

The Bereavement Experience, Risk and Support for Children with Developmental Disabilities

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Abstract

The literature review addresses the bereavement experience of children with developmental disabilities (DD), as it is often not publicly acknowledged or socially supported by professionals or caregivers (Doka, 1998). This review draws from the fields of disability, grief/bereavement and counselling to assist counselling psychologists and alternative professionals in their improvement of the supports and care they are currently providing to bereaved children with DD. Recommendations from the analysis of the existing literature include meeting the child where they are at, acknowledging that further psychoeducation on death and emotions may be required, not underestimating the child's response to grief, and consulting whenever necessary with other professionals. Future research directions are also addressed to focus attention on the efficacy of the techniques and models in bereavement counselling, and to highlight the perspectives of bereaved children with DD.

The Bereavement Experience, Risk and Support for Children with Developmental Disabilities

It is well documented that the effects of bereavement and loss have a profound impact on children with disabilities (Brickell & Munir, 2011). Despite this, the majority of research in this arena has been concentrated on understanding the grief process and the reactions of these children in comparison to children without disabilities (Sormanti & Ballan, 2011). Further, the limited literature that exists on bereavement and individuals with disabilities focuses on how to support adults with disabilities, on the bereavement of caregivers and how these can support children with disabilities through their grief (Fernández-Ávalos et al., 2020; Oekerman, 2001; Young, 2016). Therefore, this review will focus on outlining the overlooked grief process and the necessary supports needed to care for children with developmental disabilities (DD) after a loss (Brickell & Munir, 2011).

Defining Developmental Disabilities in Children

The term developmental disabilities (DD) refers to conditions that manifest during the developmental period in the form of impairments in physical, learning, language, or behavioural areas (Zablotsky et al., 2019). According to Markell and Hoover (2010), the designation of a DD in a child helps to distinguish between diseases and syndromes that impact a child's cognition and learning at birth, during early childhood or unfold with development, from those that are acquired (e.g., brain damage from injury). Causation for these disorders in children varies from chromosomal abnormalities (e.g., Down syndrome), genetic inheritance/variations (e.g., phenylketonuria, autism spectrum disorder) and maternal diseases or conditions that affected fetal development during pregnancy (e.g., maternal-fetal rh incompatibility, fetal alcohol syndrome from alcohol use). Given that the nature of these conditions are lifelong, children diagnosed with DD are cited to necessitate services to address behavioural and developmental challenges throughout their lifetimes (Boulet et al., 2009).

Relevance of Research

Adjusting to loss and coping with grief is particularly complicated for children with DD given the multiplicity of losses they incur throughout their lives (Markell & Hoover, 2010). Aside from death, these multiple 'layered' losses include disrupted relationships with family members who have withdrawn physically or emotionally, interpersonal problems with peers, turnover among educational and health aides, and secondary losses in health and functioning (Ballan & Sormanti, 2006). Additional losses experienced throughout their lifetime may further include a loss of identity, loss of ability, loss of accessibility, loss of opportunities and loss of independence (Read & Elliot, 2003).

Despite these losses, the capacity for children with DD to experience grief and bereavement has only been acknowledged and evaluated in the literature in the past 20 years (Hollins & Esterhuyzen, 1997). One explanation for this gap may be due to the erroneous assumptions that surround the experience of children with DD. The first of these includes the belief that children with DD do not possess the emotional, cognitive, learning skills and functioning required to form relational bonds strong enough to result in grief, or the intellectual capacity to understand the concept of death (McEvoy et al., 2002). In turn, expressions of grief in children with DD are often misinterpreted, overlooked, minimized, attributed as symptoms of their disability, or go unsupported (Hollins & Esterhuyzen, 1997). Information about death is often withheld, provided without much detail, or presented inaccurately through the use of abstract concepts following the death of a loved one (Clements et al., 2004; Sormanti & Ballan, 2011). Another misconception includes the belief that children with DD are fragile, and in turn, likely to grieve so intensely that they need to be sheltered from death and grief due to their believed incapability to comprehend or make wise decisions on their behalf (Markell & Hoover, 2010). Consequently, caregivers, teachers, friends and family members often attempt to protect children with DD by excluding them from important conversations (e.g., death, afterlife) and rituals (e.g., funerals) following a loss (Ducy & Stough, 2018; Sormanti & Ballan, 2011).

Regardless of whether the source of this research gap is attributed to one of these faulty notions or other factors, literature on children and adults with DD now disproves these assumptions (McAdams-Ducy, 2014; Sormanti & Ballan, 2011). After the death of a loved one, children with DD are noted to experience similar grief reactions to their typically developed peers following a loss: (a) somatic complaints, (b) relationship difficulties, (c) social withdrawal, (d) increased compulsivity and (e) intense frustration (Kauffman, 2005). However, due to difficulties with communication, comprehension, and understanding from others, children with DD may also experience behaviors such as aggression, anxiety, confusion, loneliness, self-harm, and disruptive conduct amid grief (Hume et al., 2016; Markell & Hoover, 2010).

The grief reactions of children with DD are often discounted, because their grief is not publicly acknowledged or socially supported (Doka, 1998). This review would like to posit that this specific population is deserving of direct compassionate, timely and effective supports just as much as their typically developing peers. Given that children with DD are prone to develop adverse health reactions and mental health disorders such as schizophrenia, affective, and adjustment disorders (Hollins & Esterhuyzen, 1997), they may also present with breathing difficulties, disorientation, hyperactivity, suicidal ideation, self-harm, and actions involving their own feigned deaths (Mitchell & Clegg, 2005).

Purpose of Review and Research Questions

Despite these realities, children with DD have historically not had the same access to appropriate supports during times of loss or grief, nor have health or teaching professionals been trained to support them (Somarti & Ballan, 2011). Much of the existing research on this topic has focused on understanding the differences in the grief experience of children with DD versus those without DD. The research concentrates on supporting parents and caregivers, through their grief after a loss (Fernández-Alcántara et al., 2016). The following literature review will seek to provide an overview of the limited research that exists regarding supports for bereaved children with DD following a loss. It will particularly highlight

information regarding support provision for this population, to help inform the practice of helping professionals (e.g., teachers, counsellors, aides) who may work to fill or advocate for the closing of this gap (Ducy & Stough, 2018). Given that current research on bereavement for children with DD indicates that a team approach is essential to support them through a grieving process (Lawhon, 2004), increasing the accessibility of this information to mental health professionals, teachers, district-level staff trained in crisis support and paraprofessionals working in related service providers, family members, peers, and others who work with these children is of the utmost importance (Ducy & Stough, 2018).

To further focus this review, the following research questions will be addressed:

1. What factors moderate the bereavement experience and risk for children with DD after a loss?
2. How could these factors be used to inform support provision amid the bereavement experience of children with DD?
3. What implications could these findings have on counselling approaches towards support provision for this population following a loss?
4. Should children with DD receive counselling bereavement supports directly?

Further, due to a significant paucity in the literature for bereaved children with DD, it should be noted that this research will be broadly focused on evaluating supports following a death. Additionally, the term direct support will be used to describe care that is directly given to children with DD rather than through someone else (i.e., caregiver, family member).

Self-Positioning Statement

This section will include a brief overview of the author's personal and professional biases concerning the study of grief and loss for children with DD. It will also include a section dedicated to signal specific strategies that the author plans to use to minimize bias.

Personal Biases

Earlier this year, the author and her family lost four family members consecutively, her grand-uncles Francisco Leon, Giovanni Leon, Igor Subero and great grandmother Josefina, within the same two-month period. Losing these relatives so closely helped to sharpen the author's interest in grief and loss, as their consecutive deaths significantly impacted her overall functioning outside of her home. Though none of her grand-uncles or great grandmother had a DD, the multiplicity of loss theme that encompasses the experience of grief and loss in children with DD is one that drew the author to study this specific population, as this mirrored what transpired in her own life. In turn, due to her ties to the topic, the author would be remiss to discount the plausibility of how these recent experiences of loss in her own life could cloud her interpretation, or reporting, of the research. For instance, given her personal beliefs that after a loss everyone is impacted in some way and all individuals are deserving of support to effectively manage their grief, the author remained attentive to evidence selection bias as she sifted through the research (Drucker et al., 2016) and cognisant of older studies which could contradict her belief about everyone's capacity to grieve.

Professional Biases

For the four years of her undergraduate degree, the author worked with children and adults with disabilities in a hospital and church setting. Though the work was not always easy, this experience was one the author considers to have been personally rewarding and gratifying. While she did not work with this population in the context of counselling or grief work, the influence that these experiences could play on her perception of the population being evaluated in this review was not overlooked. Additionally, given that a vast number of individuals she worked with were subject to discrimination and further marginalization due to their disability, the author incorporated a social justice lens into the review. It is the author's hope that the use of this lens served to honour the unique experiences of this population, and demonstrated her own passion and support for the topic and community.

Strategies to Minimize Bias. To minimize bias, the author attended grief therapy throughout the duration of this review, to ensure that her own grief was overlooked. Additionally, given the emotional nature of the topic at hand, a top priority for the author included prioritizing her own emotional wellbeing to ensure that this did not deteriorate or impair the research review process. To achieve this, the author chose to consult with her research instructor at times to discuss strategies relating to research selection and exclusion, or to obtain impartial feedback on her writing. Additionally, the author chose to prioritize her self-care throughout this process by scheduling regular break times that included going for walks by herself or with friends/family, to help her manage the emotional and psychological demands that a research process can have on a person (Kumar & Cavallaro, 2017).

Review of the Research

This section has as its main objective to delineate the variables that the existing literature has associated with the risk and experience of bereavement for children with DD, given that research on childhood bereavement has historically focused on outlining experience moderators to inform resource provision (Christ & Christ, 2006; McClean & Guerin, 2019). To ease comprehension, this segment will be divided into four parts: the first will detail the scope of the review; the second will describe the methods used to uncover the material; the third will outline what grief looks like for children with developmental disabilities; and, the final will address the seven variables associated with the bereavement experience of children with DD.

Scope of the Review

This review focuses on two main aspects of childhood bereavement for children with DD: the factors which moderate the experience positively or negatively, and the risk/safety concerns associated with grief. To help address these, the following parameters were applied to define the variables:

- Studies with bereaved children with DD under the age of 18 were included, to accommodate for the paucity in research for this population.

- DD was broadly defined as broad conditions that manifest during the developmental period in the form of impairments in physical, learning, language or behavioural areas. This included conditions such as autism spectrum disorder (ASD), fetal alcohol syndrome and Down syndrome.
- Bereavement or grief and loss for children with DD was defined as children who have lost a parent, sibling or caregiver rather than an immediate relative or friend, to again accommodate for the lack of literature available in the topic.
- The search included the investigation of existing influencing and protective factors that might impact the outcomes of grief for bereaved children with DD after a loss.
- The search explored evidence on the efficacy of supports for bereaved children with DD after a loss, such as support groups, death education and counselling.

Review Methods

A search was carried out using the PsychInfo, CityUniversity of Seattle Library databases and Google Scholar. Search items included the use of the following terms or similar, as well as combinations of the following terms: children, youth, young people, developmental disabilities, bereavement, grief, loss, support, risk, impact, outcomes, experience. Key Canadian government websites, reports and books were searched to obtain information for the review. To keep the information current, the search was restricted to articles that were published within the last five to ten years with a few notable exceptions to support the need for further research to be conducted. Over 80 publications, books and reports were selected from this search process, based on the relevance of each abstract reviewed in respect to the topic at hand.

Bereavement in Children with DD

According to research, the presence of a developmental disability does not inhibit, or protect a child from the profound emotional experience of grief (McClellan & Guerin, 2019), in fact, many are likely to

experience similar physiological, mental health, emotional and behavioural reactions to children without a disability (Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Mitchell & Clegg, 2005). For instance, similarly to children without disabilities, researchers have found that after a loss both groups experience physiological issues such as stomach aches, disorientation, fatigue, breathing difficulties and changes in appetite among others (Sormanti & Ballan, 2011). It is important to note that many children with DD also suffer from a variety of associated medical conditions that may require intensive health and physical care interventions following a loss, which in turn may present multiple coping challenges to them and their families (Blackman, 2016; Everratt & Gale, 2004; Young, 2016). One marked difference also depends on the way observers may interpret these symptoms as a part of grief or the disabilities, provided that due to lack of training and education, many may overlook possible grief responses in children with DD as symptoms of their disability (Everratt & Gale, 2004; Sormanti & Ballan, 2011). Additionally, another difference includes the children's ability to appropriately communicate this discomfort which may be impaired in those with developmental disabilities as a result of language, cognitive or intellectual deficits, and in turn be expressed through other means such as acts of outward aggression (i.e., yelling, hitting), to project emotional and physical pain (Burlton, 2018; Everratt & Gale, 2004; Sormanti & Ballan, 2011).

According to Sormanti and Ballan (2011), children's experiences of loss are associated with a variety of mental health problems as well as emotional reactions, which left untreated, could result in more detrimental outcomes. In this sense, children with and without disabilities may experience mental health difficulties such as anxiety, depression, mania, schizophrenia, affective and adjustment disorders (Burlton, 2018; Hollins & Esterhuyzen, 1997; McClean & Guerin, 2019). Interestingly however, a recent 2019 study that sought to evaluate the conceptualization of death in depressed three to six-year olds who were typically developed, found that these held more advanced understandings of death than those who were not depressed (Hennefield et al., 2019). Although these findings did not evaluate

children with DD, it may be worthy for more research to investigate the role that depression could play in their advanced understanding of death as well, when compared to other children with DD who are not depressed. It is also documented that this emotional bereavement experience for children may include struggles related to anger, phobias, confusion, discomfort, loneliness, traumatic grief reactions, social withdrawal, and relationship difficulties, low self-esteem, self-worth and difficulty with educational achievement, for both groups (Sormanti & Ballan, 2011).

An example of how these emotional grief reactions may look different in children with disabilities could be understood through the five-year comparative study conducted by Christ and Christ (2006) which explored the way children with disabilities responded to the loss of their firefighter dads after the World Trade Centre attack. Although the study also serves as a unique example of grief reactions following a sudden or traumatic loss, this study also provided several contrasting examples of how grief may differ between children with and without disabilities. For instance, one of the themes that was identified in the early stages of the study, was that children with cognitive disabilities also displayed less 'noticeable' responses during the first two years when compared to their siblings and peers who lacked a disability. Alternatively, these children reported increased distress around intrusive thoughts and recollection of memories than children with disabilities. Further, children with disabilities in this study also noted a decreased desire to attend funerals, due to a persistent denial or hope that their fathers were alive or would come back. In fact, one nine-year old child in the study was convinced Spiderman had plucked his father out as the tower was falling, but because his father had been hit by a rock he likely developed amnesia and would soon return once his memory came back. This latter illustration, is a good example of a how fantasies of reunification served as an emotional coping strategy for emotional distress after a loss.

According to the aforementioned study by Christ and Christ (2006), similar reactions between children with and without disabilities after a loss included sleep problems, difficulty concentrating in

school, fluctuating grades, social withdrawal, separation anxiety and a variety of phobias and anger management problems. For some, these symptoms were severe and prolonged and caused major disruptions in school and at home, while for others symptoms were intermittent. This latter finding, is important to note, as research indicates that increased frequency and severity of maladaptive behaviors in children amid grief, indicate a recognition that something has changed and the child is attempting to cope with that change. As such, a failure to identify and respond to underlying grief may lead to additional developmental and emotional disruption for children with DD (Clements, 2004), prolonging or otherwise complicating the grieving process (MacHale & Carey, 2002; Sormanti & Ballan, 2011).

Although there are various symptom similarities between children with and without DD, the main differences lie in the expression of these symptoms, as well as in the lack of identification of grief for children with disabilities. According to Dodd and colleagues, (2008), this latter point poses a significant health concern for children with DD, as existing studies appear to observe an enduring/pathological grief response lasting more than six months alongside significant functional impairment in children with DD. In the literature, it is debated whether these prolonged responses to grief are normal among children with DD as a result of their disability, or pathological as a result of the (a) co-occurrence of losses such as displacement from home depending on loss, (b) persistent challenges in communicating effectively about emotionally charged topics and (c) difficulty understanding the concept of loss (Sormanti & Ballan, 2011). It is of paramount importance to recognize these reactions of grief in children, provided that in addition to being more prone to develop complicated grief reactions (MacHale & Carey, 2002; Sormanti & Ballan, 2011), children with DD are also prone to develop increased aggression and self-harming behaviours following a loss (Kauffman, 2005). Though it should be noted that self-harm (Licence et al., 2019; Murray, 2003) and suicidal ideation (Hardan & Sahl, 1999; Ludi et al., 2012) are a known risk for this population particularly during adolescence, increased stressors such as a loss may undoubtedly increase this risk as well as they do for typically developed teens. Thus, identification of children who

may be at higher risk for pathological grief is of paramount importance to mitigate risk and the prolonged coping and adjustment response of grief in the population.

Influencing Variables of Bereavement Experience

Aside from the aforementioned differences in grief for children with DD when compared to those without DD, discussed below are seven variables that appear to influence and mitigate the bereavement experience after a loss. These seven factors include the role of developmental disability in bereavement, experiences and death conceptualization, discussions regarding death, grief responses, education on emotions, bereavement supports and the negative grief implications.

Role of Developmental Disability in Bereavement

The first factor identified in this literature search, comprises the role the disability plays in a child's understanding or experience of the bereavement process. Given that physical, cognitive, emotional and learning disabilities can all effectively challenge a child's ability to experience, process or understand the bereavement process. It is therefore relevant to understand the extent to which DD can curtail this process in order to determine the appropriate level of support needed. Upon review, the following section will discuss the influencing role that cognitive functioning and attachment can have on the bereavement experience of children with DD.

Cognitive Functioning. Children who have higher degrees of limited cognitive functioning may be more directly affected in their ability to understand the grief process and death (Markell & Hoover, 2010). These limitations might affect children's conceptualization of death, memory, and ability to create meaning after a loss, becoming another potential source of vulnerability for this population (Bricknell & Munir, 2011).

According to Markell and Hoover (2010), the four concepts of non-functionality, irreversibility, inevitability and universality of death are essential for understanding loss. To understand these concepts, Oltjenbruns (2001) notes that children must attain Piaget's concrete operations stage of

development, which typically occurs when a child has a mental age of about nine. However, due to limited cognitive functioning children with DD may experience delays in this stage attainment, which in turn could complicate their conceptualization of these necessary concepts. Although, given that Hunter and Smith (2008) note that some children are able to attain a clear understanding of these four concepts at a slightly lower mental age, others, such as Slaughter (2005) warn against the belief of absolutes when it comes to understanding how or when children with DD can grasp these concepts. In fact, Kauffman (2005) notes that despite the presence of cognitive limitations or delays in developmental stages, children with DD are able to understand death related concepts such as the irreversibility and non-functionality, depending on experiences and education.

In turn, a child with DD's ability to cognitively understand abstract concepts, as well as their developmental stage, are both additional factors that should be considered when assessing a child's varying need for support after a loss. As a result, it is recommended for professionals to not adopt a one-size-fits-all approach to understand their experience, but rather one that is developmentally and biologically informed in accordance with the child's cognitive development (Poltorak & Glazer, 2006) as well as the degree of their disability (Markell & Hoover, 2010). A more profound cognitive functioning limitation may impact this conceptualization of death more significantly than if their disability only impacted their cognitive functioning in a mild manner.

Attachment. An additional theme to consider under this variable includes the child's ability to form an attachment despite the presence of their disability (Dodd & Guerin, 2009; MacHale & Carey, 2002; Sormanti & Ballan, 2011). This is relevant to note as research has found a connection between attachment, grief and adaptation to bereavement (Fraley & Shaver, 1999); children with DD who face difficulties forming relationships may experience complications with grief and coping after a loss. For instance, depending on the disability's impact on their speech, language or communication, a child with DD may struggle to form relationships due to difficulties with speech, emotional expression or ability to

indicate a need for support when a child may require it (Markell & Hoover, 2010). In turn, increased distress can be experienced after a loss due to their inability to articulate to others how they are feeling or what they need, and as such, children with DD may require additional levels of attention or support after a loss (McEnhill, 2010). Therefore, depending on the child's disability and its corresponding impact on the bereavement process, each experience of grief will be unique and in turn, support should be personalized to fit or correspond with the child's immediate needs.

Experiences and Death Conceptualization

According to Kauffman (2005), one of the reasons why children with DD are able to understand death-related concepts is due to lived experiences. For instance, given that a nine-year-old child will encounter many more experiences than a five-year-old, these experiences may serve the older child by providing them with more opportunities that may teach them about irreversibility, non-functionality and how to cope with it (Markell & Hoover, 2010). However, given that children who struggle with cognitive flexibility occupy more dependent positions within the family structure, the access to opportunities for change or growth following a loss may be limited (Bricknell & Munir, 2011).

This relationship between experiences and death conceptualization is also further supported by McClean and Guerin's (2019) findings from their qualitative analysis. In their study, 12 psychologists who worked with children with intellectual disabilities noted that those with intellectual deficits were still able to hold an awareness of death from watching television or experiencing death within their communities, rather than from other adults or professionals. As a result, while children with DD's understanding of death and the grieving process may be unrealistic and limited, this does not seem to impede their ability to grieve or experience bereavement. To accommodate for this, the study suggested caregivers/professionals provide opportunities for children to ask questions and for caregivers to allow the child to experience life's 'little' disappointments rather than to protect them in hopes of better preparing them for death.

Conclusively, given the relationship between a child's level of cognitive disability and a child's prior experience of death, experts believe that as a result, children require more rehearsal and reinforcement to form their concept of death (MacHale & Carey, 2002; McAdams-Ducy, 2014; Sormanti & Ballan, 2011). Existing research has described the benefits of practical actions, and structure, such as incorporating grief into schedule, visiting the location at which the child was most accustomed to seeing the deceased, and allowing them to attend the funeral and burial (Burlton, 2018; McClean & Guerin, 2019; Sormanti & Ballan, 2011). With this, one key aspect to note includes the assurance that this exposure will be done to a degree that each child is comfortable with, and understands. This exposure of course may vary depending on developmental stage and age of the child.

Discussions Regarding Death

According to McClean and Guerin (2019), following a loss, families of children with DD often engage in three patterns of avoidance regarding discussions surrounding the death. The first of these includes absolute avoidance, wherein the child is not informed of the death and details surrounding the loss are hidden from them in totality without any conversation (i.e., children are not told their parent has died). The second pattern of avoidance includes informing the child of the death, but excluding them from conversations and involvement in bereavement rituals (i.e., funerals). The third pattern of avoidance includes protecting the child through lies by omitting facts (i.e., children are told mom has gone on a trip). These patterns are important to be aware of, as they could signal potential sources of distress for children if they receive conflicting reports or explanations following a loss. It is also important to notice that aside from their attachment to the deceased, limited access to information does not mean they will not be impacted by a loss (Somarti & Ballan, 2011). Simply, they will be left with unanswered questions as a result of a lack of communication as well as face additional barriers to obtain these answers due to their limited (if any) opportunities to talk with others about the loss.

Additional challenges regarding communication of death with children with DD, may be faced through the use of metaphorical or vague explanations for the loss. Given that children with DD are concrete thinkers, they may experience difficulty with abstract concepts and concepts relating to the permanence of death (Barnes et al., 1998; McClean & Guerin, 2019; McEvoy et al., 2011). Existing literature on communication about death highlights the utilization of various mediums and multi-sensory components to ensure comprehension and understanding of these concepts despite existing limitations. Some examples of these strategies include (Banda et al., 2009; Hume et al., 2016; Lewis, 2019) avoiding the use of euphemism to explain death, instead, using concrete simple words such as “die”, “dead” or death” in explanations and discussions, assuring children of the nature of death (i.e. death is not a punishment, contagious or a result of their thoughts, wishes or behaviours). Strategies also include allowing children the opportunity to ask questions and being patient with them, as their limited cognitive functioning may require the sharing of information and details surrounding the death to be repeated over time until it is fully understood. An example of this could be seen in the article written by Beltran-del-Olmo (2004) where an autistic child repeatedly asked his mom questions regarding his deceased father, due to a lack of clarity over specific details following the death. An example of these questions asked is “Did Jesus steal my daddy?” (Beltran del Olmo, 2004, p. 1) which shows the difficulty some children experience grasping abstract terms and concepts relating to death, permanence and life.

In the aforementioned analysis by McClean and Guerin (2019), there was a noted disagreement between psychologists regarding whether death should be discussed with children with DD prior to a bereavement experience. According to some, there is a need for death to be normalized and proactively discussed with this population before it occurs, to normalize the multiplicity of losses they will undoubtedly face throughout their lives (Sormanti & Ballan, 2011). To ease these conversations, some professionals have suggested the use of visual materials or social stories to help illustrate concepts

surrounding death. Several have also recommended the use of books, or other media resources, to be used with children to facilitate discussions and understandings of death (Barnes et al., 1998; McClean & Guerin, 2019; McEvoy et al., 2011). To further reiterate this point, additional professionals in the study by McClean and Guerin (2019) advocated for the incorporation of regional programs that could standardize information provided to professions, aides and caregivers working with children with DD. By contrast, other psychologists in this same analysis disagreed with this proactive approach, due to fears of frightening children if material is shared too abruptly. Regardless of the stance on proactive communication however, it is relevant for all caregivers and professionals to know how to discuss these themes effectively, should a child with DD ask or need further clarification after a loss.

Grief Responses

As noted in the beginning of this review, while the reactions to grief may be similar in children, the presence of a DD can impact how the grief is expressed, and can appear as incongruous to untrained observers (Burlton, 2018; Sormanti & Ballan, 2011). In turn, the following section will be dedicated towards outlining two major themes which distinguish these responses from children without disabilities, per the nature of the child with DD's relationship with the deceased and the associated risk of their responses.

Nature of Relationship with the Deceased. The first factor to note, includes the nature of the relationship with the deceased (McClean & Guerin, 2019). Preliminary studies appear to indicate that a child's stress and anxiety following a loss are significantly impacted by the degree of closeness and the extent of dependency (Burlton, 2018; Schut & Stroebe, 1999) with the deceased person. In fact, in situations of extreme dependency, the child may struggle with separation anxiety, guilt, decreased self-confidence, self-esteem and perceived insecurity (Brickell & Munir, 2011; Sormanti & Ballan, 2011). Moreover, children with DD may also exhibit protest behaviors aimed at defending themselves against feelings of abandonment and helplessness if they were close with the deceased (Kauffman, 2005),

particularly if the deceased was a primary caregiver or parent who took care of the child's special or even basic needs such as food, shelter and daily care, or was highly involved in their lives (Brickell & Munir, 2011). Such a loss may prove to be a significant change to the child's overall routine, and may result in a series of secondary losses through changes in familiar activities, daily schedules and surroundings, especially if there is a move to a different school or home following a loss. This is relevant to note, because existing literature does find a correlation between significant changes following a loss and how this may place children at increased risk for developing psychological and behavioural disturbance if the new caregiver is not as involved as the deceased (Brickell & Munir, 2011). An additional example of a disturbance that may occur after the loss of a close caregiver, is the loss of predictability, consistency and safety. As a result, it is not uncommon for children with DD to develop repetitive behaviours such as twirling, rocking, hand flapping (Sormanti & Ballan, 2011) among other emotional responses, as a way to find comfort.

According to Brickell and Munir's (2011) literature review, children without DD were identified to be at higher risk for developing behavioural and psychiatric responses to grief when they had a close or high involvement relationship with a now deceased caregiver, and a low involvement relationship with their new caregiver. Although this study did not evaluate children with DD, the potential similarity in findings should not be dismissed for this population. Given the intrinsic involvement of caregivers that aid in the basic care of children with DD through tasks such as bathing, dressing and feeding any changes to their routine, could impact the development, social experience and emotional regulation of children with DD, given the established role that caretakers have in their life (Crowell et al., 2019).

Problematic Grief Responses. Children with DD may experience negative outcomes associated with the experience of disenfranchised grief, and this may expose them to additional hurdles and pathological grief responses (Somarti & Ballan, 2011) that may impede their ability heal in comparison to children without DDs. Some examples of these pathological grief responses include: (a) co-occurrence

of secondary losses (i.e., move from family home), (b) persistent challenges in communicating effectively about emotionally charged topics, and (c) difficulty in reaching an understanding regarding the meaning of the death despite this being a common coping strategy used by those in the general public (Holland et al., 2006). In turn, any combination of these factors may further challenge a child with DD's ability to return to a baseline level of coping after experiencing a significant loss. Moreover, a failure to identify and respond to underlying grief in children with DD may lead to additional developmental regressions (e.g., bed wetting) and emotional disruptions (Clements et al., 2004), thus prolonging or otherwise complicating their respective grieving processes (MacHale & Carey, 2002).

In fact, in a qualitative study that questioned psychologists on their experience with grieving children with disabilities, several discussed that the grief for this population will often come out in things that may be challenging and sometimes that can be externalized through their behaviours or other times they can internalize it (McClellan & Guerin, 2019). In this sense, externalized grief was reported to manifest itself in challenging behaviours such as hitting out, self-injurious behaviour, refusing to go to school/leave the house, and shouting or crying. Internalized grief was said to consist of seeking time alone, absconding, loss of appetite or energy and sleep disruption. Furthermore, during these interviews, there were also several references to the presence of development regressions such to as "babyishness in the language" and bedwetting or sucking of thumbs in their grief, which although not overly discussed in existing literature cannot be overlooked. Ultimately, regardless of expression, professionals in this study made note that despite the disenfranchised grief response these children obtain (i.e., not publicly acknowledged, socially supported, or openly mourned) (Doka, 1989), their grief expressions are just as profound as that of others who do not have a DD.

Education on Emotions

Another notable variable to impact the experience of loss for children with DD is education on emotions (McAdams-Ducy, 2014). According to McClellan and Guerin (2019), children with DD and their

caregivers often lack formal instruction when it comes to emotional awareness in themselves as well as others. Altogether, this instruction is relevant to teach children with DD to be prepared for death rituals (e.g., funerals) by normalizing the emotions they might experience in themselves or in others in that event. Additionally, if they are older, additional instruction distress regulation may also help to recognize instances where they can seek help when these emotions become too much for them to handle on their own (Burlton, 2018; Sormanti & Ballan, 2011).

As noted in a previous section, some caregivers may avoid having conversations with children with DD due to fears that they might be too vulnerable to grasp distressing topics or survive distressing events. In the McClean and Guerin (2019) study, some psychologists proposed that caregivers should delicately and strategically prepare children for what they might feel or see during a distressing event such as a loss, and this may serve to enhance their resiliency. One recommended approach to achieve this included teaching children about emotions through the use of naturally occurring situations where powerful emotions may arise. For instance, a caregiver who cries after watching Mufasa's death in the Lion King while their child gets angry at them for crying due to discomfort, may use that opportunity to normalize different emotional reactions after a specific event. In another study, the use of social stories was sponsored as an effective teaching tool to teach children with disabilities in Malaysia about emotions (Rahim & Mansor, 2010). Much like children who lack appropriate grasp on the conceptualization of death, children with DD who lack appropriate education on emotions will similarly struggle following a loss, and may be predisposed to higher levels of distress, due to lack of understanding and awareness on such topics (Sormanti & Ballan, 2011).

Bereavement Supports

Other variables that moderate the bereavement experience of children with DD, include the access and nature of existing bereavement supports. Upon review of the literature of these existing themes, their impact on the bereavement experience on children with DD is discussed below.

Access to Supports. In Canada, supports for individuals with DD are provided by the federal, provincial, and municipal government, and by not-for-profit organizations (Mccoll et al., 2017). Of the government programs that are available, the majority focus on ensuring supports and benefits are available for housing, income, education and caregivers throughout an individual's development (Berrigan et al., 2020). Based on these guidelines, each province in Canada is left to implement their own system for service delivery and support provision and of these, although none appear to address the need for specialized bereavement or grief supports. This reality has left non-profit organizations to fill the gap by providing these essential services and supports for bereaved children and adults with DD. However, due to an erroneous longstanding assumption that individuals with disabilities regardless of age are incapable of grieving (Brickell 2011; Burlton, 2018), even these specialized non-profit services are scarce to find across Canada, for adults and children with DD. Therefore, several children with DD who require such services, are often referred to obtain support from online resources, grief and bereavement organizations, school or hospital social workers, clergymen or family physicians.

Interestingly, few studies on grief and loss have noted the role that schools and special education teachers could play in the provision of grief support for children with DD, given the amount of time and familiarity children develop in their respective schools and homes (Allred, 2014; Christ & Christ, 2006; Ducey & Stough, 2018; McAdams-Ducey, 2014). Although necessary training and education is needed for these to identify these reactions in children with DD, the positive effects of these supports have been noted as a potential source for ongoing support and guidance through the bereavement process. A child's ability to have access to these resource providers (who are ideally educated or equipped in this area), may impact their bereavement experience. It should be noted that training for teachers, caregivers and professionals on this area, is limited according to existing research (Ducey & Stough, 2018).

Non-profit organizations and health care professionals face similar barriers to educators and schools to provide adept grief services for children with DD, as trainings for work with this population are limited and the majority services and programs available are specifically designed for those without disabilities (Ducy & Stough, 2018). In fact, according to the services listed in the national resource listings of Canadian Alliance for Grieving Children and Youth, which detail third-party grief support service providers who serve children, teens and their families, there are no services across Canada that currently provide specialized grief services for children with DD (Canadian Alliance for Grieving Children and Youth, 2021). Despite this lack of provision, non-profit programs such as the Rainbows for All Children Canada for example, still noted to provide direct support for any bereaved child across Canada. However, given their design, some of these services much like those from other similar organizations may be inaccessible to some children with DD due to communication or attention impairments, which may impair participation (Ducy & Stough, 2018; McClean & Guerin, 2019). Similarly, depending on the family's financial resources, the child's time restrictions, ability to be confronted with unfamiliar experiences and individuals (Sormanti & Ballan, 2011), their access to supports may be further inhibited. As a result, researchers have alerted for the need for improve access to specialized bereavement services to exist for children with DD, to help support this population and close this gap (Blackman, 2001; Sormanti & Ballan, 2011).

Nature of Supports. Existing research on grief and loss, has directly focused on supporting parents, caregivers (Fernández-Alcántara et al., 2016), and teachers (Ducy & Stough, 2018; Lawhon, 2004; McAdams-Ducy, 2014) of children with DD through their grief and loss, rather than the children themselves. This is unfortunate, considering that according to McClean and Guerin (2019), several professionals believe that children with DD would similarly benefit from the same supports as typically developed children following a loss. Additionally, dated research has also noted to the similar benefits of death education to become normalized, for children with DD (Yanok & Beifus, 1993). According to the

psychologists in the McClean and Guerin's (2019) study however, effective bereavement support for children with DD does not involve a quick explanation or a single session provided by a professional or educator, but would be ongoing to fit the nature of grief.

Support for bereaved children with DD may also be provided from a range of sources including families (McEvoy & Smith, 2005), learning disability community professionals and other care workers (Read & Elliot, 2007). Support may involve using a creative approach to grief facilitation, incorporating artwork, photographs, memory and life books and pictorial formats (Read et al., 1999). Additionally, support may also involve working from a range of different levels and offering short- and long-term, reactive and proactive, helping strategies (Read & Elliot, 2007). It should be noted that even with the presence of trained professionals, the lack of evidence-based tools for assessment and communication with this specific population, also seem to pose a barrier (Blackman, 2001; Dodd & Guerin, 2009).

Negative Grief Implications

Given that the bereavement experience of children with DD is moderated by a variety of variables, it is relevant to highlight the varying degrees of risk that can accompany these experienced variables in children with DD. Although further research on risk factors and resilience may be beneficial to address the paucity that exists on risk the risk associated with the experience of grief in children with DD, the identification of children with DD who are higher risk, as noted by the presence of these factors, may be essential when it comes to assessing the need for support provision.

According to Burlton (2018), there are ten risk factors that peril the bereavement experience of children with DD:

- a dependant relationship with the deceased, thus causing turmoil and difficulty with adaption after loss;

- impaired functioning as a result of mental health concerns for the surviving caregivers, which may impair their ability to take care of the child or notice their grief reactions as they occur;
- non-existent death education or communication about death post or pre-loss;
- a lack of specialized social and community bereavement supports available to help children with DD cope after a loss;
- difficulty with the overall conceptualization of death for the child due to cognitive impairments, including the understanding the concepts of non-functionality and permanence of death;
- a lack of involvement in mourning rituals, such as funerals post-loss;
- the presence of speech and language difficulties in the child with DD, which may impede their ability to participate in grief programs or ask for help when needed;
- an overall lack of hope or low self-esteem in the child before the loss; and
- the presence of secondary losses after the loss, including changing of schools, teachers, homes, or loss of friendships.

When contrasted, the risk factors outlined in this list have significant overlap with the variables of grief experience noted above. As a result of this noticeable overlap, some researchers believe that perhaps the reason why children with DD may have a different grief experience than typically developing children, is in light of the presence of several naturally-occurring risk factors within their everyday disenfranchised experience (Bricknell & Munir, 2011). Regardless, it is relevant to underline the importance of noting the presence of these factors as they occur when helping a child with DD manage their grief. The presence of two or more of these may increase the risk of suicide, self-harm, aggression, disruptive conduct, incidence of mental illness or may lead to prolonged and disenfranchised grief responses in this population (Burlton, 2018).

Summary of Review Findings

This review aimed to underline the need and gap that exists in bereavement-specific services for children with DD. Given that amongst the many findings, the research highlights the reality that children with DD are able to experience grief following the death of a loved one, regardless of their capability to comprehensively conceptualize death.

Findings from this review also appear to suggest that children with DD may be inherently more vulnerable to develop adverse grief reactions due to the overlapping presence of risk factors such as suicide, self-harm, aggression or prolonged and disenfranchised grief responses. In turn, this reality might reveal an overarching lack of awareness, understanding and research that informs individuals, families, practitioners, schools, agencies and governments of the bereavement experience and expression of grief for children with DD. Therefore, highlighting the need, and importance for direct supports for bereaved children with DD to exist, given the increased vulnerability of bereaved children with DD is important.

Implications for Counselling Psychology

Relevance of Childhood Bereavement Research

Previously, childhood bereavement was a vastly overlooked topic of research, due to the mistaken belief that children do not have the ability to grieve or need to be protected and sheltered from pain following a loss (Wolfenstein, 1966). Despite this, present data indicates that bereavement during childhood is quite common; children can cope with loss but depending on the variables present, their wellbeing, development, attachment, and success may be negatively impacted (McManus & Paul, 2019). This data has helped to raise awareness and recognition of bereavement in children, which has resulted in an unprecedented growth to create policy and increased specialist service provisions to respond to the needs of bereaved children (Munroe & Kraus, 2010). Additionally, some Scandinavian nations, have responded by creating an expansion of supports for children through their health care and

school system. In Denmark for instance, this has led to the creation of standardized bereavement response plans (or b-plans) throughout the school system, which has led to most teachers reporting that they feel equipped to support bereaved children in schools (Lytje, 2016). This is a stark contrast from teachers or health professionals across the globe, who are citing the opposite (Ducy & Stough, 2018).

Relevance of Childhood Bereavement Research for Children with DD

In contrast to research conducted to further understand bereavement for typically developed children, similar studies for bereaved children with developmental disabilities are sorely lacking. This is relevant when one considers the multiple losses incurred by all individuals, not just children with DD, throughout their lives (Markell & Hoover, 2010). Some examples of these multiple losses include: (a) loss of identity, (b) loss of ability if conditions deteriorate, (c) loss of opportunities due to their disability, (d) loss, changes or turnover in caregivers and educators and (e) losses in relationships/friendships due to disability, school, or life changes (Sormanti & Ballan, 2011). Additionally, while there is some overlap in the research fields of grief and disability, neither has been sufficiently examined for children with DD, and has instead focused on adults with DD (Markell & Hoover, 2010). Alternatively, most research on grief and loss for children, has focused on evaluating this experience as it occurs for typically developed children, rather than those with DD (Kauffman, 2005). This reality is perhaps reflective of the erroneous biases that surround their capacity to form adept attachments, emotional skills or have sufficient cognitive capacity to understand the concept of death or experience bereavement (Dodd & Guerin, 2009; MacHale & Carey, 2002; Sormanti & Ballan, 2011). Further, as mentioned above, this gap could also be further explained by the misconceptions that surround bereavement for children in general, irrespective of the presence of a DD.

Regardless of the reason for this gap, further research in this area is relevant as this would further support the dispute of these erroneous beliefs and encourages further advocacy in policy and service-provision to exist. Due to this lack of understanding, this has led for the needs of children with

DD to be overlooked in professional practice after a loss. After conducting a review of existing literature on the topic, the implications uncovered are discussed in length below.

Relevance of Findings from Review

The first implication obtained from this research includes the reality that the experience of grief for children with DD can vary widely, for a variety of moderating factors that have been identified in the research. While some grief reactions bear a resemblance to typically developed children, these findings highlight that bereavement for children with DD may be expressed according to particular strengths and vulnerabilities relating to the nature of their relationship with the deceased, family dynamics, learning or disability. Additionally, this study has highlighted the existence of an overlap between variables of grief experience and risk factors noted to peril the bereavement experience of children with DD. The presence of this overlap can serve to explain the noted divergence in experience and responses, between children with and without DD. Some children with DD may be more susceptible to develop complicated/adverse grief reactions due to the presence of increased risk factors and stress within their overall experience (Perry, 2004), leaving them with decreased supports and impaired coping abilities. Based on these findings, clinicians working to support bereaved children with DD should look out for the following warning signs which may signal an increased vulnerability to developing adverse grief reactions: (a) dependant relationship with the deceased, (b) mental health of the surviving caregiver, (c) cognitive impairments that impede conceptualization of death, (d) lack of death education or conversations about death post or pre-loss, (e) lack of specialized bereavement supports, (f) lack of involvement in mourning rituals, (g) presence of speech and language impairments, (h) lack of hope or low self-esteem in child, and (i) presence of secondary losses. Additionally, given the limited access to bereavement services that are specifically tailored for this population, the profession of counselling psychology should be invited to include children with DD in mind for future grief programming.

The second implication for these findings, includes the need for children with DD to have similar opportunities as their typically developed counterparts to obtain supports, space and opportunities to restore their lives following a loss, if they need. Given the associated risk tied to the lack of bereavement services, including an increased propensity to develop self-harming behaviours, aggression and suicidal ideation among other adverse reactions, it is important for this gap to be closed. Additionally, it is hoped that by conducting research in this area, and developing a greater understanding of the grief experience for children with DD, their needs will be better understood and recognized via policy and service provision will be implemented for this population.

A third implication comprises an increased awareness on the role of parents, educators, schools, clinicians and support provision on the experience of grief and bereavement for children with DD. In the case of parents, educators and clinicians, through their identification of grief responses as distinct from the disability of a child, reflexive experiences and expectations of the observed grief in they expect to see in the child should change. Alternatively, the findings raise awareness on the erroneous fallacies that surround grief, and could encourage parents/caregivers to have open and factual conversations about death and the feelings and emotions associated with the experience. In turn, the role of parents/caregivers as 'fountains of information' and role models is highlighted. Additionally, parents may be uniquely positioned to assist schools and bereavement service clinicians in understanding their child's strengths, what works well as well as any other areas of vulnerability for them, amid bereavement. However, given the risk associated with this experience and the stress that already encompasses being part of a family with a child who has a DD, the efficacy of their role to support children amid grief may depend on the nature of their attachment, their access to relevant resources and education to help teach the child about grief and loss, and their physical and emotional availability to meet their needs when they are grieving.

Given the time constraints for several non-full-time caregivers, another implication from this review includes an emphasis on the role of schools, bereavement services and the increased need for relevant professionals such as counselling psychologists, to be trained to support/guide this population through their grief. Given the unique placement of schools to provide informal supports to children with DD, notice gaps in functioning, knowledge and their ongoing relationship with children throughout their development, their role in support provision should not be overlooked (Holland, 2008). These individuals can assist by adeptly educating children on grief and loss, normalize their experience, informally supporting them when needed, and help teach them how to notify their parents/caregivers when they notice a perceived risk (e.g., suicidal ideation) or experience a need for further support (Akerman & Statham, 2011; Holland, 2008; Lowton & Higginson, 2003).

An additional implication includes the understanding that given the recent COVID-19 pandemic schools, governments and bereavement services may need to work together to effectively meet the needs of grieving children with DD amid isolation and beyond the pandemic (Eapen et al., 2021). Given that without the support of bereavement services, isolated school settings may not feel equipped to address the bereavement needs of children with DD, under a new socially distanced or online format. By contrast, without the support of schools, practitioners such as counselling psychologists may be poorly equipped to practice, without access to assessment information that may be relevant for their case conceptualization (i.e., grades, conduct). Provided this new precedence increased accessibility through policy changes to ease information-sharing and collaboration between schools and practitioners, it would likely enhance the efficacy of support for bereaved children with DD amid the pandemic (Eapen et al., 2021; Liddle et al., 2018; McManus & Paul, 2019). Additionally, the need for this collaboration is further enhanced due to the variety of factors highlighted in the review, that influence and impair the experience of grief in children with DD. To help children cope amid the present pandemic, a more effective approach should include increased collaboration between health professionals and schools to

improve supports for children with DD (Liddle et al., 2018). Aside from the clear benefits of telehealth, which have served to bridge gaps in service delivery across the globe for children with DD (Eapen et al., 2021), this format could be beneficial for families worried about COVID-19 contamination and even after the pandemic. Additionally, this could also aid to sponsor change in the way Canadian provincial and federal governments communicate and invest in the health care and education sectors. Inversely, it should be noted that the efficacy of these formats (in-person versus online) and interventions for grief support, should be investigated with this population given that research on this arena has been vastly overlooked, particularly that for online formats.

Finally, in terms of implications for bereavement services, this review also indicates that the degree of accessibility for bereaved children with DD, should be improved. Given that despite the presence of exceptional organizations, there is a need for improved trainings for professionals (Read & Elliot, 2007), and for services to eliminate barriers that impede participation from this population. To achieve this, services may need to provide group or individual sessions for bereaved children, or use developmentally appropriate books and resources to support children with DD who may have troubles communicating or interacting due to their disability. Provided that research is vastly lacking, it may be necessary for researchers and bereavement services to work together to uncover further evidence to inform specialized professional trainings, practice and improve service provision for this population since the pandemic. On top of all this, the differences in experiences for children with DD may further impact bereavement service practice through the addition of several components to ensure efficacy of therapy (i.e. art, music) and understanding. While these resources do exist (Forrester-Jones & Broadhurst, 2007; Hume et al., 2016), several studies have noted professionals often feel like they are “pulling at straws” when responding to student grief due to lack of training (Ducy & Stough, 2018). Therefore, this finding serves to further enhance the aforementioned need for further research and

trainings to exist to improve access and service provision of grief services for children with DD in a variety of contexts.

Implications for Support Provision for Children with DD

As addressed above, a series of implications could be drawn regarding support provision for children with DD. The first of this, is regarding the child's access to supports being a moderator and risk factor that could stand to peril or improve their experience. To date, most studies on this subject, have centered on increasing accessibility for children with DD by providing direct supports through their parents, via support groups (Lo, 2010) and behavioural parent training (Plant & Sanders, 2007) by teaching them the best way to address the needs of their children at home.

Along this same tangent, accessibility to grief supports for children with DD has been addressed in some countries such as the United Kingdom, through schools and bereavement training for educators, staff and educational psychologists (McManus & Paul, 2019; Ducey & Stough, 2018). This sort of assistance makes sense, given that bereavement responses for this population include an impact on academic achievement. Moreover, given the amount of time older school aged children may spend in schools in contrast to home, schools may be placed in a unique position that may enable them to respond to the needs of bereaved children with DD, and support their experience.

Additionally, within their role as educators, teachers may be able to address another additional bereavement factors including appropriate education and clear conversations about death, loss and change with this population. Further, this role could potentially provide children with an avenue to ask questions regarding any discrepancies on their conceptualization of death, which can happen when others use metaphors to describe this. In the case of Canada, no such training programs exist, and few studies have highlighted for the potential role of schools as safe spaces to allow children with the potential to process their bereavement (Jonas-Simpson et al., 2014).

Another implication from the findings of this review, includes the potential for direct provision to children through specialized counselling support, given their ability to grieve and respond to a loss similarly to their typically developed counterparts. While research on this idea is scarce, few studies have indicated that direct psychosocial supports for children with DD can be beneficial (Chitiyo et al., 2008). However, alternative research on childhood bereavement has found that this is not always helpful, necessary, and can be ineffective when it is the only service that is accessed for support (Currier et al., 2007; McManus & Paul, 2019). In turn, further research to ascertain the efficacy of direct supports for children with DD is warranted. Additionally, these findings may indicate an increased acknowledgement on the significance of a tiered approach to support children's bereavement. Provided that a collaborative and integrative approach to care may provide direct grief support for children when necessary (Auon et al., 2018; Jones et al., 2015; McManus & Paul, 2019).

Recommendations for Practice

Increased Accessibility to Trainings

Given the lack of accessibility to trainings for professionals, post-secondary institutions or regulatory bodies may wish to provide induction courses or trainings to prepare students or professionals for work with this population. Additionally, although limited, any knowledge of existing trainings for specialized work in this area, may be pivotal for practitioners to consider accessing to ensure they are providing effective care. To help close this gap, schools, psychologists and medical professionals who wish to provide bereavement care may consider collaborating to create additional training opportunities. Additionally, clinicians or agencies are also encouraged to engage in public advocacy at various government levels to help raise alarm over scarcity in services and need for further financing for services, trainings or scholarship to be conducted, to help address this gap.

Improve Accessibility to Services

Due to the overall lack of bereavement services available, it is actively recommended for practitioners or agencies to consider creating or providing grief services that are specifically tailored to support bereaved children with DD and their families. To ensure an appropriate execution of these services, it may be relevant for psychologists to join consultation groups and support services available to staff, due to the emotional toll that they may experience from working with such a population and to accommodate for lack of experience (Ducy & Stough, 2018). Due to the lack of existing data to support provision for children with DD, service audits at this level should also be considered, to improve services over time. Cross-sector partnerships between schools, psychologists and medical professionals who wish to provide bereavement care may also be beneficial to create services that may be effective for children with DD and their families. Professionals should be aware of overarching protocols on typical grief programming that is not tailored if they work in an agency setting, as this may dictate the need to advocate for modifications to fit the population that is to be supported.

Finally, it may be relevant for interested practitioners to be aware of provincial and national policies which govern their practice or work with children with DD. Professionals should not underestimate their role as potential advocates to call for relevant developments in healthcare and education reform, in a way that may benefit collaboration of professionals and work with this population amid and post pandemic. It may be relevant for professionals to remain aware of new legislations and how these may impact their practice. From an advocate perspective, it is also essential to note the significant challenges that exist for children with DD and their families, particularly when noting the lack of specific bereavement services that exist. It may also be essential to promote to the government increased investments into this sector to sponsor further research and to incentivize the creation of specifically tailored agencies and services across Canada.

Increased Collaboration Between Professionals

Given the diverse impact of the bereavement for children with DD across various levels, as well as the physiological, emotional and psychological needs they may have in the form of grief reactions, increased collaboration may be required for bereavement care. One example of this may include work between psychologists and doctors to treat physiological distress and to rule out alternative conditions. Additionally, psychologists may opt to work alongside school educators or special needs aids who have been working with the child to assess their strengths, needs and impact of grief in their academic achievement and social connection with others since the loss. In turn, the concept of an open system that is open to change rather than a closed one, is essential for care in the reduction of risk and enhancement or resilience for children with DD. To support this, it is important to note the findings of Majer and Seligman (1976), who uncovered that a lack of collaboration in care resulted in increased anxiety, helplessness and deficient professionals despite past competency or experience, in the realm of bereavement. Therefore, the lack of inclusion of families, schools and related professionals may provide an explanation as to why psychological supports may not always be helpful, when it is the only service that is accessed for support (Currier et al., 2007; McManus & Paul, 2019).

Therapeutic Guidelines

Guidelines for Work with Parents & Other Professionals

Clinicians should adopt a proactive approach where they use psychoeducation to: (a) teach caregivers, families and educators how to recognize grief responses (particularly those that peril their safety or that of others); (b) teach about the way a child with DD's conceptualizes death and experiences grief despite cognitive delays; and (c) instruct on how to use natural experiences of loss to teach children about emotional awareness, death and role model ways to cope with loss (McClellan & Guerin, 2019).

To aid with the psychoeducation, some overarching guidelines to help parents effectively explain death to a child with DD it is recommended that they (a) allow the child to participate in grieving rituals;

(b) use biologically correct and honest explanations that are to the child's developmental stage and accommodate for any deficits; (c) avoid using euphemisms or abstract concepts, but rather keep answers short, clear and understandable; (d) emphasize it is not the child's fault; (e) prepare for the child to ask insensitive questions after the explanation is made; and (f) remember that an overt expression of sadness (e.g., crying, tears) is not a sign that the child did not understand what was explained. Instead, given that loss in children with DD can express their experience of loss through physiological, psychological, behavioural or emotional manifestations (e.g., upset stomach, irritability, self-harm), educators or parents should be prepared recognize different signs that further support is needed. Additionally, it is relevant for individuals delivering the news of a death to be wary of the role their own mental health and attachment to the child as this may impact the delivery of news, and their support to the child after the explanation is delivered.

It is relevant to underline the need for practitioners to provide ongoing support to caregivers and teachers in an on-going basis, to accommodate for the nature of grief that is experienced by the child with DD. To accommodate for these expenses, clinicians should be prepared to connect families or caregivers with relevant government or community resources that may help them to finance these visits. Moreover, it is recommended for clinicians to remain up to date on their knowledge about these different resources, as well as the regulations (e.g., privacy) that govern the nature of care and communication between providers (e.g., doctors, teachers) to enhance care. Further, at this stage it may also be relevant for counselling professionals to remain cognizant of the correlation between the caregiver's mental health and their support for children post loss as a potential risk factor that may peril their experience. In turn, it may be relevant for clinicians to incorporate an approach that will provide the necessary support to caregivers who are struggling with their mental health alongside children with DD, to prevent a negatively impact on the caregiver's ability to cope or take care of the child.

Guidelines for Work with Bereaved Children with DD

According to McClean and Guerin (2019), the following four guidelines are all relevant to help guide bereavement work with children with DD: (a) meeting the child where they are at, (b) awareness that further psychoeducation on death and emotions may be required, (c) not underestimate the child's response to grief, and (d) consult whenever necessary with other professionals. In turn, the remainder of this section, will be dedicated towards explaining these guidelines further to provide more practical guidelines for work with bereaved children with DD.

The first of these guidelines includes meeting the child where they are when they begin counselling, being aware of the impact and role that their disability might play by watching language and therapeutic work to ensure it is appropriate to the child's learning and needs. For instance, a child with DD who struggles with concentration may require more direction or flexibility during certain activities to accommodate for this difficulty. Most importantly, it is relevant to note with this final guideline that each child is unique and therefore their experience of grief is unique, so the therapeutic work should not include implementing a one-size fits all approach. It is recommended for practitioners to be ready to use a variety of different resources to assist in their therapeutic work such as videos, movies, art activities and books on grief to tailor for deficits that may impede comprehension of concepts due to the disability.

A second guideline includes a notable awareness that further psychoeducation on death and emotions may be required for work with children with DD. This can be accomplished through concrete and clear explanations of these concepts rather than vague or metaphorical ones delivered in a manner that is appropriate to the child's developmental stage, while also noting their cognitive or verbal deficits. Additionally, clinicians should be prepared to answer any questions children may have on these matters due to patterns of avoidance at home on matters relating to death or because of erroneous assumptions that imply they cannot handle such teachings. To ensure the delivery of these teachings are effective, it is once again recommended for practitioners to be willing to use a variety of tools to teach these

concepts such as movies, TV shows, workbooks, art, music and books. For instance, in the McClean and Guerin (2019) study, some psychologists mentioned that visual materials or social stories could be used to help illustrate concepts surrounding death. Several psychologists reported using books about grief and death, specifically citing that they have books such as *Badger's Parting Gifts* by Susan Varley and *Water Bugs*, and *Dragonflies: Explaining Death to Young Children* by Doris Stickney (Markell & Hoover, 2010) to help teach children with DD about death. This way, the clinician would be proactively working to meet existing gaps on death education and would be equipping the child with tools to recognize basic emotions to improve support and communication about their present experience if they are able to. To further complement these teachings, it is relevant for the practitioner to instruct caregivers or parents to take advantage of ongoing examples of emotions or death (e.g., a child cries in a playground or an ant is stepped on) to continue to reinforce learning on these concepts. Finally, when selecting resources to use with children with DD, it is best to avoid books that have euphemisms and to talk to the children using honest, simple language. It is also important to have an open agenda throughout the session to accommodate for questions and difficulties and to remember to listen and observe the child's non-verbal responses after sharing to ensure they are not feeling overwhelmed (Markell & Hoover, 2010).

Third, it is relevant for the clinician to not underestimate the child's response to grief while in counselling by remaining cognizant of the various grief responses that may plague bereaved children with DD after a loss: stomach aches, disorientation, fatigue, trouble breathing, increased mental health difficulties, anger, suicidal ideation, self-harm, aggression, confusion, phobias, regression (e.g., bed wetting), social withdrawal, low self-esteem and difficulty with educational achievement, among others. Additionally, to accommodate for any existing risk, it is relevant for the practitioner to remain aware of the child's relationship to the deceased, as well to remain watchful of any risk factors present that may peril their bereavement experience. These risk factors include: a dependant relationship with the deceased, mental health of the surviving caregiver, non-existent education or communication about

death, lack of supports, difficulty conceptualizing death, lack of involvement in mourning rituals, presence of speech and language impairments, lack of hope or self-esteem and secondary losses. Finally, should imminent risk present, practitioners should be ready to comply with existing ethical restrictions that force the clinician to breach confidentiality with the child's parent/guardian or refer the client if further support is needed in an area where the professional lacks competency.

Fourth, due to the presence of significant gaps in services, it is relevant for the practitioner consult whenever necessary with other professionals to ensure they are always practicing in a manner that manages biases, and complies with ethics guidelines that govern the profession. Additionally, it may be relevant for the practitioner to be keenly aware of gaps, and be ready to collaborate or refer whenever necessary to accommodate for the unique experience of grief in each child. Moreover, due to the emotional toll that can be attached to the nature of grief work, it is recommended for professionals to seek counselling or engage in thorough self-care whenever needed to accommodate for the emotional toll associated with grief work. Finally, given the lack of access to trainings, it is pivotal for clinicians to remain cognizant of their areas of competency and ethically ensure that they do not practice outside of this, to comply with ethical guidelines that govern the profession.

Fundamental Next Steps for Research

As discussed throughout this review, there is a paucity of research regarding bereavement care for children with DD. To fill this gap, the following section highlights six key themes that encompass fundamental next steps that researchers should take to help inform specialized support provision in counselling psychology for bereaved children with DD.

The first of these themes includes closing the research gap by evaluating the efficacy of in-person or telehealth counselling with this population for the purposes of bereavement given that research is highly contradictory. This is relevant to consider given the increased difficulties that children with DD experience when they attend in-person health care appointments, including difficulty complying with

the demands of examinations, self-injurious behaviours, hyperactivity, aggression and destruction of property (Liddle et al., 2018), professionals could take advantage of telehealth as a way to mitigate these concerns. Additionally, virtual appointments could serve to enhance quality of care by saving travel time for the family, and enhance comfort and safety of the child as they remain in their home for care (Eapen et al., 2021). Unfortunately, a lack of information on this topic, has undoubtedly left professionals feeling unprepared as noted in the previous review, when dealing with both in-person or telehealth care. Moreover, while research on this is present for children without DD, more specified research in this regard may help to acknowledge children's unique set of needs amid bereavement and in turn, inform specialized counselling provision. Additionally, given the recent shift to online formats over the previous pandemic period, it may be relevant to evaluate this efficacy under a randomized controlled trial (RCT) setting. Given that despite existing reviews that predict this efficacy due to increased potential for access, flexibility and potential for collaborations, there is no study that has corroborated this assumption.

The second theme includes more methods and data collection that incorporates the perspective of bereaved children with DD in grief counselling. These studies would emphasize the importance of a child's voice challenging stereotypes that view them as helpless and provide clinicians, educators and caregivers with a unique window into their experience of grief. That said, while with children with such complex needs can be a lengthy, arduous and challenging process due to the presence of language and communication deficits (Burlton, 2018). To accommodate for deficits, future studies could evaluate the use of telehealth means and dyadic interviewing techniques amid interviews, to include the child with DD and their key supporting figure in the research to improve communication, access and comfort for participation.

A third theme comprises the need for more research to investigate the efficacy of certain counselling theories, models and techniques with this population during grief counselling. Further

research is still needed to affirm what the best approaches to use are for effective care. More research in this arena may help counselling psychologists expand their toolbox and improve their competency with this specialized population and ensure no further harm is done by clinicians during treatment.

The fourth recommendation for future research recommends investigating the overall efficacy of counselling support provision as a bereavement treatment for children with DD. Further study on this is essential given that it is presently unclear which essential variables or services may be most beneficial for bereaved children with DD to access to obtain support. Understanding this efficacy further may serve to provide further proof of the need to increase accessibility of services.

The sixth area of further research addresses the need to evaluate specific factors related to the effectiveness of collaborations between professionals (e.g., teachers, psychologists and doctors). It may be beneficial to also evaluate the effectiveness of these collaborations under telehealth compared to in-person formats when providing bereavement care (e.g., as highlighted by the demands social-distancing due to the COVID-19 pandemic).

Lastly, it is relevant for additional studies to explore the role of culture and faith within the realm of bereavement in children with DD. Given that both of these variables can inform various practices, traditions and expectations for life after death, it may be relevant to explore these in greater detail. In turn, doing such scholarship could be considered essential, given the way these could impact support provision in children with DD.

Reflexive Self-Statement

Upon reflection, the completion of this review has allowed for my development as a counselling psychologist in a variety of ways. I feel more confident in my abilities to recognize grief and risk amid bereavement for children with DD, and how this may inform support provision. That said, my development in this regard does not imply that I did not face any challenges as I completed the literature review and implications section. These will be explored below in further detail.

Due to the lack of research that exists on the bereavement experiences for children with DD, I found the literature review portion a little more challenging and time-consuming. In turn, it was challenging for me as a researcher to include current and relevant research to build on the existing data and address the gap in the literature for bereaved children with DD. Additionally, due to the dearth of research, I was forced to make decisions that made the review more general, thus explaining my decision to expand my search to children with DD rather than more specified syndromes. Further, due to this gap in the literature, some studies evaluated bereavement in children with specific disorders or disabilities that fall under the DD umbrella, yet used these findings to discuss how bereavement in children with DD, a reality which in turn, overlooks the diversity of children who fall under this clinical term. In retrospect, this process could have been simplified through a shift in focus by contrasting and comparing bereavement and grief in children with DD and their typically developed peers rather than experience and risk. However, the aim of this literature review was to provide practical assistance to counselling professionals in the way they support bereaved children with DD. Due to the absence of data which evaluated the experience of bereavement from the side of children with DD, upon reflection I would have appreciated more data/methods/approaches that addresses the perspective of bereaved children with DD in grief counselling. Provided that overlooking their unique experiences, needs and views professionals may be doomed to provide services that may not be adept for them.

Through reflexive journaling, I realized that there is a need for further collaboration with and between professionals to improve patient care and outcomes in Canada. This posed a unique challenge, as it called into question the efficacy of counselling as a sole source of support for individuals children with DD who are grieving. As a future counselling psychologist, this finding made the research findings and implications difficult to write given the idea that my future profession would not be enough to help this population.

A secondary challenge I faced during my writing of the implications section, included the significant number of studies which evaluated implications from an educational psychology perspective rather than from a counselling psychology perspective. In turn, the implications drawn as a result, should be subject to further investigation to affirm the efficacy of such claims. Additionally, the lack of data that included the perspective of children with DD as participants may call into question to real needs of this population in a grief counselling context. Therefore, the writing process of this section was highly difficult, due to the lack of supporting data to reaffirm or confirm my claims. That said, due to my personal experiences working in Parliament Hill in Ottawa, as well as for the Government of Alberta, I was proud to include a social justice component into my writings by encouraging for further advocacy and research. My hope behind this aim, was to continue to support for the removal of barriers which inhibit or impair the delivery and access to grief supports for this population in Canada, given the ethical duty we have as professionals to maintain our responsibility to society under Principle IV of the Code of Ethics (Canadian Psychological Association, 2017).

Overall, despite the presence of these challenges, I have thoroughly enjoyed the completion of this research project and research process. It has helped to enhance my knowledge of the grief process for this population, and has further exposed me additional areas of psychology including educational psychology. Additionally, I feel like these findings have contributed to my further appreciation of grief work with children, let alone children with disabilities. As well as exposed me to the overall complications encountered by counselling psychologists and parents who seek to care or working with a bereaved child with a DD.

Discussion of Review Results

The response to the following questions posed at the beginning of this review, will be discussed in this section. To review, these questions were:

1. What factors moderate the bereavement experience and risk for children with DD after a loss?
2. How could these factors be used to inform support provision amid the bereavement experience of children with DD?
3. What implications could these findings have on counselling approaches towards support provision for this population following a loss?
4. Should children with DD receive counselling bereavement supports directly?

In response to the queries posed, this review unveiled that there are a variety of factors which past research on the topic have identified which appear to moderate the experience and risk of bereavement for children with DD. The variables of experience included: the role of disability in bereavement, discussions regarding death, the presence of other factors which may influence their conceptualization of death, grief responses, education on the topic and their access to supports. By contrast, the risk factors identified included communication with the bereaved about death before the loss, availability of supports, ability to understand death, lack of involvement in mourning rituals, presence of speech/language difficulties, attachment with the deceased, their surviving caregiver's mental health, presence of secondary losses and protective factors.

When collectively reviewed, these findings unearth significant overlap, therefore suggesting that the differences between children with DD and their typically developed peers may occur due to the presence of several risk factors in their overall experience of grief. It could be posed that children with DD may be inherently prone to develop adverse and prolonged grief reactions due to this overlap. Therefore, these findings might aid support provision by highlighting the need to address gaps in practice and a need for further professional trainings and bereavement services to exist to help clinicians mitigate risk.

In terms of counselling implications, four major themes were outlined: (a) increasing the accessibility to trainings for professionals; (b) improving the accessibility to bereavement services; (c) increasing collaboration between professionals; and (d) providing therapeutic guidelines for work with parents, other professionals, and children with DD. Lastly, regarding the need for children with DD to have direct access to counselling, existing research appears inconsistent regarding the solitary access to counselling supports as sole forms of assistance amid childhood bereavement. Therefore, in accordance with existing research, it is recommended that counselling supports are accessed or referred by other professionals only when families or children deem it necessary for support.

Conclusion

This literature review draws from the fields of disability, grief/bereavement and counselling to assist counselling psychologists and alternative professionals in their improvement of support, and care of bereaved children with DD. Due to the complex needs and strengths children with DD have, a series of recommendations have been made based on the research uncovered, including: (a) meeting the child where they are at, (b) awareness that further psychoeducation on death and emotions may be required, (c) not underestimate the child's response to grief, and (d) consult whenever necessary with other professionals.

To address the significant research gaps that exist in this area, this review also recommends more research to fill the following research gaps: (a) the efficacy of online or in-person provision; (b) the perspective of bereaved children with DD in grief counselling; (c) the efficacy of theories, techniques and models in bereavement counselling with children with DD; (d) the overall efficacy of counselling as a treatment in bereavement care; (e) the factors related to the effectiveness of collaborations between professionals in bereavement care; and (f) the role of culture and faith in bereavement for children with DD. Closing these gaps would further clarify what factors moderate the bereavement experience and risk for children with DD after a loss, what can be used to inform support provision, and how this

influences counselling approaches for children with DD and their ability to receive these supports directly.

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