WHEN STUDENTS GRIEVE: TEACHERS OF STUDENTS WITH INTELLECTUAL DISABILITIES

A Dissertation

by

ELIZABETH HOPE MCADAMS DUCY

Submitted to the Office of Graduate and Professional Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSPOHY

Chair of Committee,	Laura M. Stough
Committee Members,	M. Carolyn Clark
	Yvonna Lincoln
	Dalun Zhang
Head of Department,	Victor Willson

May 2014

Major Subject: Educational Psychology

ABSTRACT

The identification and provision of support for the emotional needs of children with intellectual disabilities is essential as these students are often "disenfranchised grievers"-- meaning their grief is not recognized by others. The purpose of this study was to explore the experiences of teachers who have had elementary students with intellectual disabilities who have lost a parent or guardian. Additionally, this study documented behavioral changes and grief symptoms noted by teachers in their students, as well as how teachers responded to these perceived expressions of grief. Five teachers participated in two interviews designed to elicit information on their experience with grieving students. Constructivist grounded theory methods were used to analyze the data.

Findings indicated that students were deeply impacted by the death of their parent or guardian. They displayed a range of grieving symptoms such as crying and aggression. Teachers overwhelmingly supported their grieving students despite being emotionally impacted themselves. They responded in ways suggested by grief and educational professionals such as when they provided concrete and simple explanations to assist with student understanding of death. Teachers expressed concern about the surviving caregivers' own grief and the subsequent impact on their students. Teachers also highlighted the need for more grieving resources.

DEDICATION

This work is dedicated to my beautiful children, Patrick and Madeleine. I am honored to be your mother. I love you both more than all the stars in the sky. Always, always, follow your dreams!

ACKNOWLEDGEMENTS

Thibaut, my dearest husband, thank you for your immense patience, love, and encouragement. I could not have accomplished this without you! Je t'aime de tout mon coeur!

I owe my deepest gratitude to Dr. Laura Stough. Thank you for your enduring support and guidance throughout this academic and emotional journey! I have learned immensely from you.

I send deep appreciation to Drs. Carolyn Clark, Yvonna Lincoln, and Dalun Zhang. I greatly value their wisdom, encouragement and advice.

To my sister, Annie, you are an inspiration to me. Thank you for constant support.

Dad, I am grateful for your unconditional love and encouragement of my intellectual and spiritual development. Thank you also for reminding me to "always stop and smell the roses."

To my mother, thank you for a lifetime of unwavering love, support and expressions of pride. It was because of your example that I dreamed big and persevered.

Thank you to the teachers who graciously told their story. This research would not exist without their interest, enthusiasm and dedication.

Finally, thank you to all the individuals with intellectual disabilities who I have had the pleasure to know. Thank you for enriching my life and making me a better person.

TABLE OF CONTENTS

Page

CHAPTER Page

LIST OF FIGURES

Page

LIST OF TABLES

Page

CHAPTER I

INTRODUCTION

> Mourning is one of the most profound human experiences that is possible to have. The deep capacity to weep for the loss of a loved one and to continue to treasure the memory of that loss is one of our noblest human traits
>
> —Shneidman

As an undergraduate, I volunteered at the nursing home where my sister worked as a social worker. It was in this environment that I had a haunting encounter with a young man. His name was William. He was a 33-year-old man with Down syndrome. I happened to glance at him when I walked by his room. He did not return my glance. He sat on the edge of his bed, his hands folded in his lap, his feet turned inward. His gaze was steadily fixed at the cold nursing room floor. His shoulders slumped over. Sadness consumed his face. I stood there for a moment, transfixed by his immense grief. He seemed so alone. My sister told me that he had arrived at the nursing home following the death of his father.

I wondered about his situation. Why was a 33-year-old man in a nursing home? Who was going to be there to talk to him about his father? Who was going to sit with him while he cried? William is just one example of a person with intellectual disability not appropriately supported during their grieving process.

Historically, people with an intellectual disability (ID) have suffered tremendously from dehumanizing societal practices. Smart (2009) noted, “Intellectual functioning was considered to be the defining feature of humans and if a person lacked

the capacity, then he or she was often considered subhuman" (pg. 201). As a result of such views, people with ID have been institutionalized. They have been isolated from family members and society. Their graves marked by numbers instead of names. They have been the recipients of forced sterilizations and government experiments. They have been murdered as a result of eugenics movements.

In recent times, society has made tremendous strides away from the inhumane historical practices towards valuing the diversity of human functioning. Evolving during the civil rights era, the Disability Rights Movement was the impetus for numerous advances in the quality of lives for people with disabilities. National legislation such as the American with Disabilities (ADA, 1990) and the Individuals with Disabilities Education Act (IDEA, 2004) mandated inclusionary practices for people with disabilities. Despite such advances, people with ID continue to encounter negative attitudes and stereotypes that ignore their human rights. People with ID are bombarded by offensive language used in everyday conversations (e.g. "What a retard!") and in the media. People with ID frequently lack access to accessible services, live in poverty, have high unemployment, and are at a higher risk for physical and sexual abuse than is the general population (Administration on Developmental Disabilities, 2000; Smart, 2009). Further, the psychological and emotional needs of people with ID often are ignored (Blackman, 2002).

People with ID confront misconceptions about their mental health. An erroneous assumption is that people with ID are always happy and therefore incapable of experiencing a full range of emotions including sadness, depression, and grief (Storm,

1990). These assumptions are particularly dangerous as individuals with ID are at increased risk of developing psychopathology such as depression and complicated grief (Dodd et al., 2008; Dykens, 2000; Tonge & Einfeld, 2003). The United Nations Convention on the Rights of Persons with Disabilities (2006) states, "Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others" (p.13). This study examined how people with ID were supported in their experience of the "noblest human trait"- that of grieving.

Purpose

Studies have shown that teachers can be effective in supporting students who are grieving (Blackburn, 1991; O'Conner, 2002, Reid & Dixon, 1999). However, little is known about how teachers support grieving students with intellectual disabilities. The purpose of this study was to explore the experiences of teachers who have had elementary students with intellectual disabilities who have lost a parent or guardian. Additionally, this study documented behavioral changes and grief symptoms noted by teachers in their students, as well as how teachers responded to these perceived expressions of grief.

Research Questions

1. What were the experiences of teachers of elementary students with intellectual disabilities who have lost a parent, guardian or primary caretaker?
2. What behaviors of students who have lost a parent, guardian or primary caretaker did teachers observe in the classroom?

3. How did teachers respond to students with intellectual disabilities who have lost a parent, guardian or primary caretaker?

CHAPTER II

REVIEW OF LITERATURE

Intellectual Disability

It is estimated that 7 to 8 million individuals in the United States have an ID (American Association on Intellectual and Developmental Disabilities, [AAIDD], 2010). The term "intellectual disability" replaced the term "mental retardation" in 2010. The term "intellectual disability" better aligns with contemporary constructs of disability as resulting from the interaction between individual impairment and social-environmental contextual factors (Schalock et al., 2007). However, "intellectual disability" is more than a diagnostic category. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 stressed that

> Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of the United States society (Administration on Developmental Disabilities, 2000, p. 2).

The diagnostic criterion of intellectual disability includes limitations in intellectual functioning and limitations in adaptive behavior including conceptual, social and practical skills (AAIDD, 2010). These limitations must be present before the

age of 18. As a result of such limitations, people with ID often need supports to assist with daily functioning (Thompson et al., 2009).

Supports for people with intellectual disability

Luckasson et al. (2002) defined supports as ‘‘resources and strategies that aim to promote the development, education, interests, and personal well being of a person and that enhance individual functioning” (p. 145). Human beings are social creatures and use a variety of supports throughout their lifetimes. For example, a person may need temporary support from friends after a surgery or an unemployed person may receive financial support from family members. The supports used by people with ID differ in intensity and type than those used by most people (Thompson et al., 2009). For example, a person with ID may need cognitive supports across his or her lifetime such as having a teacher explain academic concepts in a concrete manner during their childhood or receive reminders from coworkers when on the job during adulthood.

In 1992, the American Association of Intellectual and Developmental Disabilities (AAIDD) introduced a classification model that included differential levels of support defined as intermittent, limited, extensive, and pervasive. Supports can include both material supports, such as medical equipment, or human supports, such as teachers (McDonnell, Hardman, & McDonnell, 2003). AAIDD (1992) stressed that the need for these supports arises from a mismatch between an individual’s personal competency and the demands of the environment. Such a view reflects an ecological philosophical view of disability (Thompson et al., 2009). Levels are used to identify the intensity of supports needed by an individual with ID and are seen as occurring across a number of

life domains including work, self-determination, relationships, health and wellness, and emotional well being (Thompson et al., 2009). Supports for people with ID are particularly important when they experience a loss. C*omplicated grief*, in which grief is prolonged and interferes with daily functioning, can occur in people with ID at an increased rate when they do not receive appropriate support (Dowling, Hubert, White & Hollins, 2006; Raji & Hollins, 2003).

Grief

Grief has been defined as the "psychological reaction to an experience of loss" (Kauffman, 2005) and is conceptualized as an internal reaction to loss (Doka, 2002). Grief is typically a reaction to a variety of losses including death, divorce, disaster, or relocation (Kaufman, 2005) and is considered part of the normal human emotional experience. However, five to ten percent of grievers experience a severe reaction to the death of a loved one and require professional assistance (Doka, 2013). In recognition that individuals incapacitated by grief may need professional intervention, the Diagnostic and Statistical Manuel of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) removed the "bereavement exclusion" from the Major Depressive Disorder diagnosis used in previous editions (Doka, 2013). As a result, those who experience the death of a loved one can now be diagnosed with Major Depressive Disorder (MDD) two weeks following the loss. In order to be diagnosed, the individual must demonstrate: (a) a persistent depressed mood, (b) two or more of the following symptoms-poor appetite, insomnia, low energy, low self-esteem, poor concentration, and feelings of hopelessness (5th ed.; DSM-5; American Psychiatric

Association, 2013). In recognition that most bereaved individuals do not develop depression, the DSM-5 calls for careful clinical judgment before a person is diagnosed with MDD and that appropriate responses to a loss must be distinguished from the presence of an actual Major Depressive Episode (MDE). The DSM-5 further emphasizes that symptoms of grief often differ in frequency and type compared to a MDE. For example, symptoms of grief often "decrease in intensity and occur in waves" while MDE is more persistent. A grieving person usually maintains self-esteem, unlike a depressed person, and thoughts about death and dying are limited to the deceased and possibly "joining the deceased" in times of grief "whereas in MDE such thoughts are focused on ending one's own life because of feeling worthless, undeserving of life, or unable to cope with the pain of depression" (5th ed.; DSM-5; American Psychiatric Association, 2013). The expression and duration of grief vary from culture to culture (5th ed.; DSM-5; American Psychiatric Association, 2013) and grief is subject to societal rules that define and, in some cases; limit the role of the griever (Doka, 2002).

Grief in Individuals with Intellectual Disability

Historically, individuals with ID have been viewed as incapable of grief (Brickell & Munir, 2008, Dodd, Dowling, & Hollins, 2005; Kauffman, 2005). This perspective stemmed from questions about whether individuals with ID appropriately reacted to the loss of a loved one and if they had the ability to understand death concepts (Brickell & Munir, 2008; Dodd et al., 2005). As a result, people with ID were not always supported in expressing the "noblest human trait" of grieving. For example, after an adult resident at a state institution lost her mother, a researcher was told by the residential staff, "her

mother's been dead over a year, and she still thinks every Sunday that she might come and visit. We've decided not to tell her what's happened. She won't understand" (Oswin, 1991). Such practices lead to dehumanizing attitudes towards people with ID and make expressions of grief socially unacceptable (Kauffman, 2005). These attitudes are still present despite recent literature that has shown people with ID do grieve and are capable of cognitively understanding death (Bonell-Pascual et al., 1999; Gilrane-McGarry & Taggart, 2007; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997).

Grieving adults with ID

Research studies on grieving people with ID primarily include adults. These studies tend to primarily focus on reactions to loss and on their cognitive understanding of death. Studies report that adults with ID respond to the loss of a loved one with a range of reactions, varying from minor behavioral changes to the development of psychopathology. Harper and Wadsworth (1993) interviewed 43 adults with ID who had lost a parent, stepparent, sibling, roommate, relative, or pet within three years of the event. Participants reported how they continued to experience different facets of loss including loneliness, anxiety, sadness, depression, dislike of residential placement, decrease in activities, and behavior problems. In another study, adults with ID communicated the emotional impact of their loss with statements such as "I was so stunned. I couldn't talk, I couldn't accept it" and "It was very, very hard for me. I didn't talk to my mother. My parents could see the look on my face, sad" (McEvoy, MacHale, & Tierney, 2012). Other studies have been based on reports of caregivers on observed behavioral changes in adults with ID. Behavioral symptoms reported in these studies

included reports of crying, sadness, irritability, sleep difficulties, fatigue, loss of appetite, hostility to others, body aches, anxiety, lethargy, inappropriate speech, and hyperactivity (Bonell-Pascual et al., 1999; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997). Reports on grief reactions in adults with ID have also included self-injurious behaviors and self-blame as well as verbally expressed anger towards the deceased (Clements, Focht-New, & Faulkner, 2004; Kauffman, 2005; Oswin, 1991). Studies have primarily reported behavioral manifestations of grief; however, people with ID can show a range of emotional, physical, cognitive, behavioral, and spiritual expressions of grief (Hospice Association of America, 2013).

The issue of cognitive understanding of death is often addressed in the available literature. Researchers suggest that the concept of death includes understanding of non-functionality (understanding the body can no longer move), irreversibility (understanding the deceased person cannot return), and universality (understanding everyone dies) (Kauffman, 2005; Markell & Hoover, 2010). Researchers have mixed conclusions on whether people with ID are able to understand death cognitively.

Several studies have documented that people with ID cognitively understand death. Case study reports by Kaufman (2005) illustrated how adults with mild to moderate ID[1] verbalized their understanding of the concepts of death. For example, one man demonstrated the concept of non-functionality by repeating "My father lying in the

[1] Former constructs of ID used definitions based on an IQ score and used the terminologies of *mild* (IQ of 50-70), *moderate* (IQ of 35-50), *severe* (IQ of 20-35), and *profound* (IQ of 20-25). These terms are no longer considered appropriate when referring to people with ID. However, for the purposes of this literature review, I use the language employed by researchers as published in their studies.

coffin, not moving." In another study, Harper and Wadsworth (1993) administered a survey that included questions to assess cognitive understanding to 43 adults with ID, 39 of whom had moderate to severe ID. Findings showed 29 of the participants, including those with lower IQs, answered correctly to six or more of the eight questions such as "Can dead people feel hot or cold" and "Does everyone die someday?" These same respondents were interviewed on their experience with death and were asked, "What does it mean to die?" Participants demonstrated their conceptual understanding of death through statements such as "can't see or hear" and "can't feel or breathe." Collectively, these studies demonstrate that some people with ID are clearly able to understand the concepts of death.

Other researchers have found that people with ID demonstrated difficulty grasping death concepts due to limited cognitive functioning (Lavin, 2002; McEvoy et al., 2012). McEvoy et al. (2012) interviewed 34 adults with ID (21 with mild ID and 13 with moderate) about their cognitive understanding of death. Findings indicated that only 8 participants had full understanding of death, 24 participants had partial understanding of death and two had limited understanding of death. The authors' indicated that partial understanding could cause a person with ID to develop incorrect conceptualizations about death and found that "death comprehension was positively correlated with cognitive ability and adaptive functioning" (pg. 191). These authors further stressed the importance of verbal explanations and reminders on the loss of their loved one, a conclusion echoed by many other researchers (Dodd et al., 2005; Kauffman, 2005; Lavin, 2002; Lipe Goodman, 1983; Markell & Hoover, 2010).

Despite these mixed findings, most researchers currently agree that people with ID can experience grief without having cognitive understanding of it (Dodd et al., 2005; McEvoy et al., 2012; Murray, McKenzie, & Quigley, 2000). Markell and Hoover (2010) stress that people with more severe ID will not be able to voice their grief reaction but will show grief through their behavior. Researchers have even challenged assumptions about cognitive understanding in grieving individuals with ID. McEvoy, Reid and Guerin (2002) examined the cognitive understanding of death and emotional awareness of 41 adults with ID. Participants were asked to respond to a short story about a grandson dealing with his grandfather's death. Findings indicated that the majority of the participants had incomplete understanding of death; however, 76 percent of participants were able to correctly identify emotional responses when given a series of vignettes on death situations. Participants were asked to point to a sad or happy face when asked how the person would feel. Some participants made statements such as "bound to feel terrible" and "he will cry." The authors pointed out that while participants did not posses cognitive understanding they were able to attribute appropriate emotions to the death context. The authors argue that the focus should be on how people with ID express emotion rather than dwelling on their cognitive understanding of death.

Grieving children with ID

Studies available on grief and ID tend to focus on adults and give little attention to the grieving experience of children. In addition, there is a paucity of studies that empirically address the phenomenon of grieving children with ID. Tonge and Einfeld (2003) longitudinally examined the predictors and patterns of psychopathology in

children with ID. One finding indicated that participants with the highest level of psychopathology also had higher numbers of reported psychosocial and environmental issues, one of which was the loss of a parent. A case report of a 9-year-old boy with ID reported that the child slept in his deceased father's bed, talked often about his father, and cried frequently (Clements et al., 2004). There are also anecdotal reports of grieving in children with ID (e.g. Cathcart, 1995; Markell, 2005; Markell & Hoover, 2010; Ray, 1978). Researchers, because of the lack of empirical studies, draw from two separate tracks of research, one on grieving children without ID, the other on grieving adults with ID, to form suggestions on how caretakers should address grief in children with ID (Brickell & Munir, 2008; Everatt & Gale, 2004; Markell & Hoover, 2010; Sormanti & Ballan, 2011; Trublood, 2009).

Children without disabilities have been reported to demonstrate a range of reactions including shock, anger, guilt, and anxiety in connection to grief (Eppler, 2008; Haine, Ayers, Sandler, & Wolchick, 2008). The death of a parent has been described as the "most traumatic event that can occur in a child's life" (Cerel, Fristad, Verducci, Weller & Weller, 2006, p.681). Grief is intensified when the parent is a primary caregiver and the change in the child's support system impacts their familiar routines and emotional stability (Heath et al., 2009). Although children can be resilient after the death of a parent, some who have lost a parent demonstrate lower levels of self-esteem and self-efficacy (Christ, 2010; Haine et al., 2008; Worden & Silverman, 1996) and often demonstrate academic difficulties (Haine et al., 2008). Psychologists suggest children react differently to death based on their developmental age (Christ, 2010;

Dowdy, 2008). For example, preschool children may demonstrate clinginess and bedwetting, elementary students may demonstrate somatic complaints such as sleep disturbances, and middle and high school kids can evidence substance abuse or withdrawal (National Association of School Psychologists, 2010). Authors have suggested, but have not empirically studied, that children with ID may display these same grief symptoms (Brickell & Munir, 2008; Everatt & Gale, 2004; Markell & Hoover, 2010). However, other researchers suggest that children with ID are more likely to display self-stimulatory behaviors such as hand flapping or self-injuries behaviors such as self-biting (Sormanti & Ballan, 2011). Increased frequency and severity of such behaviors may indicate that the child is attempting to cope with a change in their environment (Sormanti & Ballan, 2011; Trublood, 2009). The observation of behavior changes is critical in determining if there is a need for grief support. Researchers suggest that caregivers are important informants on reporting changes of behavior (Sormanti & Ballan, 2011) and teachers are in a good position to observe behavior, due to the amount of time spent with their students (Schonfeld & Quackenbush, 2010).

Again, researchers have drawn from literature on children without disabilities and adults with ID to hypothesize about the level of conceptual understanding of death in children with ID. Researchers find that children's conceptual understanding of death becomes more sophisticated with age (Christ, 2010; Corr, 1995; Healy-Romanello, 1993; Hope & Hodge, 2006). For example, infants have no cognitive understanding of death but can react to emotional changes in their surviving caregiver, while adolescents have the full conceptual understanding of death and can anticipate how a death will

impact areas of their life (Healy-Romanello, 1993). As such, researchers and school psychologists suggest that caregivers (e.g. parents and teachers) should take into account the developmental level of the child when discussing parental death. Caretakers of children with ID are faced with the complexity of tailoring their grief support to not only a child's developmental level but also ensuring that such support is age appropriate (Markell & Hoover, 2010). As is the case with adults with ID, researchers recognize that children with ID might need extensive support in understanding death concepts (Markell & Hoover, 2010). However, while some children with ID might not have cognitive understanding of death, some researchers argue that they are still able to grieve loss (Markell & Hoover, 2010).

Grieving challenges for individuals with ID

Children and adults with ID are at risk for experiencing complicated grief after the death of a parent (Dodd et al., 2008; Dowling et al., 2006; Everett & Gale, 2004; MacHale & Carey, 2002). Complicated grief occurs when a person continues to exhibit "grief related symptoms beyond a time that is considered adaptive" (Dodd et al., 2008). These symptoms include separation distress including, loneliness, pre-occupation with thoughts of deceased, searching for the deceased, and symptoms of traumatic distress including (e.g. anger, shock and disbelief) (Dodd et al., 2008). People with ID are at risk for developing complicated grief as their loss is often not acknowledged, not identified or not appropriately supported (Dowling et al., 2006; Raji & Hollins, 2003). As a result, individuals with ID may be at risk for experiencing complicated grief (Brickell, &

Munir, 2008; Dodd & Guerin, 2009; Kauffman, 2005, Markell & Hoover, 2010; Sormnati & Ballan, 2011).

Limited verbal skills can make it difficulty for a person with ID to effectively communicate their grief to others (Brickell & Munir, 2008) and thus can cause the grief to go unidentified (Gentile & Hubner, 2005). Clute (2010) states, "When communication is challenged, behavior is the most common and frequent means of expression." Changes in behavior can also include physical symptoms or somatic complaints (Sormanti & Ballan, 2011; Everatt & Gale, 2004). However, even when possessing low verbal skills, grieving people with ID can voice their feelings and symptoms when asked (Brickell & Munir, 2008, Dodd et al., 2008; Harper & Wadsworth, 1993). Caregivers should monitor people with ID for expressions of grief symptoms. These include observable behaviors such as an increase in aggression, crying, or an increase in sleeping.

Diagnostic overshadowing, in which caregivers attribute behavioral symptoms to characteristics of ID rather than to a grief reaction, can complicate monitoring behavioral symptoms (Brickell & Munir, 2008; Gentile & Hubner, 2005, Hospice Foundation of America, 2013). For example, a student with ID who normally displays aggressive behavior might engage in more frequent outbursts after the death. In diagnostic overshadowing, the student's "impaired intellectual functioning "often distracts the observer from recognizing the accompanying emotional disturbance (Gentile & Hubner, 2005, p. 57). The student's aggressive behaviors are attributed to ID instead of to grief. Diagnostic overshadowing may also prevent a caregiver from distinguishing between normal and complicated grief reaction (Brickell & Munir, 2008) and subsequently

prevent appropriate treatment (Gentile & Hubner, 2005). Training on grief symptoms might assist caretakers in appropriately identifying signs of grief in people with ID.

Complicated grief can also occur as a result from secondary losses, such as a displacement from a familiar home environment (Sormanti & Ballan, 2011). The death of a parent often results in secondary losses for people with ID (Dodd et al., 2005; Hollins & Wadsworth; McHale & Carey, 2002; Read & Papakosta-Harvey, 2004). For example, Bonell-Pascual (1999) reported that adults with ID experienced high frequency of a change in residence after a parent's death. People with ID also may lose familiar activities or move from a private home into congregate care. Children with ID are especially at risk for unstable family situations following the death of a loved one and for experiencing secondary losses such as change in the school placement or change of primary caregiver (Brickell & Munir, 2008; Sormnati & Ballan, 2011).

Grief Support

Grieving individuals need support and understanding in order to navigate the grieving process in a healthy manner (Hoover et al., 2005). People with ID may need extensive support in order for them to cope with the loss (Conboy & Hill, 1994; Hoover et al., 2005). However, getting appropriate support can be difficult because people with ID may not have the same access to other social grieving supports as people without disabilities. Grief support usually comes from a person's immediate social support network such as family, friends, and coworkers (Worden, 2001). However, social support networks for people with disabilities are often smaller and less varied than people without disabilities (Eisenman, 2007; Smart, 2009). The limited social networks

of people with ID are evident in times of bereavement (Blackman, 2002). In addition, people with disabilities tend to have more paid supports (e.g. employment coach, residential caregiver) than natural supports (e.g. parents, friends, neighbors) (Nisbet, 1992). The death of a parent or caregiver for an individual with disability also results in a loss of an essential member of an already fragile natural support system.

Individuals can become disenfranchised when their grief is not supported. Disenfranchised grief is defined as "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publically mourned, or socially supported" (Doka, 2002, p.4). Disenfranchised grief can occur when the relationship is not recognized, as in the case of a same-sex partnership; when the loss is not acknowledged, as in the case of a miscarriage; or when the griever is not supported, as often the case with people with ID (Doka, 2002; Lavin, 2002).

Research on support for grieving individuals with ID

Available research presents conflicting information on how grieving people with ID are currently supported in their grief. Studies suggest that people with ID are not appropriately supported in their grief and they continue to be disenfranchised; however, a group of emerging studies report on how people with ID have been appropriately supported.

Lack of support

The majority of research shows that inadequate supports are provided to grieving people with ID. Studies show that adults with ID have been excluded from attending funerals (e.g. Hollins & Esterhuyzen, 1997; Raji & Hollins 2003; Read & Elliot, 2007;

Summers, 2003) and it is estimated that 15 percent of people with ID are not included in grief rituals at all (Markell, 2005). Caregivers also do not give information on the death of a loved one (e.g. Clements et al., 2004). Hoover, Markell and Wagner (2005) surveyed 57 staff at two different residential centers for adults with ID on their views of grief and people with ID. Findings indicated that, although care staff believed individuals with ID had the right to engage in grieving practices, staff demonstrated overprotectiveness and infantilization towards grieving adults with ID. For example, one participant said, "I believe they have a right to know so they can grieve the loss—If they can understand the dying process" and many participants felt that the caregivers (or family members) "knows best" and not the bereaved individual. Caregivers discouraged talk about loss by adults with ID in another study, illustrating that grief support was often incomplete and discontinued (Dowling et. al, 2006). People with ID have been informants on their own post-bereavement support. In one study, 16 grieving people with ID reported that while staff offered practical supports such as attending funerals and other rituals, they were not helpful with emotional support (Gilrane-McGarry & Taggart, 2007). McEvoy et al. (2012) interviewed 34 grieving adults with ID and just under half of them reported they were supported following their loss. Other studies have indicated that caregivers of adults with ID tend to attribute behavioral symptoms displayed by grieving individuals with ID to the disability rather than to the grief reaction (Hollins & Esterhuyzen, 1997). Collectively, these studies indicate that some caregivers espouse traditional assumptions of the grieving process and can contribute to disenfranchised grief by people with ID.

Appropriate support

There are a number of studies that document how grieving adults with ID may be appropriately supported when grieving or on the effectiveness of grieving interventions (see Clute 2010 for review). This emerging body of literature provides guidance for professionals looking for help in supporting grieving individuals with ID (Clute, 2010). For example, narrative therapy was shown to be effective for a 24-year-old man with Down syndrome grieving the loss of his father (Matthews & Matthews, 2005). Grieving workshops were found to be beneficial for a group of adults with ID and provided them a supportive space to verbalize their reactions to their loss and feelings of grief (Read & Papakosta-Harvey, 2004). A recent collection of Irish studies provides encouraging examples of paid caregivers who appropriately supported grieving adults with ID. The caregivers held positive attitudes towards their grieving clients with ID, felt their clients with ID understood the concepts of death, and were effective in supporting their grieving clients (Dodd et al., 2005; Gilrane-McGarry & Taggart, 2007; MacHale, McEvoy & Tierney, 2009). These results contrasted strongly with previous studies, suggesting that cultural differences in the experiences of people with ID may exist (Dodd et al., 2005). For example, Irish staff disliked using medication for behavioral problems and thus may have been more proactive in providing other supports (Dodd et al., 2005). Bonell-Pascual et al. (1999) reported that grieving people with ID who were able to attend funerals showed significant improvement in problematic behavior.

Regardless if findings indicate either a lack of support or appropriate support, researchers agree there needs to be increased training of caregivers on how to

appropriately support grieving people with ID (McEvoy & Smith, 2005). It should be noted, however, that available studies focus on adults with ID and did not examine how caregivers supported grieving children with ID.

Suggestions for support

Researchers and psychologists have made suggestions on how different caregivers can appropriately support people with ID. Kauffman (2005) suggested

> Grief support needs to begin with recognition of grief by the community in which the person lives. Simply providing an adequate social context for the person to experience his grief is the most basic sense of facilitating the mourning process (pg. 8).

People with ID may not need formal intervention but instead supportive environments with individuals prepared to provide informal supports (Clute, 2010). Gaventa (2011) suggested a "community of supporters" consisting of individuals from different aspects and phases of the person's life, as a promising way to support grieving people with ID. For example, clergy, siblings, friends, former caregivers and residential staff can collaborate together to support a grieving individual with ID. Teachers also have been identified as possible key supports for their grieving students with ID (Everatt & Gale, 2004; Gaventa, 2011; Sormanti & Ballan, 2011).

Teachers as Supports for Grieving Students

The social and emotional well-being of children is a critical component of healthy development (Liew & McTigue, 2009; Siegler, Deloache & Eisenberg, 2006). Children with disabilities typically experience lower levels of socio-emotional well-

being than do their peers without disabilities (Montie & Abery, 2011). The teacher-child relationship is an important aspect of socio-emotional well-being. In addition to providing academic instruction, teachers have been found to be important providers of social-emotional supports. Teachers often serve as important emotional figures for students. Rowling (2008) stated, "Teaching is a profession where emotional connections are made; it is based on human interaction. Teachers care for their pupils" (pg. 246). Relationships with teachers that include closeness, support and open communication benefit children of all ages socially, emotional and academically (Hughes & Kwok, 2005; Murray, 2002).

Only a few studies exist on the relationship of teachers with students with disabilities. One such study found that students with disabilities who reported a warm and supportive teacher-student relationship had higher levels of adjustment in the areas of depression, anxiety, school competencies, and conduct (Murray & Greenberg, 2001). However, the majority of students with disabilities also reported higher levels of conflict with their teachers than did students without disabilities (Murray & Greenberg, 2001). This poor relationship was echoed in other studies that report that teachers of young students with mild to moderate ID have lower quality student-teacher relationships than those with students without ID (Blacher, Baker & Eisenhower, 2009; Eisenhower, Baker & Blacher, 2007; McIntyre, Blacher & Baker, 2006). These studies did not include students with severe levels of ID. The lack of attention to students with ID and their relationships with teachers is alarming given that supportive teacher relationships have

been found to impact the psychological functioning of children exposed to traumatic events (Barrett, 2008).

The research literature suggests that teachers are critical supports for students in emotional times, such as after the death of a loved one (Blackburn, 1991; O'Conner, 2002, Reid & Dixon, 1999; Schonfeld & Quackenbush, 2010). Reid and Dixon (1999) note "Teachers are in the unique position to assist grieving children because children are most likely to select someone they know with whom to discuss loss." Researchers further suggest that concerned teachers can provide security and can be instrumental in facilitating psychological adjustment after a loss (Papadatou, Metallinou, Hatzicristou, & Pavilidi, 2002). Wolmer, Laor, & Yazgan (2003) recognized the supportive stance of teachers and proposed a re-conceptualization of the teacher's role from simply teacher to educator who provides emotional support to students after loss.

Teachers have bereaved students in their classroom. A recent survey showed that 69 percent of 1,253 teachers reported having at least one student who lost a parent, guardian, sibling or close friend to death within the year (American Federation of Teachers/New York Life Foundation, 2012). Studies document that teachers can provide effective supports to their bereaved students (Christ & Christ, 2006; Eppler, 2008; Machon, Goldberg & Washington 1999; Rowling, 2008; Spall & Jordan, 1999). Bereaved students have indicated they talk to teachers when feeling sad about the loss of the loved one (Eppler, 2008). British researchers conducted interviews to examine the effect of bereaved students on school staff (Lowton & Higginson, 2003). Participants included four general education teachers, one special educational needs coordinator, and

eight principals. Participants indicated they connected families with bereavement organizations and implemented a number of strategies to support their students that lost relatives or parents. These strategies included notebooks to facilitate communication with parents, "time out" cards that allowed the student to indicate when they needed a break from school activities, and reduced school days for students who were grieving. The authors reported the percentage of students with special education needs for each participant. For example, one general education teacher had a total of 350 students with 35% receiving special education. However, the specific disability diagnoses were not mentioned and is unknown if students with ID were included in the classroom. In one of two published studies, on special education teachers, Christ and Christ (2006) used a case study approach to examine the responses of children with learning disabilities who lost their firefighter fathers in the U.S. 9/11 Twin Towers attacks. Findings indicated that special education teachers were instrumental in providing access to guidance counselors and bereavement therapy. Special education teachers were also more effective in identifying supports needed and responded more rapidly and more efficiently than did teachers of students without disabilities. However, the Christ and Christ study did not include students with ID. In a second study, Ducy and Stough (2011) found special education teachers highly supportive to students who lost possessions and housing in a natural disaster. Students in this study had not lost a family member, however.

Teachers have expressed discomfort about talking to students about death (Cullinan, 1990, McGovern & Barry, 2000, Papadatou et al., 2002; Read & Dixon, 1999). Researchers in Greece surveyed 590 teachers on their experience with bereaved

students who had lost a relative. Findings indicated that 40% of teachers initiated discussions with the bereaved student, 15% talked to the student only after the child initiated, while 45% of the teachers completely avoided the topic of death. Teachers reported being uncomfortable talking to the student and viewed the loss as a private affair. The majority of these teachers (88%) also reported feeling inadequately trained to deal with bereaved students, a finding echoed in several other studies on teachers of students without disabilities (e.g. Cullinan, 1999, Machon et al, 1999, Papadatou et al., 2002; Reid & Dixon, 1999; Spall & Jordan, 1999). Teachers reported in a survey that it was their lack of training that hindered them to support their grieving students over other factors such as a busy schedule, personal inexperience or being uncomfortable with death (American Federation of Teachers/New York Life Foundation, 2012).

Studies have also examined the emotional impact experienced by teachers when encountering bereaved students. Spall and Jordan (1999) administered a questionnaire to 30 teachers to investigate teachers' perspectives about supporting students who experienced loss. Results indicated that teachers' encountered high levels of strain, felt emotionally drained, and felt the loss personally. Teachers also felt conflicted in their roles as an emotional support to students (Rowling, 2008). Rowling (2008) posited that teachers have the need to "be human," as teaching involves human interactions, but at the same time teachers themselves seem to believe they should "be professional." This conflict of roles led to Rowling (2008) to include teachers as a type of "disenfranchised grievers." Schonfeld and Quackenbush (2010) stress the importance of teachers

addressing their own emotional impact and make a number of suggestions such as talking with others, talking with professionals and building skills for stress management.

Recent literature suggests that teachers of students with ID can be effective in providing supports to their grieving students. Several researchers have developed guidelines on assisting individuals with ID with the loss of a parent (Kauffman, 2005; Markell & Hoover, 2010; Schonfeld & Quackenbush, 2010; Sormanti & Ballan, 2011). Markell (2005), based on personal experience and observations of special education teachers, developed a guidebook containing a number of rituals for caregivers to use when supporting grieving individuals with ID. For example, a teacher can play music that reminds the student of the person who died or collaborate with the student to write a story about the deceased. In one study, Sheppard (2006) described a personal development program designed for adolescents with intellectual disabilities. The program was implemented over a period of 4 months and included seven different components including one on grief and loss. The grief component served as a way for teachers to approach the subject of death with students but the students were not actively grieving. The teachers who implemented this program expressed interest in receiving more training on the topic of grief and loss.

There is a lack of empirical studies on teachers of grieving students with ID. Teachers of students with ID typically spend a significant amount of time with their students, enabling them to provide more ample support than that available from a school psychologist or counselor. Students with ID may need more reassurance, patience, and understanding from teachers to appropriate support their grieving process (Schonfeld &

Quackenbush, 2010). Teachers of students with ID have been found to provide emotional supports to students post-disaster (Ducy & Stough, 2011) but in this study, grief due to the loss of a parent was not investigated. In this study, students expressed emotional responses to losing their homes and belongings, specialized resources and services, and familiar routines as a result of Hurricane Ike. For example, one teacher described one student with ID as "devastated with pain" when he saw all of his belongings broken and spread across the yard. Teachers talked to their students about the disaster and offered reassurance and encouraging words. Teachers, despite being impacted themselves by the storm, focused on supporting their students across all phases of the disaster.

CHAPTER III

METHOD

This study utilized a qualitative research design. Qualitative researchers "study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them" (Denzin & Lincoln, 2011). Qualitative researchers who study special education are not concerned with the frequency of student behaviors but instead focus on the meanings that teachers and others assign to behaviors they observe (Jacob, 1990). This study explored the experiences of teachers with students with ID who lost a primary caregiver to death. Qualitative inquiry afforded a deep exploration of this phenomenon by asking teachers' to share, reflect, and explain their experiences with students who had lost a primary parent or guardian to death.

Constructivist Paradigm

Qualitative research does not require the use of a particular paradigm and qualitative researchers are free to utilize different epistemological lenses (Denzin & Lincoln, 2011). This study was conducted within the constructivist paradigm and followed the ontological, epistemological, and methodological consequences for working within the constructivist paradigm. The constructivist paradigm views reality not as a single entity but rather as consisting of multiple socially constructed realities that are shaped by an individual's experience (Lincoln & Guba, 1985). Constructivist inquiry seeks to gain understanding of these multiple constructions through an

intertwined relationship between the knower and the known (Lincoln, Lynham & Guba, 2011; Lincoln & Guba, 1985). The constructivist paradigm tends to utilize qualitative data collection methods, such as interviews and observations. Such methods rely on the researcher as the "human instrument" as human beings are believed to be the only instrument that can explore, expand, and process the multiple realities presented by others (Lincoln & Guba, 1985).

The constructivist paradigm was chosen as it aligns with my own view of disability. I embrace the social constructivist view of disability, in particular. Social constructivists are interested in examining the socially constructed meaning assigned to human variation (Linton, 1998) and typically view disability as the result of social, political, and economic phenomenon rather than as an individual deficit (Davis, 2006; Linton, 1998). I believe the social constructivist paradigm best captures the complex meaning of disability experience (see Avramidis & Smith, 1999; Ferguson, Ferguson & Taylor, 1992; Linton, 1998). Ferguson et al. (1992) remarked:

> Interpretivism maintains that disability is not a factor entity, whose nature is just waiting to be discovered. Disability is rather an experience waiting to be described or, more precisely, a social construction of multiple experiences waiting to be described (pg. 296).

In positioning myself within the interpretive paradigm, I viewed this study as an opportunity to form an entangled relationship with knowledgeable participants as we embarked together on a complex journey of constructing, negotiating, and attempting to render interpretations of the experiences they had with grieving students with ID. I

acknowledge that I interviewed teachers *about* their experiences with individuals with disabilities, rather than directly interviewing individuals with disabilities. However, Ferguson and colleagues (1992) note that when studying disability, not all inquiry must focus on the perspective of people with disabilities and that "…interpretivism can even empower groups such as teachers and other practitioners by legitimizing their credibility and the authenticity of their perspectives through collaborative research" (pg. 301). By interviewing teachers rather than their students, I focused on the meanings that teachers ascribed to their students behaviors rather than on their direct reactions to their students.

Values

Inquiry is value-bound: researchers' own values and assumptions influence the research process (Lincoln & Guba, 1985). Rowling (1999), who studied teachers' experiences with bereaved students, noted "Subjectivity, rather than being a hindrance, was vitally important to begin to develop an understanding of grief experiences in the context of school communities" (pg. 174). My own assumptions about disability, grief, death, social support, and the role of teachers have all have influenced my selection of the research problem, choice of research paradigm, and development of this study's methodology. My values are as follows:

First, I am a former teacher of students with ID who taught two students who lost their mothers and one student who lost his sister. I noticed behaviors from all three students that included crying, change in activity level, change in disposition, increased clinginess, and talk about missing their loved one. I supported the students in several ways; by talking to their remaining parent, attending the funeral, talking about their

loved one, discussing their grief, giving one student a journal, and giving students my personal contact information.

Second, I believe teachers are responsible for nurturing students' social and emotional needs. I supported all of my own students after their losses. I assume that other teachers similarly emotionally and instrumentally support grieving students with intellectual disabilities, while also recognizing that it is possible that teachers may choose not to do so. To address these assumptions, I questioned teachers about their reactions to their students who had lost a parent rather than about how they emotionally or socially supported them. I then probed about the type of supports provided only if the teachers responded that they had provided special supports to their students who were grieving.

Third, I view disability as socially constructed and believe society often prevents individuals with ID from adequately grieving, for example, discouraging a child with ID from attending a loved one's funeral. I assume that all individuals who provide services to individuals with disabilities are legitimately interested in providing appropriate support during the grieving process, which again, may be an inaccurate assumption.

Fourth, as a teacher, I myself experienced disenfranchised grief. My close friend, Gale, experienced unimaginable tragedy when her daughter was murdered. Gale was a friend but also was the teaching assistant in my classroom. I tried first and foremost to support Gale as a friend through her grief. I also actively grieved the loss of her daughter as I also had a relationship with her and sought meaning in such tragedy. However, I was also a teacher. I had a classroom full of children to protect and tried to maintain as much

normalcy as possible. This was challenging given that people would come in my classroom seeking updates on the case. I cautioned parents about their children seeing the case reported by the media. I felt great conflict amongst my roles as a friend and as a teacher and, because of these multiple roles, often was a disenfranchised griever.

Five, as all people do, I have experienced the loss of loved ones. My family, friends, and colleagues were instrumental in supporting me in my grief. For example, I lost my Aunt Maryann while I was an undergraduate. She was my Godmother and we were extremely close. My mother drove from our hometown to tell me of her death in person because she did not want me to be alone. My friends made many visits, phone calls and sent condolences. My parents paid for my ticket to California to make sure I could attend the funeral. All of my professors were very understanding and accommodating. My family and I continue to have conversations about her and share our memories. I entered this study assuming that social supports are similarly important and appreciated by the grieving individual.

Finally, my husband's mother died when he was 11. My own mother's mother died when she was 12. They have both talked about the difficulties and life changes they faced as a result of losing their mothers at a young age. My experience with both my husband and mother has shaped my belief that losing a parent in childhood can be traumatic and disruptive.

Participants

Participant selection

Purposeful sampling was used to select teachers of elementary students with ID who had lost a primary caregiver. Purposive sampling was employed to ensure that participants had experienced the same phenomena of interest (Creswell, 2007; Polkinghorne, 2005). Approximately 2.5 million or 3.5% of children under age 18 in the United States have experienced a parental death (Social Security Administration, 2000). In 2007, 533,426 students aged 6-21 with the primary diagnosis of ID received special education services under IDEA (Department of Education, 2010*).* It thus can be roughly estimated that 19,000 students with ID in the U.S. have experienced the death of a parent. This number represents only students who carry ID as their primary disability and this number can be assumed to be higher if those with a ID as a secondary diagnosis were included.

Teachers in this sample resided in Texas, Arizona, or California. These locations were selected due to my own travel constraints. However, there was no reason to assume that the experiences of teachers supporting children who are grieving differ across the United States. Participants were recruited through professional teaching and disability organizations, school regional centers, special education conferences, parent groups, community grieving groups, teacher education programs at several universities, as well as through my own personal and professional contacts. For example, recruitment materials were sent through TASH (formerly The Association of the Severely Handicapped) and the Council for Exceptional Children (CEC) chapter list serves, and

through the Association of University Centers on Disabilities (AUCD). Contacts at regional educational centers, who service public school districts, were asked to forward information to Special Education program directors, coordinators and teachers.

A total of 27 people communicated interest in participating in the study. Of those 27, only 7 met the original screening criteria. Five special education teachers were interviewed and included in this study, while the other two did not respond to repeated requests for an interview. Three additional teachers were interviewed, although their data were not included in the analysis for several reasons. One was not the teacher of record when the death occurred. A second had a student whose father was deceased but he was not the primary caregiver. As I did not find this information out until I met with these teachers, I conducted these interviews anyway. However, I did not transcribe these interviews nor use them in the analysis. A third teacher met all the criteria except she taught a grieving 16 –year- old. In order to focus on only the experiences of teachers of children, this data was set aside and her data was instead used to compare with the categories developed from the five participants. Participants were given a $20 honorarium for participating in the study. Recruitment efforts continued throughout the analysis phase of the study.

Participant criteria

Participants met all the following criteria to qualify for this study; (a) they were certified special educators, (b) had currently or previously taught elementary aged children with an ID, and (c) had taught a student with ID within the last ten years who had lost a parent.

The teachers recruited all held special education certification. Interviewing only certified special education teachers allowed me to ask if they received any formal training on supporting grieving students with ID during their undergraduate or certification programs. There was not a minimum number of years of teaching experience required.

The teachers all taught students with ID. Their students had a variety of diagnose such as Fragile X syndrome and Down syndrome. Four of the five students had ID as their primary diagnosis. One student received special educational services under the diagnostic category of autism but had a secondary diagnosis of ID.

The teachers taught elementary students aged 7-12. Elementary aged students with ID were targeted for a number of reasons. First, elementary students spend more time during the school day with one teacher than do secondary students. Thus these teachers had more opportunity to observe grief behaviors and more opportunity to respond to the grieving student. Second, grieving behaviors displayed by young children, as described by the National Association for School Psychology (National Association of School Psychologists, 2010), are more concrete and observable than are those listed for secondary students. For example, elementary behaviors include inability to pay attention, repeated telling or acting out of the event, somatic complaints, and aggressive behaviors, while the behaviors of high school students are less readily visible, and include experiencing flashbacks, emotional numbing, or peer relationship problems. It was assumed that teachers might be better able to observe and describe concrete behaviors displayed by elementary students with ID. Finally, grieving children with ID

have been neglected in the literature. Studies that examine grieving behaviors in elementary students and the responses of their caregivers do not exist. Thus, a focus on elementary children lends opportunity to contribute new information to the existing literature.

Participants all taught a student who had lost a parent within the last 10 years. Participants were expected to recall their experiences with these grieving students. Typically, recall of significant memories, such as of death, is strong (Chawla, 2006). The qualitative method of interviewing provides an opportunity for participants to engage in unconstrained recall, thus aiding in the accuracy of the memory (Chawla, 2006).

The students all had lost a parent or guardian who was a primary caregiver. In order to be considered a primary caregiver, the parent or guardian had to have been directly involved in the child's daily care and could have been one of several people. For example, one teacher did not qualify because the deceased father was not living at the home and had limited communication with the child. The loss of a primary caregiver can be particularly devastating to the child with ID (Brickell & Munir, 2008). The primary caregiver may have been the only person that effectively communicated with the child and also the only family member who could have efficiently navigated the disability-related support system (Brickell & Munir, 2008). Guardians and primary caregivers were included for situations where the parent was no longer in the child's life or not the primary caretaker. In this study, one student had lost her mother, one student lost his grandmother, and three students had lost their father. In the case of the grandmother, the mother was incarcerated and the grandmother had always been the primary caregiver.

The student called her “mama”. Two of the fathers lived in the home and were very active in their children’s lives and care. The other deceased father had recently moved out of the home due to divorce but shared custody with the student’s mother. The father was very involved and the child had spent every other week with him.

Data Collection

Face-to-face interviews were conducted with each teacher. Interviews were recorded and transcribed verbatim as recording interviews helps the beginner researcher to give the participant full eye contact and attention (Charmaz, 2006). Recordings also help the beginner researcher to analyze their questions and to evaluate whether they should be changed (Charmaz, 2006). Transcribed interviews were sent to each participant for member checking. Only one of the teachers returned the transcript and those edits consisted of minor content and punctuation additions. Analysis of the transcripts began immediately after each interview and continued while additional interviews were being conducted. Field notes were taken after each interview and included technical information and observations such as the tone of the interview. Interviews took place at locations convenient for the teachers, such as a coffee shop or at their house. Second interviews were conducted by phone in order to clarify and gather more information on the teachers’ experience. All second interviews were transcribed and sent to the participants. One of the teachers made punctuation changes to her second transcript. Teachers were given a copy of the initial interpretations of the data and asked to provide feedback. Only one teacher responded by thanking me, but did not make any comments on the data.

Semi-structured interview

Interviews allow for an in-depth exploration of the targeted experience and are designed to elicit participants' interpretation of their experience (Charmaz, 2006). Interviews were the primary method of data collection for this study. The first interviews ranged from 42 minutes to 87 minutes and the second interviews ranged from 15 minutes to 30 minutes. Semi-structured interviews were used to interview participants as they have been found to be appropriate for beginner researchers (Riessman, 2008). Interview questions were detailed enough to convince evaluators that the questions would not harm the participants but also open enough that they respected the emergent design inherent to qualitative inquiry (Charmaz, 2006). The initial interview questions (see below) changed based on the ongoing analysis during the data collection. For example, I added in the question, "Tell me about your experience with the surviving caregiver" after the first participant talked extensively about the surviving caregiver because I wanted to explore if this was an important issue for other participants. The questions for the second interview varied depending on each of the unique experiences shared by the teachers. However, they were designed to elicit specific information to advance interpretative analysis and the emerging categories (Charmaz, 2006).

Initial interview questions

a) Take a moment to think of a student that lost a parent or guardian. Tell me about your experience with that student.
b) Could you describe any behaviors that you noticed or observed from this student after the death of his/her parent or guardian?

c) How did you react to this student losing a parent or guardian?
d) Tell me about your thoughts and feelings when you were dealing with this student
e) What do you think are the most important ways to handle a bereaved student?
f) After having these experiences, what advice would you give someone who has just discovered that a student lost a parent or guardian?
g) What was your experience with school counselors or school psychologists?
h) What was your experience with other teachers?

Participants were asked to focus their experience with the student using the critical incident technique. The critical incident technique is "essentially a procedure for gathering certain important facts concerning behavior in defined situations" and is "used to collect data on observations previously made which are reported from memory" (Flanagan, 1954, p.14). Two of the teachers mentioned other students who had lost a caregiver but, in their interview, focused on the one student who met the screening criteria.

Demographic information

Demographic information was collected on each of the teacher participants. Demographic information included gender, ethnicity, age, number of years teaching, number of years teaching students with ID, and areas of certification. Information was also collected on the number of students who had lost a parent, the students, and the age of the students. However, the names of students and any other detailed identifying information were not elicited. Demographic information was obtained at the end of the interviews.

Analysis

Interpretation occurs during the analysis phase and involves the "researchers understanding of events as related by the participants" (Corbin & Strauss, 2008, p. 48). Grounded theory methods were used to analyze the data. Grounded theory is an appropriate analytic method for exploring phenomena that has not previously been investigated (Birks & Mills, 2011), as was the case with these teachers who taught grieving students with ID. Constructivist grounded theory methods were used instead of the more traditional grounded theory approach (e.g. Charmaz, 2006). Charmaz (2011) notes,

> Constructivist grounded theory adapts the methodological strategies of Glaser and Strauss's but integrates relativity and reflexivity throughout the research process As such, this approach loosens grounded theory from its positivist, objectivist roots and brings the researcher's roles and actions into view. (Charmaz, 2011, pp. 364-365).

The constructivist grounded theory approach allowed me to acknowledge how my own experiences with students with ID contributed to my selection of the research problem and these experiences shaped my construction of the participants' experience.

Constructivist grounded theory's epistemological underpinnings are rooted in pragmatism and symbolic interactionism, which posit that people do not simply react to a stimulus but instead continually interpret situations before reacting (Charmaz, 2006; Glaser & Strauss, 2008). As such, constructivist grounded theorists are concerned with examining how participants explain their statements and actions (Charmaz, 2006). In this

study, teachers were asked to explain how they responded to their students who had lost a caregiver.

Different levels of grounded theory analysis can be employed, depending on the aim of a study, and theory development is not always the goal of the analyst (Corbin & Strauss, 2008). I did not aim to develop theory in this analysis but did use constructivist grounded theory methods to analyze the data. Although Charmaz's (2006) constructivist approach guided my analysis, I also borrowed from other grounded theorists (Corbin & Strauss, 2008; Glasser & Strauss, 1990) when I felt they would help to advance my analysis.

Analytical steps

The first step of analysis was a coding process in which the researcher asks analytic questions in order to focus further data gathering (Charmaz, 2006). Constructivist grounded theory coding occurs in at least two different phases- initial coding, and focused coding (Charmaz, 2006). I utilized the constant comparative method (Glasser & Strauss, 1967) while coding the first transcript by comparing data produced within the same interview. I continued to use the constant comparative method throughout the whole analysis process to make "comparisons at each level of analytical work" (Charmaz, 2006, pg. 54) such as when I later compared data across the first and second interviews and then across participants.

For the initial coding phase, I first organized the data by unitizing each piece of data onto an index card (Lincoln & Guba, 1985). The units of data varied in length from a few words to a paragraph. There were a total of 1,086 index cards for the first and

second interviews. Each index card included a participant number, a transcript number, and the interview question. I chose this method of organizing data because I was able to better visualize the development of the categories (e.g. larger stacks indicated stronger categories) and to physically manipulate the data. I took each card and assigned a provisional code with a sticky note and attempted, whenever possible, to use words that reflected action (usually gerunds) in order to detect process (Charmaz, 2006). "Process coding" (Saldana, 2013, p. 96) was used, as I was interested in the "ongoing action/interaction/emotion" taken by the teachers in response to their grieving students (Corbin & Strauss, 2008, pp.96-97). In vivo codes were also used as much as possible. Examples of initial codes include "discussing death," "allowing him to cry," "communicating with parent," "connecting parents to resources," "feeling helpless," "pulling at straws," "student crying," and "student talking about missing mom." I grouped cards with the same or similar initial codes together. The initial coding process helped to "separate data into categories and see processes" (Charmaz, 2006, pg. 51). Focused coding, which was the second phase of coding, involved synthesizing the codes generated in the initial coding process and making analytic decisions about categories (Charmaz, 2006). Specifically, I coded data based on conceptual similarity, identified major and minor categories, collapsed subcategories under a main category, refined existing categories, identified properties and dimensions of categories, and wrote initial descriptions of the categories (Charmaz, 2006; Saldana, 2013). For example, the initial codes "allowing him to cry" and "discussing death" were grouped under a focused code of "types of supports" while "communicating with parent," "connecting parents to

resources" were grouped under "teacher and surviving caregiver interactions." Field notes were reviewed for any information that could add to the categories.

Charmaz (2006) explains, after initial and focused coding, "we may follow special procedures to elaborate our codes" (p.42). I engaged in two analytical exercises in order to advance my categories. First, I felt it was necessary to make a "fresh coding and return to the data" and recode all of my data to "spark new ideas" (Charmaz, 2006). Saldana (2013) explains, "rarely will anyone get coding right the first time. Qualitative inquiry demands meticulous attention to language and deep reflection on the emergent patterns and meanings of human experience. Recoding can occur with a more attuned perspective" (pg. 10). I started the coding process over by resorting the cards and applying initial and focused codes. The recoding process provided new insights, forced a return focus on the participants' voices, allowed for more detailed category explanations, and built my confidence about the resultant categories before moving to more advanced analytical methods. For the second analytical exercise, I used axial coding (Glaser & Strauss, 1990) in order to further develop each of the categories by identifying linkages between a category and its subcategories (pg. 97). I applied the paradigm model to each category (Glaser & Strauss, 1990) to identify the phenomenon and, whenever possible, the context, causal conditions, intervening conditions, actions/interactions, and consequences. I used the model, as a general framework, but was careful not to force any data into its components (Charmaz, 2006; Birks & Mills, 2011), and in order to avoid making the analysis rigid (Corbin & Strauss, 2008). I used diagrams to visually represent the relationships between a category and its subcategories. Through this process, I fine

tuned each of the separate categories, wrote clearer descriptions, specified properties and dimensions, and grappled with initial ideas of how they related to each other.

I then engaged in theoretical sampling in order to further refine the emerging categories (Charmaz, 2006). Charmaz (2006) explains, "while engaging in theoretical sampling, the researcher seeks people, events, or information to illuminate and define the boundaries and relevance of categories" (p.89). Theoretical sampling can include observations, new participants or involve only asking earlier participants further questions or ask about uncovered topics (Charmaz, 2006). I conducted second interviews with each of the participants and asked focused questions in order to better define the emerging categories. As suggested by Charmaz (2006), I anticipated the need for theoretical sampling to define categories and gained permission to conduct second interviews in the research proposal. The data from these interviews were all transcribed, coded and used to complete the descriptions of categories.

As mentioned before, it was not my intention to develop a full-grounded theory but instead I utilized grounded theory methods to analyze the data. However, I felt it was important to go beyond category descriptions by examining how conceptual categories were related. Memo ordering (Charmaz, 2006), identifying a core category and developing a storyline (Corbin & Strauss, 2008) guided my analytical decisions on how to best organize categories and determine their relationships. Charmaz (1990) explains that a constructivist "creates an explanation, organization, and presentation of the data rather than discovering order within the data" (p. 1169). As such, I presented findings by providing category descriptions grounded in participant voices, visually displayed

categories in an integrative diagram, and included a storyline to explain their connections.

Memos

Memo writing served as the core of my analysis and provided me a space to continually analyze data, codes, and conceptual categories (Charmaz, 2006). I began writing memos during the initial coding and continued throughout the entire analytical process. My memos were sometimes typed, handwritten in a “memo” notebook, included in my reflexive journal or scribbled on a scratch of piece of paper when I had an “aha” moment. Raw data was included throughout the memos in order to keep my reflections grounded to the participants’ experience (Charmaz, 2006). In my memos, I explored ideas, made constant comparisons, identified gaps in data, and defined categories (Charmaz, 2006). Memo writing is also the part of the process in which the focused codes from the analysis were raised to conceptual categories and where connections between categories were made (Charmaz, 2006).

I included diagrams in the memos throughout the analytic process in order to organize data, explore relationships between categories and integrate my ideas (Corbin & Strauss, 2008). My initial diagrams were simple and helped me to "think about possible relationships" between categories while later diagrams represented more complex relationships (Corbin & Strauss, 2008, p. 125). I used the software, Inspiration 9, to explore advanced relationships and construct the final diagram. I used a final diagram to "reduce the data to its essence" and visually display the integration of categories (Corbin & Strauss, 2008, p. 125). While writing memos, I identified gaps in

my analysis and also expanded my questioning beyond "how" the teachers reacted to "why" they reacted (Charmaz, 2010).

Study Trustworthiness

Several methodological criteria were followed in order to establish trustworthiness. In interpretive inquiry, the foundational trustworthiness criteria involve addressing credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). These criteria are important for demonstrating that interpretivist inquiry employs a systematic, thorough, and conscious method (Lincoln, 1995).

Credibility

Three different steps were used to address credibility.

1. Triangulation. Multiple interviews and field notes were collected to triangulate the data. The first interview was conducted face-to face and was used to answer initial research questions. The second interview was conducted with each participant to clarify and elicit more information. Demographic information was collected on the first interview and field notes were taken for each interview.

2. Member checks. The participants were sent copies of their interview transcripts and were encouraged to make edits, comments, and clarifications. The study participants also received a summary of findings and were asked to make comments and clarifications before the results were finalized. The interpretative paradigm requires that the researcher approach methodology using both a hermeneutic approach, in order to represent constructions accurately, and a dialectic approach, in order to continually compare and contrast those constructions (Guba, 1990). The use of triangulation and

member checks helped ensure that hermetic and dialectal methods were being employed

3. Peer debriefing. Peer debriefing is necessary in order to discuss the ongoing findings with a "disinterested" peer in order to keep the researcher honest, test hypotheses, and have a means for catharsis (Lincoln & Guba, 1985). Peer debriefing was done throughout the analysis process with my doctoral advisor.

Transferability

Transferability is determined by the reader of the research and requires working hypotheses and thick descriptions (Lincoln & Guba, 1985). Field notes, demographic information, and interviews were used to develop thick descriptions of the context experienced by teachers.

Dependability and confirmability

Dependability and confirmability both require the use of an audit trail. An audit trail was kept and included; audio recordings of all interviews, typed transcripts, hard copies of all correspondence with participants, copies of data elicited from member checks, and all notes and documents developed during the analyses.

Reflexive journal

The use of a reflexive journal applies to all four areas of trustworthiness criteria and is a resource for the researcher to make judgment calls throughout the inquiry process (Lincoln & Guba, 1985). A reflexive journal was kept. The reflexive journal included three different sections; (a) daily schedule and logistics of the study, (b.) a personal diary for reflection, and (c) analytic and observational memos (Charmaz, 2006;

Lincoln & Guba 1985). The reflection section of the journal was a helpful space for me to record my own emotions in dealing with the emotionally charged issue of grief (Rowling, 1999).

CHAPTER IV

RESULTS

The research questions for this study were (a) What were the experiences of teachers of elementary students with intellectual disabilities who had lost a parent, guardian or primary caretaker? (b) What were the behaviors of students who had lost a parent, guardian or primary caretaker that teachers observed in the classroom? and (c) How did teachers respond to students with intellectual disabilities who had lost a parent, guardian or primary caretaker? These questions were answered using constructivist grounded theory methods (Charmaz, 2006). Results are presented with participant profiles, detailed category descriptions grounded in the voices of the teachers, an integrative diagram and storyline.

Participant Profiles

Before categories are presented, I introduce the five teachers who reported on their experiences with grieving students with ID. It was only through their willingness to tell their stories that I was able to answer the research questions. Profiles below include teacher demographic information, as well as details about their students. Table 1 and Table 2 provide summarized information.

Table 1

Teacher Demographics

Teacher	Gender	Age	Ethnicity	Years of Teaching Experience
Dana	F	30	White	6
Michelle	F	30	White	7
Annie	F	50	Hispanic and White	8
Beth	F	52	White	18
Kathleen	F	63	White	25

Table 2

Student Information

Teacher	Student	Student Age	Student Disability	Student Ethnicity	Deceased Caregiver	Cause of Death	Surviving Caregiver	Time since death occurred
Michelle	Chris	7	Intellectual Disability	African American	Grandmother (legal guardian,)	Cancer	Aunt	7 months
Beth	Tim	7	Autism, Intellectual Disability	Hispanic	Father	Carbon Monoxide poisoning	Mother	5 years
Annie	Molly	9	Autism, Intellectual Disability	White	Mother	Cancer	Father/student lives in group home	2 years
Dana	Liam	10	Down syndrome	White	Father	Cancer	Mother	8 years
Kathleen	Max	12	Fragile X Syndrome	White	Father	Unknown, sudden	Mother	6 months

Michelle

Michelle, 30 years old, taught in a rural school district in a small town. She taught students with ID and other disabilities in the same school for all of her 7 years of teaching. She held a masters in special education and was certified in special education, general education, and as a principal. Michelle had had a close relationship with the deceased caregiver, who had talked openly with Michelle about her diagnosis, treatment, and approaching death. Michelle greatly admired her optimism throughout the ordeal.

The deceased caregiver was the student's grandmother and had gained custody when the mother was incarcerated. Chris, aged 7, had limited contact with his biological mother and considered the grandmother "mama." After the death, Chris's aunt came to take care of him and they had moved to a new city by the time of the second interview. Michelle was instrumental in preparing a smooth transition for him to the new school district. She also maintained contact with the caregiver, who was thrilled to report that Chris was doing well at his new school.

Dana

Dana, also aged 30, was the only participant not currently teaching. She taught students with disabilities for six years before stopping to pursue her doctorate in special education. Eight years had passed since her student lost his caregiver, but Dana easily recalled the experience. The loss happened during her first year of teaching and impacted her deeply. At the time of the interview, Dana had her own children and one had autism. She shared that she often reflected on how her own son would be impacted

by her or his father's death. She worried that he would not understand that his father had not left him by choice.

Dana's student, Liam, was drastically impacted by the death of his father and displayed extreme behaviors in the classroom. The following school year, he moved to another town with his mother and sister to be closer to family. Dana was concerned with his drastic change in behaviors and worried about his future. By the time of the second interview, she had contacted a former colleague who still had contact with the family and learned Liam had adjusted to his mother's remarriage and was doing very well.

Annie

Annie, 50 years old, was extremely warm and friendly and started and finished the interview by hugging me. She was the only teacher who did not teach in a public school. She taught at a charter school for students with a variety of disabilities who needed extensive supports. As Annie explained, "districts give us difficult cases." The goal of the school was for students to transition back to public schools. Annie had 8 years of experience and was certified in special education and autism. She strongly believed special education practices focused too much on modifying behavior and not enough on the social and emotional needs of students. Annie herself had a child with a disability and knew her student's parents through a parental support group.

Molly, Annie's student, was 9 years old when her mother died of cancer. In preparing for the approaching death, her parents decided to place Molly in a group home a month before the death. Initially, Molly had some issues with the transition, but two years after the death seemed to be doing well and referred to the group home as "her

home". Two years after the death, her father remarried. Annie expressed sadness that Molly was not always involved in family activities.

Beth

Beth, 52 years old, had 18 years of experience as a general and special education teacher. She spent the last 13 years teaching students with ID but returned to general education at the time of the second interview. Beth had the incredibly difficult task of breaking the news to the student about his father's death. Her student, Chris, then asked her to attend the funeral and stay with him during the wake and burial. Beth talked openly about how challenging it was for her to have this experience so soon after her own mother's death.

Chris's parents were recently divorced and he spent every other week with his dad. They were very close, loved to play baseball together, and the father was instrumental in Chris' care. Chris' father died of carbon monoxide poisoning soon after moving into a new apartment. Chris was actually supposed to be at the apartment but stayed with his mother at the last minute. Understandably, his mother was incredibly distressed about how close Chris had been to being affected in addition to her ex-husband. Beth remained in touch with Chris and his mother years after the death. Chris was now in Beth's afterschool program and he was doing very well.

Kathleen

Kathleen, 63 years old, had 25 years of teaching experience with students with ID. She was certified to teach bilingual children as well as those with moderate/severe disabilities, autism and emotional disturbance. Kathleen was a grandmother and believed

her student similarly viewed her as a grandmother. Her caring nature was apparent when she provided cookies and drinks during the interview and sent me home with toys and clothes for my own children. Kathleen shared the very personal story of her older brother dying when he was 12. She talked about how difficult it was for her when her family did not talk openly about the death and she continued to process emotions from this experience.

Max's father died suddenly and Kathleen felt it was not her business to ask details about his passing. The family had moved from his house into government housing after the death. Max was the only student who was not doing well at the time of the second interview. Max was displaying an increase in aggressive behaviors and Kathleen talked about her concerns about his home life.

Summary of Categories

Analysis of the data from this study produced categories that surrounded the phenomenon of managing the grief response of students with ID. Five primary categories were produced. The category, *Supporting Grieving Students,* was identified as the core category as it "represents the main theme of the research" (Corbin & Strauss, 2008). I was able to "trace connections between" teachers supporting their grieving students and all of the other categories (Birks & Mills, 2011). Teachers responded to their students' loss of a primary caregiver by supporting them in their grief. Their supportive actions were present in the other four categories—*student impact, surviving caregiver impact, teacher impact* and *school-wide supports*. Table 3 provides the name

and definitions of the categories. Table 4 summarizes the categories, their sub-categories and properties. The bolded text in Table 4 reflects when the core category appeared in the other categories. For example, the teachers' supportive focus was evident in the category of student impact when they acted to prevent further changes. The action codes (gerunds) used during initial and focused coding were preserved in Table 4 to emphasize the action of the teachers.

Table 3

Categories and Definitions

Category	Definitions
1. Supporting Grieving Students (Core Category)	Teachers reacted to their students losing a parent by continually acknowledging and supporting them in their grief.
2. Impact on Student	Students were all negatively impacted by the death of a significant person in their lives.
3. Impact on Surviving Caregiver	Surviving caregivers were negatively impacted by the death of the caregiver.
4. Impact on Teacher	Teachers were personally impacted by the experience of the student losing a parent.
5. School Wide Supports	Bereaved students returned to school after the death. Students sometimes found support from others in the school context.

Table 4

Categories, Subcategories and Properties

Category	*Subcategories*	*Properties*
1. Supporting Grieving Students (Core Category)	Being a supportive presence	Acknowledging grief Establishing security Observing students
	Types of supports	Maintaining routines Maintaining expectations Supporting emotionally Talking openly Implementing activities
	Influences on supportive actions	Pulling at straws Referencing past experiences Following school policies Following professional advice Ignoring influences Researching Knowing students well Knowing limits Student cognitive functioning
	Explaining supportive action	Emphatic personalities Doing their job Acknowledging emotions
	Outcomes of supporting students	Establishing connections Feeling closer to student Facing the unexpected Call for more training
2. Impact on Student	Displaying behavior	Types of behavior Teachers distinguishing grieving behaviors **Teachers reacting to behaviors**
	Experiencing additional losses	Type of changes **Teachers expressing concern** **Teachers acting to prevent further changes**
	Functioning of Surviving Caregiver	Caregivers grieving Quality of care **Teachers expressing concern** **Teachers responding emotionally**

Table 4 Continued

Category	*Subcategories*	*Properties*
3. Impact on Surviving Caregiver	Assuming new role	Death of caregiver Difficult situation
	Teachers reacting to surviving caregiver	Acknowledging situation Acknowledging grief **Evaluating caregiver actions**
	Teachers and surviving caregiver interacting	**Communicating about student impact** Asking advice Giving advice Connecting to resources Communicating about personal impact **Establishing boundaries** Connecting to resources Calling for resources
4. Impact on Teacher	Experiencing a range of emotions	Emotionally difficult Sadness Frustration Shock Sympathy Vulnerability
	Personalizing the experience	Reflecting on their own lives Reflecting on their own experience with loss
	Grieving the deceased caregiver	Talking openly with caregiver Relationship with caregiver
	Dealing with their emotions	**Separating their feelings** Difficult Some support from colleagues Having a safe place
5.) School Wide Supports	School Counselor	**Teachers seeking support** Counselor responses **Teacher evaluating counselor actions**
	School Employees	Supporting students Forming relationships **Teachers encouraging supports** **Teachers encouraging relationship**s
	Peers	Supporting Students **Teachers facilitating support** **Teachers talking to students about death**

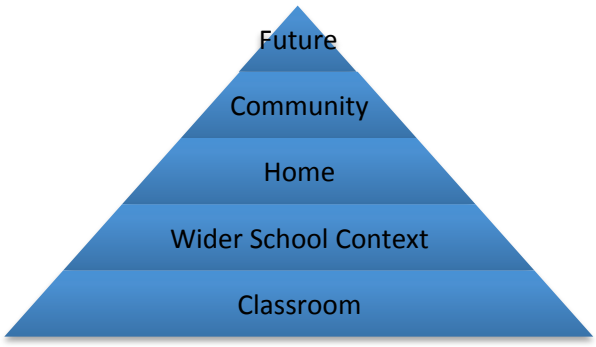
Descriptions of Conceptual Categories

The five categories are described in detail and grounded with participant voices. Quotes were cleaned up to assist with readability. Italics are used throughout the text to emphasize subcategories, properties of the categories. The properties are the "characteristics" of the category (Charmaz, 2006) and the dimensions are the "variations within properties that give specificity and range to the category" (Corbin & Strauss, 2008).

Supporting grieving students-the core category

Teachers responded to their students with empathy. Teachers' supportive efforts were concentrated in the classroom and involved direct interactions with the student and teacher. However, teachers sometimes extended their supports to the wider school context, home and community. In these different contexts, teachers sometimes interacted with other people important to the child to facilitate assistance to the student. For example, Michelle talked to the surviving caregiver about how to address the student's behavior at home and Annie talked with the caregivers at Molly's group home about the decline in her level of care. Teachers' caring actions also extended across time in that they expressed concern about how the death might impact their students in the future. For example, Dana said, "I don't know where he is and I don't know what his adulthood will look like if this was such a step back, you know, the regression, and did he ever get over the depression and grief?" Teachers also took steps to mitigate the impact on students' future. Figure 1 illustrates the multiple contexts where teachers supported students.

Figure 1: *Multiple Contexts of Support*



The death of a caretaker expanded the supportive stance of the teachers. Teachers addressed the academic, social and behavior needs of students before the death. After the death, teachers were faced with how to further assist their grieving students. The description below details how these teachers chose to respond to grieving students (*being a supportive presence and supporting in different ways)*, identifies *influences on their supportive actions*, explores possible *explanations for their supportive responses* and details *outcomes of teachers supporting their students*.

Being a supportive presence for grieving students

Teachers felt it was important to be stable and supportive presences for their students during this immensely difficult time. They achieved this by *acknowledging student grief, establishing security* and *carefully observing students*.

Teachers acknowledged their students' grief and felt it was essential to give students "space," "opportunities," and "time to grieve." Because of this, students openly grieved their profound loss in the teachers' presence, "We would just let him go where

he wanted to cry and when he was ready he could come back" (Dana) and "We realized not to be so quick to say 'stop crying, come on we have to go do this' but allow that to happen, to let him cry." (Michelle) Despite good intentions from caregivers, students were at times not supported appropriately in their grief at home. For example, Liam's father was "erased" when the mother removed all pictures of him and refused to talk about him. Chris was not allowed to attend his mother's funeral and was further disenfranchised when his surviving family members did not explain what had happened to his mother. His confusion can only be imagined,

> She actually passed away at home, when he was gone. He saw her in the morning, she was there in bed and he came to school. I talked to the aunt and she said "my mother just passed away and when he gets home she is not going to be here because they are going to take her". So they said that he came in and was looking for her and was asking "where is mama? where is mama?", looking in the house.

Teachers *established themselves as trusting adults*. They wanted students to feel secure and cared for in their presence as described by Beth, "teachers need to provide security for them…so they know they always have that and they don't have to worry about that. They know someone is there for them." This again often contrasted with what the students encountered at home. As Kathleen explained, "I do let him know… yes, I am upset (with his behavior) but I am not going to start crying and hitting you because that is what he gets at home*."* Teachers knew student grief would probably manifest behaviorally and they *watched carefully for behavior changes*, "I have been waiting and

looking for anger. I am always diligent about watching. I want to be there if it does happen I want to be there to help him through it." (Kathleen) Four out of the five teachers waited until the student displayed behavior while one teacher initiated support before the student displayed changed behaviors. All the teachers continued to watch for signs throughout the school year and took their cues from the students. Beth stressed, "You just have to be in tune with your children so you can anticipate what they need and anticipate the opportunity for them to express themselves."

By *acknowledging student grief, establishing security, and carefully observing students*, teachers were thus able to deliver a variety of supports to their grieving students.

Types of supports

Teachers assisted their bereaved students in a number of different ways. Teachers *maintained familiar routines* for students and kept the environment "normal" and "stable." Kathleen said, "It was hard in the sense that you want to smother the child but I also knew how important it was to keep normalcy for him." Teachers *held high expectations* for the students although Annie explained she *lowered academic expectations temporarily* for her student because she "knew she was internally in pain." Teachers also *cared for the emotional needs of students*. It was important for them to communicate to students they were loved. Comfort was provided through hugs and reassuring words. Other times it was just being there with the student, "Sometimes we could only sit quietly beside her while she cried." (Annie) Beth's ameliorating presence was felt during one particularly emotionally charged moment:

> He just started sobbing. He was just sitting there sobbing and rocking and I just sat there with him, went up to him, and I curled up like he was and I just put my hand on him and he held on and we just rocked. He said "I will never get to see my daddy again". I said "yes you will get to see your daddy again one day, it is all right". He goes "I am the man now", and I said, "you are still a boy, you are going to be a boy for a long time".

They *talked openly to their students about death*. Annie had "talking time" with her student when Molly verbalized missing her mother. Kathleen explained to Max about what to expect at his father's funeral. Teachers knew the importance of talking but always followed the students cue and did not "force them to talk." Kathleen explained, "the child will give you permission to talk as much or as little as you need to if you are listening to them, if you really listening to the kids, or you know, just watching them." Teachers *engaged their students in a number of activities*. Together, students and teachers made cards, read books, colored pictures, wrote letters, waved to the deceased parent in heaven, and created social stories. Activities were sometimes a way to remember the deceased, such as a picture of the deceased taped to the student's desk or how Beth, "would let him go to the computer because the funeral home had a picture of him. He knew how to look it up and watch the video of his dad." Activities also honored the deceased such as when they released balloons. Teachers also used a number of strategies to help the students' process their emotions including tearing up paper or letting them go for a walk. Annie shared how she comforted her student when she got flustered, "we sing her songs so she starts singing and I start singing and we spend a few

minutes singing and then she comes down. It really centers her; it really gives her a focus."

Influences on supportive actions

None of the teachers received training on how to support grieving students during their undergraduate, graduate or teacher certification programs. Hence, they dealt with this incredibly difficult experience without preparation. Two of the teachers (Michelle and Dana) had never encountered a student losing a parent before and *felt completely unprepared* to meet their students needs, "I was at a total loss. I was pulling at straws" and "I did not know what to do, I had never been taught what to do." Kathleen, Beth and Annie had experiences with other students losing a parent or encountering intense loss. They *referenced those previous experiences* when talking about their response to the current situation. Teachers also drew from their own grief experiences to guide their reactions to the student. For example, Kathleen shared,

> We talked about it in class. He seemed to really like that we were open about it because a lot of people will be hush hush. I remember when my brother died, "Oh, we don't talk about Sam at all." I mean that was just how our family dynamic was; and I finally said, "No he is my brother and I need to talk about him."

Teachers were all cognizant of the sensitive nature of the topic of death, particularly given the school context. Michelle said, "We did not know how far ahead as the school to push the issue, or if it was appropriate." They were mindful of *school policies* and teachers offered explanations when they affirmed students with physical

touch and religious references. Teachers *sought advice from counselors* to guide their supportive response. Teachers also felt it was important to respect *parents' advice* on how to approach the situation. However, teachers also *ignored these influences* if they felt they did not appropriately address the needs of their grieving student. For example, Annie shared "There is a no-hugging policy at our school. I did break that rule for her benefit on several occasions when she cried so hard, and she clearly was explaining how she missed her mom.*"* Dana, supporting her decision to tape a picture of the student's deceased father, said, "Mom wanted us not to mention it, not to have pictures, nothing. She wanted it like he never existed and later that did not work for us. We did let him have a picture." Beth went against the advice of the school counselor and informed her student about the death herself.

Teachers, despite not receiving any previous training, made their own efforts to *educate themselves* about appropriate ways to support bereaved students. They researched grief but found few resources to guide their actions. Michelle, who came across an "old textbook" commented, "the research was very limited but it said to allow them to talk when they are ready." Overall, teachers were frustrated with the lack of information on grieving available.

Teachers in this study believed *they knew their students well*. They felt the nature of the special education classroom facilitated this closeness and set them apart from other teachers. Teachers were with their students for the majority of the school day, had small class sizes, and sometimes had students in their classrooms for years. This familiarity influenced how these teachers assisted children. They knew students needed

death explanations and attention that matched their learning style. Annie used social stories and conversation cards because her student had successfully used them with other concepts. Dana found that reading a book about death was not helpful because "that is not how he learned." Teachers' familiarity with their students also made them aware of whether they were grieving and needed support or just trying to "get out of doing his work." For example, Beth said, "I knew the difference between when he really needed a moment or just wanted to stop working." Dana explained, "He was never that kid (try to get out of classroom). I don't think to this day that was why he would leave the classroom. I think he was really trying to regulate his emotions."

Teachers felt students viewed them, in part, as "counselors" or "therapists" but *recognized their role was limited* in this capacity as they were not trained as mental health professionals. Michelle commented, **"**You can only control what happens in the classroom." Annie offered the following advice to other teachers, "Avoid therapy, you are not a therapist. Know where your limitations are. Your strategies are pocket sized, the life changing therapy, that is a separate section; it is not your section." Dana talked about the frustration of her limited role,

> I felt like I was never doing enough for him, so every day I thought, what can I do for him today to make it easier for Liam? And there was nothing ever that I could really do, so it was definitely a feeling of helplessness when it came to trying to serve his needs.

Dana and Beth, understanding their own limitations, connected the student and their family to outside grieving supports (e.g. counselors who specialize with students with disabilities, play therapy and grieving support groups).

Teachers talked about *students' cognitive functioning* and how it related to their understanding of death. Three of the teachers wondered if the student fully understood that their parent had died. Dana said, "I don't know if he understood that his dad did not have a choice, that his dad did not abandon him, that his dad passed away." Dana's student, Liam, was the only student described without any verbal ability. Dana recognized that his limited verbal and cognitive functioning was the reason for his extreme behavior changes after his father's death. The other four students were reported as verbalizing statements like "Mama gone," "Mommy in heaven," and "I don't have a mama." and "My dad is a spirit", and teachers sometimes speculated they were making attempts to understand the death. Students' inability to understand death concepts and low cognitive functioning did not mean the teacher did not acknowledge grief. Instead, the *student's cognitive functioning* influenced how the teachers supported these students. Teachers felt it was important to be concrete with their explanations. Beth had the unimaginable task of telling her student directly about the death of his father. She retold their exchange, which took place as they sat on the couch at his house:

> He brought up "Well, I am supposed to be at my dad's" and I said "I know you are supposed to be at your dad's but you are not going to get to go to your dad's. "Well why" and so he was the scientific kind of kid so I told him, "you are moving to a new apartment". "Yes" and then I said, "well there was some poison

> that got into the apartment and your dad went to sleep and he is not going to ever wake up again." Which is exactly what happened, I needed to be very factual and he said, 'he is dead and I said, "yes he is dead."

He asked her later about the poison, She said, "I went and explained it all. I had printed up some articles for him. That is how he deals with [things]. He deals with the facts." Teachers were not always sure how to approach the subject of death because of the student's level of cognitive functioning. Michelle found it difficult not to say things such as "they went to heaven," "they went to Jesus," "Mama is not hurting anymore" that she usually would say to a child without disabilities as she knew her student only understood concrete information and struggled with how to communicate the abstract concept of cancer.

Explaining supportive actions

Teachers expressed that they *possessed certain personality traits* that caused them to respond in a supportive manner. They described themselves as being innately nurturing, caring and empathetic. Their empathy was clearly evident during the interviews when they described how they sympathized with their students and how their "heart broke" for them. Teachers believed they were called into the profession of teaching because they possess these traits. Michelle commented, "It is just the nature of teachers, it is innate, it is the same for nurses and others in the medical field, the caregiving role, it is just what we are supposed to do." Teachers believed that this caring inclination extended to their grieving students,

> We just do it [enter into the teaching profession] to support the kids and be there no matter what. This is just one of those "no matter what" situations. We know we have to be strong, we are just going to manage and do what we have to do no matter what the situation. I mean look at the tornados that hit Oklahoma, teachers immediately jumped to save children's lives when their own lives were at stake and their own children's' lives where probably at stake. They still did what they had to do. I think it is internal. (Dana)

Annie questioned if teachers who lacked caring would even respond to their bereaved students. Kathleen and Dana suggested that people who were not empathetic would not be successful teachers and believed, "To be a good special education teacher you have to have empathy…you have to believe in the human unit… the humanity of that being no matter what…we always have empathy towards these kids…that is what makes us good teachers" (Kathleen) and believed they should find a new profession.

Teachers believed that *students' emotions* should be addressed in addition to academics. As Annie said, "you have to treat the whole child including their emotions." Teachers believed this should not be different for students with ID. Teachers never questioned whether people with disabilities could grieve or not and felt the grief of their students should be "honored" and "validated." They responded, "of course they grieve" and asserted that students' limited cognitive functioning did not mean students were incapable of grief. Dana explained, "an IQ score does not mean they do not realize their dad is not longer there." They stressed that, similar to all people, the grieving needs of students with ID will be unique for each individual. Teachers believed not

acknowledging and supporting their students "was not a good idea", "silly" and Beth commented, "It is a travesty to not acknowledge ID people as complete humans."

Outcomes of supporting students

Teachers viewed their support as a way to *establish connections*. Death caused a severe disruption in the students' lives. Teachers made efforts to connect students with the deceased and with others. Dana referenced the picture of Liam's dad, "it seemed to help him a little bit just to have some kind of connection with his dad after his death" and Beth felt that releasing balloons on the deceased father's birthday helped to "make a connection." Teachers also wanted to connect with their students. For example, Kathleen felt that she connected with Max when she asked for eye contact from him or provided a reassuring pat on the back. Teachers felt their students should not be excluded from, but rather connected to, the human experience of grief, "with grieving there should be a connection with people, especially with someone with disabilities" (Beth) and "we all are in it, it is nothing horrible and a part of human experience." (Annie)

Four out of the five *teachers felt closer to their studen*t after the experience. As Michelle explained, "I feel like I am very protective of him. We have gone through a process…. I think we are connected further with this experience." Teachers believed students saw teachers as trusting and caring adults after this experience. Beth remained close to her student years later. She explained, "We are very close. He is more comfortable with telling me things. He knows I was there when he was in a vulnerable position. He knows I won't judge, that I am just going to listen." Two of the students expressed gratitude to their teachers. Kathleen explained she felt closer to the student

after he thanked her, she said, "I was surprised and profoundly pleased he said that because that shows he processed something. I have a bond with him it became stronger when he grieved and I let him grieve in my classroom." Dana felt her relationship was always close with her student. She felt the experience did not bring them necessarily closer, but instead changed "the level of supports." She explained, "He still saw me as a safe person to go to."

Teachers described their experiences as "eye-opening." Some teachers felt they now knew to be prepared for the "*unexpected*." Dana explained, "When you go into teaching you don't expect death you don't expect a student to die and you don't expect a parent to die, because you are teaching young kids." Some became aware of how grieving behavior appeared in children with ID. Others were surprised with how personal the experience was. Some teachers described the experience as difficult and that it would have been helpful to receive prior guidance. Teachers were all frustrated with the lack of training and available information on grieving students with disabilities. Annie explained;

> There is no professional recognition of it. It is like an experience you are supposed to have, it is something you are supposed to attend to, you are supposed to have the judgment to accommodate the academics and the emotional balancing, but there is no context to it professionally.

All of these teachers *called for more knowledge, training, and resources* on how to support grieving students with ID. Teachers felt an exchange of knowledge with other teachers also would be helpful. For example, Kathleen suggested communication among

teachers throughout the child's schooling would help with transitions and continued support. Two teachers took direct actions to begin the professional recognition of this topic. One now includes grieving as a topic in her courses for pre-service special education teachers. The other has exchanged ideas with other teachers on how best to support grieving students.

Impact on student

The *students were all impacted* by the death of their primary caregiver. They *lost a significant person in their lives*. In some cases, the deceased caregiver was the sole financial provider, but in all cases, the deceased was a loving and involved presence. Teachers described the deceased caregivers' influence. Beth said, "the person who died was his anchor, his cheerleader" and Dana talked about Liam's deceased father,

> His dad was very supportive, absolutely loved him, did everything for him. Dad was incredibly involved. Dad would drop them off, and dad would sit down and eat breakfast with him in the classroom and it was just one of those perfect families that everyone strives to have and that is what he had.

The impact described by teachers ranged from *minimal*, "He was honestly pretty resilient through the whole thing. It was never prolonged, and we quickly picked up when the second caregiver came along," to *severe*, "I think everything fell apart in his life and I think it was just too much for him. I mean, he lost everything." (Beth) Teachers were concerned about how this experience would impact their students' future.

The teachers talked about the students being impacted in three ways—*students displaying behaviors*, *students experiencing additional losses*, and *surviving caregiver functioning*.

Students displaying behaviors

All of the *students displayed behaviors* after the death of their parent. Teachers described the *type*, *intensity, location, and timing* of the behaviors. Teachers observed *overt behaviors* such as crying, yelling, aggression, and refusal of activities, anger, and loss of interest in familiar activities. Teachers believed that students displayed their grief primarily through their behavior. Michelle said,

> He had never had any major behaviors before. I don't remember him having the crying. He would do a lot of crying…He did some at home and at school it was like something we had never heard. He would get upset and cry.

A few times the teachers specifically mentioned grief when describing the student's behavior. Dana said, "He would produce tears and he would cry and throw a grieving fit." Three of the teachers described behaviors that indicated a mood disturbance. For example, "Her level of anxiety started changing "(Annie) and "I think it was depression because he had all of those depressive signs we are supposed to look for in the kids that do talk. You know the behavior changes, the withdraw." (Dana) Students *sought physical closeness* with the teacher. For example, Michelle said, "he had those days that he wanted to be comforted and he would sit on your lap." Students with verbal ability *made statements and asked questions* about the deceased such as, "Is my Mom in heaven?," "Mama gone," "I don't have a mom" and "I'm sorry I pulled my

Mom's hair. Does she forgive me?" Other students *said they missed the deceased parent*. Tim and his father used to dress up in black suits and watch the movie "Men in Black." A few times after the death, Tim wore his suit to school and Dana felt this communicated that he missed his father.

Some students *regressed on IEP goals* including academic skills, following directions, completing routines and social skills. Annie noticed an increase in seizures from her student after the death and the student regressed after each of these episodes. Some teachers had to reteach academic skills after the death.

The *degree of behaviors* varied and related to how the student was impacted. For example, one teacher only noticed a few minor behaviors and believed the student was adjusting well overall. On the other hand, Dana described how Liam's behavior changed drastically after the death. Before the death, Liam was "one of the easiest students", but after,

> He did a 180 afterwards. I mean it went off a cliff. It was just so significant that he was one of the most difficult kids in the classroom at that point, screaming, hitting, throwing things, definitely knocking everything off his desk, but out of anger.

Behaviors also *varied in timing* and changes in behavior were displayed immediately after the death, days after the death, or even weeks after. Teachers tended to provide a timeframe for the occurrence of the behavior they observed. For example, Annie said, "I would say maybe ten days and then after that we started seeing signs of her distress. The severity and intensity of her coping difficulties increased greatly."

Students also *displayed behaviors around the birthdays of the parents and around holidays*. During the follow up interview, two of the teachers reported *behaviors gradually faded* and the student began to talk about or cry about the deceased caregiver occasionally. Kathleen, at the first interview, reported that her student displayed few overt behaviors immediately after the death and initially believed that the impact to the student was minimal. However, at the second interview, she was concerned over *an increase in his behavior*. She said, "He has progressively had harder times in behavior aspects and has had to be sent to the office a couple of times. He was exhibiting more aggressive behaviors since his dad died."

Students *displayed behaviors in the classroom and larger school context* such as recess. Beth observed behaviors *outside of the school*, "he just started yelling and we were outside of the funeral home and he just yelled for a good five or ten minutes, then he sat down and started sobbing, so that was his first real release." Parents informed teachers about other behaviors displayed at home such as crying and nightmares.

Kathleen had *difficulty distinguishing between grieving behavior* and behaviors that were related to Max's disability. When asked, "How did you know the behaviors were grieving or related to the death?," teachers talked about the timing of the behaviors, new or different behaviors, and their intensity. For example, Annie explained,

> I think the main thing that I saw was crying, more crying than I have ever seen, and crying even when it was not provoked. I just saw an intensity in the known behaviors and then I saw crying and unusual behavior ...it was hysterical crying.

Teachers reacted to students' behavior by providing supports. Teacher supports were tailored to the behavior being displayed. For example, in reaction to Liam's extreme regression, Dana felt it was important to give him space. She described one situation in particular,

> His anger outbursts were just downright scary. We had to clear the classroom several times. I refused to restrain him, and so we would just let him tear up whatever he wanted as long as he was safe, because I did not think that adding a restraint to prevent my classroom from being destroyed was the appropriate method. Because I think that would have made him more traumatized, so we never did restrain him. We just let him we kind of kept him in a corner with stuff that he could not hurt himself with. If you want to throw the blocks, then throw the blocks.

Beth allowed Tim to text and call his mother after his father's death during the school day because "he was afraid of her to get out of his sight and he was afraid something would happen with her during the day, that was his biggest thing."

Students experiencing additional losses

Students not only experienced parental loss but also *encountered additional losses* as a result of the death. Students' daily schedules changed, resulting in *losses of familiar activities and routines*. For example, students rode the bus instead of being dropped off by the deceased parent and students no longer participated in familiar activities. Michelle talked about the changes Chris encountered, "his granny mama would allow him to go out and she would call for him and he would come back to the

house. So they had their own system and when the aunt came it was different." Students also *lost familiar homes* when they relocated following a death. Their new residences were not as ideal as the living situation before, "They had to leave their house and move into low income housing" (Kathleen) and "I kind of feel that this young lady who lost her mom, had a double dosage of adjustment because about a month before her mother passed they put her in a group home." (Annie) Students also had *changes in the quality of care*. Annie noticed the group home often sent her student to school unkempt and in inappropriate clothing. Michelle noticed changes in Chris's care when his uncles temporally took care of him after the death,

> He was her baby, the mama, and I think he even slept with her and things like that. I think that element was gone, when she was gone, too, that nurturing because it was a house of guys taking care of him and we also saw a decline in cleanliness when grandmamma was gone because he would smell of urine and things…and then he was always shiny when he would come to school and we saw that was different… he was just not polished like when she was there.

Teachers were especially *sensitive* to how people with disabilities could be negatively impacted by disruptions in their familiar routines and surroundings. Beth empathetically "ached" for her student, **"**They were dealt a tough hand anyways, having them to get up and deal with a new schedule and handle change, they just don't deal well with change. It really is just sad.*"*

Teachers acted to minimize additional changes in their students' lives. Annie told the ARD committee, which was considering transferring a student to another school,

“ yet another change, I really hope that you are in a position to rethink that, given the circumstance.” Michelle explained how she contemplated personal actions to prevent further changes in her student life:

> We were anticipating it [the death] so my husband and I actually had a discussion like um what would what if we needed to have the student? What if he needed to come to my house? And thankfully his aunt stepped up, because I knew he would severely regress if he was placed or would be a ward of the state, you know, or had to, you know, go live in foster care.

Functioning of the surviving caregiver

Surviving caregivers had to adjust to being a single parent while also coping with the loss of a loved one. Teachers described how *grief of the surviving caregivers impacted their students*. Students sometimes assumed a caretaker role. For example, Tim felt he needed to continually reassure and comfort his mother. Max had to take care of himself, his mother, and his younger sister because the mother was not functioning well. Kathleen highlighted the difficulty of a child taking on such a role ‘he did not know how to do that. You know he just does not have those living skills.” Students were often negatively impacted by the actions of their caretakers. For example, Dana described how Liam’s relationship with his mother became strained after the death,

> She seemed to focus on the sister more after the death because before it seemed pretty equal in her eyes. But I think she could talk to the sister about what was going on and so I think that made her feel better and so I think she developed more of a relationship with the little sister. Liam was kind of left off a little bit to

> decide because she did not know how to comprehend, but she knew how to comfort the sister.

Teachers reacted emotionally to the negative impact on their students; Kathleen said, "if anything, I grieve for the fact that he does not have a buffer with his mom" Kathleen further explained how she was almost took action due to his mother's limited functioning:

> She did a lot of yelling she did a lot of, you know. We came very close to wondering if she was hitting him, so we addressed some issues that we were borderline calling CPS being called in. So we had some real big issues on that because she was not able to care for herself, let alone her children and a lot of it was the grieving process because she had to deal with the money and the support and the grandparent was her parent so that fell into it too so he was in a catch-22 situation in that he was getting it from all sides and not having really stable support.

Michelle was the only one who did not see her student as negatively impacted by the functioning of the surviving caregiver. She believed it was because his Aunt "always appeared to be strong to us so if she did any grieving it probably would be in private."

Impact on surviving caregiver

Surviving caregivers were all impacted by the death. Four of the caregivers were surviving spouses, while one was the daughter of the deceased caregiver. They *grieved a profound loss* while simultaneously *assumed the role as sole caregiver* to a child with ID. The surviving caregivers, when the death was anticipated, were prepared somewhat,

while others were thrust into the role unexpectedly. Teachers reacted to the impacted surviving caregivers by *acknowledging their difficulty and grief* while also *evaluating their actions with the student*. As a result of the death, the *teachers and surviving caregivers had a number of interactions*.

Teachers acknowledging situation

Teachers *sympathized* with the caregivers' and their immense loss, "mom got depressed. You know, I don't think you could ever prepare for the loss of a spouse" (Dana) and "everyone loses it after they lose someone including the surviving spouse, who has just lost their everything." (Annie) Teachers *recognized the difficulties* the caregivers were facing. They discussed the challenges of navigating the special education process, make life changes and sacrifices and care for siblings—all while immersed in grief. Dana talked about Liam's mother;

> It was usually a struggle for mom to get him in and you know, she was grieving and little sister was grieving. And then she had this new child essentially (because of the drastic change of his behavior) and so she was more frazzled. I think she ended up leaving her job.. he had significant life insurance so she did not have to work but she also did not have that friend network and a job and She had always worked and she loved her job and she lost that.

Teachers evaluating caregiver actions

Teachers evaluated actions of the surviving caregiver after the death. Their evaluations ranged from *positive to negative*. Teachers were always mindful of the difficult situation the caregivers faced, as Annie pointed out, "you are just not walking in

their shoes" and how they were able to handle the situation. Michelle believed Chris's caregiver was being "super supportive,"

> She would show a lot of interest like I went to do a home visit a couple times and she had put his little paperwork on the wall you know. So it was neat that she assumed that role quickly you know, and she had no real experience with mothering, so she did it well.

On the other hand, Dana felt "frustration with his mom for not looking into a counselor and for not looking at what she could have done differently for him." Initially, Annie felt the father did an amazing job of supporting the student. She explained he was instrumental in easing her transition to the group home and was an active presence at school after the death. However, later in the interview, she reported that her student was negatively impacted when the father went on a mission trip shortly after her mother's death. Annie felt this was an inappropriate choice as the student was left without anyone to support her.

> When dad first went to Africa, it was like what the heck? You're going to Africa when your wife has not even been dead for six months! You're going to Africa and your daughter is not going to see you for 60 days? I was actually mad. I was mad at him for going to Africa.

Interactions between surviving caregiver and teachers

Interactions between the surviving caregivers and teachers changed in the context of the death. They now discussed the impact of grief on the student in addition to

everyday classroom issues. Communication occurred both ways. Teachers sometimes sought advice from parents about how to handle the difficult subject. Michelle said,

> I personally think that you need to talk to the parent and see what their wishes are because I was always very wary of what they have they told him. I am really not interested in starting a conversation that they don't wish to have with him.

Other times parents sought advice from teachers such as when Molly's father asked "What can I do to help my daughter?" Teachers, in turn, sought consultation on student behaviors, provided suggestions on how to support the student at home, and sometimes *connected them to resources.* Chris's aunt faced caring for a student with a disability for the first time. Michelle was then instrumental in answering the aunt's questions about the special education process.

Communication between the surviving caregivers and teachers *turned personal* after the death. Surviving caregivers talked to the teachers about their own personal impact and grief. Teachers' *comfort levels varied* when the surviving caregiver revealed this type of information. Dana felt teachers were viewed as counselors and explained,

> I think the caregiver sees us as a very safe person to come and talk to. So the mom would come in all the time and talk about how things were at home and how she was at home and how it was hard still being in the house.

Beth *felt closer* to her student's mother after the death, She said, "We became closer. I lost my mother right before so I had been through the process. I understood. I was able to relate to their experience. We would talk." Michelle maintained friendly communication with the caregiver even after the family moved. Kathleen and Annie,

however, *felt uncomfortable* when they felt the surviving caregiver revealed too much personal information. Annie talked about being caught off guard,

> I was not necessarily prepared for the amount of grief that the surviving parent had. I was not prepared for the way they needed to express themselves and how they needed to share. I was not ready for that. This surviving parent was very forthright about his grief and direction of their future to the point where I thought it was past a professional line. I had to ask the parent to take me off the email because the way that the parent wanted to share with me was way too personal for me. I did not need that much information to be the child's teacher. I thought the parent would have support in their own life, their own relationships, their own circle, and spiritual and counseling connections to shelter me from some of that information that I really did not need to know.

Kathleen and Annie needed to *establish personal and professional boundaries*, "A teacher has to be very aware of being professional, but real in a way they acknowledge what the students is going through." In all cases teachers always focused on the student, " It is first and foremost about what the student is going through." (Annie)

Teachers believed caregivers would benefit from resources on supports for bereaved students and their families.

Impact on teachers

Teachers were personally impacted by their student's loss. Their emotional impact was evident in their body language during the interviews (e.g. leaning towards researcher or looking away), speech (e.g. inflections and hesitations) and reactions to

direct questions about the personal impact. Some teachers felt more comfortable talking about their feelings while others seemed to quickly change the subject and return the focus to the students. As a novice researcher, it was difficult for me to push further with this issue because of their sensitive reactions. They talked about their impact in four different ways—*experiencing a range of emotions*, *personalizing the experience*, *grieving the deceased caregiver* and *dealing with their emotions*.

Experiencing a range of emotions

All teachers said they were moved emotionally by the experience. They expressed a range of feelings such as sadness, frustration, shock, sympathy, or vulnerability. Kathleen said, "I was torn up by it, you know, just to put myself in the mind of a child. I wish it did not happen." Beth described the intense emotion she experienced after having to tell her that his father had died. She shared, "I cried all weekend, it was so emotionally draining" and "it really felt like an out of body experience like I was watching I felt like I was a person watching what was going on." Dana talked about how she felt helpless, "He wants his dad and he wants something you can't produce. He wants his old life back and that is something you can't do for him." They were *deeply affected* by the experience and described it as being *very difficult*. Beth said, "I don't ever want to deal it with a child (losing a parent), it was too hard" and Michelle said, " I never experienced anything like this and I don't want to again."

Personalizing the experience

Teachers *related the experience to their own lives.* Beth reflected on the fragility of life, "it makes you realize how vulnerable we all are and to make sure everyday is

important to these kids and yourself." Teachers thought about how they would act if a similar situation happened to them. For example, Dana reflected on how her own child, who also had a disability, would be impacted by her death. Annie pondered the difficulty of losing her spouse or "life blood." Two teachers talked about how the experience *awakened their own grief* related to losing a loved one. They related to the sadness and difficulty the child experienced. Kathleen shared, "I personalized it a lot and I would hope that he would not have as much damage as I caused on my own self when my brother died." Kathleen talked openly about her grief experience with Max,

> I experienced my brother dying when I was twelve so and I used that experience to share with Max how I felt and I verbalized a lot of how I hated everybody and I did not like myself and I felt guilty so I used words that he might not be able to understand, but he was listening.

It was difficult for Beth to have this experience with her student occur so close to her own personal loss,

> I was very emotional. It was personal. I had lost my own mother. It brought those emotions back to life but also their grief, the person who died was his anchor, his cheerleader. That tears your heart out. I went through depression with them, I felt their pain and what they were going through.

My field notes included comments such as "very intense" or "emotionally charged" when Kathleen and Beth shared their own personal experiences.

Grieving the deceased caregiver

Three of the five teachers knew the deceased caregiver. In these cases, all three died of cancer and *talked openly* with the teachers about their illness, their approaching death, and their students' care. Michelle shared how she was especially worried about Chris's care after a particularly moving conversation with his grandmother, She explained, "the grandmother when she was very sick and at the hospital called me and said, 'Michelle, please take care of our baby' and I said 'yes mam, you know I will'." Teachers described their *relationship with the deceased caregiver*. Michelle said, "the grandmother and I had a close relationship", Dana expressed, "It was one of the stronger parent-teacher relationships than normal" and Annie knew the deceased caregiver from their membership in a support group for parents with disabilities. She shared the exchange between the two at the beginning of the school year, "I said 'oh my god I know you' and we gave each other a big hug." They were all saddened by the death of the surviving caregiver. For Dana, this was a new experience, "That was my first time that I lost someone I knew, now that I think about it, because I had not lost any of my family prior".

Dealing with their emotions

Teachers felt it was necessary *to put their emotions aside* to effectively support students. Teachers discussed how this was *not easy*. Beth remarked, "then it became I had to take care of him and when that was done I had to take care of myself that was very difficult" and Dana shared,

> It was hard for me to grieve while helping the family grieve and so it was just really a personal struggle in that I had to maintain the day-to -day so I felt like I had to be somewhat strong for them and try not to break down with the mom.

Teachers talked about dealing with their emotions away from students and felt doing so was essential to effectively assist their students. Kathleen said she put her feelings aside to help Max,

> I have to in order to be better for him. I mean in the instance I am not emotional I can't with kids with disabilities in any situation whether they are grieving or anything if they are having a tantrum you do not become emotional you have to put the barrier up you deal with what they need.

Some teachers dealt with their own emotions at "another place" and "time." Annie found support from her colleagues who took over the class momentarily when she needed to step out. She also explained another way she dealt with the emotionally charged experience, "I think I have a safe place for how I feel. I keep a journal. I journal everyday about teaching and I think that helps me to deal with things safely."

School wide supports

All students returned to their schools immediately after the death. While students spent the majority of their time with teachers they also interacted with others in the school context. Specifically, teachers focused on student interactions with *counselors, other school employees*, and *peers*. These individuals were sometimes helpful to the student and initiated supports independent of the teacher. Other times, teachers

interacted with *counselors, other school employees and peers* to facilitate supportive actions between them and their students.

School counselor

Four of the teachers sought advice from the school counselor about how to respond to the bereaved students (Annie did not have a counselor at school). The school counselors were viewed as experts on grief and teachers expected them to implement grieving interventions. However, teachers reported *mixed experiences* to their requests for assistance. Counselors ranged in their reactions and either did not respond, gave teachers advice and resources or met directly with students. Teachers *evaluated the counselors' reactions* based on how they perceived the student was being supported. Dana explained her feelings when the counselor did not offer support either to her or her bereaved student,

> Frustration with our counselors because they should have found out what to do, that is their field and it is their job to help students in the school and that means all the students and I don't know why my kids did not count.

On the other hand Kathleen expressed gratitude for the help received, "the counselor is a very wonderful, quiet woman that will call him in maybe once every month just to check on him." Michelle found it helpful when her counselor brought up how culture can influence a family's response to grief. Teachers commented on the lack of training counselors receive about students with disabilities and believed their response, supportive or not supportive, was influenced by experience with students with

intellectual disabilities. Two of the students received support form the district school psychologists but on a limited basis.

Other school employees

Bereaved students did not always receive support from school mental health professionals, but often did have supportive interactions with other school employees, "everybody at the school has embraced him and that is something that has been very important." (Kathleen) Paraprofessionals, principals, school secretary, other teachers, speech pathologists, and coaches were all identified as people who were helpful to the grieving student. For example, a paraprofessional openly talked to a student about his dad, while a principal visited the classroom to check on the student. One principal allowed a dying father to spend a significant amount of time at school with his son, which was normally against school policy. Interactions between a school employee and grieving student sometimes evolved into an *influential relationship*. Interestingly, there was a gender component to these relationships. Three out of the five students were boys who lost fathers. Their teachers talked about how these male students had warmed up to a male figure at school after their loss. Dana said, "he was probably the most important person for Liam." Although school employees cared for students on their own, teachers sometimes interacted with them to help facilitate support. They *collaborated* with disability professionals, informed general education teachers about student needs, and connected students to a trusting adult such as when Kathleen strove to establish a relationship, "the PE teacher that was out on duty, we talked and Max came over and I

said Max we have Mr. Brown here and he knows about your dad, so he can take care of you too."

Peers

All of the bereaved students were in classrooms with other children with disabilities. Some *classmates were sensitive* to the grieving student and *initiated supportive interactions*. Annie explained Molly's peers' empathic reaction after she broke down in tears,

> Multiple students went up to her and hugged her and told her it was going to be okay and another held her hand and brought her to her desk saying it was going to be okay, so that was really special you know. And other students would say 'you are okay'.

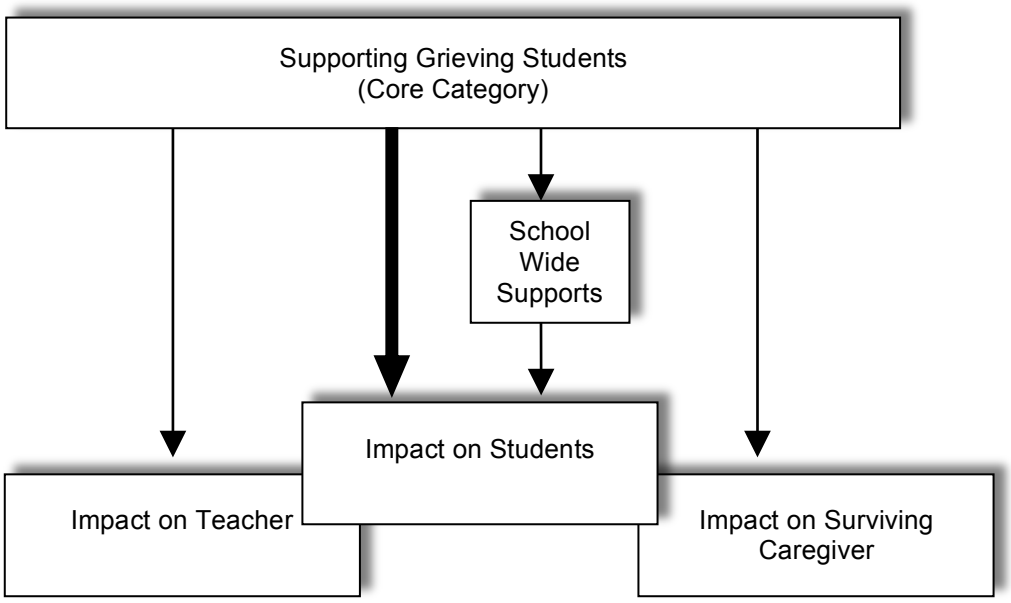
Dana described how Liam's peers tried to be supportive but he had lost interest in social activities after the death, "they tried and tried until the last day of school. They would say, hey give me a high five', and he would always walk right by them. " Teachers *interacted with classmates* in an effort to create a supportive environment. Kathleen openly discussed the situation with all of her students, "I did explain to them (the other students) we are going to be patient. Max is going to have some troubles sometimes and we need to be very understanding because he just lost his daddy.*"* Teachers also *included peers in activities* to remember the deceased caregivers such as releasing balloons or making birthday cards. Annie prided herself on creating a caring classroom environment form the beginning of the school year—not just when a death occurred—and felt this contributed to the social development of her students. Teachers also used the

experience to talk to students for the first time about the sensitive topic of death and to check their understanding about the concept of death. Students did not always demonstrate full understanding, but teachers felt it was important to address their loss.

Integration of Categories

The core category, which was *Supporting Grieving Students*, orders the diagram below as it "subsumed" all other categories (Corbin & Strauss, 2008). However, Figure 2 is not meant to represent a theory but instead graphically represents the relationship amongst the five categories. A description of the relationships between these categories follows the diagram. Storylines are used in grounded theory to assist with integration of categories (Corbin & Strauss, 2008). The description that follows is, in essence, a storyline that pulls together the major categories.

Figure 2: *Integration of Categories*



Teachers in this study acted by strongly *supporting grieving students* with intellectual disabilities. Their supportive focus drove their actions with children as well as their actions to facilitate *school wide supports*. The *impact on students* was always at the forefront of teacher concern. Teachers recognized how the grief had *impact on the surviving caregivers* and often provided them support. However, the *impact on students* was always at the center of their interactions with the surviving caregivers. Teachers maintained their attention on how to mitigate the negative *impact on students*, even if they had to put aside the their *impact on themselves as teachers*.

The death of the parent had a profound *impact on students* and this loss was evidenced by behaviors such as intense crying and aggression. They were additionally impacted by secondary losses such as moving or when their caregivers had difficulties stemming from their own *impact as surviving caregivers*. Students' grieving needs were sometimes not supported at home, but they found comfort in the school context. They were comforted primarily through their teachers but also found *school-wide supports*.

CHAPTER V

DISCUSSION AND CONCLUSION

There is growing recognition that teachers are responsible not only for nurturing the academic skills of their students but also for their students' social and emotional development (Bernard, 2006; Curby & Brock, 2013; Durlak, Weissberg, Dymnicki, Taylor & Schellinger, 2011; Murray, 2002; Smith & Emigh, 2008). While researchers suggest that teachers can be important social supports for grieving students (Reid & Dixon, 1999; Schonfeld & Quackenbush, 2010), there is little in the research literature about how to best assist children with ID. In addition, teacher preparation competencies do not address how to support grieving children with disabilities (e.g. Council for Exceptional Children, 2009). As children with ID are at risk for increased levels of psychopathologies such as depression and anxiety after the death of a loved one (see Tonge & Einfeld, 2003), this oversight is alarming. In addition, children with ID may experience grieving complications if their caregivers are not appropriately responsive (Sormanti & Ballan, 2011).

This study explored the experiences of teachers whose students with ID had lost a parent or guardian. The results of this study yielded descriptions of behaviors displayed by grieving children and examined how teachers responded to these students. This chapter will discuss the results within the original research questions and includes implications. Limitations and suggestions for further research follow this discussion.

Research Question #1: What Were the Experiences of Teachers of Elementary Students with Intellectual Disabilities Who Had Lost a Parent, Guardian or Primary Caretaker?

Teachers in this study shared several experiences as part of dealing with children in their classrooms. Each was impacted personally by the experience and some found it difficult to communicate with the surviving caretakers.

Personal impact of experience

Teachers were strongly impacted by the grieving experiences of children with ID. They described the experience as profoundly difficult for them and were caught off guard by their own emotional responses. Teachers felt a range of emotions (e.g. sadness, frustration and vulnerability) and were "heartbroken" about their students' experiences. Research has reported that teachers of children without disabilities are similarly impacted emotionally when children lose a parent (Papadatou et al., 2002; Rowling, 2008; Spall & Jordan, 1999). For two teachers in this study, the experience triggered memories of their own personal losses and evoked strong feelings of grief. These teachers used their own personal experiences to guide them in how to support their students, a response also found in another study (Lowton & Higginson, 2003).

Teachers felt they had to suppress their emotions in order to appropriately assist their students, a result also found in studies on students without disabilities (Lowton & Higginson, 2003; Rowling, 2008, Spall & Jordan, 1999). Teachers often believe they need to remain in control of their emotions in the classroom context (Emmer & Stough, 2001; Jennings & Greenberg, 2009; Lowton & Higginson, 2003; Rowling, 2008). As a

result, teachers are at risk for becoming disenfranchised grievers (Lowton & Higginson, 2003; Rowling, 2008; Spall & Jordan, 1999) if they do not display emotion in an attempt to appear "professional" (Rowling, 2008). Two teachers in this study could be characterized as disenfranchised grievers as they reported it was difficult for them to manage their emotions.

Professionals suggest that teachers are in a prime position to assist children as they usually have some "emotional distance" from the loss (O'Conner, 2002; Schonfeld & Quackenbush, 2010). However, in this study, three teachers had close relationships with the deceased and, as a result, were also grieving while simultaneously assisting their students. The difference in these results may be due to the educational role of teachers selected for this study: special educators tend to have frequent contact with the parents of their students (Spann, Kohler & Soenksen, 2003), which may have facilitated formation of close relationships with them. It should be recognized that teachers might also grieve the death of a caregiver.

Communication with surviving caregivers

Parents often seek advice from teachers following a death (Machon et al., 1999; Schonfeld & Quackenbush, 2010). In this study, parent-teacher communication became intimate when the surviving caregivers shared their feelings about their loss and their functioning. Similar to results from Papadatou et al. (2002), three of the teachers in this study were comfortable with these personal exchanges. However, the two other teachers felt it was important to create distance and not to be the caregiver's confidant. Teachers are expected to communicate competently with parents even when the topic is difficult

(Cohen & Mannarino, 2011, Schonfeld & Quackenbush, 2010), however, some teachers were not comfortable speaking about personal information with parents.

Research Question #2: What Behaviors of Students Who Had Lost a Parent, Guardian or Primary Caretaker Did Teachers Observe in the Classroom?

Teachers in this study watched closely for behavior changes and observed a range of grieving behaviors. Two of the children were possibly experiencing complicated grief due to the intensity of their behaviors.

Observing carefully

Grief reactions can be subtle in people with ID and caregivers need to watch closely for behavioral changes (Hospice Foundation of America, 2013). Teachers in this study anticipated behavioral manifestations of grief and carefully observed their students. Teachers in other studies have been reported as responsive to bereaved students without ID; however, they did not pay the same level of attention to behavioral changes (Christ & Christ, 2006, Eppler, 2008; Lowton & Higginson, 2003; Machon et al., 1999; Rowling, 2008; Papadatou, 2002; Spall & Jordan, 1999). Teachers in this study were all certified in special education and had a minimum of 6 years teaching experience. Their background and expertise may explain their awareness that they needed to monitor behavioral changes.

Types of grief-related behaviors

This was the first study in which the classroom behaviors of bereaved children with ID have been systematically recorded. The reactions of children with ID in this study add to understandings of how grief reactions are manifested in the classroom

context. Teachers observed a variety of grief expressions in the children. Examples included crying, yelling, displaying anger, verbalizing their feelings, refusing normal activities, academic regression, distraction during class activities, a loss of interest in peers and preferred activities, and seeking comfort from teachers. These are similar to behaviors described by teachers of students without ID (Christ & Christ, 2006, Papadatou, 2002) and consistent with behaviors of grieving children identified by other professionals (Eppler, 2008; Haine et al., 2008). In addition, these behaviors are consistent with those displayed by adults with ID (Bonell-Pascual et al., 1999; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997). Researchers have also documented these behaviors in anecdotal and case reports in children with ID (Kauffman, 2005; Markel & Hoover, 2010) and hypothesized about their occurrence (Sormanti & Ballan, 2011).

Some students in this study were aggressive and one student increased her self-injurious behaviors after their loss. Researchers hypothesize that children with ID will engage in more aggressive and self-harming behaviors than will bereaved students without ID (Everatt & Gale, 2004; Sormanti & Ballan, 2011). Grieving adults with ID have been reported to make somatic complaints (e.g. stomach aches) and other researchers hypothesize that children with ID will also manifest somatic complaints (Kaufman, 2005; Sormanti & Ballan, 2011). However, teachers in this study did not report somatizations, although this could be as a result of limited ability to verbally communicate physical pain.

Trajectories of grief

Individuals experience adaptive grief in their own way and should not be expected to grieve according to a particular pre-conceived timeframe (Cohen & Mannarino, 2011). However, there are times when the identification of behaviors is particularly important (Sormanti & Ballan, 2011). Complicated grieving behaviors are often the same as normal grieving behaviors but differ in duration and severity (Schuurman & Decristofaro, 2010). Three of the five children displayed behavioral decreases over time, indicating a normal grief trajectory. On the other hand, two children in this study were possibly experiencing complicated grief. Complicated grief can occur as a result of secondary losses (Sormanti & Ballan, 2011). One student had an increase in aggression after encountering the secondary losses of moving to a new home and having an unstable home environment. Another teacher expressed great concern over the severity of her student's grieving behaviors and believed he was deeply depressed. Sormanti and Ballan (2011) suggest caregivers, including teachers, should assess for signs of complicated grief every six months and be prepared to educate others on the signs of complicated grief.

Research Question #3: How Did Teachers Respond to Students with Intellectual Disabilities Who Had Lost a Parent, Guardian or Primary Caretaker?

Teachers responded to students by acknowledging their grief and supporting them directly. Their responses stand out when compared to the inaction of teachers who felt uncomfortable and apprehensive talking about death or who ignored the needs of grieving students (Lowtown & Higginson, 2003; McGovern & Berry, 2000; Papadatou

et al. 2002), teachers in this study talked openly with children about death, funerals, and their feelings of missing the deceased. Further, their actions are in contrast with the dominant narrative that caregivers usually do not acknowledge or respond appropriately to grieving people with ID (Clements et al., 2004, Hollins & Esterhuyzen, 1996; Hoover, Markell &Wagner, 2005; Markell, 2005; Raji & Hollins 2003; Read & Elliot, 2007; Summers, 2003). Instead, their actions mirrored compassionate actions described in studies of teachers of children without ID (Bennett & Dyhouse, 2005; Christ & Christ, 2006; Eppler, 2008; Lowton & Higginson, 2003; Machon et al., 1999; Rowling, 2008; Spall & Jordan, 1999) as well as those of teachers of students with ID impacted by disaster (Ducy & Stough, 2011). Despite not being trained, teachers instinctively responded to their students in ways recommended by researchers and professionals. Teachers maintained routines, held high expectations, cared for emotional needs, made cards, read books, wrote letters, gave "breaks" from the classroom. .

Some of the strategies used by teachers in this study have been identified as critical for children with ID (Markell & Hoover, 2010; National Association for School Psychologists, 2005; Sormnati & Ballan, 2011). For example, teachers provided concrete and simple explanations to assist with student understanding of death. They "affirmed a range of emotions, cognitions, behaviors, and physical reactions" including crying (Sormanti & Ballan, 2011, p.187). Additionally, they encouraged activities such as music and drawing that might facilitate non-verbal expressions of grief.

Significance of Results

Teachers of students with ID have been identified as potentially supportive to grieving students (Everatt & Gale, 2004; Gaventa, 2011; Sormanti & Ballan, 2011); however, this study was the first that examined this phenomenon. Given that the emotional needs of these students were not always appropriately attended to at home, teachers served an important emotional function. Encouraging other caregivers of adults and children with ID to respond in a similar manner may help to prevent disenfranchised grief in this population.

The stable presence of these teachers was especially important to their children. Special education teachers may have their students the majority of the school day and have students for a number of years. This consistency provided essential stability to students during the grief process, especially given the limited functioning of their surviving caregivers. Surviving caregivers' own grief can sometimes interfere with meeting the needs of their children adequately (Blackburn, 1991; Christ, 2010; Christ & Christ, 2006; Healy-Romanello, 1993; Mahon, Goldberg, & Washington, 1999; Schonfeld & Quackenbush, 2010), as was the case for the caregivers in this study. As the results indicated, one surviving caregiver's level of functioning after her loss interfered with her subsequent ability to support her child. The mother struggled financially, demonstrated extreme emotions, and often screamed at her child. Another teacher believed that the parent and child relationship was damaged by the death. One surviving caregiver placed his child in a group home rather than raising her alone, a concerning

choice given that the relationship with the surviving parent can impact a child's resiliency during the grieving process (Haine et al., 2008).

Teachers in this study were profoundly important and prevented grieving complications for these children with ID. For example, teachers' attention to behavior changes prevented diagnostic overshadowing. Diagnostic overshadowing can prevent caregivers from accurately identifying grief in people with ID (Brickell & Munir, 2008; Gentile & Hubner, 2005). Unlike their peers, students with ID may not be able to verbalize their grief, which makes the careful attention of these special education teachers particularly important. Teachers recognized crying as a concrete sign of grief. Additionally, teachers took important steps to help minimize the impact of secondary losses on children. Secondary losses are recognized as possible emotional complications for grieving children with ID (Brickell & Munir, 2008; Hospice Foundation of America, 2013; Sormanti & Ballan, 2011) that can lead to mental health issues (Haine et al., 2008). Teachers were concerned about these secondary losses and served as key informants. For example, when two of the students moved to new schools, their teachers communicated with their new teachers about their needs. Another teacher talked continually to the caretakers at the group home, which aligned with what researchers suggest as a promising way to support grieving people with ID (see Gaventa, 2011).

Implications

Implications for future research

This study was instrumental in demonstrating how students were impacted by the loss of a parent and how teachers responded to the emotional needs of their students.

However, further research is needed to advance understandings of the emotional lives of children with ID. Additionally, research on their caregivers is essential to further understandings of how to best support them and their grieving children.

Different student populations

Future studies should look at how other student populations were impacted by the death of a surviving caregiver. This study only included students with ID aged 7-12. More research is needed on the classroom grieving experience of students of all ages. Adolescents tend to demonstrate different grieving behaviors than younger students and also have different support needs (Christ, Siegel & Christ, 2002). This study also only looked at students with ID. Studies should explore the grieving experience of students with other disabilities. For example, there are students with autism without an ID. They might have specific concerns about funeral rituals such as concern over the change in schedule or social anxiety and require supports such as bringing a picture schedule of events or practicing what to expect at the funeral (Doka & Helbert, 2013).

Student teacher relationship

The student-teacher relationship is important, as students are most likely to discuss their loss with someone they know and trust (Reid & Dixon, 1999). Further, Barrett (2008) notes, "supportive relationships with teachers are important predictors of the psychosocial well being of children who have experienced traumatic events" (p. 217). Teachers felt they had strong relationships with their students and most felt closer to the children after the experience. Teachers of students without disabilities also reported a stronger relationship with bereaved students (Papadatou et al., 2002).

Interestingly, the closeness reported by teachers in this study contrasts with studies that showed students with ID had poor and strained relationships with teachers (Blacher et. al, 2009; Eisenhower et al., 2007; McIntyre et al., 2006). Further research could explore the impact of stressful events on the relationship of students with ID and their teachers.

Different aspects of loss

Grief not only occurs with the death of a parent but from other losses (Hospice Foundation of America, 2013). Another study showed how teachers supported students with ID encountering losses from disaster (Ducy & Stough, 2011). Future research could examine how children with ID are impacted by other forms of loss such as the death of a friend or loss from a divorce and how caregivers responded. Children with ID themselves may be powerful informants on their own impact. Adults with ID have reported on their grieving experience as well as their perception of supports (Harper & Wadsworth, 1993). Including children's voices may help to gather a more complete picture of their reactions to loss and subsequent support needs.

Research on surviving caregivers

The surviving caregivers in this study were deeply impacted by the loss of their loved one and encountered difficulties that related specifically to having a child with ID. Surviving caregivers of children with ID may have particular difficulties after the loss of a spouse. Under normal circumstances, parents of children with disabilities "can face significant challenges that can lead to personal distress which in turn can adversely affect the wellbeing of the child and the entire family unit" (Resch, et al., 2010, p.146). Death adds another contextual layer to the normal stresses of raising a child with an ID.

Single mothers of children with disabilities have been found to be more vulnerable to severe depression than are mothers living with a partner (Olsson & Hwang, 2008). The literature on "grief" and "parents and caregivers of children with ID" addresses grief associated with the disability diagnosis, but there are no existing studies on the experience of surviving caregivers with children with ID. As such, this is the first study to record how surviving caregivers of children with ID were impacted. Future research should explore their experience as a bereaved parent and how they cope while raising a child with ID. Findings may lead to the development of appropriate support mechanisms for the surviving caregiver and provide much needed stability for the child. Additionally, resources are needed for surviving caregivers, including community support groups to assist caregivers with their own loss and also those of their grieving child.

Implications for training

As pointed out by one teacher, there is "no professional context" for the issue of mental health, including grief, of students with ID. All teachers in this study called for training and resources on how to effectively respond to grieving children, a request echoed by teachers of students without disabilities (American Federation of Teachers & New York Life Foundation, 2012; Cullinan, 1999, Machon et al, 1999, Papadatou et al., 2002; Reid & Dixon, 1999; Spall & Jordan, 1999). Books are available on how to support grieving students with developmental disabilities (Forrester-Jones & Broadhurst, 2007; Helbert, 2013; Markell, 2005; Schonfeld & Quackenbush, 2010) as well as advice available on websites such as National Association of School Psychologists (2005).

However, teachers in this study did not access these resources. Training and available resources at the pre-service teacher education level is needed in order to take a proactive stance in grief response.

Grief education should not be a one-time occurrence and should be ongoing (Hospice Foundation of America, 2013). Including culture in grief training for teachers may help to increase awareness on different cultural practices (Schonfeld & Quakenbush, 2010). Surviving parents sometimes do not provide children with adequate grieving opportunities at home (Eppler, 2008; Lehman, Lang, Wortman & Sorensen, 1989). Researchers suggest encouraging surviving caregivers to include the child in mourning rituals such as funerals to facilitate appropriate grieving support at home (Schonfeld & Quackenbush, 2010; Sormanti & Ballan, 2010). However, there is little information on how these suggestions may contradict a families' own cultural grieving practices. As such, teachers are left to navigate these difficult situations without guidance. In this study, some children were disenfranchised grievers at home. For example, one student was not initially told his mother died. Another mother took down all pictures of the deceased father. Teachers in this study did not make suggestions to the parents on how to respond and were apprehensive about interfering with a "personal family matter." Such uneasiness highlights how communication about family decisions can be difficult. Teachers may benefit from guidance on how to make suggestions to families while also respecting their cultural grieving practices

Researchers and professionals generally agree that school mental health professionals and teachers must collaborate on how to meet the needs of grieving

students effectively (Cohen & Mannarino, 2011; Heath & Cole, 2012; Schonfeld & Quackenbush, 2010; Sormanti & Ballan, 2011). However, in this study, successful collaboration did not always occur and in only two cases were counselors seen as helpful. These two counselors had previous experience with students with ID. On the other hand, two teachers felt the school counselor was unwilling and/or unaware of how to help children with disabilities. Such mixed responses from school mental health professionals is not too surprising, as students with ID have received limited attention in the school psychology and school counselor literature. Only a few recommendations exist on the support of children with ID (e.g. Sormanti & Ballan, 2011; Stough & Baker, 1999; National Association of School Psychologists, 2002). Additionally, school counselor graduate programs rarely contain coursework on students with disabilities. Teachers, for their part, also need to be open to collaborate with school mental health professionals. One teacher in this study disregarded the counselor's advice and instead followed the advice of an outside mental health professional. To facilitate successful collaboration, school mental health professionals should be trained on the grieving needs of all children, including those with disabilities and teachers should "carefully consider" advice (Cohen & Mannarino, 2011).

Implications for practice

Acknowledging emotional impact

To prevent disenfranchised grief, teachers' emotional impact needs to be acknowledged and appropriately managed (Lowton & Higginson, 2003; Rowling, 2008; Spall & Jordan, 1999). Managing emotions can be incredibly hard for teachers

(Issenbarger & Zembylas, 2006; Jennings & Greenberg, 2009). One teacher in this study who felt she appropriately managed her emotions discussed how she found social support from colleagues, which is suggested as an effective coping strategy for teachers in grief situations (Rowling, 2008; Schonfeld & Quackenbush, 2010). Teachers may also benefit from ongoing forums where they voice their emotional impact (Rowling, 2008). For teachers in this study, the research interview process served as an avenue for teachers' feelings to be articulated and acknowledged. Teachers in a similar study also were reported to be as eager to discuss their feelings and experiences with death, but felt they needed permission from someone to do so (Blackburn, 1991).

Acknowledging emotional impact not only benefits teachers but also might facilitate students' healthy expressions of grief (Heath & Cole, 2012; Spall & Jordan, 1999). However, only one teacher in this study shared with her student that the death had affected her as well. Teachers in this study may have possibly helped their students by expressing and talking about their own feelings. Of course, teachers would have to judge the intensity of such expression (Spall & Jordan, 1999), but some evidence suggests that students with ID may possibly benefit from teachers' emotional modeling. Children with disabilities often need intervention, direct instruction, and modeling to build social and emotional skills (Fox & Lentini, 2006; Montie & Abery, 2011). These skills include recognizing their feelings, recognizing others' feelings, regulating emotions, and demonstrating empathy (Brusnahan & Gatti, 2011). Teachers should consider if displaying and modeling their grief may be appropriate and beneficial.

Demonstrations of teacher caring

Teachers described themselves as empathetic. Such emphasis on caring for students is not surprising. Teachers are recognized for their caring orientations (Noddings, 1992; O'Conner, 2008; Rowling, 2008) and love and caring are the most frequent positive emotions addressed in the teacher literature (Sutton & Wheatley, 2003). Noddings (1984) stressed that caring must go beyond feelings and consist of responsive action. Additionally, teachers often identify emotions as "key influences" on their interpretations of their actions (Emmer & Stough, 2001, p. 107). All teachers in this study believed their inherent nurturing qualities drove them to comfort grieving students. Teachers felt it was their job to assist children in all situations Researchers recommend the inclusion of the construct of caring in teacher education (Smith & Emigh, 2005). However, educational policy and teaching standards often ignore the role caring plays in the teaching profession (O'Conner, 2008). The recognition of teachers' caring action in the context of grieving is important. Cullinan (1990) found that

Teachers with the most empathy, and who see their role to include helping grieving students, perceived themselves as being more effective in counseling grieving students, while teachers who did not perceive themselves as helpful to grieving students also did not feel it was their role to help and did not know the right things to say (Cullinan, 1990, p.156). Addressing concepts of care with pre-service teachers may lead to supportive responses to student's emotional needs—including in times of grief. For practicing teachers, careful attention is needed to their stress levels especially in the emotionally charged context of grief. Issenbarger and Zembylas (2006) stress that caring

for students can be a positive experience for teachers but also that caring can be a negative experience and lead to burnout.

Limitations

This study had a number of limitations. First, only the perspectives of teachers were included. The perspectives of school counselors, other school employees, the surviving caregivers, and the children themselves may have contributed to richer understandings of how students were supported in their grief.

Secondly, although grounded theory does not require a minimal number of participants and category saturation should "supersede" a focus on the number of participants required (Charmaz, 2006) the results in this study are based on data from only five participants. Including more participants would have helped to further explore the properties of the categories.

Further limitations included a potential sample bias. Teachers sometimes chose not to support their grieving students (Cullinan 1990; Machon, et al., 1999; Papadatou et al., 2002); however, all teachers in this study were supportive of their grieving students. It is possible that teachers who did not react to grieving students or who perceived themselves as not helpful chose not to participate in this study. In addition, grief is a "deeply felt human experience" (Rowling, 1995). It is possible that some teachers chose not to participate because of the strong emotional nature of the subject.

Finally, this study only included interview data and not observational data. Observations would have allowed recording interactions between teachers and students,

as well as student grieving behaviors. Furthermore, observations would have provided an opportunity to examine contextual factors present in the special education classroom.

Conclusion

> There is a sacredness in tears. They are not the mark of weakness, but of power. They speak more eloquently than ten thousand tongues. They are the messengers of overwhelming grief, of deep contrition, and of unspeakable love.
>
> —Washington Irving

People with ID have been denied the human right to grieve, both historically and in present times. They have not always had someone to sit quietly by them, hug them, dry their tears, or say, "I am sorry for your loss." The children in this study clearly felt the loss of their mother or father. Sometimes they were able to articulate their grief but usually displayed it through their behavior. They were sad. They were angry. They sought comfort. They cried.

Students need to be supported in their grief. Teachers in this study responded compassionately to their students' emotional needs. Due to their teachers' caring actions, children in this study did not become disenfranchised grievers but instead were acknowledged grievers. Teachers continually affirmed their grief. Teachers provided them a safe outlet for openly displaying their profound loss. They carefully observed students and delivered supports based on their students' needs. Teachers understood that the limited verbal ability and cognitive functioning of their students' meant that they might manifest their grief behaviorally. Teachers watched. Teachers waited. Teachers listened. Teachers comforted. Teachers honored the sacredness of tears.

REFERENCES

Administration on Developmental Disabilities. (2000). *Developmental Disabilities Assistance and Bill of Rights Act of 2000*. Retrieved from the U.S. Department of Health and Human Services website: http://www.acf.hhs.gov/programs/add/ddact/DDACT2.html

American Association on Intellectual and Developmental Disabilities. (2010). *Intellectual disability: Definition, classification, and systems of supports.* (11th ed.), Washington, DC, AAIDD.

American Federation of Teachers and New York Life Foundation. (2012). *Grief in the classroom: Groundbreaking survey of educators shows overwhelming interest in helping grieving students-and strong demand for training, more support.* Retrieved from the American Federation of Teachers website: http://www.aft.org/pdfs/press/release_bereavement121012.pdf

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 2, 104 Stat. 328 (1991).

Avramidis, E. & Smith, B. (1999). An introduction to the major research paradigms and their methodological implications for special needs research. *Emotional and Behavioral Difficulties, 4*(3), 27-34.

Barrett, E. J., Ausbrooks, C. Y. B., & Martinez-Cosio, M. (2008). The school as a source of support for Katrina-evacuated youth. *Children Youth and Environments*, *18*(1), 202-235.

Bennett, P. L., & Dyehouse, C. (2005). Responding to the death of a pupil–reflections on one school's experience. *British Journal of Special Education*, *32*(1), 21-28.

Bernard, M. E. (2006). It's time we teach social-emotional competence as well as we teach academic competence. *Reading & Writing Quarterly*, *22*(2), 103-119.

Birks, M. & Mills, J (2011). *Grounded theory: A practical guide*. London: Sage.

Blacher, J., Baker, B. L., & Eisenhower, A. S. (2009). Student–teacher relationship stability across early school years for children with intellectual disability or typical development. *American Journal of Developmental Disabilities*, *114*(5), 332-339.

Blackburn, M. (1991). Bereaved children and their teachers. *Bereavement Care, 10*(2), 19-21.

Blackman, N. (2002). Grief and intellectual disability: A systematic approach. *Journal of Gerontological Social Work*, 38(1/2), 253-263. doi: 10.1300/J083v38n01_09

Bonell-Pascual, E., Huiline-Dickens, S., Hollins, S., Esterhuyzen, A., Sedgwick, P., Abdelnoor, A., & Hubert, J. (1999). Bereavement and grief in adults with learning disabilities: A follow-up study. *The British Journal of Psychiatry, 175*, 348-350.

Brickell, C. & Munir, K. (2008). Grief and its complications in individuals with intellectual disability. *Harvard Review of Psychiatry, 16*(1), 1-12. doi:10.1080/10673220801929786

Brusnahan, L. S., & Gatti, S. N. (2011). *Where Does Social-Emotional Well-Being Fit into the School Curriculum?*. Retrieved from: http://www.ici.umn.edu/products/impact/241/5.html

Cathcart, F. (1995). Death and people with learning disabilities: Interventions to support clients and carers. *The British Journal of Clinical Psychology*, 34, 165-175.

Cerel, J., Fristad, M., Verducci, J. Weller, R. & Weller, E. (2006). Childhood bereavement: Psychopathology in the 2 years post-parental death. *Journal of the American Academy of Child Adolescent Psychiatry, 45*(6), 681-690. doi:10.1097/01.chi.0000215327.58799.05

Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine*, *30*(11), 1161-1172.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.

Charmaz, K. (2011). Grounded theory methods in social justice research. In N.K. Denzin & Y.S. Lincoln (Eds.), *SAGE handbook of qualitative research* (4th ed., pp. 359-380). Thousand Oaks, CA: Sage Publications.

Chawla, L. (1998). Research methods to investigate significant life experiences: Review and recommendations. *Environmental Education Research, 4*(4), 383-397.

Christ, G.H. (2010). Children bereaved by the death of a parent. In C. A. Corr & D.E. Balk (Eds.), *Children's encounters with death, bereavement, and coping* (pp. 169-190). Springer Publishing Company.

Christ G.H., & Christ, T.W. (2006). Academic and behavioral reactions of children with disabilities to the loss of a firefighter father. *Review of Disability Studies, 2(3),* 68-77.

Christ, G. H., Siegel, K., & Christ, A. E. (2002). Adolescent grief. *JAMA: The Journal of the American Medical Association*, *288*(10), 1269-1278.

Clements, P. T., Focht-New, G., & Faulkner, M. J. (2004). Grief in the shadows: Exploring loss and bereavement in people with developmental disabilities. *Issues in Mental Health Nursing, 25*(8), 799-808.

Clute, M. (2010). Bereavement interventions for adults with intellectual disabilities: What works?. *Omega*, *61*(2), 163-177.

Cohen, J. A., & Mannarino, A. P. (2011). Supporting children with traumatic grief: What educators need to know. *School Psychology International*, *32*(2), 117-131.

Conboy-Hill S. (1992*).* Grief, loss and learning disabilities. In A. Waitman & S. Conboy Hill (eds.), *Psychotherapy and mental handicap, (pp.* 150–170). London: Sage.

Corbin, J. & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Los Angeles: Sage.

Corr, C.C. (1995). Children's understanding of death: Striving to understand death. In K. J. Doka (Ed.), *Children mourning, mourning children*. (pp. 3-16). Washington, D.C.: Hospice Foundation of America.

Council for Exceptional Children. (2009). *What every special educator must know: The international standards for the preparation and certification of special education teachers.* Retrieved from Council for Exceptional children website:

http://www.cec.sped.org/Content/NavigationMenu/ProfessionalDevelopment/ProfessionalStandards/What_Every_Special_Educator_Should_Know_6th_Ed_revised_2009.pdf

Creswell, J. (2007). *Qualitative inquiry & research design: choosing among five approaches*. Thousand Oaks, CA: Sage.

Cullinan, A. (1990). Teachers' death anxiety, ability to cope with death and perceived ability to aid bereaved students. *Death Studies, 14*, 147-160.

Curby, T. W., & Brock, L. L. (2013). Teachers' emotional consistency matters for preschool children. Research Brief. *National Center for Research on Early Childhood Education.*

Davis, L. (2006). Introduction. In L. Davis (Ed.), *The disability studies reader* (2nd ed., pp. xv-xvii). New York: Routhledge.

Denzin, N.K. & Lincoln, Y.S. (2011). Introduction: The discipline and practice of qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), *SAGE handbook of qualitative research* (4th ed., pp.1-43). Thousand Oaks, CA: Sage Publications.

Dodd, P., Dowling, S. & Hollins, S. (2005). A review of the emotional, psychiatric and behavioral responses to bereavement in people with intellectual disabilities. *Journal of Intellectual Disability Research, 49*(7), 537-543.

Dodd, P. & Guerin, S. (2009). Grief and bereavement in people with intellectual disabilities. *Current Opinions in Psychiatry, 22*, 442-446. doi: 10.1097/YCO.ob013e32832e2a08

Dodd, P., Guerin, S., McEvoy, S., Buckley, J. Tyrrell, J & Hillery, J. (2008). A study of complicated grief symptoms in people with intellectual disabilities. *Journal of Intellectual Disability Research, 52*(5), 415-425. doi: 10.1111/j.1365-2788.0143:x

Dodd, P., McEvoy, J., Guerin, S., McGovern, E., Smith, E., & Hillery, J. (2005). Attitudes to bereavement and intellectual disabilities in an Irish context. *Journal of Applied Research in Intellectual Disabilities, 18*(3), 237-243.

Doka, K. (2002). *Disenfranchised grief; new directions, challenges, and strategies for practice*. Champaign, IL: Research Press.

Doka, K. (2013, May 29). Grief and the DSM: A brief Q&A. The Huffington Post. Retrieved from:// http://www.huffingtonpost.com

Doka, K. & Helbert, K. (2013). Assisting grieving individuals on the autism spectrum. [Video podcast]. Retrieved from http://hospicefoundation.org

Dowdy, L. (2008). Children bereaved by parent or sibling death. *Psychiatry, 7*(6), 270-275.

Dowling, S., Hubert, J., White, S., & Hollins, S. (2006). Bereaved adults with intellectual disabilities: A combined randomized controlled trail and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research, 50*(4), 277-287.

Ducy, E.M. & Stough, L. M. (2011). Exploring the support role of special education teachers after Hurricane Ike: Children with significant disabilities. *Journal of Family Issues*, *32*(10), 1325-1345.

Durlak, J. A., Weissberg, R. P., Dymnicki, A. B., Taylor, R. D., & Schellinger, K. B. (2011). The impact of enhancing students' social and emotional learning: A meta-analysis of school-based universal interventions. *Child Development, 82*(1), 405-432. doi:10.1111/j.1467-8624.2010.01564.x

Dykens, E. M. (2000). Psychopathology in children with intellectual disability. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 41*(4), 407-417.

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2007). Early student–teacher relationships of children with and without intellectual disability: Contributions of behavioral, social, and self-regulatory competence. *Journal of School Psychology*, *45*(4), 363-383.

Eisenman, L. (2007). Social networks and careers of young adults with intellectual disabilities. *Intellectual and Developmental Disabilities*, 45(3), 199-208.

Emmer, E. T., & Stough, L. M. (2001). Classroom management: A critical part of educational psychology, with implications for teacher education. *Educational Psychologist*, *36*(2), 103-112.

Eppler, C. (2008). Exploring themes of resiliency in children after the death of a parent. *Professional School Counselor, 11*(3), 185-196.

Everatt, A. & Gale, I. (2004). Children with learning disabilities and bereavement: A review of the literature and its complications. *Educational and Child Psychology, 21*(3), 30-40.

Ferguson, D. (1993). Something a little out of the ordinary: Reflections on becoming an interpretivist researcher in special education. *Remedial and Special Education, 14*(4), pp. 35-43.

Ferguson, P., Ferguson, D., & Taylor, S. (1992). *Interpreting disability: A qualitative reader*. New York, NY: Teachers College Press.

Flanagan, J. (1954). The critical incident technique. *Psychological Bulletin, 51*(4), 327-358.

Forrester-Jones, R. & Broadhurst, S. (2007). *Autism and Loss*. London: Jessica Kinsley Publishers.

Fox, L., & Lentini, R. H. (2006). " You got it!" Teaching social and emotional skills. *Young Children*, *61*(6), 36-42.

Gaventa, B. (2011, December). End of life, grief and loss supports with people with significant disabilities. Presentation at the meeting of TASH, Atlanta.

Gentile, J. P., & Hubner, M. E. (2005). Bereavement in patients with dual diagnosis mental illness and mental retardation/developmental disabilities: Case reports. *Psychiatry (Edgmont)*, *2*(10), 56.

Gilrane-McGarry, U. & Taggart, L. (2007). An exploration of the support received by people with intellectual disabilities who have been bereaved. *Journal of Research in Nursing, 12*(2), 129-144. doi: 10.1177/1744987106075611

Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Guba, E. (1990). The alternative paradigm dialog. In E. Guba (Ed.), *The Paradigm Dialog*. Newbury Park, CA: Sage Publications.

Haine, R., Ayers, T., Sandler, I., & Wolchik, S. (2008). Evidence-based practices for parentally bereaved children and their families. *Professional Psychology: Research and Practice*, *39*(2), 113-121.

Harper, D. & Wadsworth, J. (1993). Grief in adults with mental retardation: Preliminary findings. *Research in Developmental Disabilities, 14*, 313-330. doi: 0891-4222/93

Healy-Romanello, M. (1993). The invisible griever: Support groups for bereaved children. In J. Zins & M. Elias (Eds.), *Promoting student success through group interventions*. (pp. 67-89). Binghamton, NY: Haworth Press Inc.

Heath, M. A., & Cole, B. V. (2012). Strengthening classroom emotional support for children following a family member's death. *School Psychology International*, *33*(3), 243-262.

Heath, M.A., Nickerson, A., Annandale, N., Kemple, A. & Dean, B. (2009). Strengthening cultural sensitivity in children's disaster mental health services. *School Psychology International, 30*(4), 347-373.

Helbert, *K. (2013). Finding your own way to grieve: A creative activity workbook for kids and teens on the autism spectrum*. London: Jessica Kingsley Publishers.

Hellings, J. (1999). Psychopharmacology of mood disorders in persons with mental retardation and autism. *Mental Retardation and Developmental Disabilities 5*, 270-278.

Hollins, S. & Esterhuyzen, A. (1997). Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry, 170*(6), 497-501.

Hoover, J., H Markell, M., & Wagner P. (2005). Death and grief as experienced by adults with developmental disabilities: Initial explorations. *Omega, 50*(3), 181-196.

Hope, R. & Hodge, D. (2006). Factors affecting children's adjustment to the death of a parent: The social work professional's viewpoint, *Child and Adolescent Social Work*, 23(1), 107-128. doi: 10.1007/s10560-006-0045-x

Hospice Foundation of America. (2013). *Supporting individuals with intellectual and developmental disabilities through life-ending illness, grief and loss* [video webcast]. Retrieved from http://www.hospicefoundation.org

Huges, J. & Kwok, O. (2006). Classroom engagement mediates the effect of teacher-student support on elementary students' peer acceptance: A prospective analysis. *Journal of School Psychology, 43*, 465-480. doi: 10.1016/j.jsp.2005.10.001

Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Isenbarger, L., & Zembylas, M. (2006). The emotional labour of caring in teaching. *Teaching and Teacher Education*, *22*(1), 120-134.

Jacob, E. (1990). Alternative approaches for studying naturally occurring human behavior and though in social education research. *The Journal of Special Education, 24*(2) 195-211.

Jennings, P. A., & Greenberg, M. T. (2009). The prosocial classroom: Teacher social and emotional competence in relation to student and classroom outcomes. *Review of Educational Research*, *79*(1), 491-525.

Kauffman, J. (2005). *Guidebook on helping persons with mental retardation mourn*. New York: Baywood Publishing.

Lavin, C. (2002). Disenfranchised grief and individuals with developmentally disabilities. In K. Doka. (Ed.), *Disenfranchised grief: recognizing hidden sorrow* (pp. 229-237). Massachusetts: Lexington Press.

Lehman, D. R., Lang, E. L., Wortman, C. B., & Sorenson, S. B. (1989). Long-term effects of sudden bereavement: Marital and parent-child relationships and children's reactions. *Journal of Family Psychology*, *2*(3), 344.

Liew, J. & McTigue, E. (2009). Educating the whole child: The role of social and emotional development in achievement and school success. In L. E. Kattington (Ed.), *Handbook of curriculum development* (pp. 465-478). Hauppauge, NY: Nova Sciences Publishers, Inc.

Lincoln, Y.S. (1995). Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry, 1*(3), 275-289.

Lincoln, Y.S. & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Lincoln, Y.S., Lynham, S. & Guba, E. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N.K. Denzin & Y.S. Lincoln (Eds.), *SAGE handbook of qualitative research* (4th ed.). Thousand Oaks, CA: Sage Publications.

Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York, NY: New York University Press.

Lipe –Goodson, P. & Goebel, B. (1983). Perception of age and death in mentally retarded adults. *Mental Retardation*, 21(2), 68-75

Lowton, K., & Higginson, I. J. (2003). Managing bereavement in the classroom: A conspiracy of silence? *Death Studies, 27*(8), 717.

Luckasson, R. et al. (2002). Mental retardation: Definition, classification, and systems of supports (10th ed.). Washington, DC: American Association on Mental Retardation.

MacHale, R., McEvoy, J., & Tierney, E. (2009). Caregiver perceptions of the understanding of death and need for bereavement support in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 22*(6), 574-581.

Machon, M., Goldberg, R., & Washington, S. (1999). Discussing death in the classroom: Beliefs and experiences of educators and education students. *Omega*, 39(2), 99-121.

Markell, M. A. (2005). *Helping people with developmental disabilities mourn: Practical rituals for caregivers*. Fort Collins, CO: Companion Press.

Markell, M. & Hoover, J. (2010). Children with developmental disabilities, death, and grief. In C. Carr & D. Balk. (Eds.), *Children's encounters with death, bereavement, and coping* (pp. 395-412). New York: Springer Publishing Company.

Matthews, B. & Matthews, B. (2005). Narrative therapy: Potential uses for people with Intellectual Disability. *International Journal of Disability, Community & Rehabilitation, 4(1)*.

McDonnell, J., Hardman, M., & McDonnell, A. (2003). *An introduction to persons with moderate to severe disabilities: Educational and social issues*. Boston: Pearson.

McEvoy, J., MacHale, R., & Tierney, E. (2012). Concept of death and perceptions of bereavement in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(2), 191-203. doi:10.1111/j.1365-2788.2011.01456.x

McEvoy, J. Reid, Y. & Guerin, S. (2002). Emotion recognition and concept of death in people with learning disabilities. *The British Journal of Developmental Disabilities*, 48, 83-89.

McEvoy, J. & Smith, E. (2005). Families perceptions of the grieving process and concept of death in individuals with intellectual disabilities. *The British Journal of Developmental Disabilities*, 51(1), 17-25.

McGarry, U.G. & Taggart, L. (2007). An exploration of the support received by people with intellectual disabilities who have been bereaved. *Journal of Research in Nursing, 12*, 129-144. doi: 10.1177/1744987106075611

McGovern, M. & Barry, M. (2000). Death education: Knowledge, attitudes, and perspectives of Irish parents and teachers. *Death Studies, 24*, 325-333.

McIntyre, L. L., Blacher, J., & Baker, B. L. (2006). The transition to school: Adaptation in young children with and without intellectual disability. *Journal of Intellectual Disability Research*, *50*(5), 349-361.

Milsom, A. & Akos, P. (2003). Preparing school counselors to work with students with disabilities. *Counselor Education and Supervision*, *43*(2), 86-95.

Montie, J. & Abery, B. (2011). Social and emotional well-being of children and youth with disabilities. *Impact*, 24(1), 2-3.

Murray, C. (2002). Supportive teacher-student relationships: Promoting the social and emotional health of early adolescents with high incidence disabilities. *Childhood Education, 78*, 285-290.

Murray, C., & Greenberg, M. T. (2001). Relationships with teachers and bonds with school: Social emotional adjustment correlates for children with and without disabilities. *Psychology in the Schools*, *38*(1), 25-41.

Murray, G.C., McKenzie, K., & Quigley, A. (2000). An examination of the knowledge and understanding of health and social care staff about the grieving process in individuals with learning disability. *Journal of Intellectual Disabilities*, 4(77), 77-90.

National Association of School Psychologists. (2010). *Death and grief: Supporting children and youth*. Retrieved from National Association of School Psychologists website: http://www.nasponline.org/resources/crisis_safety/deathgrief.pdf

Nisbet, J. (1992). *Natural supports in school, at work, and in the community for people with severe disabilities*. Baltimore, Maryland: Brookes Publishing.

Noddings, N. (1984). *Caring: A feminine approach to ethics and moral education*. Berkeley: University of California Press.

Noddings, N. (1992). *The challenge to care in schoo*ls. New York: Teachers College Press.

O'Connor, C. (2002). Grief and loss: Perspectives for school personnel. *Australian Journal of Guidance and Counseling, 12*(1), 97

O'Connor, K. E. (2008). "You choose to care": Teachers, emotions and professional identity. *Teaching and Teacher Education*, *24*(1), 117-126.

Olsson, M. B., & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well‐being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, *52*(12), 1102-1113.

Oswin, M. (1991) *Am I allowed to cry? A study of bereavement amongst people who have learning difficulties*. London: Souvenir Press.

Papadatou, D., Metallinou, O., Hatzichristou, C. & Pavlidi, L. (2002). Supporting the bereaved child: Teacher's perceptions and experiences in Greece. *Mortality, 7*(3), 324-339.

Polkinghorne, D.(2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology, 52*(2), 137-145.

Raji, O., Hollins, S., & Drinnan, A. (2003). How far are people with learning disabilities involved in funeral rites. *British Journal of Learning Disabilities*, 31, 42-45.

Ray, R. (1978). The mentally handicapped child's reaction to bereavement. *Health Visitor, 51*(9), 333-334.

Read, S. & Elliot, D. (2003). Death and learning disability: A vulnerability perspective. *The Journal of Adult Protection*, 5(1), 5-14.

Read, S., & Elliot, D. (2007). Exploring a continuum of support for bereaved people with intellectual disabilities. *Journal of Intellectual Disabilities, 11*(2), 167.

Read, S. & Papkosta-Harvey. (2004). Using workshops on loss for adults with learning disabilities: A second story. *Journal of Learning Disabilities,* 8, 191-208. doi: 10.1177/1469004704042707.

Reid, J. K., & Dixon, W. A. (1999). Teacher attitudes on coping with grief in the public school classroom. *Psychology in the Schools, 36*(3), 219.

Riessman, C. K. (Ed.). (1993). *Narrative analysis* (Vol. 30). Sage.

Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, *55*(2), 139-150.

Rowling, L. (1995). The disenfranchised grief of teachers. *Omega, 31*(4), 317-329.

Rowling, L. (1999): Being in, being out, being with: Affect and the role of the qualitative researcher in loss and grief research, *Mortality, 4*(2), 167-181.

Rowling, L. (2008). Linking spirituality, school communities, grief and well-being. *International Journal of Children's Spirituality*, *13*(4), 241-251.

Ryan, K. & Dodd, P. (2011). Communication contexts about illness, death and dying for people with intellectual disabilities and life-limiting illness. *Palliative and Supportive Care*, (9), 201-208.

Saldana, J. (2012). *The coding manual for qualitative researchers*. London: Sage.

Schalock, R., Luckasson, R., & Shrogren, K., Borthwick-Duffy, S., Bradley, V., Buntinx, D., …Yeager, M. (2007). The renaming of mental retardation: understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities, 45*(2), 116-124.

Schonfeld, D. & Quackenbush, M. (2010). *The grieving student: A teacher's guide*. Baltimore MD: Brooks publishing.

Schuurman, D.L & Decristofaro, J. (2010). Children and traumatic deaths. In C. Carr & D. Balk (Eds.), *Children's encounters with death bereavement and coping*. New York: Springer.

Sheppard, L. (2006). Growing pains: a personal development program for students with intellectual and developmental disabilities in a specialist school. *Journal of Intellectual Disabilities*, 10(2), 121-142.

Siegel, K., Mesagno, F. P., & Christ, G. (1990). A prevention program for bereaved children. *American Journal of Orthopsychiatry, 60*(2), 168-175. doi:10.1037/h0079187

Siegler, R., Deloache,J., & Eisenberg, N. (2006). *How children develop*. New York: Worth publishers.

Smart, J. (2009). *Disability, society & the individual*. Austin, Pro Ed.

Smith, R. L., & Emigh, L. (2005). A model for defining the construct of caring in teacher education. In R.L Smith, D. Skarbek & J. Hurst (Eds.), *The passion of teaching: Dispositions in the schools*, 27-40.

Social Security Administration. (2000). *Intermediate Assumptions of the 2000 Trustees Report.* Washington, DC: Office of the Chief Actuary of the Social Security Administration.

Sormanti, M., & Ballan, M. (2011). Strengthening grief support for children with developmental disabilities. *School Psychology International, 32*(2), 179.

Spall, B. & Jordan, G. (1999). Teachers' perspectives on working with children experiencing loss. *Pastoral Care in Education, 17*(3), 3-7.

Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities*, *18*(4), 228-237.

Storm, W. (1990). Differential diagnosis and treatment of depressive features in Down's syndrome: A case illustration. *Research in Developmental Disorders, 11*, 131-137.

Stough, L. M., & Baker, L. (1999). Identifying Depression in Students with Mental Retardation. *Teaching Exceptional Children*, *31*(4), 62-66.

Sturmey, P. Laud, R., Cooper, C., Matson, J. & Fodsatd, J. (2010). Challenging behaviors should not be considered depressive equivalents in individuals with intellectual disabilities. *Research in Developmental Disabilities, 31*, 1002-1007.

Summers, S.J. (2003). Psychological intervention for people with learning disabilities who have experienced bereavement" a case study illustration. *British Journal of Learning Disabilities*, 31, 37-41.

Sutton, R. E., & Wheatley, K. F. (2003). Teachers' emotions and teaching: A review of the literature and directions for future research. *Educational Psychology Review*, *15*(4), 327-358.

Thompson, J.R., Bradley, V.J., Buntinx,W., Schalock, R.L., Shogren, K., Snell, M.E., ….Yeager, M.H. (*2009*). Conceptualizing supports and the support needs of people

with intellectual disability. *Intellectual and Developmental Disabi*lities, 47 (2), 135-146.

Tonge, B. & Einfeld, S. (2003). Psychopathology and intellectual disability: The Australian child to adult longitudinal study. *International Review of Research on Mental Retardation,2*, 1-91. doi: 0074-7750/03

Trublood, S. (2009). *The grief process in children with cognitive/intellectual disabilities: Developing steps toward a better understanding*. (Doctoral dissertation). Available from ProQuest Dissertations and Theses database. (UMI no. 3348804).

Tsiouris, J., Mann, R., Patti, P. & Sturmey, P. (2004). Symptoms of depression and challenging behaviors in people with intellectual disability: A Bayesian analysis. *Journal of Intellectual and Developmental Disability, 29*(10), 65-69. 1080/13668250410001662856.

United Nations. Convention on the rights of persons with disabilities. Retrieved from http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

United States Department of Education. (2010). Twenty-ninth annual report to congress on the implementation of the individuals with disabilities education act. Retrieved from http://www2.ed.gov/about/reports/annual/osep/2007/parts-b-c/index.html

Worden, W.J. (2001). *Children and grief: when a parent dies*. New York: Guilford Press.

Worden, W.J. & Silverman, P. (1996). Parental death and the adjustment of school-age children. *Omega, 33*(2), 91-102.