles they adopted (e.g., one may have searched for help through social media while the other may have contacted helpers directly. One may have collected information and organized schedules while the other implemented programs within family life at home). As in Pelchat et al. (2009), mothers and fathers balanced each other’s capacities. These aspects align with discussions on the parenting styles of parents of children with autism spectrum disorder described in Maynard, McDonald, and Stickle (2016), and with the discussion on the complementary and symmetric parenting roles adopted by parents of children with ND described in McNeill et al. (2014). As in Pelchat et al. (2009), parents in this study adopted more traditional roles, with mothers leading fathers in childcare, and despite describing their journey as exhaustingly demanding, parents in this study felt connected to each other and spoke of co-help-seeking as teamwork.

This study describes ladders and snakes that highlight both shared and contrasting elements of mothers and fathers’ co-help-seeking journey. Mothers and fathers both reported help-seeking first and foremost to meet the needs of their child. Only once their child’s needs were met did they contemplate help-seeking for themselves. As in Carpenter and Towers (2008), knowing their child’s needs were being addressed provided them with a sense of relief that in turn, was experienced as helpful to them. When help-seeking for themselves, mothers were attuned to their emotional needs, aligning with findings from Derguy (2019), and they also felt more comfortable asking for what they needed. Fathers, on the other hand, were more hesitant and private, and if they asked, they sought more concrete activities to help them forget. This aligns to Pelchat et al. (2003), who found that mothers were more capable of asking for emotional help than were fathers, who were more concrete about their needs and concerned about not wanting to impose on others. It also contrasts to Derguy et al. (2015) who found that both mothers and fathers expressed emotional needs within their relationship.

Mothers were systematically invited into discussions about their child and felt included in the decision-making processes, while fathers, despite longing for inclusion, felt excluded by professionals who directed discussions towards their child’s mother, even when they were present. These findings align with the discussion of fathers “being the odd man out” in Mueller and Buckley (2014, p. 43), and highlight some systemic differences that favour mothers’ involvement and challenge fathers’ experience of help-seeking. This contrasts current knowledge about the importance of incorporating fathers in the decision-making process (Addis & Mahalik, 2003; Bogossian et al., 2017; Hartley & Schultz, 2015; McHale & Negrini, 2018). This study also described how mothers and fathers experience feeling helped differently, with mothers stating they felt helped when they were given opportunities to discuss about difficulties (e.g., individual counselling or peer support groups) and fathers preferring to participate in activities that would help them forget their troubles yet sharing that this support was not available. These findings align with some current literature about the experiences of fathers (Burrell et al., 2017; Hartley & Schultz, 2015; Paynter et al., 2017), and highlight the gendered gap that seems to exist for meaningful supports for parents of children with ND.

Limitations

There are a number of limitations to this study. This study reflects the experience of parents whose help-seeking journey began years prior, within a different social service delivery context and so it does not represent the perspectives of parents who are newly beginning their journey under changed provincial policy and regulations. Snowball sampling means that some parents might have known other participant’s identity. As most parents were interviewed on different days from their child’s other parent, it is possible that the second parent interviewed may have gained prior insight about the content of the interview and thus had the opportunity to practice their responses. As the first parent contacted about the study was asked to solicit their partner's participation, it is impossible to know if parents felt forced to participate. Mothers and fathers formed a very homogeneous sample (e.g., heterosexual, well-educated, high-income levels, long-standing Canadian citizens) within a large urban location. Findings may have varied from a more heterogeneous sample.

Recommendations for Practice and Future Research

Social workers and other health care professionals (HCP) play a crucial role in how mothers and fathers experience their journey of help-seeking. As mothers' and fathers' help-seeking stems from a vulnerable place of loss and grief, facilitating a discussion about grief would acknowledge this important emotion and provide parents a place to express and explore it in more depth. HCPs need to be aware of who may (or may not) be present for mothers and fathers from their informal support networks, what help they may be offering, and how this particular help may change over time. HCPs need to accompany mothers and fathers as they navigate a complicated and confusing formal network so that they have a clearer understanding of how it functions, what it offers, and so that they can also find the help they need more efficiently. Mothers and fathers both play crucial roles in the help-seeking process, thus it is imperative that HCPs invite both into discussions about their child and provide help that is meaningful to each of them.

To expand knowledge about help-seeking, future research could recruit a more heterogeneous sample of parents so that other perspectives are heard, focus more specifically on help-seeking for oneself, and also include the perspectives of the HCPs who provide help from formal support networks.

Key Messages From This Article

Parents of People with Disabilities: Co-parenting mothers and fathers adopt help-seeking roles that remain vastly unchanged through time. Being introspective about your roles can help you understand what each of you does, and how this unfolds in your family.

Professionals: Welcoming discussions about grief and understanding how parents engage in help-seeking can help to ensure you provide meaningful support that aligns with what each parent needs.

Policymakers: Parents have needs too. Creating policies that promote the inclusion of both mothers and fathers in discussions about their child can help ensure that their own individual parent needs are addressed.

Messages clés

Parents de d'enfants vivant avec de troubles neurodéveloppementaux: Les mères et les pères qui coparent adoptent des rôles de recherche d'aide qui restent largement inchangés au fil du temps. L'introspection sur vos rôles peut vous aider à comprendre ce que chacun d'entre vous fait et comment cela se passe dans votre famille.

Les professionnels : Accueillir des discussions sur le deuil et comprendre comment les parents s'engagent dans la recherche d'aide peut vous aider à fournir un soutien significatif qui s'aligne sur les besoins de chaque parent.

Les décideurs politiques : Les parents ont aussi des besoins. Créer des politiques qui favorisent l'inclusion des mères et des pères dans les discussions concernant leur enfant peut aider à garantir que les besoins individuels des parents sont pris en compte.

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