Parental Responses to Child-Diagnosis of Neurodevelopmental Disorder

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Abstract

Parental responses range in presentation and severity after receiving a child-diagnosis of a neurodevelopmental disorder. Diagnosis-related grief is a form of living loss and is less comprehended by society, resulting in an unrecognized grieving process. Responses parents may experience include a struggle towards optimism, hope, and acceptance of the diagnosis and an inability to utilize functional coping mechanisms. In addition, parents may face adversities such as guilt, stress, blame, isolation, uncertainty, and beliefs of incompetency. Counselling implications in the following manuscript include psychoeducation, parent training, and peer support interventions towards fostering parental self-efficacy. Further research recommendations include continued exploration of long-term outcomes of ambiguous loss and chronic sorrow parents may experience after a living loss.

Keywords: neurodevelopmental disorder, grief and loss, ambiguous loss, chronic sorrow, child-diagnosis, parental responses, self-efficacy

Parental Responses to Child-Diagnosis of Neurodevelopmental Disorder

I believe that parenthood is an extraordinary blessing marked by the arrival of a child. The experience of bringing and fostering new life into this world, either biologically or through adoption, is a miracle. Parents dream of seeing their child reach milestones in early development such as learning how to crawl, walk, talk, and become more independent. However, what happens if that child does not reach these expected developmental milestones, either permanently, or within typical limits? Any delay in early child development could indicate the onset of a neurodevelopmental disorder. According to the American Psychiatric Association (APA, 2013), some specific neurodevelopmental disorders include autism spectrum disorder, attention deficit hyperactivity disorder, intellectual disabilities, specific learning disorders, motor disorders, and communication disorders. Within these conditions, impairments range from personal, social, cognitive, academic, and motor functioning or a combination thereof. Parents may face the loss of watching their child flourish or live the life they dreamed for their child to receive. Parents may face a life of uncertainty related to their child's prognosis resulting in a grief cycle that is not defined clearly by the literature. The uncertainty and longevity of grief after a neurodevelopmental diagnosis further complicates the experiences parents may have. In my exploration of scholary research, I sought to explore the literature regarding the marginalized, unrecognized, and disenfranchised grief and loss of parents after a child is diagnosed with a neurodevelopmental disorder.

We are all affected by grief and loss, which take on many different forms. Grief and loss in response to a scenario, such as the death of a parent, can be easily understood and empathized. Alternatively, grief is less understood for people who experience less tangible scenarios, such as someone who experiences the loss of a potential life. Living losses occur when an individual is

still physically present, but is emotionally or intellectually absent. Parents can experience unrecognized living losses after a child's diagnosis of neurodevelopmental disorder; their child is still alive, but their expectations and dreams they envisioned for their child are gone (Corcoran et al., 2017; Fernańdez-Alcántara et al., 2016). Parents might face uncertainty in their child's prognosis, independence, functioning, development, and intellectual and emotional intelligence (Bravo-Benítez et al., 2019). The purpose of this comprehensive literature review is to provide an in-depth understanding of the diverse parental responses and experiences in the aftermath of a child's diagnosis of a neurodevelopmental disorder, hereafter referred to as "child-diagnosis." Further research into parents' grief experiences post-diagnosis will help provide additional recognition and understanding to the protective factors, supports, interventions, and education needed for parents (Bravo-Benítez et al., 2019; Corcoran et al., 2017; Minnes et al., 2015; Wayment & Brookshire, 2018). All areas are crucial to understand how to best support the well-being of parents and normalize living loss.

The emotional and psychological experiences parents encounter after child-diagnosis can include ambiguous loss and chronic sorrow. Ambiguous loss is an uncertain and non-finite relational loss that society does not recognize; the loss is minimized or treated as less significant because it is a living loss (Boss, 1977, 1999; Bravo-Benítez et al., 2019). We can experience losses physically or psychologically, and ambiguous loss can be separated into these two categories. Physical ambiguous loss can include a child losing a parent due to divorce or a friend moving across the country. Psychological ambiguous loss can include the loss of a parent to Alzheimer's or the loss of a child to a neurodevelopmental disorder. Parents can become frozen in this living loss due to the ambiguity (Boss, 1999). An ambiguous loss can result in disenfranchised grief, which is a form of grief unacknowledged by society (Doka, 2002).

Chronic sorrow illustrates the ongoing, cyclical, and living loss of expectations, hopes, and certainty (Olshansky, 1962).. The concept was initially coined following research that analyzed parents of children with developmental disabilities. The ongoing loss and disparity between hope and reality differentiate chronic sorrow from more recognized forms of grief. Chronic sorrow can occur after a significant loss of self that is profound and re-occurring or a loss of another person with whom we bear a deep attachment. For example, the ongoing loss of an intimate connection, bond, and relationship a mother wishes and hopes to have with her child results in chronic sorrow. Mothers can experience a deep sense of grief and loss months after their child is diagnosed with a neurodevelopmental disorder (Mahmood et al., 2015; Wayment & Brookshire, 2018).

Ambiguous loss and chronic sorrow begin to illustrate the experiences of parents concerning diagnosis-related grief. These two definitions do not follow counsellors' traditional grief models (Bravo-Benítez et al., 2019). This comprehensive literature review seeks to deepen understanding and recognition of this unique form of grief thereby highlighting the experiences of unrecognized and marginalized losses.

Self-Position Statement

I firmly believe that our experiences influence our values, beliefs, and passions. As an individual diagnosed with a specific learning disability and who has a sibling with a motor disability, I have personal experience, understanding, and biases related to the topic of review. Throughout my comprehensive literature review, I will need to be mindful that though my experiences have guided me towards this field, there are diverse perspectives related to the topic. One diverse perspective, found in Zibricky (2014), depicts the potentially marginalized position of parenthood:

> On a cold November day in Chicago, a well-known child psychologist stated, 'Your son may never come to know you as his mother. Children with autism will usually see you as nothing more than an object.' These were the first words I remember when my son Cameron was diagnosed with autism over 15 years ago … The message was clear that I as a mother could simply exit his young life by leaving motherhood at the door. Since I became a mother of a disabled child, I have encountered the beliefs created by the authoritative institutions of society including the medical institution, educational system and legal structure of society. These authoritative institutions create knowledge which the dominant culture of society then takes up as truth. (p. 39)

Though this is just one voice, it is a powerful representation of the marginalized, unrecognized, and disenfranchised grief parents may experience in the aftermath of their child being diagnosed with a neurodevelopmental disorder.

Concerning parenthood, I have an outsider's perspective; however, I have an insider's perspective on the research topic as an individual with a neurodevelopmental disorder. I also have the perspective of being a sibling to a brother with a neurodevelopmental disorder, and all three perspectives may influence my review of the literature and how I arrived at this research topic. I witnessed the challenges my parents encountered while raising two children with diverse needs; I did not comprehend the feelings of hopelessness, isolation, guilt, and blame they experienced. When completing my review, I will need to be mindful. I do not gather evidence to simply support my lived experiences; instead, I seek to incorporate diverse parent responses.

My personal experiences influenced my career choices and professional path. As someone who works as a family support worker for families with children diagnosed with autism spectrum or global developmental disorders, I recognize the potential for professional biases. My

work with these families allowed me to get a glimpse into their lives. After witnessing and listening to parental struggles, I realized their shared experiences of grief, loss, and sorrow. I also noted some protective factors. While in this professional position, I realized and appreciated the importance of appropriate and accessible support for parents and the impact normalizing and recognizing their losses would serve towards their well-being. I believe recognition of ambiguous loss has the potential to minimize experiences of hopelessness, isolation, guilt, and blame.

It is a personal presumption that all families view their child's diagnosis as a loss. I will need to consider the personal and professional biases I hold regarding neurodevelopmental disorders and create space to explore and acknowledge alternative perspectives. Disability culture is a prominent movement that advocates for inclusion and moves away from recognizing cognitive, physical, or emotional disability as a difference that perpetuates discrimination and isolation (Andrews et al., 2019). Disability culture embraces disability as an identity—not as a loss—and welcomes interdependence and the diverse ways individuals move through and experience life. To reduce my personal and professional biases during my comprehensive literature review, I will need to not generalize experiences. Just like every individual with a neurodevelopmental disorder is different, each parent experiences the diagnosis differently. The following literature review seeks to understand grief and loss manifestations, the experiences, and the presence and absence of ambiguous loss and chronic sorrow.

Literature Review

The following comprehensive literature review will deepen understanding and recognition of the unique form of grief experienced by bereaving parents after child-diagnosis, highlighting the significance of diverse parental responses and the need for acknowledgement.

The literature regarding a child diagnosis of neurodevelopmental disorders is broad in nature and scope. This literature includes research on child self-efficacy, parental explanations for diagnosis, overload, respite care, life transitions, adaptions throughout the lifespan, and effects on marriage, siblings, and grandparents. For the following literature review, I focused primarily on diverse parental responses after child-diagnosis. From the literature I examined, a significant theme that emerged was ambiguous loss, and, more specifically, subthemes such as identity ambiguity, guilt, and stress. I investigated what the literature stated regarding chronic sorrow and perceived losses, experiences of disrupted expectations, and parental isolation. I examined resiliency after child-diagnosis, incorporating Walsh's (2003) family framework of resilience, including belief systems, organizational patterns, and communication skills. Walsh defines resilience as an individual's ability to overcome challenges in life. The literature I reviewed also discussed adverse outcomes, protective factors, and gender differences in grief and loss experiences.

Conceptual Framework

Western conceptualizations of grief and loss perceive the grief process as an individualistic, primarily private, and intrapsychic process (Neimeyer et al., 2014). In contrast, the conceptual framework of the following literature review will be from a social constructionism perspective. Social constructionism is a theory that examines the creation, or construction, of meaning and understanding that form our assumptive reality (Berger & Luckmann, 1966). Social constructions, or assumptions on reality, are developed jointly and in coordination with our environment. In social constructionism theory, the belief is that knowledge is made or constructed through conversation and interaction. Interactions with others and the meaning this creates is a fundamental principle of social constructionism. Responses to grief and

loss result from societal norms and prevailing social order; social discord occurs when our responses do not align with social constructs. In social constructionism, we create narratives of loss through seeking meaning in our familial, community, and cultural spheres (Neimeyer et al., 2014). Through the lens of social constructionism, social processes such as advocacy, awareness, and psychoeducation may support parental responses to grief and loss (Flynn, 2019). The literature that follows will illustrate how our assumptive realities and the construction of meaning about diagnoses determine our experience and responses.

Models of Parenting

In my exploration of the literature, I examined research relating to models of parenting. I recognize there are numerous frameworks and theories that explain parenting models and styles. For the circumstances of my literature review, I will focus on and briefly outline attachment theory, parent-child bonds, and interactions. Attachment theory focuses on psychological connectedness, relationships, and bonds individuals create with one another, like a parent's relationship with a child (Bowlby, 1969). The theory identifies four patterns of attachment created in early childhood development as a result of parent-child interactions. These patterns include ambivalent attachment, avoidant attachment, disorganized attachment, and secure attachment. Ambivalent attachment occurs when a child has inconsistent care; their parents may appear preoccupied or emotionally unavailable. Children with ambivalent attachment are resistant and dependent. They may experience pervasive anxiety about not being loved and experience a lack of confidence. Avoidant attachment can manifest when parents have an anxious parenting style and may force their child into independence. Avoidant children internalize emotions, distress, and needs, suppressing their need for attachment. When parents experience dysregulation, are absent emotionally from their children in times of need, or have

unresolved states of mind, they can promote a disorganized attachment. Children who experience a disorganized parenting style may experience impaired psychosocial development (Howe, 2006). Children develop a secure attachment when their parent, or attachment figure, creates and models a secure base. A parent can model a secure base for their child by providing a safe, consistent, sensitive, regulated, and emotionally available bond (Al-Yagon, 2018; Howe, 2006; Lai & Carr, 2018).

Neurodevelopmental Disorders

Parents may experience an added barrier to creating a secure base, strong parent-child bonds, and interactions if their child is diagnosed with a neurodevelopmental disorder (Al-Yagon, 2018; Howe, 2006). Child factors, including diagnoses, affect parental stress levels and may impact the creation of an organized and secure base. A parent may be unable to recognize their child's needs, represent themselves as emotionally unavailable, and act insensitive to their child if there is miscommunication or lack of understanding. Parents may develop a perception that they are unable to care for their child; they may react defensively, experience emotional dysregulation, experience a lack of confidence, or appear to provide their child with inconsistent care. Parents may encounter feelings of incompetence or an absence or weakening of a parent-child bond.

Executive Functioning. In my exploration of literature regarding models of parenting, specifically the parent-child bond, research discussed how executive functioning difficulties might affect the creation of secure attachment (Al-Yagon, 2018). Specifically, the research speaks to executive functioning impairments that children may experience with attention deficit hyperactivity disorder, a neurodevelopmental disorder (American Psychiatric Association, 2013).

Authors in the literature note a moderate relation between executive functioning impairments and disorganized attachment (Al-Yagon, 2018; Salari et al., 2017).

Family Systems

My literature exploration also examined how parental experiences of grief and loss can affect the family unit. There are various family interaction models; for this literature review, I will focus on Bowen's (1978) family system theory. Bowen noted that the emotional dysfunction of one individual in the family system affects the system as a whole. Dysfunction within the familial unit occurs when family members experience fusion. According to Bowen, fusion occurs when an individual reacts emotionally, lacks flexible thinking, and experiences anxieties and fears related to emotional separateness. Levels of chronic anxiety correlate with higher levels of fusion and the inability of family members to differentiate themselves from the system. Differentiation of self occurs when a family member can withstand conflict and separate themselves emotionally and intellectually from their familial unit (Haefner, 2014). In family systems, the primary mechanisms for managing chronic anxiety include: marital disharmony, health or emotional problems, and triangulation of other family members.

Triangulation, or triangles, is a three-person relationship that attempts to stabilize anxiety experienced in a dyad (Bowen, 1978; Haefner, 2014). A key process in family system theory is first assessing then relieving anxiety within the system. Triangulation occurs when tension between two people in the family develops, and the anxiety is relieved by bringing in a third person. For example, if the parents or caregivers are experiencing difficulties in aligning on parenting techniques, they may bring in a third person to relay communication through, like another family member. Triangulation spreads out tension within the family and can stabilize the system. The following literature review supports the family system perspective that both mother

and father experiences, responses, and functioning contributes to child development. Family system theory is an essential concept to consider when assessing the impact of a child's diagnosis on family dynamics, parent-child bonds, and differentiation of self.

Traditional Grief Models

The following literature review will highlight traditional grief models' limitations and strengths to describe parents' potential grief and loss process after child-diagnosis. Traditional models of grief focus on loss after death but do not describe the process of living losses, which are not as tangible or overt (Bravo-Benítez et al., 2019). Models that focus specifically on death and overlook non-death losses limit diverse grief responses' scope and depth. One traditional model of grief and loss proposes a five-stage response. The five stages include denial, anger, bargaining, depression, and acceptance (Kubler-Ross & Kessler, 2005). Traditional models do not recognize processes specific to living loss, such as ambiguous loss, identity ambiguity, stress, chronic sorrow, parental demands, isolation, and resilience.

Though traditional models do not incorporate marginalization and unrecognized losses in their framework, in my exploration, I noticed an overlap between parents' lived experiences after child-diagnosis and the five stages of grief (Bravo-Benítez et al., 2019; Coughlin & Sethares, 2017; Fernańdez-Alcántara et al., 2016; Wayment & Brookshire, 2018). Parents experience various reactions after child-diagnosis, including shock, denial, anger, and a proactive attitude (Bravo-Benítez et al., 2019). Their reactions are similar to those experiencing a death-loss. Traditional models of grief and loss seem to provide a foundation for further understanding of living losses. The following sections will highlight processes specific to living loss experiences and build on the groundwork created by traditional frameworks.

Ambiguous Loss

A child-diagnosis of a neurodevelopmental disorder is a form of ambiguous loss, which is a living loss not recognized by society because the child appears healthy and physically present (Boss, 1977, 1999; Bravo-Benítez et al., 2019). The grief parents experience manifests internally in response to a child-diagnosis. They are denied a grieving process due to societal constructs that decide what constitutes "loss." The ambiguous loss parents experience appears in the literature through common subthemes, including identity ambiguity, guilt, and stress.

Identity Ambiguity

Identity ambiguity is the loss of one's identity and self to a child's disability (Boss, 1999; O'Brien, 2007; Wayment & Brookshire, 2018). When identity ambiguity occurs, the parent-child bond is lost; preoccupation with a child's well-being replaces parental roles and interpersonal bonding. From a family systems perspective, parents preoccupied with their child's well-being is a mechanism to reduce chronic anxiety and an indicator of fusion within the system (Bowen, 1978). Fusion can lead to further family dysfunction and emotional dependence (Haefner, 2014). Parents may experience ambiguity in setting emotional and physical boundaries and difficulty deciding where their responsibility as parents starts and ends, resulting in inconsistent parenting. When parents become preoccupied, their child may experience ambivalent attachment due to inconsistent care or parental emotional availability (Howe, 2006; Lai & Carr, 2018). Ambivalent attachment could present as a lack of confidence, feelings of being unloved, pervasive anxiety, and preoccupation with attachment figures (Bowlby, 1969; Howe, 2006; Lai & Carr, 2018).

The inability to separate one's own identity from their child's affects other parental decision-making processes, including employment, social connection, and community. Parents may quit their job to focus more on their child's care and become socially isolated (Wayment & Brookshire, 2018). Identity ambiguity positively correlates with parental distress and is a

predictor of depression in mothers; in this case, “distress” refers to a measure of anxious and depressive mood (O'Brien, 2007; Wayment & Brookshire, 2018). The literature I reviewed showed that the higher level of identity ambiguity a parent may experience after diagnosis results in higher parental distress and depressive symptoms.

Identity ambiguity can result in the loss of typical family dynamics present before the diagnosis, as families tend to adapt to the child's needs (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Nordin & Husain, 2020). Fernańdez-Alcántara et al. (2016) describe an example of changes to family dynamics:

> We have learned to be more patient; well, it has been useful for us to clarify our ideas a bit, because the thing is like I didn’t know how to think very well, it’s as if you had to structure things, learn step by step. Before, a lot had to be more done in advance. (p. 318)

From the literature I reviewed, the authors indicate positive and negative changes in the family dynamic post-diagnosis. Potential positive changes include increased daily support, therapies, improved patience, structured schedules, and enjoying the small things in life (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Nordin & Husain, 2020). Potential negative changes, or adversities, include avoiding social situations, withdrawal, sleep problems, and marital disharmony. Marital disharmony is a mechanism of dealing with chronic anxiety as a result of a lower differentiation of self (Haefner, 2014). Families can get caught in a cycle driven by a preoccupation with the disorder and child behaviours (Bravo-Benítez et al., 2019; Heiman, 2002). Parents find themselves experiencing significant changes in their social life and feeling frustrated and dissatisfied. For example, some parents say “I don’t spend time on myself. I have long hair because I can’t go to the hairdresser” (Bravo-Benítez et al., 2019, p. 10).

Guilt

The cause of neurodevelopmental disorders, such as autism spectrum disorder, is not evident in the literature (Wayment & Brookshire, 2018) or in medical research. Without an etiological explanation, many parents blame themselves for their child's diagnosis and may take responsibility for the atypical neurodevelopment. Parents may take on guilt for not recognizing symptoms sooner or for not receiving earlier or preventative care (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Heiman, 2002; Wayment & Brookshire, 2018). Parents may become overloaded and stressed finding themselves unable to fulfill all the demands and responsibilities they believe they must take on, which results in guilt. Society perpetuates the feelings of guilt, criticizing parents for their lack of skills, care, and upbringing of their child (Bravo-Benítez et al., 2019).

Stress

The transactional model of parenting behaviours was evident in the literature I reviewed regarding stress, illustrating the triadic interactions between psychological, sociological, and environmental characteristics resulting in parental stress (Abidin, 1990). Abidin (1990) developed the Parenting Stress Index, which measures parent characteristics, child characteristics, and demographic factors. Numerous studies in the literature utilize or discuss this measurement to determine parental distress after child-diagnosis (Almogbel et al., 2017; Craig et al., 2016; Jijon & Leonard, 2020; Lai et al., 2015; Minnes et al., 2015; O'Brien, 2007). The findings indicate that parental distress is significantly higher when a child has a neurodevelopmental disorder than a child developing within the normal range (Almogbel et al., 2017; Bravo-Benítez et al., 2019; Corcoran et al., 2017; Heiman, 2002; Lai et al., 2015). There are several contributing factors to how parents experience distress related to child-diagnosis,

including the level of child impairment, parental demands, prior parental health conditions, and diagnostic uncertainty level.

Child Impairment. According to the literature I examined, the distress parents experience further increases when a child has a significant cognitive impairment and a lower autonomy level (Almogbel et al., 2017; Craig et al., 2016; Lai et al., 2015). More significant tensions and difficulties in the parent-child relationship occur as behaviour manifests and impairment intensifies. Neurodevelopmental disorders may vary in functional severity throughout the child's lifespan, even within diagnoses (Almogbel et al., 2017; American Psychiatric Association, 2013; Leone et al., 2016). Parents receiving the same child-diagnosis may experience different levels of child impairment and parental distress. Distressing emotional states parents may experience due to child functioning include anxiety, desperation, and guilt:

> My stomach would churn with nerves and I'd think, 'He's going to come out in a minute and it will start.' I was like that for years. He'd come out and he'd be like a dynamo. I could do nothing with him. I had this constant stress. (Corcoran et al., 2017, p. 328)

Another participant shared:

> I understand the behaviour, but sometimes it comes to a moment that I myself feel like I cannot put up with it, you know, like it's too much. And I feel like, 'What am I suppose to do?' because it comes to a point, you don't know what else to do. (Corcoran et al., 2017, p. 328)

A participant from Corcoran et al. (2017) further explains:

> I want to love my child but you feel like there's times when I could almost hate him. You feel like you hate the child because of their behaviour and when you find out it's something that they can't help, you feel guiltier. (p. 328)

Parental Demands. Demands of a child with a neurodevelopmental disorder could include emotional, physical, and economic supports. The potential incongruency in parental demands versus resources and available supports for the child is another contributing factor to distress (Almogbel et al., 2017; Bravo-Benítez et al., 2019; Parsons et al., 2019). Parental distress is negatively associated with resources and positively associated with higher demands. The defining features of parental distress include the demands of being a parent and the perceived parenting role. These demands cause adverse psychological reactions, maladaptive functioning, and decreased well-being.

Gender Differences. The literature in the review highlights gender differences in parental distress and demands. It is important to note that the research reviewed only discussed cisgender individuals and may not account for trans or non-binary individual experiences. Fathers report less overall parental distress than mothers, which the literature indicates could be due to the differences in the resources they provide the child and perception of stress related to parenting roles (Almogbel et al., 2017; Craig et al., 2016). Fathers tend to see their parenting role by providing financial resources such as finances to aid in school, food, and therapy demands (Mahmood et al., 2015). Fathers may feel overburdened to provide financial support, whereas mothers may perceive their role as catering to the child's emotional and adaptive needs. In the literature reviewed, mothers are often represented as the primary physical and emotional caregiver, and the population research tailors toward. However, the family system research advocates that both mother and father experiences are equally important when exploring child development and familial functioning (Cabrera et al., 2018). The focus on fathers being secondary parents or simply financial providers does not reflect all fathers and families' lived experiences or perceptions.

Prior Parental Health Conditions. Historically, authors have noted it is not the parent's psychological characteristics that determine distress response but the ambiguity and uncertainty of the child-diagnosis (Boss, 1999; O'Brien, 2007). However, current literature provides evidence illustrating how prior parental health correlates with their distress response to a child-diagnosis. Research findings concluded that parents who have a prior mental health disorder or a physical disease experience higher parental distress levels (Almogbel et al., 2017; Wayment & Brookshire, 2018).

Diagnostic Uncertainty. Ambiguous loss relates to various emotions including uncertainty. Parents can experience uncertainty in their child's diagnosis, prognosis, daily functioning, independence, and development (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; O'Brien, 2007). Mothers report feeling as though they are on a rollercoaster, alternating between feelings of hope and hopelessness, control and helplessness, and stability and inconsistency (O'Brien, 2007). Mothers who reported their child was displaying varying changes in their autonomy also reported being consistently uncertain and concerned. Most parents report that the uncertainty of their child's diagnosis is more challenging to adapt to than a child's death due to unpredictability (Bravo-Benítez et al., 2019). A criterion of neurodevelopmental disorders is the onset of adaptive functioning deficits during the developmental period (American Psychiatric Association, 2013). As children reach specific milestones, there is a developmental expectation of a certain level of functioning. At each stage of development, parents remain uncertain at what level their child will function independently and what impact their disability will have on their ability.

Adverse Outcomes and Protective Factors

The literature I reviewed also indicates adverse outcomes and protective factors for parents raising a child with a neurodevelopmental disorder. Results of parenting a child with a neurodevelopmental disability can include higher health problems and disease for caregivers, including depression and anxiety (Heiman, 2002; Lai et al., 2015) and lower quality of life (Bravo-Benítez et al., 2019; Parsons et al., 2019). Health problems also impact parent-child bonds and the development of positive relationships with a child (Jellett et al., 2015; Leone et al., 2016). Protective factors include higher education, such as parents who have university degrees, which significantly reduces parental distress (Almogbel et al., 2017; Mahmood et al., 2015). Parental responsibility outside of a child-diagnosis, such as a job, was negatively associated with identity ambiguity and distress. An increase in social support was also associated with less parental distress (Jijon & Leonard, 2020; Pottie & Ingram, 2008; Wayment & Brookshire, 2018). Mediating factors noted in the literature include positive parent perceptions of their child's diagnosis, resulting in a mediated relationship between adverse outcomes such as stress and overall parental adjustment (Leone et al., 2016).

Chronic Sorrow

Parents envision a life for their children filled with opportunity, growth, joy, and ability. The ideal life parents' hope for their child may disappear with the profound realization that their child may not reach expected milestones. Parents can experience loss, failure, guilt, and resentment for losing their ideal child (Bravo-Benítez et al., 2019; Corcoran et al., 2017; Coughlin & Sethares, 2017; Fernańdez-Alcántara et al., 2016; Wayment & Brookshire, 2018). Chronic sorrow is the phenomenon first conceptualized by Olshansky (1962) to illustrate the cyclical loss parents experience after a child-diagnosis. The disparity between child capabilities and parental hopes for their child's future, independence, and functioning determines chronic

sorrow experiences. Therefore, perceptions and severity of diagnosis are essential to explore (Wayment & Brookshire, 2018). Though parents face loss at each developmental or expected milestone and life transition (Coughlin & Sethares, 2017), the following review will focus on the initial losses, including perceived loss, disruption of expectations, and isolation.

Perceived Loss

The literature illustrates two ways that parents may perceive a loss after a child-diagnosis. The first perceived loss is the loss of their ideal child (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016). Parents may experience losing their ideal or hoped-for child and expectations after child-diagnosis. Disrupted expectations include the child's expected future, functioning, independence, and family dynamic. The family functioning changes to adapt to child needs, revolving around their behavioural and emotional characteristics. Expectations fluctuate, as children may experience diverse functioning and independence depending on the situation or task. The fluctuations illustrate the cyclical nature of chronic sorrow and the ongoing pain experienced in grieving the diagnosis. Families note the difference between grieving a death and grieving an uncertain diagnosis are the periods of acceptance contrasted with the moments of pain and sadness. Some parents note grieving from a diagnosis is different from grieving a death:

> It's not the same to me. Grieving for a diagnosis of [autism spectrum disorder] is a cycle of grief that you enter and exit continuously. Each stage of the child's development makes you worry about some things and it makes you grieve again. (Bravo-Benítez et al., 2019, p. 9)

The second perceived loss is the unexpected loss of a child due to diagnosis (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016). Many neurodevelopmental diagnoses are not certain until later developmental years; therefore, parents may grieve the loss of the child

they lived with before the diagnosis. Parents may face the loss of their healthy child and replace it with ambiguity related to an uncertain prognosis and development. Loss is a subjective experience, and parents may perceive a diagnosis differently either as losing their ideal child or unexpected loss of a child. In either case, grief and chronic sorrow still manifest.

Isolation

Isolation is another subtheme noted in my literature findings related to chronic sorrow. One study found that primary caregivers, primarily mothers, of a child with a neurodevelopmental disorder experience isolation during the child-rearing process (Bravo-Benítez et al., 2019). Stigmatization parents experience during social interactions reinforces isolation and marginalization (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Lai et al., 2015). Other authors found that the whole family experiences isolation, including the child with a neurodevelopmental disorder (Mahmood et al., 2015). Parents may partake in numerous isolation tactics to cope with stigma and the inability to grieve publicly, including social isolation, isolation from family, and detachment from the child. When parents isolate, they avoid networking with others and stop seeking social support, and a lack of social support is positively associated with distress (Jijon & Leonard, 2020; Wayment & Brookshire, 2018).

Gender Differences

The literature regarding chronic sorrow in parents illustrates that a mother's experience differs from a father's (Coughlin & Sethares, 2017). In my literature review, mothers experience more sorrow than fathers; their sorrow is permanent, whereas the fathers can resolve their grief. Fathers are more likely to overcome experiences of grief and adjust to their child’s diagnosis over time through resignation (Coughlin & Sethares, 2017). More often, mothers experience periods of acceptance and recurrences of sorrow. Though stereotypical parenting roles have

changed over the years, the literature indicates mothers continue to be primary caregivers of their children. As the primary caregiver, mothers encounter daily reminders of the grieving process' cyclical nature and what they have lost. The literature views the father as taking a secondary role in their child's care (Fernańdez-Alcántara et al., 2016).

Resilience

Despite the challenges caregivers face while raising a child with neurodevelopmental disorders, including depression as the most significant factor in compromising resilience (Jellett et al., 2015), the literature highlights families' ability to cultivate resilience (Bravo-Benítez et al., 2019; Leone et al., 2016). The literature I examined regarding resilience after child-diagnosis referred to self-efficacy (Bandura, 1977, 1997; Bender & Ingram, 2018) and Walsh's (2003) family resilience framework when discussing resiliency. Self-efficacy is the perceived ability to accomplish a desired task and perform successfully (Bandura, 1977, 1997). In my exploration of the literature, self-efficacy appears to be a predictor of resilience (Bender & Ingram, 2018; Collishaw et al., 2015). Efficacious beliefs about our abilities promote resilient attitudes, behaviours, and outcomes. Further exploration of self-efficacy will occur in the section regarding implications and recommendations for the field of counselling to promote when working with parents experiencing ambiguous loss and chronic sorrow.

Walsh's (2003) family resilience framework outlines three processes leading to resilience in the family: belief systems, organizational patterns, and communication skills. The family's ability to undergo these processes effectively determines their ability to deal with adverse life circumstances and achieving family and individual resilience (Bravo-Benítez et al., 2019; Walsh, 2003). The following sections will attempt to highlight the three processes leading to family resilience.

Belief Systems

Positive belief systems in families were a significant indicator of resilience, including positive perceptions of the child's disability, acceptance, meaning-making, and social supports (Bravo-Benítez et al., 2019; Leone et al., 2016; Mahmood et al., 2015). Spiritual connections or religion were not significant resilience indicators (Leone et al., 2016; Minnes et al., 2015). The authors note that spirituality or religiosity may not capture the complexities of ambiguous loss and chronic sorrow (Leone et al., 2016; Minnes et al., 2015).

According to the literature I examined, positive parental perceptions of a child-diagnosis acted as a mediating factor between parental distress and family adjustment (Leone et al., 2016; Minnes et al., 2015). When parents accepted their child's diagnosis, they could take on positive perceptions and seek solutions and support (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Heiman, 2002). The literature indicates that once parents come to terms with their child's diagnosis, they can adapt their idealistic family dynamics and future expectations. During the acceptance process, parents can indicate the diagnosis' positive outcomes through meaning-making, including changes in values, development of patience, and increased appreciation for family. The literature I reviewed found a correlation between normalizing loss after a child-diagnosis and parents' acceptance process (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016). Child-diagnosis of a neurodevelopmental disorder is a cyclical loss; therefore, acceptance is an ongoing process, and the obstacles families face and overcome are constant. Parents are more likely to navigate community supports when they perceive their child's diagnosis with optimism and hope. However, the literature I reviewed indicated a gap in a sufficient understanding of mediating factors when social support is not accessed (Leone et al., 2016).

Organizational Patterns

Organizational patterns are the second process leading to resilience (Walsh, 2003). Three dimensions create organizational patterns in families: flexibility, connectedness, and social and economic resources (Walsh, 2006). Resilience within families occurred when parents were flexible and nurturing in their parenting style (Leone et al., 2016; Walsh, 2003). The literature I investigated found that parents who relied on restrictive boundaries and authoritarian parenting styles experienced increased distress and feelings of inadequacy (Leone et al., 2016). Connecting to the community and not isolating from society is another vital factor to resilience (Walsh, 2003; Wayment & Brookshire, 2018). Social support negatively correlates with social strain and distress (Wayment & Brookshire, 2018). Financial responsibility is a significant contributing factor to distress in parents raising a child with a disability. Parents who had reduced financial burden and more economic opportunity experienced less emotional distress (Bravo-Benítez et al., 2019; Heiman, 2002; Leone et al., 2016; Mohan & Kulkarni, 2018). However, social and economic resources were not indicators of family resilience (Leone et al., 2016; Walsh, 2003, 2006). The literature reviewed indicated that resources can promote resiliency but are not a significant determining factor.

Communication Skills

The final process Walsh (2003) outlined that leads to family resilience is communication skills. Parental distress is directly associated with ineffective and disruptive communication patterns and was a significant barrier to family resilience (Jellett et al., 2015; Leone et al., 2016; Walsh, 2003). Communication skills within the family dynamic include expressing needs, seeking support, and constructive problem solving (Bravo-Benítez et al., 2019; Heiman, 2002; Lai et al., 2015; Nordin & Husain, 2020). I will further explore Walsh's three communication

skills by incorporating the transactional model of distress and coping (Lazarus & Folkman, 1984), evident in the literature I reviewed regarding resilience.

Transactional Model of Stress and Coping. The transactional model of stress and coping (Lazarus & Folkman, 1984) is the literature's predominant coping framework. The authors categorize coping into a distinct process: the event or stressor (e.g., a child-diagnosis), parental factors, personal resources (e.g., income), situational factors, and coping responses. Coping mechanisms or strategies are commonly utilized when parents encounter significant child demands or needs. If a coping strategy does not meet the demands or is maladaptive, parents may face further distress (Almogbel et al., 2017; Bravo-Benítez et al., 2019; Isa et al., 2017; Parsons et al., 2019).

Coping responses can be problem-focused or emotion-focused (Mahmood et al., 2015; Nordin & Husain, 2020). The research found that all parents of children with neurodevelopmental diagnoses utilize some form of problem-focused coping, including planning, seeking support, and educating themselves on the diagnosis. When mothers increased their knowledge of their child's diagnosis, they felt validated and capable of managing their child's disorder (Mahmood et al., 2015). More than half of the parents in the literature practiced emotion-focused coping (Nordin & Husain, 2020). Emotion-focused responses include seeking emotional support, acceptance, expression of emotion, enhanced spirituality or religious practices, and positive reframing. Though religiosity and spiritual connections were not an indicator of resilience, the literature shows these positive coping strategies as strong predictors of less parental distress (Isa et al., 2017; Leone et al., 2016). Religion or spirituality can be a significant source of social and emotional support for families and help parents develop new meaning in their child's diagnosis. The most common coping responses for parents with children

diagnosed with neurodevelopmental disorders are seeking social support and engaging in positive reframing (Lai et al., 2015; Nordin & Husain, 2020).

Gender Differences. There are notable gender differences illustrated in the literature. One study I reviewed found that fathers will engage in problem-focused coping, as they lean towards dealing with a crisis by involving cognitive and behavioural strategies to change the situation (Mahmood et al., 2015). For example, fathers work more hours to alleviate the financial burden. Mothers will engage in emotion-focused coping and involve social support and increase communication in response to a crisis.

Considerations. Problem and emotion-focused coping responses saturate the literature; however, studies state that grouping coping responses into these two categories is too broad and leaves out conceptual distinctiveness (Pottie & Ingram, 2008). Alternatively, the literature categorizes coping responses into positive coping and negative coping responses (Mahmood et al., 2015; Pottie & Ingram, 2008). Positive and negative coping strategies align with factors that associate with resilience and parental distress. Positive coping strategies include integration, social connection, and spirituality, which are also predictors of resilience. Negative coping strategies include avoidance, ignorance, and isolation, which are factors resulting in parental distress.

Summary

The comprehensive literature review focused on specific parental responses after a child is diagnosed with a neurodevelopmental disorder. The literature I reviewed starts to paint a picture of parents' lived experiences and their diverse responses. Parents may experience ambiguous loss characterized by unrecognized loss as their child is still physically present (Boss, 1977, 1999; Bravo-Benítez et al., 2019). The grief parents experience relating to the loss of their

ideal child, or the child before the diagnosis, is cyclical, resulting in chronic sorrow (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Olshansky, 1962). Parents' struggle towards optimism, hope, acceptance, and coping is perpetuated by society condemning a living loss as a grief experience. Stigmatization of the loss can result in isolation and guilt (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Lai et al., 2015; Wayment & Brookshire, 2018). Much of the literature explored attends to a mother's experience, her perceptions of loss, and protective factors leading to resilience (Coughlin & Sethares, 2017; Fernańdez-Alcántara et al., 2016; Mahmood et al., 2015). I further explored resiliency factors through Walsh's (2003) framework of family resilience, where positive perceptions, flexibility in parenting styles, social supports, and coping strategies proved to be significant contributing factors. I reviewed the transactional model of stress and coping, and I investigated what coping strategies predict resilience and are negatively associated with parenting distress (Lazarus & Folkman, 1984).

The literature review illustrates how our assumptive reality and social constructions determine experience and response to loss. Though there is overlap between traditional models of grief and loss and the experiences of living losses, there are sufficient deficits in the frameworks. Comprehensive grief and loss frameworks should include living losses, as traditional models continue to marginalize unrecognized losses sustaining the cycle of grief.

Implications and Recommendations for Counselling Psychology

The literature I explored acknowledged the unique and often unrecognized form of grief parents might experience after their child is diagnosed with a neurodevelopmental disorder. The review deepened understanding and recognition of ambiguous loss and the chronic sorrow parents experience often and in silence. Implications across the literature I found recognized the importance of working with parents to increase validation, normalize their concerns, reinforce

the demand for social support parents can access, and strengthen parental self-efficacy. The following manuscript sections will encourage professionals to continue to enhance their competencies and knowledge of how to best support parents and families experiencing a living loss specific to diagnosis-related grief. Across the literature examined, research shares similar limitations regarding the following areas: the trajectory of family outcomes, dedication to father responses and experiences, and attention to diversity and multiculturalism. Thus, how competencies and knowledge of the counselling psychology field can further be broadened and developed through future research will be presented. Additionally, I will discuss the importance of future research needed to enhance understanding of ambiguous loss and chronic sorrow and to explore the role of parental self-efficacy in living losses. In the following sections, I will establish guidelines for implications, recommendations, and next steps for counselling psychology research based on the literature reviewed.

It is important to note that the following implications and recommendations are not specific to one area of counselling psychology, as all competencies may interact with parents or families affected by a living loss. A marriage counsellor may come across a couple dealing with marital conflict, communication issues, and unmanageable caregiver demands. A school counsellor may have numerous sessions with parents to discuss their child's behavioural issues at school. A grief counsellor may adopt traditional grief models to work with a mother grieving the loss of the dreams she once had for her daughter. A family counsellor may recognize parents projecting their problems and dysfunction onto their child. It is crucial counsellors are cognizant and knowledgeable in identifying the emotional impact of ambiguous loss and chronic sorrow so that parents can receive appropriate resources and support. The literature reviewed highlights the

importance of providing parents compassionate care, emphasizing acceptance, and fostering parental self-efficacy.

Self-Efficacy

In the aftermath of a child-diagnosis of a neurodevelopmental disorder, parental stress might rise due to several contributing factors: how they perceive the child-diagnosis, level of child-impairment, parental demands, and diagnostic uncertainty (Almogbel et al., 2017; Bravo-Benítez et al., 2019; Craig et al., 2016; Fernańdez-Alcántara et al., 2016). Stress, guilt, anger, and sadness parents may experience can become internalized as society may not recognize their grieving process. Practitioners in the field of counselling psychology can work with parents to externalize these feelings, validate emotions, normalize their experiences of ambiguous loss and chronic sorrow, and enhance intrinsic resilience factors through parental self-efficacy.

Bandura (1977) first coined the term self-efficacy. Bandura describes self-efficacy as the ability to perform a task based on personal, environmental, and behavioural factors. Self-efficacy is based on an individual's beliefs about themselves and how their perceptions affect their ability to perform. Four sources develop and enhance efficacy beliefs; these sources include performance accomplishment or mastery experiences, vicarious experiences, verbal persuasion, and emotional and physiological states (Bandura, 1977, 1997). Mastery experiences are powerful experiences that show individuals they can succeed and overcome obstacles through determination and perseverance. Vicarious experiences occur when people observe others around them and start to believe that they possess the abilities to succeed and master a task. Vicarious experiences most often occur with people we perceive as role-models. Verbal persuasion enhances self-efficacy by receiving mentorship from influential people such as teachers, psychologists, or people who have gone through similar experiences, strengthening our belief

that we will succeed. The final source of self-efficacy is emotional and physiological states. Physiological arousal is based on interpretation of a situation, especially if the source of arousal is an ambiguous situation where the resulting arousal response is dependent on our perceptions. Stress, emotional dysregulation, and other symptoms of poor mood can impact our capabilities and perceived efficacy. Fostering positive emotional reactions can bolster confidence in skills, performance, and self-efficacy.

Parental self-efficacy highlights parents' beliefs regarding their ability to perform parenting roles, duties, and demands successfully (Wittkowski et al., 2017). If parents are continually ashamed, stressed, guilted, isolated, and uncertain because of their child's diagnosis, programs should lend themselves to targeting parental competency and improving well-being (Jijon & Leonard, 2020; Minnes et al., 2015; Mohan & Kulkarni, 2018). Enhanced self-efficacy for parents experiencing ambiguous loss and chronic sorrow because of a living loss can champion positive perspective-taking, competency, increased quality of life, and improved child advocacy. Counselling psychology should create accessible resources for parents to receive specific interventions tailored to improve parental self-efficacy. Specific interventions that would bolster self-efficacy include group counselling or group support inclusive of those who have lived experience and individuals who can act as role models and mentors to parents at different stages of their child's development. Interventions should focus on mastery experiences, enhance parenting skills to promote positive belief systems, and attend to parents' emotional and physiological states to promote confidence, emotional regulation, and well-being.

Interventions

The creation of programs, services, and supports must address the unrecognized experiences of ambiguous loss and chronic sorrow parents may experience after a child is

diagnosed with a neurodevelopmental disorder. Interventions improve the well-being of the parent by taking away burden, stress, and guilt. Interventions can also be a catalyst towards parents taking back their identity as mothers or fathers, rather than as their child's therapist, teacher, or caregiver. Interventions reduce the overload of parental demands and decrease the likelihood of caregiver burnout for parents (Bravo-Benítez et al., 2019). Interventions I will highlight from the literature that foster parental competence include psychoeducation, parent training, peer support, early intervention, and school interventions.

Psychoeducation. The first intervention I recommend is for counselling psychologists to become knowledgeable and competent regarding parents experiencing ambiguous loss and chronic sorrow and to incorporate psychoeducation. First discussed concerning clients diagnosed with schizophrenia, psychoeducation is now a basic cognitive behavioural technique that focuses on educating clients on their diagnosis, problem-solving, enhancing communication, and self-assertiveness (Anderson et al., 1980). Psychoeducation is an essential component to increase parental well-being and normalize parental experiences through targeted solutions and strategies to minimize caregiver burnout. Psychoeducation can connect parents to a community of support and improve knowledge regarding their child's diagnosis (Chan et al., 2018; Corcoran et al., 2017; Craig et al., 2016; Jijon & Leonard, 2020).

Self-Care. Counselling psychologists can support parents in decreasing caregiver burnout through psychoeducation on appropriate self-care strategies. A significant finding of my literature review included parental experiences of caregiver burnout occurring due to identity ambiguity, stress, increased parental demands, and isolation (Almogbel et al., 2017; Bravo-Benítez et al., 2019; Jijon & Leonard, 2020; Parsons et al., 2019; Wayment & Brookshire, 2018). Counselling psychologists can promote specific self-care strategies targeting these facets of

ambiguous loss and chronic sorrow, including relaxation methods and expressive writing (Chan et al., 2018; Da Paz & Wallander, 2017).

Relaxation methods counsellors may employ include guided meditation, guiding the parents through focused visualization to achieve a higher awareness of their senses and breathing patterns. Potential benefits of relaxation methods are stress reduction, immediate relaxation through deep breathing, and increased emotional regulation (Da Paz & Wallander, 2017). The literature states meditation and mindfulness are reliable and valid measurable characteristics that enhance various aspects of mental health (Brown & Ryan, 2003; Gotink et al., 2015). The Mindful Attention Awareness Scale (MAAS) is one measure that assesses changes in individuals' mindful states over a period of time, focusing on the absence or presence of awareness (Brown & Ryan, 2003). This measure identifies qualities of consciousness associated with well-being and self-awareness manifested in cognitive, emotional, motivational, and physical functioning. Through awareness, individuals can improve symptoms of depression, anxiety, stress, chronic pain, and quality of life. I recommend counselling psychologists utilize relaxation methods to decrease parental stress.

The literature examined also noted the use of expressive writing as a self-care technique parents can utilize to express grief and their living loss experiences safely and in a nonthreatening environment (Da Paz & Wallander, 2017). Expressive writing is the activity of writing openly regarding a topic that elicits emotional disclosure. I recommend counselling psychologists use expressive writing as a tool in therapy sessions and a client strategy to promote the expression of strong emotions in an accessible and feasible format. Additionally, counselling psychologists can promote self-care strategies by exploring parental social supports or connecting parents to peer support, highlighted in a later section.

Community Supports. In addition to self-care strategies, I recommend counselling psychologists be aware of respite care and services to reduce parental demands and alleviate parents from day-to-day demands to plan for self-care (Chan et al., 2018; Coughlin & Sethares, 2017). Respite is a short period of relief, or a break, for parents to engage in activities they may not be able to act on due to their child's extraordinary needs. Parents who have a child diagnosed with a neurodevelopmental disorder may not have the privilege to engage in self-care activities due to parental demand and the level of diagnostic impairment. Respite allows parents to participate in activities contributing to their overall well-being and parenting abilities, such as exercise, sleep, and preferred activities. Counselling psychologists working with parents who require respite should be aware of local private agencies, community-based programs, and accredited web-based databases.

Knowledge. Diagnostic uncertainty can contribute to parental stress after a diagnosis of a neurodevelopmental disorder (Almogbel et al., 2017; Corcoran et al., 2017; Lai et al., 2015). Parents may experience fears or worries regarding their child’s diagnosis, prognosis, functioning, development, and future independence (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; O’Brien, 2007). Parents may experience a rollercoaster of emotions related to their uncertainty. One minute, they may feel in control and hopeful, and the next, they feel intrusive thoughts of helplessness, instability, and hopelessness. Knowledge of their child’s disability, ability to improve adaptive functioning, socioemotional skills, emotional regulation strategies, accommodations to learning, and behavioural interventions can decrease parental uncertainty. Psychoeducation for parents should include providing understanding and education of condition impairments and abilities, including personal, social, academic, and motor functioning or a combination thereof. Parents should have access to essential information regarding specific

interventions and programs to best support their children. Additionally, counselling psychologists can foster parental self-efficacy and parents' perceptions of their skills through increasing parental knowledge and competency.

Parent Training. Parent training programs are a primary and effective intervention targeting child emotional, behavioural, and social problems, specifically for children with neurodevelopmental disorders (Tellegen & Sanders, 2013). Parent training aims to decrease parental stress by increasing parental competency and self-efficacy, and improving parenting styles, parent-child relationships, and positive parenting traits. The literature examined illustrated the utility of a specific parent training intervention called Triple P programs (Jijon & Leonard, 2020; Tellegen & Sanders, 2013). The following sections review the Triple P programs as an example of structured, supportive interventions for families. I acknowledge that there may be other such programs in development or successfully incorporated into supporting families. Triple P was chosen as an illustrative example to provide context for components in parent training identified as successful.

Triple P Programming. Triple P stands for positive parenting program. These interventions support parents and children with disabilities (Jijon & Leonard, 2020; Tellegen & Sanders, 2013). The intervention intends to support parents in creating positive parenting strategies to manage child behaviour and developmental concerns, increase coping strategies, foster general parenting skills, and develop relationships with their children and partners. Triple P programs aim to decrease parental stress and guilt through individualized interventions focusing on training and positive strategies.

Triple P programs offer five levels of intervention and are categorized by intensity (Tellegen & Sanders, 2013). The first level of intervention focuses on communication strategies,

and the second level incorporates brief interventions such as group seminars where parents can connect with peers and gain knowledge in many domains. Domains include communication, parenting skills, and coping strategies. The third level of intervention is custom to unique parental needs, and the fourth level includes 10 distinct training sessions focusing on various topics. The format of delivery for the level four intervention is individual, group, and self-directed modules. The Triple P intervention's final level is family-focused modules and provides families experiencing numerous difficulties, incorporating parental stress and partner conflict interventions.

The literature I reviewed notes that the Triple P program measured improvement of parenting styles and strategies through the Parenting Scale. The Parenting Scale measures three factors of parenting young children, including laxness, over-reactivity, and verbosity (Arnold et al., 1993; Tellegen & Sanders, 2013). The five Triple P intervention levels improve parenting styles and strategies (Tellegen & Sanders, 2013). Incorporating positive parenting styles and strategies showed a reduction of child behavioural concerns and parental stress, where the authors measured parental stress with the Depression Anxiety Stress Scale (Arnold et al., 1993; Tellegen & Sanders, 2013).

The Depression Anxiety Stress Scale is a reliable and valid measure of adult depression, anxiety, and stress (Lovibond & Lovibond, 1995). After Triple P interventions, the literature reviewed reported a significant decrease in parental stress (Jijon & Leonard, 2020; Tellegen & Sanders, 2013). The Triple P programs also report increases in parental satisfaction and parental competency, measured by the Parenting Sense of Competence Scale (Tellegen & Sanders, 2013). The scale includes parental self-reports, including an increased sense of competency as a parent and perceived ability to care for their child (Gibaud-Wallston & Wandersman, 1978). After

completing the Triple P program, parents reported a significant increase in competence and self-efficacy (Jijon & Leonard, 2020; Tellegen & Sanders, 2013). Parents who have participated in Triple P programming have noted:

> It helped us to understand (and) deal with him a bit better … It helps really with the ideas of other parents, in the situations of other kids as well. You learn a lot from other parents … It gives me hope like that it will not be forever. (Ruane et al., 2018, p. 8)

The literature I examined also highlighted the need for marital supports, focusing on maternal and paternal parenting unification (Chan et al., 2018; Corcoran et al., 2017; Tellegen & Sanders, 2013). Triple P's level five intervention program includes improving parental conflict measured by the Perceived Relationship Quality Components Inventory (Fletcher et al., 2000) and Dyadic Adjustment Scale (Spanier, 1976). These inventories' components include satisfaction, commitment, intimacy, trust, passion, love, and subjective marital satisfaction. The Triple P program, specifically the level five intervention, significantly improved parental relationships (Tellegen & Sanders, 2013). Increased support from a partner contributed to effective parenting skills, promoted well-being, and decreased parental stress (Chan et al., 2018; Corcoran et al., 2017; Tellegen & Sanders, 2013).

The Triple P program is an example of a family-focused intervention; when parental well-being increases, so do children's (Corcoran et al., 2017; Jijon & Leonard, 2020). Parental stress, guilt, and demands generate from various factors related to their child's diagnosis, individual factors, and family context (Jijon & Leonard, 2020). Considering these findings from the literature I reviewed, individualized family-focused interventions, such as the Triple P program, are essential. Programs should consider the parents' circumstances and characteristics of the family dynamic and child's functioning. The literature examined indicates that family-

targeted programs have more efficacious outcomes than individual interventions (Chan et al., 2018). Counselling psychologists performing family-focused interventions should continue to be mindful towards providing hopeful, respectful, and compassionate care to families (Coughlin & Sethares, 2017).

The Triple P program's five intervention levels result in significant improvement in parenting styles, parenting satisfaction, adjustment, relationship, and overall self-efficacy. The literature I examined states when parents feel more competent in their parental skills, well-being improves (Chan et al., 2018). The effectiveness of psychoeducation and parent training towards promoting parental competency illustrates the need for more interventions to incorporate parental self-efficacy (Jijon & Leonard, 2020). I recommend counselling psychologists become knowledgeable and promote psychoeducational parent training programs and parental self-efficacy.

Peer Support Groups. The literature reviewed indicated support groups for parents as a factor contributing to normalizing feelings of guilt, stress, and isolation (Corcoran et al., 2017). After a child-diagnosis of a neurodevelopmental disorder, parents may encounter a unique form of grief and loss, as they are grieving the loss of a child that is still living. The living loss parents may experience can result in diverse parental responses, including ambiguous loss and chronic sorrow. The grief parents experience can manifest internally if there is a lack of recognition and acceptance of their grieving process (Bravo-Benítez et al., 2019). Peer support is a significant protective factor (Jijon & Leonard, 2020; Pottie & Ingram, 2008; Wayment & Brookshire, 2018). Peer support can validate parental stress, reduce caregiver demands, normalize typical experiences, increase parental well-being, empower parents through knowledge and skills, and enhance quality of life (Corcoran et al., 2017; Craig et al., 2016). Support groups can act as a

catalyst for vicarious experiences and enhanced efficacy beliefs (Bandura, 1977, 1997). Parents can observe other parents who have gone through similar experiences succeed and master parenthood. Parents can be role models for one another, as they share an intimate connection due to shared experiences. Ruane et al. (2018) note one parent's experience: "Meeting other parents that … are going through what you went through. (I thought) 'I'm not on my own. I'm not the only person going through this. My child isn't the only one that can't cope'" (p. 8).

Counselling psychologists should become aware of peer support groups in their clients' geographic location to connect with and receive support from other parents who may be experiencing ambiguous loss and chronic sorrow. Through empowerment, parents can overcome feelings of ineffectiveness and build confidence and support networks that promote well-being and self-efficacy.

Early Intervention. Early intervention is another essential intervention counselling psychologists can implement to support and foster parental self-efficacy. The manifestation of ambiguous loss and chronic sorrow can occur immediately after a child's diagnosis. Parents are often left alone, grieving over a loss that is unrecognized or misunderstood. Creating accessible programs and services addressing the initial feelings of a living loss will improve parental well-being and quality of life (Bravo-Benítez et al., 2019). Early intervention can also minimize the cyclical and ongoing loss parents may face, helping them reach acceptance.

There are various consequences counselling psychologists should be cognizant of if early intervention and support for living loss are continually unrecognized. Parental stress may continue to rise and lead to maladaptive coping mechanisms (Almogbel et al., 2017; Bravo-Benítez et al., 2019; Parsons et al., 2019). Parental demands may continue to increase paired with caregiver burnout. Parents may become consumed and overloaded by these demands and

uncertainty, resulting in decreased optimism, hope, and self-efficacy. Self-blame is a significant maladaptive coping strategy highlighted by the literature (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Mahmood et al., 2015).

The literature I reviewed encourages the use of early intervention programs to increase parent well-being and help parents identify ambiguous loss, process emotions, and address barriers to processing their grief (Bravo-Benítez et al., 2019). Programs for parents experiencing ambiguous loss and chronic sorrow should also include addressing parental demand, diagnostic uncertainty, and guilt. An early intervention program targeting parents who have experienced a living loss should also incorporate personal goals beyond their caregiver role, which combats ambiguous loss and identity ambiguity.

It is recommended counselling psychologists listen to their clients' experiences and create room for their stories to be heard so that they can incorporate appropriate individual early interventions into therapy. Counselling psychologists should also be aware of early intervention supports in their clients' geographical location to access appropriate resources. Early intervention can validate parents, foster competency, enhance self-efficacy, promote parental strengths, and teach adaptive coping skills while minimizing grief's cyclical and chronic nature.

School Interventions. A final recommendation regarding specific interventions counselling psychologists should recognize when working with parents after a child diagnosis of a neurodevelopmental disorder are school-based interventions. Interventions at a school level, specifically child-focused interventions, positively impact parents. There is a tremendous parental benefit and importance of creating a strong working alliance with their child’s teacher and school (Krakovich et al., 2016; Stuart & McGrew, 2009). After a child is diagnosed with a neurodevelopmental disorder, a diagnosis might provide significant clarity to the parents and the

teacher of how to best support the child academically, behaviorally, and socioemotionally in a school setting. From the literature I reviewed, child-focused interventions in a school environment reduced parental stress (Krakovich et al., 2016). School-based supports are also beneficial for families who may have significant barriers to accessing community supports, whether due to geographic location, finances, or time restraint. In the field of counselling psychology, it would be necessary for counselling psychologists to be aware of the parents' relationship with their child's school and potential school-based interventions that would be most suitable to support the child.

Next Steps for Research

The literature I examined encourages continued review of parental experiences to enhance development and understanding of appropriate interventions and programs for diagnosis-related grief (Bravo-Benítez et al., 2019; Corcoran et al., 2017; Minnes et al., 2015; Wayment & Brookshire, 2018). In my exploration of the literature, there were common themes regarding limitations and recommendations of where research should go next. Research should contribute longitudinal studies, investigate father reports, and incorporate diversity. Beyond the limitations of the literature I reviewed, I propose the next steps for research, given the gaps in my literature exploration, should investigate clinical recognition of ambiguous loss and chronic sorrow and explore the role of parental self-efficacy in living losses.

Longitudinal Research

The majority of the research studies I examined were cross-sectional studies (Ashworth et al., 2019; Bravo-Benítez et al., 2019; Chan et al., 2018; Krakovich et al., 2016; Leone et al., 2016). The authors of these studies noted a limitation of their work and identified future research requirements to include longitudinal studies. Ambiguous loss and chronic sorrow are cyclical in

nature, reinforcing the need for long-term monitoring, data collection, and identification of specific characteristics that may mediate the cycle of grief. Longitudinal research will also help distinguish the causal relationship between external and individual factors contributing to parental stress (Ashworth et al., 2019). For example, we cannot say that parents' stress is caused by their child's diagnosis if there was also an external factor, such as job loss or marital concerns, contributing to the stress. Through long-term self-reports, longitudinal research will provide more valid interpretations of the data. Longitudinal research will allow for significant findings related to the cycle of ambiguous loss and chronic sorrow, which can then inform interventions.

Father Reports

The literature reviewed illustrates a disproportionate sample bias of female primary caregivers, which has minimized father recognition and experiences. Therefore, those study results are not generalizable to fathers and limit clinical utility (Leone et al., 2016; Wayment & Brookshire, 2018). A crucial next step for the research is incorporating father self-reports and longitudinal studies assessing ambiguous loss, chronic sorrow, and gender differences. Currently, in the literature I reviewed, gender differences are present. Mothers and fathers report different parental distress and demand levels, with mothers reporting higher impairment (Almogbel et al., 2017; Craig et al., 2016; Mahmood et al., 2015). Additionally, reports of chronic sorrow differed between parental roles. Mothers reported continued chronic sorrow, whereas fathers were able to resolve their grief (Coughlin & Sethares, 2017). The literature notes that the resolution of a father's grief occurred through resignation or acceptance of an undesirable yet inevitable outcome. Father reports also indicated a lesser degree of depression and guilt; however, they worried about future problems and stigmatization. These distinct differences amongst parental

responses illustrate the importance of further studies highlighting differences between mothers and fathers regarding ambiguous loss and chronic sorrow. Additional research will lend to increased recognition and exceptional support for mothers and fathers and to the development of interventions that respond to identified parent differences. For example, interventions with mothers may focus on chronic sorrow and cyclical grief experiences, whereas interventions with fathers may incorporate psychoeducation regarding their child's diagnostic profile and prognosis.

Diversity

Populations within the literature I reviewed were ethnically homogenous. The literature notes the importance of future studies incorporating cross-cultural analysis to generalize research results to diverse cultural backgrounds (Chan et al., 2018; Nordin & Husain, 2020). The authors also noted the possibility of cultural factors influencing research outcomes, further highlighting the importance of cross-cultural studies to be performed (Nordin & Husain, 2020). Additional next steps for research related to diversity, beyond culture and ethnicity, include gender and sexual identity, education level, financial stability, relationship status, parents' age, and geographic location (Parsons et al., 2019; Wayment & Brookshire, 2018). Diverse sampling groups are essential to recognize parental responses of living loss across multiple cultures, religions, class status, and familial status. Responses to grief are not homogenous, and samples of participants should reflect this diversity. The literature I examined illustrates an evident distinction in cultural coping patterns. Collectivist cultures, such as parents of Asian background, and individualistic cultures, such as Caucasian parents, often use different coping mechanisms (Lai & Oei, 2014; Parsons et al., 2019). Collectivist cultures are more likely to use active coping strategies such as treatments, social supports, and cognitive reframing. Individualistic cultures

are likely to employ passive coping strategies like escapism, distancing, and wishful thinking. Future studies should explore cultural nuances on parental coping mechanisms.

Ambiguous Loss and Chronic Sorrow

The literature explored examined specific facets of ambiguous loss and chronic sorrow. Factors of ambiguous loss included identity ambiguity, guilt, stress, parental demand, and diagnostic uncertainty (Almogbel et al., 2017; Boss, 1999; Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Parsons et al., 2019). Parents experiencing chronic sorrow reported perceived loss, disruption of expectations, and isolation. Further research will increase understanding, competency, and clinical recognition of the specific experiences of ambiguous loss and chronic sorrow parents may experience. I believe it is an incremental next step for research to differentiate ambiguous loss and chronic sorrow from other socioemotional responses, leading to appropriate interventions, treatment, and supports. Increased awareness will minimize the possibility of a parental misdiagnosis, such as depression, and promote recognition of living loss (Coughlin & Sethares, 2017). The interventions proposed in the previous section target facets of ambiguous loss and chronic sorrow; however, the design of these interventions are not explicit to parental grief experiences. Future research should generate interventions specific to ambiguous loss and chronic sorrow to decrease identity ambiguity, guilt, stress, parental demands, disrupted expectations, and isolation.

Parental Self-Efficacy

The implications I propose and my recommendations for counselling psychology are grounded in championing parental self-efficacy. However, from my extensive review of the literature, there is no research explicitly discussing parental self-efficacy as a protective factor for parents experiencing ambiguous loss and chronic sorrow. I recommend next steps in the

research include how parental self-efficacy affects living loss experiences and parental responses after a child's diagnosis of a neurodevelopmental disorder. I propose future research investigate parental self-efficacy as a possible moderating factor for ambiguous loss and chronic sorrow through a longitudinal study of parental self-reports.

Reflexive Self-Statement

I firmly believe that our experiences influence our interests. As an individual diagnosed with a specific learning disability and other family members diagnosed with various disabilities, I am familiar with neurodevelopmental disorders, from autism spectrum disorder to motor and speech disorders. I have an intimate relationship with the impact profound and moderate disorders have on family, parents, and self. I have many personal biases that I kept in mind throughout the literature review and my implications for counselling psychology. Though my experiences have guided me towards this field, I was conscious of how my experiences may have influenced the literature I examined and my interpretation thereof. I continue to hold an insider perspective of my research topic as an individual with a neurodevelopmental disorder and an outsider perspective of not being a parent. I am also a sibling to a brother with a neurodevelopmental disorder. All three perspectives influenced my research.

While completing my research, I was mindful of my biases. My lived experiences influenced the literature initially explored and built the foundation for my original hypotheses. My research was to seek recognition for my parents' experiences, as they may be representative of many people's experiences, especially my mother, who grieved for her children in silence. She blamed herself for not being a good enough parent who did not have enough time to help her children learn how to talk, spell, or read. However, she spent each evening nurturing these skills with them. Apart from being a mother, another segment of her identity in my early development

was being a teacher. She would end her workday full of optimism after teaching English to aspirational adolescents. Nevertheless, she would end her day in tears, with the fear her daughter would never speak coherently or be able to read. As a child, we do not recognize the silent agony our parents endure. Initially, my research intended to explore the literature with hopes of increasing recognition, awareness, and understanding of this silent grief, defined as ambiguous loss and chronic sorrow. However, as I continued to engage in examining the research and mitigating my biases, I found my own awareness, understanding, and perspective changing.

Throughout my literature exploration and discussion on counselling psychology implications, I had a change in perspective. My initial interest was to cover parental grief experiences and responses after a child-diagnosis of a neurodevelopmental disorder. Initially, my hypothesis focused on the importance of improving societal identification and recognition of loss. I sought to consult literature that would reinforce the importance of further recognizing living loss. The repercussions of my review resulted in my mindset shifting to more parent-oriented implications and recommendations. I took a more empowering approach, focusing not only on parental responses and traditional grief models but the importance of perspective, resiliency, competency, and, more specifically, parental self-efficacy. My final hypothesis centers on fostering parental self-efficacy to enhance parental and child well-being. Self-efficacy is a more empowering approach because it lends itself to counsellors working with parents rather than battling against societal perspectives of non-death losses. Working directly with parents affected by non-death losses, such as a childhood diagnosis of a neurodevelopmental disorder, can enhance empowerment, self-efficacy, parent and child well-being, and generate improvements to family functioning.

My lived experience was a guiding force, and I continue to reflect on my story. When I look back, I do not see a crying mother, suffocated by blame, doubt, and guilt, who gave up on her children or herself. I see a competent, resourceful, and loving mother who fought to provide what she could for her children. She modelled parental self-efficacy even on the most challenging days and during the hopeless moments. Reinforcement from professionals cultivated my mother's belief in herself as a parent and optimism for her children. As I reflect upon her experiences, I have come to understand that these professionals normalized her parenting experiences with children diagnosed with neurodevelopmental disorders through psychoeducation, parent training, interventions, and peer support.

Conclusion

Neurodevelopmental disorders include autism spectrum disorder, attention deficit hyperactivity disorder, intellectual disabilities, specific learning disorders, motor disorders, and communication disorders (American Psychiatric Association, 2013). Child impairments range from personal, social, academic, and motor functioning or a combination thereof. Parental responses also range. Parents may face uncertainty or optimism when receiving a child-diagnosis of a neurodevelopmental disorder. Grief may accompany uncertainty parents face; specifically, ambiguous loss and chronic sorrow resulting from a living loss. Ambiguous loss results from unrecognized grief or loss; a child is still physically present but may be emotionally or cognitively absent (Boss, 1977, 1999; Bravo-Benítez et al., 2019). Chronic sorrow occurs when parents experience cyclical loss relative to their perception of the living loss (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Olshanksy, 1962). The grieving process for living loss is less comprehended and can result in an unrecognized grieving process. In my comprehensive literature review, I embarked on deepening understanding and recognition of

parental grief after a child is diagnosed with a neurodevelopmental diagnosis. I attempted to highlight diverse parental responses, experiences, and outcomes. My review proposes several implications, recommendations, and crucial next steps for research in the field of counselling psychology.

Parental responses were diverse and ranged in severity. Parents who participated in the independent research I reviewed comprised mostly mothers, supporting the assumption that mothers are usually the primary caregiver. Responses included a struggle towards optimism, hope, and acceptance, and an inability to utilize adaptive coping strategies (Bravo-Benítez et al., 2019; Fernańdez-Alcántara et al., 2016; Lai et al., 2015; Wayment & Brookshire, 2018). Through an exploration of Walsh's (2003) framework of family resilience, the literature review attempted to illustrate resilience factors. The framework noted positive perceptions, flexible parenting styles, social supports, and coping strategies as contributing factors. I incorporated the transactional model of stress and coping into my review, illustrating the predictability and association between negative coping strategies and parental distress (Lazarus & Folkman, 1984). Overall, my literature review focused on and indicated potentially adverse responses, experiences, and outcomes for parents after a child-diagnosis of neurodevelopmental disorder.

Implications, recommendations, and next steps for research I proposed are to encourage professionals to continue to enhance their competencies and knowledge regarding living loss and how to best support parents. The implications I discuss are not specific to any one field of counselling psychology, as living loss and grief affect so many potential and existing clients. In all fields, it is essential counsellors become aware and cognizant of the emotional impact, outcomes, and appropriate interventions for ambiguous loss and chronic sorrow. In the previous sections, I attempted to illustrate the importance of parental self-efficacy to abate guilt, stress,

blame, isolation, uncertainty, and beliefs of incompetence. Through my recommended tailored and individualized interventions, counsellors can foster parental self-efficacy and attempt to alleviate the cycle of grief parents may experience. I identified and explained the importance of psychoeducation, self-care, community support, peer support, increased diagnostic knowledge, parent training, early interventions, and school interventions as incremental interventions towards self-efficacy in parents.

Despite my in-depth literature review, there were clear limitations of the literature I explored and crucial next steps for research beyond the current findings. Longitudinal studies are necessary to understand the trajectory and long-term outcome of ambiguous loss and chronic sorrow parents may experience after a living loss. A majority of the research assumes mothers as the primary caregiver, resulting in a lack of father reports. Diversity is also lacking in current studies, as samples are ethnically homogenous. Beyond the limitations of my literature review, future research should further our competencies and understanding of ambiguous loss and chronic sorrow to create appropriate interventions to treat this unique form of grief. Additionally, research should investigate the role of parental self-efficacy in living losses. Throughout my implications, I recommend fostering parental self-efficacy to improve parent and child outcomes and potentially moderate the cycle of ambiguous loss and chronic sorrow. However, additional research is warranted to illustrate diverse parental responses to living loss and further understand moderating factors, specifically parental self-efficacy, in the creation of appropriate parent-focused programs.

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