Risk and Protective Factors in Predicting Post-Traumatic Stress Symptoms and Post-Traumatic Growth in Parents of Children with Developmental Disabilities

by

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List of Abbreviations Used

BHS – Barriers in Help-seeking Scale

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders-5

DD – Developmental Disabilities

PTC – Parenting Trauma Checklist

PTE – Potentially Traumatizing Events

PTG – Posttraumatic Growth

PTSD – Posttraumatic Stress Disorder

PTSS – Posttraumatic Stress Symptoms

Abstract

Parents are of crucial importance for their children with adevelopmental disability. Research has noted their heightened posttraumatic stress symptoms (PTSS) and posttraumatic growth (PTG). Based on current literature, my objectives were to expand the understanding of these parents and to examine predictors of PTSS and PTG.

A cross-sectional survey was conducted amongst 460 Canadian parents. It shows parenting trauma displayed a both negative influence on developing PTSS and a positive role in promoting PTG. Social support was protective in reducing PTSS and enhancing PTG. Barriers of seeking help were associated with increased PTSS but were unrelated to PTG. Negative parenting did not show key contributing effect to PTSS or PTG.

My study facilitates future research as several novel research questions were studied. Limitations included the COVID-19 impact, use of a cross-sectional design, a convenience sample and self-report measures. This study helps effectively identify individual cases and their specified challenges.

Chapter 1: Introduction

1.1 Overview

Parents play a crucial role in providing companionship, guidance, modelling caregiving, emotional support, and some medical assistance for their children with diseases and disabilities. These responsibilities are often accompanied by seeing their children suffering from illness. Considerable research showed that caring for children with chronic diseases can cause additional physical and emotional burden to parents (Brehaut et al., 2009; Miodrag & Hodapp, 2010; Neu et al., 2014; Seideman et al., 1997). If their children suffer from life-threatening illnesses, some of their experiences could be potentially traumatic (Seideman et al., 1997) and thus can cause mental health symptoms including posttraumatic stress symptoms (PTSS) (Miodrag & Hodapp, 2010). However, a variety of factors may hinder parents' availability and readiness to participate in treatments for their own health (Currie & Szabo, 2019; Gilson et al., 2018).

Developmental Disabilities (DD) are a significant health concern as it has an early onset and lasts for a lifetime. As defined by Centers for Disease Control and Prevention (CDC; 2020, December 12), DD is characterized by a variety of developmental and cognitive impairments that limit one's learning, behaviours, physical abilities, and learning. Examples of DD are Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Cerebral Palsy, Epilepsy, Global Developmental Delay, Down Syndrome, Fetal Alcohol Spectrum Disorder (FASD). About 1 in every 12 children in Canada is estimated to live with developmental disabilities (Arim et al., 2017).

There has been an increasing discussion of PTSS amongst parents of children with developmental disabilities (DD) (Carmassi et al., 2018; Casey et al., 2012; Iseri et al., 2006). A common finding has been that these parents experience higher levels of PTSS than parents of healthy controls (Cabizuca et al., 2009). National studies have estimated that the lifetime prevalence of PTSD was 9.2% in Canada (Van Ameringen et al., 2008). For parents with children with a DD, this prevalence can reach 22.8% (Cabizuca et al., 2009). In addition to PTSS, these parents also experience other mental health problems (O'Neill, 2004; Woolf-King et al., 2017; Scherer et al., 2019). For example, Woolf-King et al. (2017) found that in parents of children with critical congenital heart defects showing symptoms of PTSD, 25% - 50% also reported elevated symptoms of depression and anxiety disorders, and 30% - 80% reported severe psychological distress. The negative impact of traumatic events also influenced physical health and daily functioning.

However, their elevated PTSS do not appear to be merely explained by their greater exposure to potentially traumatizing events (PTE). Several studies (Brewin et al., 2000; Carmassi et al., 2021) have noted that psychosocial factors, especially social support, play an important role in the development and severity of PTSS. My study expanded the model with more factors, consisting of such parents' barriers to seeking help and negative parenting (including parent-child relationship and parenting behaviors).

The lens of positive psychology provides a novel perspective for trauma-related studies (Thomadaki, 2017). It has been proposed that traumatic events are not universally negative and that positive changes may emerge after PTE (often summarized as posttraumatic growth (PTG)). Trauma may transform parents' perceptions about their life, self-efficacy, and relationships with others (Thomadaki, 2017). In this study, I will discuss mechanisms of these positive alterations by examining contributing factors that facilitate or hinder these positive changes.

1.2 Literature Review

1.2.1 PTE and PTSS

Potentially Traumatizing Events. Potentially traumatizing events (PTE) are life-threatening situations that happen in one's lifetime. Examples of PTE are actual or threatened death, natural disasters, severe injuries, or sexual assaults (American Psychiatric Association, 2013). Witnessing or experiencing these events can cause immediate intense emotions (e.g., fear and horror) lasting from a few days to decades (American Psychiatric Association, 2013). The exposure to PTE is related to multiple mental health disorders, including anxiety disorders, depression disorders, and posttraumatic stress disorders (PTSD). Thereof, PTSD is the only disorder in the Diagnostic and Statistical Manual of Mental Disorders - 5 (DSM-5; American Psychiatric Association, 2013) that requires exposure to PTE for a clinical diagnosis (Woolf-King et al., 2017). When trauma exposure accumulates, the risk to develop

PTSD is increased, which was usually called dose-response effect or building block effect between PTE and PTSD (Elbert et al., 2015; Schauer et al., 2003).

Parents of children with DD are a potentially traumatized population as they are of higher risk to experience PTSS (Carmassi et al., 2018; Casey et al., 2012). Several studies have noted that these parents are exposed to extremely stressful and potentially traumatic experiences, such as being in Neonatal Intensive Care Units (NICU) (Lefkowitz et al., 2010) and administering cardiopulmonary resuscitation (CPR) to their children (Christofferson et al., 2019). However, their experiences, especially PTE related to caring for their children have so far not been thoroughly assessed. The absence of a validated instrument has further prevented assessment and evaluation of the prevalence of these events.

Posttraumatic Stress Symptoms. When exposed to PTE, individuals may feel negative changed in emotions, reactions, cognitions, and memories (American Psychiatric Association, 2013). In some individuals these reactions manifest chronically, this means they develop clinical PTSD or subclinical PTSS. Although not all parents of children with DD develop PTSD, substantial epidemiological evidence emphasizes a higher prevalence among these populations compared to the general population. National studies have estimated that the lifetime prevalence of PTSD was 8.3% in the U.S.A. (Kilpatrick et al., 2013) and 9.2% in Canada (Van Ameringen et al., 2008). For parents with children with a DD, this prevalence can reach 22.8% (Cabizuca et al., 2009). In subgroups even higher prevalence has been found; for example, in parents of children with epilepsy, the prevalence is as high as 31.5% (Iseri et al., 2006).

1.2.2 Posttraumatic Growth

The experience of PTE can be meaningful even though traumatic events are witnessed and experienced (Cohen et al., 2002; Hungerbuehler et al., 2011). One such meaningful outcome of trauma exposure is posttraumatic growth (PTG). The conceptualization of PTG was introduced a few decades ago by Tedeschi and Calhoun (1996). They discovered the positive legacy of trauma and stated that it consisted of various dimensions: new possibilities, changes in relating to others, personal strength, spiritual changes, and appreciation of life. A previous study concerning parents of children with chronic diseases estimated that approximately 62.7% of parents manifested at least a moderate degree of PTG (Hungerbuehler et al., 2011). This finding has been replicated in parents of children with autism spectrum disorders (Qin et al., 2021), although there have been no studies of PTG in parents of children with overall DD.

1.2.3 PTE as a Predictor of Posttraumatic Reactions

PTE and PTSS. Trauma history is an essential criterion in the clinical screening of PTSS and diagnosis of PTSD (Breslau et al., 1991). A life-threatening situation of a child with a DD is a traumatic event for their parents, based on the DSM-5 (American Psychiatric Association, 2013). In addition to traumatic events associated with parenting a child with a DD, there are also other traumatic events that parents may experience in their lifetime, such as physical assaults, life-threatening accidents, and childhood sexual abuse. These events may also contribute to a higher risk of developing PTSS (Brewin et al., 2000). Investigation of these and other trauma experienced by parents of children with serious chronic diseases are needed, but this would rely on validated, reliable, and effective instruments for these events. Such instruments are now broadly available for general PTE, such as the Life Event Checklist for DSM-5 (Weathers, Blake, Schnurr et al., 2013) and Brief Trauma Questionnaire (Schnurr et al., 1999). There is scant evidence exploring population-specific PTE; questionnaires for assessing PTE specific to parents of children with DD or other medical complexities are not available.

Trauma Events and PTG. Favourable parental changes in the aftermath of children’s DD diagnoses are not uncommon (Beighton & Wills, 2019; Forinder & Norberg, 2014; Hungerbuehler et al., 2011; Picoraro et al., 2014). In the original investigation by Tedeschi and Calhoun (1996), they noted that individuals who have survived traumatic events tended to report more positive changes than those without a history of trauma. Higher trauma exposure is associated with greater PTG (Leppma et al., 2018). Kira et al. (2013) found similar results and highlighted that this effect depends on the type of trauma experienced. For instance, events that happened a single time (e.g., car accidents) were associated with PTG, while events that happened repetitively did not show effects on PTG (e.g., serial sexual abuse). It is not clear if traumatic events that occur in different contexts play different roles, more specifically, whether parenting trauma and general trauma are both associated with PTG.

1.2.4 Social Support as a Predictor of Posttraumatic Reactions

Social Support and PTSS. Social support has a well-studied protective role for the development and course of PTSS (Cieslak et al., 2009; Hyman et al., 2003). Previous researchers have underlined that receiving support from one's social network, such as from family and peers, protected from adverse emotional consequences and facilitated adjustment (Bokszczanin, 2008; Morley & Kohrt, 2013). Bokszczanin (2008) found that adolescents with more family support had lower levels of PTSS. Morley and Kohrt (2013) also demonstrated a similar positive influence of peer support among 142 child soldiers. This finding has also been documented with veterans (King et al., 1998), individuals with medical diseases (Cluver et al., 2009), children (Paxton et al., 2004), caregivers of children/adolescents with severe diseases (Carmassi et al., 2021), and parents of cancer survivors (Kazak et al., 1998).

Social Support and PTG. Social support has been shown to promote PTG. A meta-analysis (Prati & Pietrantoni, 2009) of 103 studies synthesized that social support was moderately correlated with PTG, with a medium effect size. A longitudinal study denoted that this influence lasts for over eight years in cancer survivors (Schroevers et al., 2010). The relationship between social support and PTG was also observed in hurricane survivors living with HIV (Cieslak et al., 2009), mothers of children with autism spectrum disorders (Zhang et al., 2015), and bereaved caregivers (Cadell & Regehr, 2003). It has not been studied amongst parents of children with various types of DD, however.

1.2.5 Barriers of Seeking Help as A Predictor of Posttraumatic Reactions

Barriers and PTSS. Identification of obstacles to service access is of great importance in the post-trauma field (Ouimette et al., 2011). Such barriers help explain why, in military personnel for example, only one in four members with mental health difficulties sought help from professionals even if treatments were offered (Hoge et al., 2004). The concept of barriers of seeking help integrates complex and broad domains, ranging from characteristics of the healthcare systems and healthcare providers (Paula et al., 2020) to the individual's personal and cultural beliefs (Sritharan & Koola, 2019). From observations in epidemiological studies, barriers perceived by help-seekers may vary across population subgroups. An example is that one of the prominent barriers for veterans was stigmatization or discomfort with seeking help (Goto et al., 2002), while for parent populations, particularly parents of children with chronic illnesses, long waitlists and lack of resources were the major reported barriers (Bowling et al., 2019; Paula et al., 2020). So far there is a lack of validated instruments to quantify barriers to service use among parents affected by their children's illnesses.

Moreover, little is known on whether or how barriers of help-seeking behaviours aggravate PTSS in parents of children with DD. Referring to outcomes in other populations, barriers might have a detrimental impact on parental stress and health (Ouimette et al., 2011; Westermeyer et al., 2002). Westermeyer and colleagues (2002) illuminated that those veterans who reported barriers to accessing care exhibited high rates of concurrent and lifetime PTSS. Ouimette et al. (2011) sampled 490 patients with PTSD and revealed their posttraumatic stress symptoms, such as avoidance symptom clusters, were positively correlated with perceived barriers in seeking help.

Barriers and PTG. Modifiable obstacles affecting PTG have generally not yet been sufficiently documented. One remaining question, for example, is whether people who perceive more barriers tend to show weaker PTG. A study by Kent et al. (2013) illustrated that for cancer survivors, help-seeking behaviours could facilitate participants' PTG. In contrast, Matsui and Taku (2016) illustrated mixed findings in their review and recommended further elaboration on the social and cultural contexts of barriers. Clarifications of the barriers in help-seeking and their impact on PTG are needed to eliminate posttraumatic suffering and enhance growth following trauma.

1.2.6 Parenting as A Predictor of Posttraumatic Reactions

Parenting and PTSS. Parents who have a better parent-child relationship have been shown to be less likely to present high stress or mental health struggles (Dinshtein et al., 2011). Berz et al. (2008) stressed that parenting satisfaction was also negatively associated with PTSS. Greater parenting satisfaction was related to decreased hyperarousal and avoidance symptoms of PTSD. In contrast, hostile parent-child interactions were associated with increased likelihood of developing PTSD (van Ee et al., 2012).

Parenting and PTG. It has been found that a warmer parent-child relationship was a positive predictor of PTG for child patients with severe medical conditions (Koutna et al., 2017). This relationship was also found in an LGBTQ population (Zavala & Waters, 2021). Contrary, Qin et al. (2021) discovered mixed findings in parents of children with autism spectrum disorders. Specifically, they found that family problem solving but not family function, family relationship, or family interaction, was significantly correlated with PTG, with a weak to moderate effect size. Thus, the potential detrimental effect of negative parenting on PTG in parents of children with DD is not yet clearly determined.

1.3 Objectives and Research Questions

1.3.1 Objectives

There is extensive literature on overall mental and physical health outcomes, PTSS, and PTG in some parent groups (e.g., parents of children with autism spectrum disorders). However, how parents of children with DD are affected by their children's illness has not been thoroughly examined. The main objective of this study was to expand the understanding of parents of children with DD concerning their traumatic parenting experiences, barriers of seeking help, PTSS, PTG, social support, and access to care.

As was summarized above, how PTE, especially parenting-related PTE, influences PTSS and PTG needs to be investigated. Social support has been shown to help overcome PTSD and to promote PTG in several groups (Cadell & Regehr, 2003; Carmassi et al., 2021; Cieslak et al., 2009; Cluver et al., 2009; King et al., 1998; Paxton et al., 2004; Zhang et al., 2015). Whether these effects hold for parents of children with DD remains unknown. Furthermore, the influences of parenting and barriers to accessing mental health care on PTSS and PTG remain either unclear or controversial. The second main objective is to examine how (a) traumatic events (i.e., lifetime traumatic events and specific parenting traumas), (b) social support, (c) barriers in seeking help, and (d) parenting explain PTSS and PTG in parents of children with DD.

All factors were measured by validated scales except for parenting traumatic experiences and barriers in help-seeking because no existing validated scales were available. The third objective of my study was thus to develop and validate two scales (i.e., PTC, Parenting Trauma Checklist and BHS, Barriers in Help-Seeking scale) and to evaluate their psychometric properties.

1.3.2 Research Questions

Research Question 1: What are the levels of PTSS, PTG, trauma exposure, social support, perceived barriers of seeking help, parenting, and access to healthcare services in a sample of parents with children with DD, and how are these variables inter-related?

Research Question 2: What are psychometric properties of the author-constructed scale for potential traumatic events linked to parenting children with DD (i.e., PTC)?

Research Question 3: What are psychometric properties of the author-constructed scale for barriers in seeking help among parents of children with DD (i.e., BHS)?

Research Question 4: What are the relative contributions of traumatic events, perceived social support, perceived barriers, and parenting towards self-reported PTSS?

Research Question 5: What are the relative contributions of traumatic events, perceived social support, perceived barriers, and parenting towards self-reported PTG?

1.3.3 Hypotheses

H1 is that posttraumatic stress symptoms and posttraumatic growth are correlated with trauma exposure, social support, perceived barriers of seeking help, and parenting. H2 is that the PTC has acceptable psychometric properties. H3 is that the BHS has acceptable psychometric properties. H4 is that posttraumatic stress symptoms will be predicted by more lifetime and parenting traumatic events, more barriers to help-seeking, lower levels of social support, and more negative parenting. H5 is that posttraumatic growth will be positively predicted by more lifetime and parenting traumatic events, a higher degree of perceived social support, lower levels of perceived barriers to help-seeking, and less negative parenting.

Chapter 2: Methods

2.1 Study Design

A cross-sectional design was utilized in the study. This was chosen for three main reasons. Firstly, the first primary objective of the study is to provide descriptive information on parents of children with DD. This design is appropriate for observational purposes and investigation of multiple variables for a single time point (Mann, 2003). Secondly, it was considered as the best design for a prevalence problem (Freeman, Tyrer, & Tyrer, 2006) to describe the rate of probable PTSD in this population. Finally, this study design, although not ideal for the second study objective to examine how (a) traumatic events (i.e., lifetime traumatic events and specific parenting traumas), (b) social support, (c) barriers in seeking help, and (d) parenting explain PTSS and PTG in parents of children with DD, it provides preliminary evidence for these questions. When there is not sufficient evidence of issues, the cross-sectional method is deemed practicable (Mann, 2003).

2.2 Recruitment

Before conducting the study, a strategic plan for recruitment was developed. The strategies involved: (1) recruitment material design (i.e., advertisement images, texts, study posters, and information letters); and (2) a list of applicable recruitment avenues (i.e., relevant Canadian organizations, clinical registries, and social media platforms). Examples of the advertisement materials are available in Supplementary File 1A. The social platforms utilized for disseminating the materials were personal blogs, Facebook, Twitter, Reddit, and Kijiji. Recruitment efforts were made by the researchers in the study team and a group of study advisors and ambassadors who were parents of children with DD. The study advisors and ambassadors were recruited via an online post; they voluntarily assisted the study recruitment. After the study was approved by the IWK Research Ethics Board (REB #1025477), the researchers sent out the study materials. Email reminders were sent to the advisors and ambassadors approximately biweekly to guide them to share the advertisements with their connections. The study was named "Surviving and Thriving in Parenting Neurodiverse Children" and was open to participants from June 2020 to March 2021. This study was part of a larger research project that involved a subsequent e-health intervention program (i.e., "Life Beyond

Trauma: 1-on-1 e-NET for Parents of Neurodiverse Children") for a subsample of parents with children with DD and probable PTSD.

2.3 Participants

2.3.1 Inclusion and Exclusion Criteria

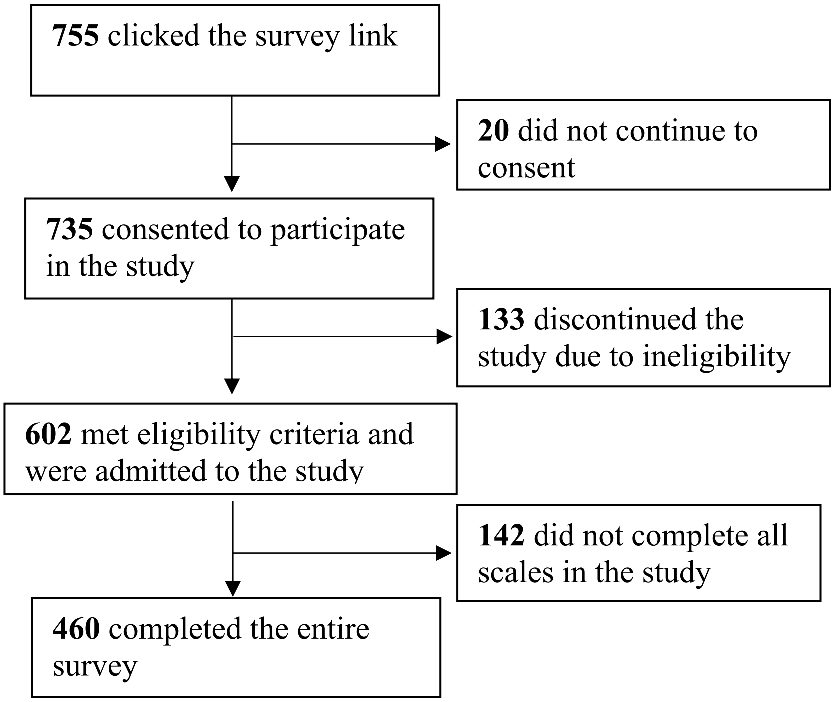
The study participants were parents or primary caregivers of children with developmental disabilities. Inclusion criteria were: (1) having a child diagnosed with a developmental disbility, including Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder (ADHD), Cerebral Palsy, Epilepsy, Global Developmental Delay, Down Syndrome, Fetal Alcohol Spectrum Disorder (FASD), severe learning disability, and any other diagnosis that influences a child moves around, communicates their ideas, processes what they hear, or remembers things; (2) being able to read, write, and understand English; and (3) living in Canada. Any of the following criteria excluded individuals from proceeding to the survey: an individual who was (1) not a parent or caregiver of a child with a diagnosis of a neurodevelopmental disorder; (2) did not live in Canada; (3) was not able to read, write and understand English; (4) did not have access to a tablet, smartphone, or a computer with high-speed internet; and/or (5) did not consent to participate in the study.

2.3.2 Flow of Participants

Overall, 755 individuals clicked the public link, and 602 parents/primary caregivers were included in data analysis (see Figure 1 for the flow of the participants). Approximately three fourths (76.41%; 460/602) of the participants completed all the scales. See Table 1 for the cumulative non completion rate for each scale.

Figure 1

Flow of Participants



Note. The 460 participants that completed the survey were sample for all research questions. The sample size for each research question depends on the missing values and non completion (see Table 1) for the specific scales used in the research question.

Table 1

Cumulative Non-completion Rates and Missing Values of the Study Scales

Scale	Cumulative non completion (non-completers/total participants)	Missing values (Not including non completers) (No. of missing items/No. of scale items)
PROMIS GPH-4 & GMH-4	4.82% (29/602)	0.04% (2/4584)
LEC-5	6.98% (42/602)	0.72% (68/9486)
PTC	9.47% (57/602)	0.55% (51/9265)
PCL-5	18.27% (110/602)	0.16% (16/9840)
SDS	18.44% (111/602)	2.92% (43/1473)
PTGI – SF	21.26% (128/602)	0.59% (28/4740)
MSPSS	21.93% (132/602)	0.21% (12/5640)
PAFAS - Parenting	22.59% (136/602)	9.83% (779/7922)*
BHS	23.59% (142/602)	1.73% (127/7360)

Note. The order of the scales in the table represents the order that the scales were administrated in the study. *Of the total 779 values in PAFAS- Parenting scale, 760 were missing because the participants indicated the item did not apply to their child. This includes some disabilities that impede certain forms of interaction between the children their parents (for example, some children might not be able to communicate verbally with their parents). Excluding this, the missing value rate was 0.24% (19/7922) for the scale.

2.4 Procedure

All participants were assessed once. The procedure of the study was: firstly, participants read a consent form (see Supplementary File 1B) and consented by clicking an OK button. All participants had the right to decline to participate at any point or to skip any question they wished. Following consent, participants were asked questions to assess their eligibility. Individuals who met all screening criteria and none of the exclusion criteria were invited to proceed to the survey. Ineligible participants were thanked for their interest and asked if they would like to be contacted for future studies. Participants completing the survey could choose to participate in a gift card draw. There were 3 draws performed; each was chosen approximately every 3 months for a $100 gift card.

2.5 Study Platform and Materials

2.5.1 Platform

The study platform was the data collection software Research Electronic Data Capture (REDCap) (Harris et al., 2009) hosted at the study team coordinated data collection institution (i.e., University of Alberta).

2.5.2 Measures

Two scales, Parenting Trauma Checklist (i.e., PTC)[1] and Barriers in Help-seeking Scale (i.e., BHS), were developed for this study because there were no existing measures for the constructs of interest.

The Development and Content Validation of the PTC. Item development of the PTC involved identification of the scale scope (i.e., domains) and assessment and consideration of content validity (Boateng et al., 2018). The domain of our scale was potentially traumatic events (PTE) among parents with children who were diagnosed with a DD. The PTE had to be directly associated with caring for their children.

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[1] A manuscript describing the process of developing the PTC and testing its psychometric properties has been submitted for publication (Xiong et al., 2021).

Development of the PTC. Sources for the items of the PTC were: (1) literature on parenting-specific PTE; (2) existing research on general PTE; (3) experiences from clinicians and researchers, and (4) experiences and suggestions from a Parent Advisory Committee (i.e., six parents of children diagnosed with DD.). This process was used to ensure that the scale represented the full range of PTE from parenting children with DD and to insure the content validity of the PTC (Anastasi, 1988).

A systematic search strategy for related quantitative and qualitative evidence was implemented, using “parent”, “trauma”, and “measure” as key searching words in PubMed, MEDLINE, PsycINFO, and GOOGLE SCHOLAR. There were no trauma checklists found for parents of children with any kind of illness. From the literature research, we found evidence of PTE directly resulting from caring for children with DD. For example, one study reported the experience of children’s admission into intensive care units (ICUs) and worries regarding that the child might die in the ICU (Balluffi et al., 2004). Another study (Christofferson et al., 2019) identified some pediatric medical events that were potentially traumatizing for caregivers, such as medical emergencies of their children (e.g., ambulance rides) and observing or participating in life-saving treatments for their children (e.g., getting CPR).

The first version of the PTC was developed and extensively discussed by the research team. All relevant elements of the instrument (i.e., items, instructions, response formats, and scoring) were carefully considered. The items were reviewed to enhance content validity in three key aspects: domain definition, domain representation, and domain relevance (Sireci, 1998). Items that did not fulfill the definition of “traumatic events” in DSM-5 were excluded. More relevant items of parents’ traumatic experiences were solicited. Instructions of the instrument were slightly adjusted.

Initial Validation of the PTC. To further strengthen face and content validity, our Parent Advisory Committee reviewed the items. Each member independently provided written feedback regarding the following aspects: (1) comprehensiveness and clarity of each item; (2) representativeness and relevance of the experiences being listed; and (3) administration of the instrument. The phrasing of the items was carefully revised; examples were added where items were difficult to understand. This version was then discussed in a joint meeting of the team and the Parent Advisory Committee. The resulting version (i.e., the PTC) was used in data collection for the current study.

The PTC consists of 17 items asking about parental PTE while caring for children with DD. All 17 items are rated with yes or no and scored 1 or 0; this yields a range from 0 to 17 *(see Supplementary File 1C)*. Internal consistency was not examined for this scale and the measure for lifetime trauma because it is not a necessary property of PTE measures (i.e., different traumatic experiences are not conceptually inter-related). Calculating such coefficients might be misleading (Netland et al., 2001).

The Development and Content Validation of the BHS. The development and validation of the BHS followed the same process as the PTC as recommended by Boateng et al. (2018). The scope of the BHS scale is potential factors that negatively affect help-seeking behaviours among parents of children with DD. A literature search confirmed no existing instrument in the described scope. Dimensions of the domain were not specified *a priori* as the barriers identified in other populations did not yield consensus on this issue (Kazdin et al., 1997; Mansfield et al., 2005; Trusz et al., 2011).

Development of the BHS. The items of the BHS were solicited from: (1) literature on parental barriers of seeking help; (2) barrier scales developed for other traumatized or vulnerable populations (e.g., veterans); and (3) experiences and recommendations from researchers, clinicians, and parents of medically fragile children. The multiple sources of input insured relevance, comprehensiveness, and representativeness of the included items.

From the literature, we found direct evidence of barriers perceived by parents of children with DD and indirect evidence of barriers experienced by comparative populations. Direct evidence revealed some common topics, such as long wait lists of services, high costs (Paula et al., 2020), depleted resources (Bowling et al., 2019), and beliefs about the disorders and child development (Sritharan & Koola, 2019). A study by Kazdin et al. (1997) had developed a scale for familial reported barriers to children's treatments for physical diseases. Their foci of the barriers involved obstacles that conflicted with interventions, concerns about interventions, the perceived relevance of interventions, and familial connection with clinicians or healthcare professionals. For use in a clinical trial, Trusz et al. (2011) constructed a scale for barriers for patients to complete PTSD interventions, regarding themes like logistical issues (e.g., financial constraints), limitation of provider availability, stigma, and pre-existing beliefs. Based on these various sources, the first version of the BHS was constructed with 19 dichotomous items rated with yes or no. Following this, the research team and the Parent Advisory Committee extensively discussed the original version of the BHS.

Initial Validation of the BHS. To ensure the adequacy of this scale, evaluation of face and content validity was also performed. This was achieved by experts (i.e., the research team) as well as the target population (i.e., the Parent Advisory Committee). In this phase, each member independently provided written comments and suggestions on the same aspects as those for the PTC (i.e., comprehensiveness of items, clarity of wording, relevance to parent experiences, scale instructions, and rating format).

Feedback was discussed, and revisions were made as follows: (1) item wording was revised to increase understandability; (2) instructions were slightly altered to match the scale domain; (3) response format was changed from dichotomous style to Likert scaling from 0 (not at all) to 4 (extremely); (4) an open-ended question (i.e., specification of other unlisted barriers) was added; (5) irrelevant items were deleted and items with overlapping meaning were merged. For instance, two items on treatment costs (i.e., "treatment expense is too expensive" and "other incidental costs are too high") were combined into a single item (i.e., "the expense and added costs (e.g., time off work, transportation) are too high").

The above process produced a 16-item BHS used in this study. It asks to what extent parents' looking for and receiving help for their mental health challenges were affected by the listed obstacles, from 0 (not at all) to 4 (extremely). The total score ranges from 0 to 64; a higher score means more barriers were encountered by the respondent. The Cronbach's α was .765 for all the items of the scale in the studied sample *(see Supplementary File 1D).*

Demographics. The measure of demographics was constructed by the research team. It consists of 17 questions, including two eligibility questions (i.e., being a parent/ caregiver of a neurodiverse child or children and living in Canada), ten questions about the parent and family (e.g., date of birth, gender, marital status, level of education, employment status, and location), and five questions on their children with DD (i.e., children's date of birth, type of children's diagnoses, year of the first diagnosis, weekly caregiving time) *(see Supplementary File 1E)*.

PTSD Checklist for DSM-5 (PCL-5; Weathers et al., 2013). The PCL-5 is a validated 20-item scale that measures PTSS based on criteria from the DSM-5 (American Psychiatric Association, 2013). The items are about the extent that participants were bothered by PTSS in the past month, measured on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely) (Blevins et al., 2015). The four subscales are in accordance with the DSM-5 criteria for PTSD: intrusions, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity. A total score (full range: 0 - 80) indicates severity of PTSS. Both total scores and subscale scores were calculated in my study.

The PCL-5 showed strong reliability and validity; high internal consistency was observed in the whole scale that included all the items (α= .94), (Blevins et al., 2015). These findings have been replicated with different populations (Ashbaugh et al., 2016; Bovin et al., 2016). The Cronbach's α coefficient for the whole scale was .941 for our sample; the internal consistency of the four subscales were also good, Cronbach's α coefficients = .876 (intrusions), .852 (avoidance), .880 (negative alterations in cognitions and mood), .822 (alterations in arousal and reactivity) *(see Supplementary File 1F).*

A cut-off score of 32 was used in this study because it is within the cut-off score interval (31-33) that was recommended by National Centre for PTSD in the USA (2016). Previous studies showed it had efficiency (Cohen's k = .58; Bovin et al., 2016), high sensitivity (72%), and specificity (92%) (Ghazali & Chen, 2018). The specificity or sensitivity was not calculated in my study because there were no equavalent scales or clinician administration to compare with.

Life Events Checklist for DSM-5 (LEC-5; Weathers, Blake, Schnurr et al., 2013). The LEC-5 is a self-rating measure to assess a broad range of traumatic experiences (Weathers, Blake, Schnurr, et al., 2013). Weathers et al. (2013) showed the LEC-5 had acceptable stability and convergent validity with other established measures on traumatic events. It was also validated in caregivers (Allen, 2015). This study employed the version with response categories revised to yes and no only (Boughner et al., 2016; Kaltenbach et al., 2018) *(see Supplementary File 1G).*

Posttraumatic Growth Inventory – Short Form (PTGI-SF; Albuquerque et al., 2018). The original Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) is a 21-item instrument that measures positive changes that the participant experience after PTE. In my study, a 10-item short-form (PTGI-SF) was used as it showed comparable validity (Albuquerque et al., 2018). The PTGI-SF is measured on a 6-point Likert scale (0 - 5) with a total possible range of 0 - 50. Higher scores in PTGI-SF indicate more positive changes were experienced by the participants. Both the original scale and the short form assess five aspects: (1) new possibilities, (2) relating to others, (3) personal strength, (4) spiritual changes, and (5) appreciation of life. Both subscale scores and a total score were calculated, which was in accordance with previous studies (Albuquerque et al., 2018; Tedeschi & Calhoun, 1996). Internal consistency of the whole scale and subsclaes was good, Cronbach's α = .877 for the whole scale, and for the subscales, Cronbach's α = .693 (new possibilities), .684 (relating to others), .842 (personal strength), .778 (spiritual changes), .697 (appreciation of life) in this study *(see Supplementary File 1H).*

PROMIS Global Health (PROMIS; Cella et al., 2010). The PROMIS instruments were administrated to test my first (i.e., to understand parental health status) and third objective (i.e., to test convergent validity of the PTC and the BHS). They include Global Mental Health (GMH-4) and Global Physical Health (GPH-4) subscales that were extracted from the PROMIS Global Health scale (Cella et al., 2010). Each subscale consists of 4 items. As was calculated in previous studies (Cella et al., 2010; Hays et al., 2017), the two subscales yielded two total scores, with higher scores meaning worse health status. Three items in GPH-4 are rated from 1 to 5, the remaining one item is rated on a scale from 0 to 10. The score range for the GPH is 3-25. The GMH-4 was rated through a 5-point Likert scale ranging from 1-5 (range = 5-25). The both scales showed high reliability and validity in primary care settings (Hays et al., 2017). Hays et al. (2017) reported the internal consistency was .81 for GPH-4 and .86 for GMH-4. In this study, the Cronbach's α = .666 and .825 for GPH-4 and GMH-4, respectively. The internal consistency for the GPH-4 (Cronbach's α = .666) was acceptable considering there were 4 items in the scale (Loewenthal, 1996) (*see Supplementary File 1I*).

The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988). The MSPSS is a commonly used 12-item self-report scale that assesses perceived support from family, friends, and significant others. The three subscales have four items each, each rated from 1 to 7 (full-scale range: 12 - 84). A total score, instead of subscales were calculated because: (1) the total score showed good internal consistencies (Cronbach's α = .88 in Zimet et al.'s study (1988)), and (2) our objective was to measure the scale as a whole concept, as practiced in previous studies (Dambi et al., 2018; Zimet et al., 1988). Levels of social support participants perceive increases with the reported total score. For our study, Cronbach's α = .924 *(see Supplementary File 1J).*

Adapted from the Konstanz INDEX (KINDEX; Spyridou et al., 2015). Access to care questionnaire in this study was extracted from the KINDEX scale. It is a brief instrument to measure a range of risk factors in trauma-related populations (Ruf-Leuschner et al., 2016; Spyridou et al., 2015). We adjusted questions 22-24 concerning access to care for mental health disorders *(see Supplementary File 1K).* The three questions in my study assessed: (1) whether parents sought professional help previously; (2) whether parents got diagnosis of a mental health disorder (e.g., PTSD); and (3) whether they believed they suffered from a mental health challenge.

Sheehan Disability Scale (SDS; Sheehan, 1983). The SDS is a six-item assessment of functional impairment (i.e., to what extent participants' functioning is affected by their PTSS). The SDS asks for functionality regarding work, social life, and family life. It is rated on a scale from 0 (not at all) to 10 (extremely) (Leon et al., 1997). The first three scorable items are used to produce a sum score, ranging from 0 to 30; a higher total score indicates greater functional impairment. The remaining three descriptive items, were reported in descriptive section, as administrated in the study by Leon et al. (1997). They consist of one dichotomous item (i.e., whether the disruptions of work they reported were because of other reasons than their PTSS symptoms) and two gap-filling items (they asked the average of days in the previous week that parents' productivity/work/life had been affected by their PTSS), It shows acceptable reliability and good validity (Leon et al., 1997). In the current sample, the internal consistency for the three scorable items was Cronbach's α = .867 *(see Supplementary File 1L).*

The Parent and Family Adjustment Scales (PAFAS; Sanders et al., 2014). The PAFAS-Parenting consists of a total of 18 items in 4 dimensions, namely parental consistency (5 items), coercive parenting (5 items), positive encouragement (3 items), and parent-child relationship (5 items). A slightly adapted version of the PAFAS-parenting was used to measure parenting practices. One item from coercive parenting (item 9) was deleted due to legal concerns because it asks about spanking children. Therefore, we used 17 items, scored from 0 to 3 on a Likert scale; the total score ranges from 0 to 51. The total score was calculated to address the research question 3 and 4 (i.e., the regression models) as they focused on broad concept of parenting; the subscale scores were also calculated in line with previous studies (Haar et al., 2020; Sanders et al., 2014).

The PAFAS was designed to measure parenting practices and family relationships; a higher score indicates more negative parenting (i.e., lower level of consistency, more coercive parenting, lower level of positive encouragement, and worse parent-child relationship). It has been validated for use with children with DD (Mazzucchelli et al., 2018). The PAFAS parenting scale used in the current study showed a Cronbach's α of .717. The Cronbach's α coefficients for the four subscales were .557 (parenting consistency), .751 (coercive parenting), .598 (positive encouragement), and .821 (parent-child relationship), respectively *(see Supplementary File 1M).*

2.6 Data Analysis

The data was downloaded from REDCap and stored in a secure software system in the designated research institution (i.e., IWK Health Centre). The data were deidentified and imported to IBM SPSS Statistics 26 and R 4.0 software for further analysis and data visualization.

2.6.1 Descriptive Statistics

Descriptive statistics (e.g., Means, SDs, frequencies) were calculated for sociodemographic questions and questions on parenting and general PTE, PTSS, PTG, social support, barriers in seeking help, parenting, global health, access to care, and functional impairment. A cut-off score of 32 was used to obtain a provisional diagnosis of PTSD (i.e., whether participants developed PTSD based on their self-report in this study). The DSM-5 criteria were used for a sensitivity analysis, using the outcome from the cut-off method as the true value and accuracy, sensitivity, and specificity as the summary statistics. Correlational coefficients were also calculated between the listed variables. Psychometric properties of the two self-constructed scales (i.e., the PTC and the BHS) were examined (see Table 2). Statistical tests included tests of dimensionality, reliability, and validity.

Table 2

The Psychometric Property Tests of Two Author-constructed Scales

Name of Scale	Psychometric Property	Calculation Approach
Parenting Trauma Checklist (PTC)	**Dimensionality**	Multiple Correspondence Analysis (MCA)
	Validity	(1) Convergent validity as reported by correlations between parenting trauma and global health, functional impairment, lifetime trauma, and PTSS; (2) Predictive validity as reported by a hierarchical regression analysis (parenting trauma as a predictor and PTSD symptoms as outcome variable)
Barriers in Help-seeking (BHS)	**Dimensionality**	Principal Components Analysis (PCA)
	Reliability	Internal consistency as reported by a Cronbach's α coefficient
	Validity	(1) Convergent validity as reported by its Pearson's correlation coefficients with global health and social support; (2) Discriminant validity as reported by its correlation with parenting

2.6.2 Testing of Study Hypotheses

To test hypothesis 4 and hypothesis 5, two hierarchical regression models for PTSS (i.e., Model 1) and PTG (i.e., Model 2) were run. As presented in Figure 2 and Figure 3, five risk and protective factors were examined - lifetime trauma events, parenting trauma events, social support, barriers in help-seeking, and parenting style. A cut-off score of 32 was used to obtain a provisional diagnosis of PTSD (i.e., whether participants developed PTSD based on their self report in this study); the five factors predicting the dichotomous PTSD variable (i.e., whether PTSD was present) were explored by a binomial logistic regression. This is analyzed in addition to the prediction model of the continuous PTSS variable (i.e., Model 1).

Figure 2

The Predictors and Outcome Variables for the Regression Model 1

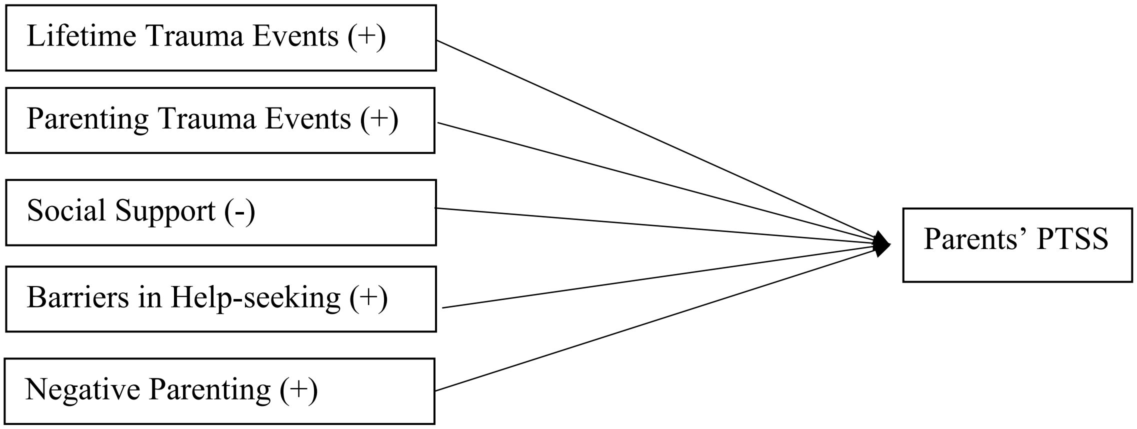
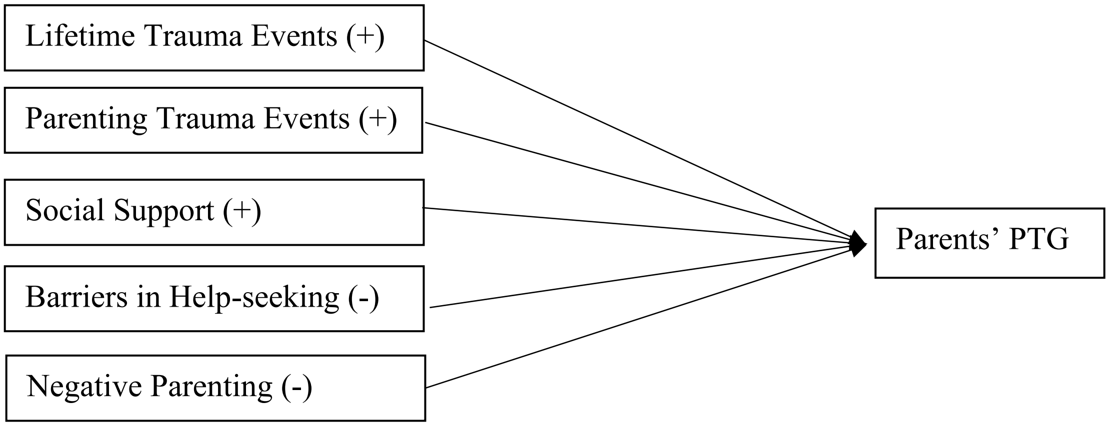


Figure 3

The Predictors and Outcome Variables for the Regression Model 2



2.7 Data Preparation

2.7.1 Missing Values

A key challenge is that some scales were not completed (i.e., non completion). Non completion occurred when participants stopped filling in scales before they had completed all scales. They did not request withdrawal of their data from the study. In addition, participants omitted answering specific questions (i.e., missing values). Missing values were handled by two consecutive steps. Firstly, the case means (i.e., means of all the items in one scale) with over 25% of missing items were omitted. This was practiced according to current knowledge on the influences of missing values and data imputation approaches. Investigation from Shrive et al. (2006) affirmed that cases with high missing rates affected imputation accuracy. For example, in a scenario of 10% missing, the imputation methods caused approximately 10% error; however, if missing was 30%, the error climbed to as high as 23.6%. The second step was that the rest of missing values was replaced with the variable means. Only a small proportion of values (1.09%) was imputed.

The cumulative non completion and exclusion criteria of 25% missing yielded different samples for testing each research question. A total sample of 602 participants was reported in sample characteristics. Afterwards, this sample was compared to the characteristics for the regression sample of 385 parents. The regression sample for testing the fourth and fifth research questions was smaller than the number of participants who finished the survey (*n* = 460); it excluded cases with over 25% missing in any of the 7 variables in Model 1 (see Figure 2) and Model 2 (see Figure 3). The sample for other research questions also depended on the remaining individuals after excluding respective missing cases. Samples for testing research question 1 are stated just ahead of findings for each relative variable. Samples for evaluation of the scale validation (i.e., tests of research question 2 and research question 3) were 543 and 456 for the PTC and the BHS, respectively.

2.7.2 Model Setup for Hierarchical Multiple Regression Models

To conduct hierarchical multiple regression models, relative assumptions of the models (i.e., Model 1, PTSS as the dependent variable; Model 2, PTG as the dependent variable) were tested, including (a) normally distributed residuals, (b) homoscedasticity, (c) multicollinearity, (d) independence of residuals, (e) linearity, and (f) absence of influential outliers. Firstly, the assumption of the normal distribution of residuals was confirmed by visual inspection of the histogram of the distribution of residuals and a P-P Plot of residuals. Secondly, the assumption of homoscedasticity was tested by a scatterplot of residuals. The assumption was met as the residuals remained at a constant level. Then, the absence of multicollinearity was verified through visual inspection of tolerance values and bivariate correlations between the independent variables (i.e., parenting and lifetime traumatic experiences, social support, barriers in seeking help, and parenting style). None of the correlation coefficients was greater than .70. Similarly, none of the tolerance values for the five predictors was less than .10. These indicated that multicollinearity of the independent variables was not a concern in the models. There was independence of residuals, as assessed by Durbin-Watson statistics of 1.960 for model 1 and 1.936 for model 2. Following this, linearity between each independent variable and the dependent variable in question was validated by visual inspection of scatterplots for the respective factors. An exception was that no evidence of linearity was found between barriers and PTG, so barriers was not used as an independent variable in model 2. Finally, multivariate outliers were assessed by Mahalnobis distance values. No significant outliers were found.

2.7.3 Model Setup for Binominal Logistic Regression

The scale of testing PTSS had a widely used cut-off score (i.e., 32) to calculate the presence of PTSD as a provisional diagnosis. Therefore, an additional binomial logistic regression was performed to ascertain the effects of lifetime trauma, parenting trauma, social support, barriers in seeking help, and parenting, on the likelihood that participants showed a provisional PTSD diagnosis. Linearity of the continuous variables concerning the logit of the dependent variable was assessed via the Box-Tidwell (1962) procedure. Based on this assessment, all continuous independent variables were found to be linearly related to the logit of the dependent variable (i.e., presence of PTSD). There were four standardized residuals with values beyond 3 standard deviations (-3.723, -3.479, -3.111, -3.029), which were deleted to minimize influences from the outliers.

Chapter 3: Results

3.1 Summary

The chapter starts with descriptive results of sociodemographic information and each of the key study variables, composed of parenting and lifetime PTE (as assessed by the PTC and the LEC-5, respectively), PTSS (as assessed by the PCL-5), PTG (as assessed by the PTGI-SF), social support (as assessed by the MSPSS), barriers in seeking help (as assessed by the BHS), parenting (as assessed by the PAFAS - parenting subscale), global mental health (as assessed by the GMH-4, physical health assessed by the GPH-4), access to care (as assessed by the KINDEX), and functional impairment (as assessed by the SDS). Afterwards, correlational relationships between the variables are briefly summarized; the Pearson's product-moment correlation coefficients between PTSS, PTG, and their components are reported. This is followed by evaluations of psychometric properties of the PTC and the BHS scales.

Hierarchical linear regression models with five independent variables (i.e., parenting and lifetime PTE, social support, barriers in help-seeking, and parenting style) are summarized for both PTSS (Model 1) and PTG (Model 2). Additionally, a binomial logistic regression to predict PTSD provisional diagnosis (as classified by a cut-off score of 32) was run with the same five independent variables of regression Model 1.

3.2 Demographics

3.2.1 Characteristics of Total Sample

A total of 602 parents of children with developmental disabilities (DD) formed the total sample for the study. The participants were from several provinces across Canada: mainly Ontario (*n* = 232, 41.58%), Alberta (*n* = 130, 23.30%), and British Columbia (*n* = 93, 16.67%). A summary of the characteristics of the sample is presented in Table 3. Most participants were female (94.0%), biological parents (90.3%), and in a marital or common-law relationship (77.9%). The participants' average age of was 43.24 years (*SD* = 7.63, *range* = 24 - 72). Their children were diagnosed with a variety of DD, including autism spectrum disorders (40.7%), ADHD (36.0%), intellectual disabilities (24.1%), and global developmental delay (22.8%) (One child may be classified in more than one type, depending on number of diagnoses the child had). These children had been diagnosed for an average of 7.86 years (*SD* = 5.72, *range* = 0 - 34). The parents reported on average 112.49 hours spent caring for their children with DD every week (*SD* = 53.11, *range* = 0 - 158).

3.2.2 Characteristics of Regression Sample

As there were cumulative non-completion during the survey, the regression sample was a smaller sample of 385 parents. Characteristics of the sample set of the two major regression models are presented in Table 1 of Supplementary File 2. Independent sample t-tests with Bonferroni correction were conducted to examine if there were differences in characteristics of continuous demographic variables between the regression model sample and other parents in the total sample. For the key demographic variables in the regression sample, namely age of the parents (*M* = 43.14, *SD* = 7.40), age of children (*M* = 11.71, *SD* = 5.72), number of children (*M* = 2.22, *SD* = 1.14), number of children with DD (*M* = 1.42, *SD* = 0.78), years of children' s diagnoses (*M* = 7.62, *SD* = 5.54) and parent weekly caregiving hours (*M* = 114.51, *SD* = 52.41), they did not show statistically significant difference from the other cases (i.e., the cases that were excluded from the regression analysis due to non completion and/or missing values). Similarly, chi-square tests with Bonferroni correction of categorical demographic variables did not find statistically significant discrepancies in the distribution of sex, parents' relationship with children, education level, employment status, location and setting, or marital status. A statistically significant difference was found in the rate of different types of the children's diagnosis, $\chi^2(10) = 43.738$, $p < .0005$, Cramer's V = .183. A post hoc analysis revealed that, compared with other participants, the regression sample had significantly higher proportions of parents of children with autism spectrum disorders, ADHD, and global developmental delay, and significantly lower proportions of parents with children with cerebral palsy and epilepsy. No difference was found between the two sample in terms of the rate of parents of children with intellectual disability, learning disability FASD, down syndrome, spina bifida, and other unlisted diagnoses.

Table 3

Sociodemographic Characteristics of the Whole Sample (n = 602)

Demographic Characteristics	***N***	***%***
Sex	**600**	
Female	564	94.0%
Male	36	6.0%
Relationship	**601**	
Biological Parent	543	90.3%
Adoptive Parent	51	8.5%
Step-parent	2	0.3%
Legal Guardian	3	0.5%
Foster Parent/Other	2	0.4%
Level of Education	**590**	
High School	64	10.8%
Occupational/Technical/Vocational Training	125	21.2%
University Degree	367	62.2%
Other	34	5.8%
Employment Status	**594**	
Full-time Employment	215	36.2%
Part-time Employment	106	17.8%
Other	273	46.0%
Marital Status	**602**	
Married	425	70.6%
Domestic Partnership	44	7.3%
Other	133	22.1%
Location	**598**	
Urban Setting	256	42.8%
Suburban Setting	219	36.6%
Rural Setting	113	18.9%
Remote Setting	10	1.7%
Type of Child's Diagnosis	**602**	
Autism Spectrum Disorders	245	40.7%
Attention Deficit Hyperactivity Disorder	217	36.0%
Intellectual Disability	145	24.1%
Global Developmental Delay	137	22.8%
Learning Disability	116	19.3%
Cerebral Palsy	99	16.4%

Table 3

Sociodemographic Characteristics of the Whole Sample (n = 602)

Epilepsy		89	14.8%
Fetal Alcohol Spectrum Disorder		38	6.3%
Down Syndrome		21	3.5%
Spina Bifida		4	0.7%
Other[1]		200	33.2%
	M	*SD*	*range*
Age of Parents (in years)	43.24	7.63	24-72
Age of Child (in years)[2]	11.72	6.05	2-42
Number of Children	2.25	1.14	1-9
Number of Neurodiverse Children	1.39	0.76	1-8
Years of Children’s Diagnoses[3]	7.86	5.72	0-34
Weekly Caregiving Hours	112.49	53.11	0-168

Note. 1. Example of other diagnoses included Chromosome 18 duplication syndrome, Rett syndrome, and neurofibromatosis.
2 & 3. This information was reported based on the participant’s child with a DD. If they had more than one child with a DD, they were asked to report the conditions for the child with the most severe challenges. In the case of equal challenges, they answered based on their oldest child with a DD.

3.3 Research Question 1: Descriptive Statistics

3.3.1 Descriptive Statistics of PTE

Descriptive analysis of the key study variables is presented in Table 4. The parents experienced an average of 5.01 general PTE (*SD* = 3.01) and 5.84 parenting PTE (*SD* = 3.63). Most parents (95.87%) endorsed at least one general traumatic event as indicated in the LEC-5. The three most frequent experiences were transportation accidents (66.8%), unwanted or uncomfortable sexual experiences in their lifetime (except for sexual assaults) (56.2%), and physical assaults (57.6%). A similarly high proportion of the sample endorsed at least one parenting PTE (93.92%), as assessed by the PTC. The frequencies of the listed parenting traumas are shown in Table 5; the highest endorsed items were experiencing a medical emergency of their children (67.2%), seeing their children undergoing a medical procedure (66.9%), and witnessing a life-threatening situation of their children (53.0%). The point-biserial correlation between PTC items and PCL-5 scores exhibited in Table 5 manifests that, in contrast to other items, some PTC items were correlated with PTSS to a higher extent. The PTC7 (i.e., the fear that their child would die while waiting for care) and PTC12 (i.e., witnessing serious self-harming behavior of their child) showed significantly modest correlation with PTSS, $r_{\text{bp}}(489) = .234$, $p < .001$ and $r_{\text{bp}}(489) = .228$, $p < .001$, respectively.

Table 4

Means, Standard Deviations, and Correlations between Study Variables

Variable	*M*	*SD*	1	2	3	4	5	6
1. PTSS	35.54	18.00	/					
2. PTG	24.88	11.25	.12* [.03, .20]					
3. Lifetime Trauma	5.01	3.01	.38** [.30, .45]	.09 [-.00, .18]				
4. Parenting Trauma	5.84	3.63	.35** [.27, .42]	.18** [.09, .26]	.38** [.31, .45]			
5. Social Support	55.35	15.84	-.27** [-.35, -.19]	.20** [.11, .28]	-.18** [-.27, -.10]	-.07 [-.16, .02]		
6. Barriers in Help-Seeking	20.93	9.28	.37** [.29, .45]	-.03 [-.13, .06]	.20** [.11, .29]	.13** [.04, .22]	-.27** [-.36, -.19]	
7. Parenting^1	14.22	5.65	.10 [-.00, .19]	-.17** [-.26, -.07]	-.03 [-.13, .07]	-.15** [-.25, -.05]	-.18** [-.28, -.09]	.09 [-.01, .19]
7a. Parenting Consistency	5.54	2.57	.15** [.05, .24]	-.01 [-.11, .08]	-.06 [-.16, .04]	-.01 [-.11, .08]	-.12* [-.22, -.03]	.20** [.11, .30]
7b. Coercive Parenting	4.41	2.39	.09 [-.01, .19]	-.08 [-.17, .02]	-.03 [-.13, .06]	-.13** [-.23, -.03]	-.10 [-.19, .00]	.04 [-.06, .13]
7c. Positive Encouragement	2.02	1.67	-.12* [-.21, -.02]	-.11* [-.21, -.01]	.07 [-.03, .17]	-.13** [-.23, -.04]	-.00 [-.10, .10]	-.12* [-.21, -.02]
7d. Parent-child Relationship	2.25	2.73	.05 [-.05, .15]	-.20** [-.30, -.11]	-.02 [-.12, .08]	-.09 [-.19, .01]	-.20** [-.29, -.10]	.04 [-.06, .14]

Note. M and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. * indicates $p < .05$. ** indicates $p < .01$.

1. Higher scores for parenting (as assessed by PAFAS-Parenting scale) indicate more negative parenting skills were used in parent-child interactions.

2. The variables 7a, 7b, 7c, and 7d are four subscales of the PAFAS-parenting scale.

Table 5

*Frequency of the PTC Items and Correlations with the PCL-5**

Item	Frequency	%	r_{pb}
PTC1 - Witnessing a life-threatening situation of your child	287	53.0%	.177**
PTC2 - Witnessing a severe accident or injury of your child	125	23.1%	.203**
PTC3 - Experiencing a medical emergency of your child	365	67.2%	.203**
PTC4 - Seeing your child undergoing a medical procedure	363	66.9%	.174**
PTC5 - Your child undergoing a life-threating surgery	132	24.4%	.099*
PTC6 - Hearing of a life-threatening event of your child	127	23.4%	.191**
PTC7 - Fearing that your child would die while waiting for care	163	30.0%	.234**
PTC8 - Receiving diagnosis of life-threatening disability of your child	190	35.1%	.137**
PTC9 - Being in the ICU/NICU/PICU with your child	277	51.0%	.090*
PTC10 - Witnessing a child not in your care die or being critically ill	181	33.4%	.132**
PTC11 - Applying life-saving procedures to your child during crisis	116	21.4%	.174**
PTC12 - Witnessing serious self-harming behavior of your child	137	25.3%	.228**
PTC13 - Birth was life-threatening for mother or child	197	36.5%	.189**
PTC14 - Miscarriage	199	36.8%	.110*
PTC15 - Death of your child	27	5.0%	0.016
PTC16 - A situation in which your child threatened the health or life of you or someone else	89	16.4%	.175**
PTC17 - Other situations that were extremely frightening when caring	188	35.3%	.227**

Note. * The table is also used in a submitted manuscript that includes the research question 2 of this study (Xiong et al., 2021) .

3.3.2 Descriptive Statistics of PTSS, Functional Impairments, and PTG

Concerning trauma-related reactions, the sample reported an overall average score of 35.54 (*SD* = 18.00) on the PTSS (intrusion symptoms *M* = 9.11, *SD* = 5.13; avoidance *M* = 4.05, *SD* = 2.52; negative alterations in cognitions and mood *M* = 13.06, *SD* = 7.12; alterations in arousal and reactivity *M* = 10.20, *SD* = 5.58). Approximately 58.2% parents qualified for a provisional PTSD diagnosis, as calculated by a cut-off score of 32 on the PCL-5 scale. A sensitivity analysis was performed by comparing the cut-off score of 32 and DSM-5 criteria for providing the provisional PTSD diagnosis.

The rate of full PTSD and partial PTSD as calculated by the DSM-5 criteria was 54.2% and 13.8%, respectively. The use of DSM-5 criteria showed relatively high accuracy (88.2%), sensitivity (86.4%) and specificity (90.7%).

Functional impairments of PTSS were examined by the Sheehan Disability Scale. The participants reported an overall moderate level (*M* = 13.17, *SD* = 8.39) of functional impairments due to their posttraumatic stress symptoms. The participants reported that their PTSS caused them unable to carry out normal daily responsibilities for on average 1.17 days in the previous week (*SD* = 1.89). For the remaining days in the previous week, they reported on average 2.13 days (SD = 2.34) of reduced productivity even if they were able to carry on school and/or work duties.

They reported an overall moderate level of PTG (*M* = 24.88, *SD* = 11.25), with higher levels of changes in appreciation of life (*M* = 6.82, *SD* = 2.52) and personal strength (*M* = 5.99, *SD* = 3.04), and slightly lower levels of changes in seeing new possibilities (*M* = 4.52, *SD* = 2.83), relating to others (*M* = 3.95, *SD* = 2.80), and spiritual change (*M* = 3.13, *SD* = 3.06).

3.3.3 Descriptive Statistics of Health, Barriers, and Access to Care

To depict the socio-psychological profile of the sample, several other factors were also examined - overall mental and physical well-being (as assessed by GMH-4 and GPH-4, respectively), barriers of seeking help, and access to care. Overall, the participants showed moderate health status (GMH-4 *M* = 14.93, *SD* = 2.99; GPH-4 *M* = 11.95, *SD* = 4.04).

A generally high prevalence of barriers was observed (*M* = 20.93, *SD* = 9.28) especially on taking caregiving as a priority (i.e., participants perceived this priority affected their seeking-help for their own mental health challenges) (93.4%), not having enough time (90.4%), and high costs (85.8%); see Table 6 for more information.

While caring for the children with DD, 76.67% (355/463) of parents sought professional help from a doctor, a therapist, or a clinic for mental health difficulties. Of the 355 parents who accessed professional care, 245 (69.01%) got diagnoses of at least one mental health disorder from a medical doctor or a psychologist. Specifically, a total of 75.10% (*n* = 184) of the parents reported depressive diagnoses; 74.28% (*n* = 182) reported anxiety disorder diagnoses, and 46.53% (*n* = 114) reported posttraumatic stress disorder diagnoses. Among the 245 diagnosed individuals, 76.73% (n = 188) received more than one diagnosis. For example, of the reported PTSD diagnoses, 91.23% (104/114) were comorbid with another mental health disorder: 14.91% (17/114) with depressive disorders only, 16.67% (19/114) with anxiety disorders only, and 59.65% (68/114) with both anxiety and depressive disorders.

Table 6

Frequency of the BHS by Items

Item	*M*	*SD*	A little bit to Extremely[1]	Moderately to Extremely[2]
(1) I don't have enough time	2.54	1.34	90.4%	74.0%
(2) Support is too far away	1.52	1.38	66.2%	47.4%
(3) The expense and added costs (e.g., time off work, transportation) are too high	2.44	1.44	85.8%	70.0%
(4) I don't have access to support that is based on the latest research.	1.35	1.42	58.4%	39.8%
(5) I don't know how to get access to support.	1.2	1.32	56.1%	36.4%
(6) The waiting lists are too long	2.01	1.56	74.1%	58.5%
(7) I am not emotionally ready for receiving support	0.79	1.05	47.0%	20.7%
(8) It might not be confidential	0.56	1.06	29.1%	14.6%
(9) Support would not be helpful for me	0.62	1.04	33.7%	17.3%
(10) Support involves loss of control/autonomy	0.58	0.93	36.2%	14.3%
(11) I don't want to be labelled as having a mental illness	0.76	1.2	38.1%	19.3%
(12) I feel guilty for having mental health challenges from caring for my child	1.5	1.46	63.1%	43.9%
(13) My child and my family are my priority; I have to focus on caregiving	2.75	1.3	93.4%	78.3%
(14) The people around me discourage me from seeking help for mental health challenges	0.3	0.72	18.8%	7.9%
(15) I want to avoid talking about stressful experiences in my life	1.27	1.24	65.4%	35.5%
(16) Other[3]	0.68	1.33	23.6%	20.4%

Note. 1. A little bit to Extremely refers to the rate of participants experienced the barrier to a little bit to an extreme extent according to their self-report.

2. Moderately to Extremely refers to the rate of participants that reported the barrier was at a moderate to an extreme level.
3. There are 40 effective answers on the other barriers. The most common barriers the participants reported were that there were no specified treatments for them (e.g., therapists might not have enough understanding for their situations as a caregiver of a children with a DD) ((*n* = 13/40, 32.5%) and financial issues (n = 7/40, 17.5%).

3.3.4 Bivariate Correlations

To test hypothesis 1, bivariate correlations were calculated (as shown in Table 4) to clarify significant associations between the major variables. The hypothesis was partially supported. In terms of PTE, there was a significant, moderately strong correlation between lifetime trauma and parenting trauma, $r(538) = .384, p < .001$. No evidence of significant correlation was found between parenting and lifetime trauma, $r(394) = -.03, p = .527$. Interestingly, there was significantly negative correlation between parenting trauma and parenting, $r(397) = -.15, p < .001$. This means that higher exposure to parenting traumatic events was associated with less negative parenting.

To examine the association between PTSS and PTG, Pearson product-moment correlations were calculated between the two factors and their components. As shown in Table 7, a statistically significant, but weak, correlation was found between PTSS and PTG. Higher symptoms were associated with higher levels of positive changes in the aftermath of trauma exposure. Compared to other changes, the change of appreciation of life manifested a relatively consistent positive association with PTSS and its subordinate symptom clusters (i.e., intrusive symptoms, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity).

Table 7

Correlations between PTSD and PTG with Confidence Intervals

Variable	(***M***)	(***SD***)	PCL_5	Intrusion Symptoms	Avoidance	Negative Alterations in Cognitions and Mood	Alterations in Arousal and Reactivity
(***M***)			35.54	9.11	4.05	13.06	10.20
(***SD***)			18.00	5.13	2.52	7.12	5.58
PTG	24.88	11.25	.12* [.03, .20]	.15** [.06, .24]	.13** [.04, .22]	.04 [-.05, .13]	.11* [.02, .20]
Relating to Others	2.08	1.43	.00	.08	.00	-.06	.01

Table 7
Correlations between PTSD and PTG with Confidence Intervals

			[-.09, .09]	[-.01, .17]	[-.09, .09]	[-.15, .03]	[-.08, .10]
New Possibilities	2.29	1.43	.12*	.13**	.13**	.05	.12**
			[.03, .20]	[.04, .22]	[.04, .22]	[-.04, .14]	[.03, .21]
Personal Strength	3.05	1.55	.01	.04	.04	-.01	-.01
			[-.08, .10]	[-.05, .13]	[-.05, .13]	[-.10, .08]	[-.10, .08]
Spiritual Change	1.61	1.57	.14**	.15**	.14**	.08	.16**
			[.05, .23]	[.06, .23]	[.05, .23]	[-.01, .17]	[.07, .24]
Appreciation of Life	3.43	1.30	.19**	.21**	.18**	.12**	.16**
	2.08	1.43	[.10, .27]	[.12, .30]	[.09, .27]	[.03, .21]	[.07, .25]

Note. M and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. * indicates $p < .05$. ** indicates $p < .01$.

3.4 Research Question 2: Evaluation of the Parenting Trauma Checklist

3.4.1 Dimensionality, Reliability and Convergent Validity of the PTC

The evaluation of the PTC scale was based on a sample of 543 parents after excluding non-completion and missing cases. The assessment of the PTC consisted of an evaluation of dimensionality, reliability, and validity. A Multiple Correspondence Analysis (MCA) was run to estimate dimensional approximation. The first principal axis explained 94.3% of the principal inertia, Eigen Value = 0.084. This suggests that a unidimensional MCA gives a good approximation of the latent trait (parenting trauma).

There were statistically significant, but weak positive correlations between PTC and the parents' overall physical well-being (as assessed by PROMIS Global Health GPH-4), $r_s(540) = .170, p < .001$, and between PTC and functional impairment due to PTSS, $r_s(451) = .289, p < .001$. These suggest more exposure to parenting traumatic events was associated with worse health status (as a higher score in the PROMIS Global Health scale indicates worse health outcome) and more functional impairment. A statistically significant, moderate positive correlation was observed between parenting trauma and PTSS, $r_s(489) = .346, p < .001$. A slightly stronger positive correlation was found between the lifetime traumatic events and the PTC, $r_s(538) = .384, p < .001$. These illuminate that, compared to the overall well-being and functional impairment, parenting trauma was more strongly associated with lifetime trauma and trauma-related symptoms, see Supplementary File 2 Table 2 for details.

3.4.2 Predictive Validity of the PTC

To test hypothesis 2, hierarchical multiple regression was also conducted to analyze the effect of parenting trauma load on parents' PTSS scores (see Supplementary File 2 Table 3 for details). It was kept in the supplementary file because the following Table 9 included the same information (i.e., a model with lifetime trauma and parenting trauma predicting PTSS) but different sample sizes (in research question 2, the predictive validity test included a sample size of $n = 488$; in research question 4, sample size $n = 385$). The effects of lifetime trauma and parents' caregiving trauma as two predictors of the PTSS scores was statistically significant, $R^2 = .191$, $F(2, 485) = 57.19$, $p < .001$; $R^2 = .191$. Lifetime trauma was a significant predictor of the PTSS, $F(2, 485) = 80.19$, $p < .001$, $R^2 = .142$.The addition of parents' caregiving trauma led to an increase in R^2 of .049, $F(1, 485) = 29.49$, $p < .001$. The table also illustrates that parenting trauma measured by the PTC scale was a significant predictor of PTSS severity over-and-above general lifetime trauma. Therefore, hypothesis 2 was supported in this study.

3.5 Research Question 3: Evaluation of Barriers in Help-seeking

3.5.1 Dimensionality of the BHS

The exclusion criteria of missing data and non completers left a sample of 456 parents for assessment of the BHS scale. For the scale evaluation, dimensionality, reliability, and validity were also calculated. To assess structure of the BHS, a principal components analysis (PCA) was run on the 15-item BHS scale on 456 parent participants. The open-ended question (item 16 that reported other barriers that were not listed in the BHS checklist) was not included in the calculation of dimensionality. This is because: (1) the last open-ended question was not suitable for the factor extraction conceptually (i.e., the pertained aspects in this item depended on individual's answers), and (2) an exploratory analysis showed that it did not appear in any component load (rotated component coefficients = .220, .055, .095, .113 for component 1, 2, 3, and 4, respectively). The applicability of PCA analysis for the data set was assessed before the analysis. Inspection of the correlation matrix showed that all variables had at least one correlation coefficient greater than 0.3. The overall Kaiser-Meyer-Olkin (KMO) measure was .79 with individual KMO measures all greater than 0.6 corresponding to classifications of ‘Mediocre’ to ‘Marvelous’ according to Kaiser (1974). Barlett’s test of sphericity was statistically significant ($p < .0005$), indicating that the data was likely factor analyzable.

The PCA revealed four components that had eigenvalues greater than one and which explained 24.72%, 12.45%, 9.25%, 7.76% of the total variance, respectively. Visual inspection of the scree plot indicates the four components should be retained. The four components explained 54.17% of the total variance. A varimax orthogonal rotation was employed to aid interpretability. The interpretation of the data was consistent with the attributes that the questionnaire was designed to measure, with support accessibility items on component 1, personal belief items on component 2, emotional readiness on component 3, and resource availability on component 4. There were no hyperplane items (items with loadings on no factor). The item 2, 3, 8, and 15 had salient loadings on more than one factor, see Table 8 for details. The component that an item belongs to depends on the magnitude of factor loadings and the concept that the item content conceptually overlaps with. All the four components had sufficient items (item $n > 3$). All communalities are strong (communalities = [.433, .653]). Note that item 8 (i.e., “It might not be confidential”) was classified in component 2, although it had higher loading in component 1, for two reasons: (1) the item conceptually overlapped with personal belief more than with support accessibility; and (2) the loading in component 2 was acceptable (component coefficient = 0.477 for component 1 and 0.366 for component 2). Four factor scores were calculated and entered a second PCA to assess whether the components converged into a single factor (i.e., barriers in help seeking). The second PCA confirmed a single attribute (eigenvalue = 1.89); therefore, the use of a single total score to interpret perceived barriers is supported. Component loadings and communalities of the rotated solution are presented in Table 8.

Table 8

Rotated Structure Matrix for PCA with Varimax Rotation of a Four Component BHS

Item	Rotated Component Coefficients				
	Component 1	**Component 2**	**Component 3**	**Component 4**	**Communalities**
Item 6 The waiting lists are too long	**0.745**	0.078	-0.028	0.059	.566
Item 4 I don't have access to support that is based on the latest research.	**0.743**	0.017	0.146	0.083	.580
Item 5 I don't know how to get access to support.	**0.723**	0.247	-0.037	0.064	.590
Item 12 I feel guilty for having mental health challenges from caring for my child.	0.080	**0.749**	-0.051	0.262	.639
Item 11 I don't want to be labelled as having a mental illness	0.072	**0.671**	0.303	-0.078	.553
Item 14 The people around me discourage me from seeking help for mental health challenges	0.217	**0.571**	0.108	-0.221	.433
Item 15 I want to avoid talking about stressful experiences in my life	0.080	**0.516**	0.398	0.207	.473
Item 8 It might not be confidential	0.477	**0.366**	0.331	0.024	.472
Item 9 Support would not be helpful for me	-0.065	-0.059	**0.758**	-0.028	.584
Item 10 Support involves loss of control/autonomy	0.154	0.275	**0.722**	-0.022	.621
Item 7 I am not emotionally ready for receiving support	0.077	0.198	**0.653**	0.158	.496
Item 1 I don't have enough time	-0.043	0.048	0.086	**0.801**	.653
Item 3 The expense and added costs (e.g. time off work, transportation) are too high	0.361	0.000	-0.031	**0.608**	.501
Item 13 My child and my family are my priority; I have to focus on caregiving	-0.030	0.470	0.050	**0.511**	.486
Item 2 Support is too far away	0.462	-0.103	0.084	**0.497**	.478

Note. Factor loadings in the component they were classified into were bolded.

3.5.2 Reliability, Convergent Validity, and Discriminant Validity of the BHS

The reliability was evaluated by internal consistency. The Cronbach's α was .77 for the BHS whole scale, .69 for the component 1 (support accessibility), .67 for the component 2 (i.e., personal belief), .60 for the component 3 (emotional readiness), and .57 for the component 4 (resource availability). The convergent validity of the BHS was evaluated by its correlation with global health status and social support. Discriminant validity was tested by its correlational relationship with parenting.

There were statistically significant, moderate, positive correlations between barriers and the parental well-being (physical health, $r(453) = .276, p < .0005$; mental health, $r(453) = .325, p < .0005$), which means a higher level of barriers in receiving psychological support was associated with generally poorer health status. A statistically significant, moderate negative correlation was observed between BHS and social support scores, $r(451) = .273, p < .0005$. This means higher barriers in seeking support were associated with lower perceived social support. There was a marginally significant and weak correlational relationship between barriers and parenting, $r(391) = .092, p = .070$, indicating there was no reliable or strong correlation between parents' experiencing of barriers in seeking support and their parenting styles (see Supplementary File 2 Table 4 for details).

The three subscales of the BHS (i.e., support accessibility, personal belief, and resource availability) also showed weak to moderate positive correlations with parental global mental and physical health challenges ($r(453) = [.16, .32], p < .05$) and moderate negative correlation with social support after their children's diagnoses ($r(451) = [-.27, -.15], p < .01$). The emotional readiness subscale did not reveal significant correlations with global mental health ($r(453) =.05, p = .13$), physical health ($r(453) = .05, p = .32$) as well as social support ($r(451) = -.07, p = .13$).

3.6 Research Question 4: Risk and Protective Factors of PTSS

3.6.1 Hierarchical Linear Regression Model of PTSS

Hierarchical linear regression was run to determine if the addition of social support and then of barriers in help-seeking and parenting separately improved the prediction of PTSS over and above traumatic events alone. See Table 9 for full details on each regression model. The full model of traumatic events, social support, barriers in seeking mental health help, and parenting in predicting PTSS was statistically significant, $R^2 = .305, p < .0005$; adjusted $R^2 = .296$. The addition of social support to the prediction of PTSS led to a statistically significant increase in R^2 of .036, $F(1, 381) =$

18.097, $p < .0005$. Similarly, the addition of barriers in help-seeking to the prediction of PTSS led to a statistically increase in R^2 of .052, $F(1, 380) = 27.909$, $p < .0005$. The addition of parenting to the prediction of PTSS also led to a statistically increase in R^2 of .012, $F(1, 379) = 6.620$, $p < .05$.

A further exploration of the effects of different dimensions of the BHS in full model 1 indicates that support accessibility (*beta* = .14, $p < .01$) and personal beliefs (*beta* = .18, $p < .01$) were significant predictors of parents' PTSS. As presented in Table 10, higher barriers in seeking help accessibility and personal beliefs were associated with higher PTSS. The barriers in emotional readiness (*beta* = - .07, $p = .352$) and resource availability (*beta* = .08, $p = .114$) were not significant predictors of PTSS. No evidence of significant association was found between higher barriers in emotional readiness and PTSS. While higher barriers in resource availability were positively correlated with higher PTSS ($r(383) = .28$, $p < .0005$), this effect was not confirmed in the predictive analysis in the context of other predictors.

3.6.2 Binominal Logistic Regression Model of PTSS

The logistic regression model was statistically significant, $\chi2(5) = 91.186$, $p < .0005$. The model explained 28.5% (Nagelkerke R^2) of the variance in the development of probable PTSD and correctly classified 70.1% of cases. Sensitivity was 81.5%, specificity was 52.9%, positive predictive value was 72.41% and negative predictive value was 65.32%. Amongst the five predictor variables, four were statistically significant: lifetime trauma, parenting trauma, barriers in seeking help, and social support, as shown in Table 11. More lifetime trauma and parenting trauma were associated with an increased likelihood of exhibiting PTSD; more barriers in seeking help were positively correlated with exhibiting PTSD, and increasing social support was marginally associated with a reduction in the likelihood of exhibiting PTSD. These results largely replicate the prediction of continuous PTSS except that parenting did not independently contribute to probable PTSD at the categorical level.

Table 9

Regression Results Using PTSS as the Criterion

Predictor	*b*	*b* 95% CI [LL, UL]	*beta*	*beta* 95% CI [LL, UL]	sr^2	sr^2 95% CI [LL, UL]	Fit	Difference
(Intercept)	1.24**	[1.07, 1.40]						
Lifetime Trauma	1.91**	[1.44, 2.38]	0.38	[0.28, 0.47]	.14	[.08, .21]		
							R^2 = .142** 95% CI[.08,.21]	
(Intercept)	1.02**	[0.84, 1.20]						
Lifetime Trauma	1.39**	[0.90, 1.88]	0.27	[0.18, 0.37]	.06	[.02, .11]		
Parenting Trauma	1.14**	[0.73, 1.55]	0.27	[0.17, 0.37]	.06	[.02, .11]		
							R^2 = .205** 95% CI[.14,.27]	ΔR^2 = .063** 95% CI[.02, .11]
(Intercept)	1.67**	[1.32, 2.02]						
Lifetime Trauma	1.25**	[0.76, 1.73]	0.25	[0.15, 0.34]	.05	[.01, .09]		
Parenting Trauma	1.08**	[0.68, 1.49]	0.26	[0.16, 0.35]	.06	[.02, .10]		
Social Support	-0.13**	[-0.19, -0.07]	-0.19	[-0.28, -0.10]	.04	[.00, .07]		
							R^2 = .241** 95% CI[.17,.31]	ΔR^2 = .036** 95% CI[.00, .07]
(Intercept)	1.11**	[0.72, 1.51]						
Lifetime Trauma	1.08**	[0.60, 1.55]	0.21	[0.12, 0.31]	.04	[.01, .07]		
Parenting Trauma	0.98**	[0.59, 1.37]	0.23	[0.14, 0.32]	.05	[.01, .08]		
Social Support	-0.09**	[-0.15, -0.03]	-0.14	[-0.23, -0.05]	.02	[-.00, .04]		
Barriers in Help Seeking	0.36**	[0.22, 0.49]	0.24	[0.15, 0.33]	.05	[.01, .09]		
							R^2 = .293** 95% CI[.21,.36]	ΔR^2 = .052** 95% CI[.01, .09]
(Intercept)	0.79**	[0.32, 1.25]						
Lifetime Trauma	1.09**	[0.62, 1.56]	0.21	[0.12, 0.31]	.04	[.01, .07]		
Parenting Trauma	1.05**	[0.66, 1.45]	0.25	[0.16, 0.34]	.05	[.01, .09]		
Social Support	-0.08**	[-0.14, -0.02]	-0.12	[-0.21, -0.03]	.01	[-.01, .03]		
Barriers in Help Seeking	0.35**	[0.21, 0.48]	0.23	[0.14, 0.32]	.05	[.01, .08]		
Parenting	0.30*	[0.07, 0.53]	0.11	[0.03, 0.20]	.01	[-.01, .03]		
							R^2 = .305** 95% CI[.22,.37]	ΔR^2 = .012* 95% CI[-.01, .03]

Note. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. sr^2 represents the semi-partial correlation squared. *r* represents the zero-order correlation. *LL* and *UL* indicate the lower and upper limits of a confidence interval, respectively.* indicates $p < .05$. ** indicates $p < .01$.

Table 10

Regression Results using Barrier Components as Predictors

Predictor	*b*	*b* 95% CI [LL, UL]	*beta*	*beta* 95% CI [LL, UL]	sr^2	sr^2 95% CI [LL, UL]	*r*	Fit
(Intercept)	0.80**	[0.33, 1.27]						
Lifetime Trauma	1.00**	[0.53, 1.47]	0.20	[0.10, 0.29]	.03	[.00, .06]	.38**	
Parenting Trauma	1.03**	[0.64, 1.42]	0.24	[0.15, 0.34]	.05	[.01, .08]	.38**	
Social Support	-0.07*	[-0.13, -0.01]	-0.11	[-0.20, -0.02]	.01	[-.01, .03]	-.27**	
BHS Support Accessibility	0.11**	[0.04, 0.19]	0.14	[0.05, 0.23]	.02	[-.00, .04]	.30**	
BHS Personal Belief	0.19**	[0.06, 0.31]	0.16	[0.05, 0.27]	.02	[-.00, .04]	.33**	
BHS Emotional Readiness	-0.05	[-0.17, 0.06]	-0.05	[-0.14, 0.05]	.00	[-.00, .01]	.05	
BHS Resource Availability	0.08	[-0.02, 0.17]	0.08	[-0.02, 0.17]	.00	[-.01, .02]	.28**	
Parenting	0.26*	[0.03, 0.49]	0.10	[0.01, 0.18]	.01	[-.01, .02]	.11*	
								R^2 = .320** 95% CI[.23,.38]

Note. A significant *b*-weight indicates the beta-weight and semi-partial correlation are also significant. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. sr^2 represents the semi-partial correlation squared. *r* represents the zero-order correlation. *LL* and *UL* indicate the lower and upper limits of a confidence interval, respectively.
* indicates $p < .05$. ** indicates $p < .01$.

Table 11

Logistic Regression Predicting Likelihood of PTSD.

Predictor	*B*	*SE*	Wald	*p*	Odds Ratio	95% CI for Odds Ratio	
						Lower	Upper
Lifetime Trauma	3.113	0.815	14.587	.000	22.5	4.553	111.192
Parenting Trauma	2.227	0.692	10.375	.001	9.276	2.392	35.974
Social Support	-0.261	0.103	6.435	.011	0.771	0.63	0.942
Barriers in Seeking-Help	1.196	0.239	25.09	.000	3.307	2.071	5.281
Parenting	0.454	0.377	1.453	.228	1.574	0.753	3.293
Constant	-1.839	0.806	5.209	.022	0.159		

3.7 Research Question 5: Risk and Protective Factors of PTG

Hierarchical linear regression was run to determine if the addition of social support and then of parenting improved the prediction of posttraumatic growth over and above traumatic events alone. See Table 12 for full details on each regression model. The full model of traumatic events, social support, and parenting to predict PTSD symptoms was statistically significant, $R^2 = .094$, $p < .0005$; adjusted $R^2 = .085$. The addition of social support to the prediction of posttraumatic growth led to a statistically increase in R^2 of .054, $F(1, 381) = 22.536$, $p < .0005$. The addition of parenting to the prediction of posttraumatic growth did not lead to a statistically significant increase in R^2 of .008, $F(1, 380) = 3.436$, $p = .065$. This means that higher exposure to lifetime and parenting trauma and greater social support were associated with higher PTG. A noteworthy finding is that the predictive effect of parenting trauma (*beta* = .16, $p < .01$) was higher and more reliable than that of lifetime trauma (*beta* = .08, $p = .137$).

Table 12

Hierarchical Regression Results Using PTG as the Criterion

Predictor	*b*	*b* 95% CI [LL, UL]	*beta*	*beta* 95% CI [LL, UL]	sr^2	sr^2 95% CI [LL, UL]	Fit	Difference
(Intercept)	2.23**	[2.01, 2.45]						
Lifetime Trauma	0.68*	[0.06, 1.30]	0.11	[0.01, 0.21]	.01	[.00, .04]		
							R^2 = .012*	
							95% CI[.00,.04]	
(Intercept)	2.08**	[1.84, 2.32]						
Lifetime Trauma	0.32	[-0.35, 0.99]	0.05	[-0.06, 0.16]	.00	[-.01, .01]		
Parenting Trauma	0.79**	[0.24, 1.35]	0.15	[0.05, 0.26]	.02	[-.01, .05]		
							R^2 = .032**	ΔR^2 = .020**
							95% CI[.00,.07]	95% CI[-.01, .05]
(Intercept)	1.09**	[0.62, 1.57]						
Lifetime Trauma	0.53	[-0.12, 1.19]	0.09	[-0.02, 0.19]	.01	[-.01, .02]		
Parenting Trauma	0.88**	[0.33, 1.42]	0.17	[0.06, 0.27]	.02	[-.01, .05]		
Social Support	0.20**	[0.11, 0.28]	0.24	[0.14, 0.33]	.05	[.01, .10]		
							R^2 = .086**	ΔR^2 = .054**
							95% CI[.04,.14]	95% CI[.01, .10]
(Intercept)	1.44**	[0.84, 2.04]						
Lifetime Trauma	0.53	[-0.13, 1.18]	0.08	[-0.02, 0.19]	.01	[-.01, .02]		
Parenting Trauma	0.80**	[0.26, 1.35]	0.16	[0.05, 0.26]	.02	[-.01, .05]		
Social Support	0.18**	[0.10, 0.26]	0.22	[0.12, 0.32]	.04	[.01, .08]		
Parenting	-0.30	[-0.62, 0.02]	-0.09	[-0.19, 0.01]	.01	[-.01, .03]		
							R^2 = .094**	ΔR^2 = .008
							95% CI[.04,.15]	95% CI[-.01, .03]

Note. b represents unstandardized regression weights. *beta* indicates the standardized regression weights. sr^2 represents the semi-partial correlation squared. *r* represents the zero-order correlation. *LL* and *UL* indicate the lower and upper limits of a confidence interval, respectively. * indicates $p < .05$. ** indicates $p < .01$

Chapter 4: Discussion

This chapter discusses the study findings in the context of existing literature on trauma symptomatology, PTG, and relevant psychosocial factors, with a special focus on parents of children with DD. The chapter begins with a summary of the study characteristics. Subsequently, key findings are explained and compared with current knowledge in related fields. Then, the strengths and limitations of the study are discussed and recommendations for future research topics are elucidated. Lastly, the chapter addresses implications for stakeholders and disability communities.

4.1 Study Summary

A web-based survey was administrated to collect a total of 602 Canadian parents of children with DD in 2020 to 2021. This survey gives an overview of the parents' current sociodemographic status, overall physical health, mental health, support from their social networks, general and parenting trauma history, posttraumatic stress symptoms and growth, and access and barriers to psychological treatments. Additionally, two scales concerning parenting trauma events (i.e., the PTC) and barriers of seeking help (i.e., the BHS) were established and initially validated. The study utilized two main multiple hierarchical regression models to explore the risk and protective factors of parental posttraumatic stress symptoms and posttraumatic growth.

4.2 Discussion of Findings

4.2.1 Parenting PTE, PTSS, and PTG

The study revealed higher rates of PTSD prevalence (58.2%) and more severe overall posttraumatic symptomatology ($M = 35.54$, possible range 0 - 80) compared to other studies. For example, Carmassi et al. (2018) revealed that 37.3% of the 134 sampled parents of children with epilepsy met PTSD partial diagnoses. Another study (Casey et al., 2012) found around 20% of the 265 parents of children with autism spectrum disorder manifested PTSD. There are several possible explanations for the inconsistency. First and foremost, my study recruited a convenience sample, which might not be generalizable to the overall prevalence of PTSD among parents of children with a DD. Currently, there is no or little available documentation of large population-based epidemiological surveys on PTSD prevalence among parents of children with diagnoses of DD. In addition to this, the current study was conducted in a special time period during COVID-19 pandemic. The negative impact of the lockdown manifested on public mental health, especially stress (Bentenuto et al., 2021), which can contribute to a possible heightened prevalence. Parents of children with an IDD might have been particularly affected (Shorey et al., 2021). Thirdly, Carmassi et al. (2018) and Casey et al. (2012) used different scales from PCL-5 in my study (i.e., the Trauma and Loss Spectrum-Self Report (TALS-SR) and the LA Symptom Checklist (LASC)).

The presented study also discovered a medium level of parental PTG among parents of children with an IDD ($M = 24.88$, possible range 0 - 50), which is consistent with other studies among parents of children with DD (Beighton & Wills, 2019; Hungerbuehler et al., 2011; Picoraro et al., 2014; Qin et al., 2021). The findings suggested one of the positive consequences from the traumatic experiences associated with caring for children with DD is parental personal growth, especially their appreciation for life (Forinder & Norberg, 2014).

There was a positive, but weak correlation between posttraumatic stress symptoms and posttraumatic growth ($r = .12$, $p < .05$). Low correlations were consistently found across respective components for the both variables ($r = [-.06, .21]$). This means individuals with higher overall posttraumatic stress symptoms were consistently associated with higher growth in every aspect. Levine et al.(2008) found that the association between PTSS and PTG was a curvilinear (inverted-U) relationship: PTG was at the highest level when PTSS were at moderate levels. However, results in this study did not imply this tendency. One of the major distinctions between the two studies is that sample from Levine et al. (2008) was low trauma burdened adolescents whereas this study involved a highly trauma burdened sample. For example, the parents in this study had high prevalence of PTSD (58.2%) and multiple trauma events (lifetime number of traumas $M = 5.01$, $SD = 3.01$, lifetime number of parenting traumas $M = 5.84$ $SD = 3.63$). Levine et al.'s study (2008) sampled 4054 adolescents with a low percentage meeting PTSD criteria (5.50%) in response to exposure to terror (i.e., a single traumatic event).

4.2.2 Parenting Trauma Checklist

One major contribution of this study is that the PTC scale was developed to identify and quantify parental stressful life experiences from their caregiving duties. The scale captured the events with high population and symptom relevance. The population relevance was clear in that 95.87% endorsed at least one event. The clinical relevance was indicated by its relationship with posttraumatic stress symptoms. Higher exposure to these parenting stressful events was associated with a higher likelihood to develop PTSS, with an effect size comparable to that of the general trauma (parenting trauma $r = .35$; lifetime trauma $r = .38$). The predictive effect from parenting trauma was found over and above the effect from the general lifetime trauma. This suggests the usefulness of the PTC in measuring traumatic events for the caregivers and parents of children with chronic illnesses.

The stressful parenting events observed in the present study are consistent with the results of existing studies using qualitative methods (Bessette Gorlin et al., 2016; Christofferson et al., 2019). The author-constructed PTC attested to the presence of parenting PTE shown in previous studies and, additionally, provided the frequencies and severity of the events. Some of these traumatising parental experiences included: (1) witnessing life-threatening procedures of one's child (Christofferson et al., 2019; 66.9%); (2) being in intensive care units or pediatric intensive care units (Vanderbilt et al., 2009; 51%); (3) applying life-saving procedures to one's child (Christofferson et al., 2019; 21.4%); and (4) witnessing children's harmful behaviour issues (Bessette Gorlin et al., 2016; 16.4%).

4.2.3 Barriers in Help-Seeking

Systematically detecting the barriers that these parents perceive when seeking mental health treatments for themselves is an important contribution of this study. The predominant barriers were that their priority role as a caregiver and time to care for their family negatively affected their help-seeking behaviors (93.4%) and that they did not have enough time for their own health challenges (90.4%). These same barriers are in line with previous research among parents of children with disabilities (Currie & Szabo, 2019; Gilson et al., 2018). The responsibility of caring for their medically fragile children hindered the parents' motivation and resources to deal with personal psychological problems. Principal components analysis of the BHS checklist yielded four dimensions with acceptable internal consistency for the 4 subscales and for the whole scale: *support accessibility* (four items), *personal belief* (four items), *emotional* *readiness* (three items), and *resource availability* (four items). The total scale and three of the four subscales (i.e., support accessibility, personal belief, and resource availability) also maintained good construct validity, with moderate positive correlations with parental mental and physical health challenges ($r = [.16, .32]$, $p < .05$) and moderate negative correlation with social support after their children's diagnoses ($r = [-.27, -.15]$, $p < .01$). The emotional readiness subscale showed poor construct validity.

Some barriers unveiled in my study had also been reported in prior literature. For instance, a narrative review (Sritharan & Koola, 2019) of 21 studies identified that limited access to services and negative personal beliefs about the services were key barriers faced by immigrant families with children with autism spectrum disorders. Bowling et al. (2019) also found that insufficient treatment resources and lack of support were two major barriers from interviews with 24 parents of children with DD. A recent survey (Paula et al., 2020) conducted in six Latin American countries also indicates the same barriers in families of people with Autism spectrum disorder: the long waitlists (BHS item 6; 50.2%), high service costs (BHS item 3; 35.2%), and lack of access to treatment (BHS item 4; 26.1%). The current study found these barriers were experienced by higher proportions of the parents: 58.5% (long waitlists), 70.0% (high service costs), and 39.8% (lack of access to treatment) facing each of these barriers, respectively, to moderate to extreme extents. These differences can potentially be explained by different country settings between the two studies. Moreover, high costs of the services may be perceived by more Canadian parents than the parents in Latin American countries given differences in healthcare costs for psychological services in the two environments (i.e., middle-income country and high-income country) (OECD, 2021). In fact, as was stated by Paula and colleagues (2020), parents from their investigated countries exhibited different extents of the various barriers.

4.2.4 Risk and Protective Factors of PTSS

Parenting Traumatic Events and PTSS. Multiple hierarchical regression illustrated that, as expected, parenting trauma was a positive predictor of PTSS. More exposure to parenting trauma was connected to more severe symptoms. This effect is added to the predictive effect from general PTE. The study confirmed a major finding of a previous investigation of posttraumatic stress for mothers with children in NICUs

(Vanderbilt et al., 2009). They elucidated that having a newborn in the NICU was significantly associated with their symptom severity (*beta* = 0.81, $p < .05$). Our study did not generate as high parameter (*beta* = 0.27, $p < .01$) due to two possible reasons. One main interpretation is the differences between the two samples and relevant independent variables in the regression analysis. This study was tested on parents of children with a variety of DD, the previous study compared mothers of children in the NICU and the well-baby nurseries. The parenting traumatic events entered as the second parameter and the assessment was based on its effect over and above the effect from general traumatic events, while in the previous study it was entered as the first predictor of their model. Another possible interpretation is that the study from Vanderbilt et al (2009) tested the effect of the current NICU experience, while we tested the history of the NICU experience. It has been established that the adverse effects of trauma on PTSS tend to decline with time (Santiago et al., 2013).

The present study contributed to the existing literature of stressful events related to caring for children with DD: it showed certain parenting trauma events were more closely related to the occurrence of PTSS, such as fearing that one's child would die while waiting for care ($r = .234$, $p < .001$) and witnessing serious self-harming behaviour of one's child ($r = .228$, $p < .001$) as compared to their children's life-threatening surgery ($r = .099$, $p < .05$) and being in the ICU/NICU/PICU with their children ($r = .090$, $p < .05$). This implies the feasibility of detecting parenting trauma of higher clinical significance and its ability to predict PTSS more precisely in the parent population. We also suggest that in addition to assessing general traumatic events (e.g., sexual victimization, physical assault, motor vehicle accident), it is worth considering population-specific traumatic events to gain a deeper understanding of trauma pathology.

Social Support and PTSS. The regression analysis verified the negative moderate relationship between social support and PTSS in hypothesis 4 ($r = -.27$, $p < .01$; *beta* = -.12, $p < .01$). This finding supported a result from a systematic review, concluding that social support was one major protective factor of PTSS among caregivers of children and adolescents with severe diseases (Carmassi et al., 2021). The effect size was lower than that presented in a review from Brewin et al. (2000; weighted average $r = -.40$) and higher than a study of the relationship in 331 parents of childhood cancer survivors (*r* = -.13, *p* < .05) (Kazak et al., 1998). The different effect sizes may mean that the protective effect of social support for general trauma-exposed adults (Brewin et al., 2000) is higher than that for parent populations (i.e., parents of children with DD in my study and parents of cancer survivors from Kazak et al. (1998).

Barriers of Seeking Help and PTSS. Barriers of help-seeking evaluated with the BHS scale in this study were significantly positively correlated with parents' PTSS (*r* = .37, *p* < .01; *beta* = .23, *p* < .01). This effect was manifested mainly through support availability (*beta* = .14, *p* < .01) and personal beliefs (*beta* = .18, *p* < .01). As was hypothesized, higher experienced barriers to seeking mental health care were correlated with higher PTSS. A search of the current literature did not detect studies that directly tested this relationship in the same or similar population. This result was consistent with prior investigations in veterans (Ouimette et al., 2011; Westermeyer et al., 2002). Ouimette et al. (2011) revealed moderate positive correlations between barriers and veterans' reported PTSS (*r* = [.15, .35], *p* < .01; *beta* = [.08, .23], *p* < .01). This means that the relationship between these two variables may be independent of specific traumatized populations and/or types of trauma exposure. The present study provided more information on the types of barriers that increased the likelihood of manifesting PTSS. There is a need for continued research into the effect of the BHS and its components on PTSS in multiple populations.

Parenting and PTSS. Parenting only showed a weak effect on PTSS (*r* = .10, *p* = .05; *beta* = .11, *p* < .01) and an insignificant contribution to the PTSD calculated by a cut-off score of PTSS (*B* = .454, *p* = .228). As there is currently a paucity of literature that explores parenting and its influence on PTSS among parents of children with DD, the novel exploration in this study was not exactly comparable to existing studies. Christie and colleagues (2019) synthesized 27 studies on the influence of parental PTSS on parenting, in terms of parenting satisfaction, stress related to parenting, parent-child relationship, and parenting behaviours. They suggested that parents' PTSS were correlated with higher parental stress, lower parenting satisfaction, and less optimal relationship between children and parents, as well as more negative parenting practices. The direction of findings is consistent with those reported in my study. Christie et al. (2019) also pointed out varying effect sizes (as indicated by correlational coefficients, Cohen’s d, and Odds Ratio) ranging from very small to large. In my study, a weak (small) effect was found between parenting and PTSS; there was no evidence of a significant effect of parenting on the provisional diagnosis of PTSD. This implies that negative parenting was not a key contributor to parents’ PTSS or a determinant of PTSD. Findings from Berz et al.'s (2008) study with female veterans, suggest that the association between parenting and PTSS differs for the various PTSD symptom clusters. They found that parenting satisfaction showed distinct but stronger bonds with avoidance (r = -.23, p < .01) and hyperarousal symptoms (r = - .29, p < 01) than with re-experiencing symptoms (r = .10, p > .05). It is important to keep in mind the nuances of the parenting concepts being evaluated across studies. The present study focused especially on negative parenting behaviours and parent-child relationships while the studies from Berz et al. (2008) and Christie et al. (2019) both examined parenting satisfaction.

4.2.5 Risk and Protective Factors of PTG

PTE and PTG. As hypothesized, the exploration of risk factors of PTG firstly identified that both lifetime trauma events and parenting trauma events were independent positive predictors of PTG, both with small effect sizes. Parenting trauma (r = .18, p < .0005, *beta* = .15, p < .01) showed a stronger relationship with trauma-related growth than did lifetime general trauma (r = .06, p = .06, *beta* = .11, p < .01). When parenting trauma and other predictors were added into the model, the effect of lifetime trauma became smaller and even insignificant (*beta* = [.05, .09] across different steps in the regression model) while the effect from parenting trauma was more robust (*beta* = [.16, .17], p < .01). The prior research had explained the positive relationship between PTE and PTG by comparing people with and without a history of trauma exposure (Tedeschi & Calhoun, 1996). To our knowledge, this study is the first to directly compare both the effects of parenting trauma and lifetime general trauma. The present study found that the strength of the linear relationship between these traumatic events and PTG may depend on the type of PTE. In this study, for example, the traumatic events linked to parenting a child with medical complexities like DD played a firmer, though small, role in the positive changes after trauma. This warrants the need to explore a population-specific trauma to confirm this effect in other samples and settings.

Social Support and PTG. As was expected, social support was a key facilitator to one's positive changes after the occurrence traumatic events in this sample ($r = .20$, p < .0005, *beta* = .24, $p < .01$). The moderate effect size in this relationship is consistent with that found in a meta-analysis from Prati and Pietrantoni (2009; pooled $r = .26$, $p < .01$). Studies of parents of children with autism spectrum disorders (Zhang et al., 2015) and bereaved HIV/AIDS caregivers (Cadell & Regehr, 2003) also explored and confirmed the effect. The homogeneity of the findings from a variety of populations indicates that individuals who received more support from their social network experienced an increased likelihood to perceive more positive changes after trauma.

It should be noted that the measurement of social support and PTG are both based on parents' self-report in a cross-sectional design. It could mean that parents who perceive higher social support tended to perceive higher PTG, and vice versa. It should also be noted that other factors, such as optimism and coping strategies, may play a role in this effect. For example, it was found that perceived social support and PTG both showed positive associations with optimism (Karademas., 2006; Prati & Pietrantoni., 2009). This indicates optimistic individuals may tend to perceive higher social support and more PTG.

Parenting and PTG. As was shown in the multiple regression analysis of the study presented here, there was a small effect of parenting on PTG ($r = -.17$, $p < .01$; *beta* = -.009, $p = .065$). This supported my hypothesis 5: less negative parenting behaviours and parent-child relationships were correlated with more posttraumatic growth among parents. A recent survey (Qin et al., 2021) on 205 parents of children with autism spectrum disorders, published after the conduct of this study, examined the relationship between posttraumatic growth and family function ($r = -.011$), including affective involvement ($r = .10$), family interaction ($r = .026$), family problem solving behaviors ($r = -.298$, $p < .01$). Of these variables, they found only problem solving was significantly correlated with posttraumatic growth. These two recent studies implied that unlike in other populations (e.g., patients with life-threatening medical diseases and LGBTQ groups), parenting behaviours and parent-child relationships were not key promoting factors of posttraumatic growth in parents of children with DD (Koutna et al., 2017; Zavala & Waters, 2021).

Barriers and PTG. Finally, there was no significant relationship between barriers and PTG in the present study (r = - .03, p = .458), which was inconsistent with my hypothesis 5. The parents in the study had an overall moderate level of posttraumatic growth; facing more barriers during seeking treatments did not exert the expected negative impacts on parents' PTG. In a study from Kent et al. (2013), they found being able to seek support was positively correlated to higher PTG (*beta* = .19, p < .0001). It is notable that, in contrast with my study, they measured the actual support participation, instead of perceived willingness or barriers during seeking support. A second explanation is that this parent sample was confronted with generally moderate levels of barriers (M = 20.84, SD = 9.27 possible range 0 - 64), whereas Kent et al tested several samples with diverse support participation rates (African American 30.6%, Hispanic/Latina 67.2%, Non-Hispanic White 75.5%). This points to the need for future investigations of my research questions in diverse populations.

4.3 Strengths, Limitation and Future Directions

4.3.1 Strengths

A strength of my study is the large, nationwide, and diverse sample. A total of 602 parents participated in the survey and 460 of these parents completed all the questionnaires in the survey; with 385 completing sufficient items on all measures to be used in my main regression analyses. These parents had varied ages, employment statuses, levels of education, and children with a range of diagnoses. The large sample size and the diversity adds statistical power of our conclusions. A second strength is that the study developed and tested two questionnaires, both with acceptable-to-good psychometric properties, as noted in the findings. Both tools were the first attempts in their domains, contributing to the ease of conducting quantitative research in their respective fields. A final main strength is that the study examined several novel research questions that have been rarely researched previously. For example, the study of population-specific trauma, negative parenting, and their impacts on people's PTSS and PTG are all understudied topics. My study told us whether and to what extent each of these factors and outcomes are harmful or meaningful for parents of children with medical complexities like DD.

4.3.2 Limitations and Future Studies

Impact of COVID Pandemic. One limitation and characteristic of this study is the special time it was conducted. The study was conducted between June 2020 and February 2021, when the COVID-19 pandemic threatened Canadians (Government of Canada, 2021). The rapid change of lockdown policies caused great uncertainty and influenced families with children with a DD (e.g., reduced childcare services and homeschooling), and thus, as stated above, has profoundly changed stress levels in the general public. This may also have impacted the generalizability of the results of the study. For example, the high rate of PTSD in my study might not represent day-to-day situations but rather the potential exacerbation of PTSD due to traumatic parenting experiences by COVID-19 related stressors (Tang et al., 2020). My study, however, provided evidence for parental well-being during COVID-19, which could facilitate research in the aftermath of this pandemic. Future studies can be implemented to investigate how to implement post-pandemic treatments for parents of children with DD, using findings from this study as a baseline.

Study Design and Sample. A second limitation consists of the use of a cross-sectional design instead of a longitudinal design and the recruitment of a convenience sample. Future research should consider using a longitudinal design to demonstrate the causal relations between the risk and protective factors studied here and PTSS and PTG outcomes. The next phases are to extend relevant research topics and facilitate the application of research by initiating evidence-based, patient-oriented support programs for parents who experience traumas in caring for their children. Such studies will be beneficial for clarifying the causation of PTSS and PTG among parents of children with DD, which my study was not able to uncover with the cross-sectional design.

The convenience sampling approach performed in this study has a limitation: representativeness of the sample cannot be claimed. In the future, representative national samples could be recruited to evaluate the reproducibility of the findings. Future research should utilize a sampling method with higher representativeness, such as stratified sampling.

Measures. Finally, there are some limitations to the measurement tools employed. The completion rate for my survey was 76.41% (460/602). Certain types of

DD might affect children's ability to interact with parents (e.g., hearing loss), so some questions in the parenting scale utilized in the present study did not apply to those parents. These caused relatively high levels of missing data in the PAFAS parenting scale (9.83% missing in all completers). In future, the applicability of the measures should be checked before launching studies in specialized populations. Research on the applicability of the PAFAS scale for parents of children with different types of disorders should be tested to inform future investigators.

The two author-constructed scales regarding parenting trauma experiences and barriers were only being initially validated. Neither of them was retested or validated in multiple samples. Further studies are required to evaluate the scales in multiple samples and cultural settings.

4.4 Implications of the Study

The current study has several implications. Firstly, the high prevalence of self-reported PTSD (58.2% as screened by a cut-off score in the PCL-5) among parents of children with DD suggests that, prompt efforts to provide diagnoses for these parents should be facilitated by the current healthcare system. For those who already have a diagnosis of PTSD, timely treatments should be delivered by doctors, psychologists, and other mental health practitioners to avoid long-term consequences of parental stress on parents themselves and their children. Health professionals with expertise in DD should be well informed that the treatments for children and the events children go through might also affect parental mental health and confidence to manage children's behaviors (Brookman-Frazee & Koegel, 2004). It is advisable that experts consider implementing a parent-clinician model instead of a clinician-directed model as it would be beneficial for both parents and children (Brookman-Frazee & Koegel., 2004). That means parents should actively engage in children's treatments and related decisions.

Secondly, the parenting trauma checklist provided a pathway to effectively identify individual specified challenges, which might have not been well-recognized in the existing literature and in health professionals (Stecker et al., 2013). The scale is a reliable, easily administered, and efficient screening tool to solicit and quantify traumatic experiences. It can be used by health care providers and the patient themselves to gain a better understanding of the experiences of the patients and to facilitate the establishment of adequate, efficient, personalized, and trauma-focused treatments.

Thirdly, this study brought a novel perspective for disability communities. Caring for children with DD were often deemed as burdensome, stressful, and challenging. This study suggests that these burdens were evident and that there was also a promoting role of parenting trauma on parental posttraumatic growth. Clinical personnel can apply this suggestion to their communication and therapeutic activities with parent patients. Dissemination of this finding may bring a sense of hope and self-efficacy to parent populations. Furthermore, a dose-response effect of parenting trauma on their symptomatology suggests that, in clinical settings, sole evaluation of general trauma might not be sufficient or effective; rather, the impact of multiple traumas should be seen as cumulative, and it is important to consider the full range of traumatic experiences a parent of a DD child may have had to endure. Evaluation of parenting trauma will bolster understanding of trauma pathology, especially for those with high exposure to parenting stressful events but not lifetime trauma events.

In addition, the barrier in help-seeking scale expands the current literature on barriers in potentially traumatized populations. My study found that, from an individual perspective, some parents might not feel emotionally ready for intensive treatments (e.g., one-on-one exposure therapies). This implies that some less intensive but more accessible support should be allocated. This includes information-based letters, websites, and pamphlets to ease parents' readiness for seeking help for their own mental health problems. The identification of these obstacles reduces the information gap between researchers/care deliverers and support seekers. Researchers and health care providers experience barriers to recruiting patients in their support programs and clinical trials (Donovan et al., 2014); meanwhile, patients might feel their barriers were not well-known or understood by researchers and practitioners. Thus, from a clinical perspective, this work fuels those efforts in patient-oriented care that aims to eliminate the barriers to seeking mental health care. From an institutional viewpoint, due to the adverse impacts of barriers, policymakers could introduce more health education programs to achieve two main goals. These include: (1) to reinforce public literacy on the evidence regarding psychological interventions, including their feasibility, effectiveness, and possible adverse impacts, and (2) to increase service availability by providing more accessible evidence-based interventions.

The positive influences of social support in both decreasing PTSS and elevating PTG imply that psychological treatments designed to enhance the accessibility of support networks are meaningful to maintain familial well-being and functioning. The difficulty towards strengthening social support is that it needs efforts from national and provincial institutions, mental health specialists, as well as the general public. One solution is to first enhance knowledge mobilization regarding parental challenges so that individuals and institutions have clues to offering emotional and material support to these parents.

4.5 Conclusion

In conclusion, the present study describes the situation of parents of children with DD pertaining to their PTSS, PTG, exposure to parenting and lifetime traumatic experiences, and barriers of help-seeking. Generally high levels of PTSS, moderate levels of posttraumatic growth, exposure to multiple traumatic events, and substantial barriers of accessing care were found. Two checklists with acceptable to good psychometric properties were established to assess parenting trauma and barriers to seeking help, respectively. From a nationwide sample, risk and protective factors of posttraumatic stress and growth were examined and the relative hypotheses were tested. Parenting trauma displayed both a detrimental influence on developing PTSS and a beneficial role in promoting PTG. Social support was protective for parents as it showed negative associations with PTSS and a positive association with PTG. Barriers (especially barriers in support accessibility and personal beliefs) were found to be a risk factor for PTSS, but were unrelated to PTG. Although negative parenting was weakly related to PTSS, it was not a key contributing factor to either PTSS or PTG. My study increased understanding of parents of children with DD. Findings from my study can be used to benefit the disability communities in various ways. It guided allocation of resources to prevent chronic consequences of their mental health challenges. It also warrants development of PTSD treatments that overcome the barriers to treatment (e.g. time, cost, distance). Strategies to overcome the perception that parents should not get treatment because their role is to care for their children will be required if available treatments are to be used.

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Appendix A: Supplementary Materials[1]

Supplementary File 1A – Study Flyer

Supplementary File 1B – Online Consent

Supplementary File 1C – Parenting Trauma Checklist

Supplementary File 1D – Barriers for Help-seeking Scale

Supplementary File 1E – Demographics

Supplementary File 1F – PTSD Checklist for DSM-5

Supplementary File 1G – Life Events Checklist for DSM -5

Supplementary File 1H – Posttraumatic Growth Inventory-Short Form

Supplementary File 1I – PROMIS Global Mental Health and Global Physical Health

Supplementary File 1J – The Multidimensional Scale of Perceived Social Support

Supplementary File 1K – The Konstanz INDEX-Adjusted Questions

Supplementary File 1L – Sheehan Disability Scale

Supplementary File 1M – The Parent and Family Adjustment Scales-Parenting Subscale

Supplementary File 2 – Additional Tables and Figures

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[1] The supplementary files are in additional attachments of the thesis; they are available at Dalspace.