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Grief and Loss: Supportive Stories for Children with Autism

Danielle Kirsten Lewis

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Educational Specialist

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ABSTRACT

Grief and Loss: Supportive Stories for Children with Autism

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The effect of grief on children with autism is an under-researched area of study. Until recently, it was often assumed that individuals with autism did not have the capacity to grieve. Because of deficits in social skills, interpersonal relationships, and language and communication skills, these individuals are especially vulnerable as they navigate the challenging social and emotional aspects associated with bereavement and grief. Bibliotherapy is offered as supportive strategy for bereaved children, providing them with structure and guidance through a time of uncertainty and change. This study is based on two focus groups, one with teachers of children with autism ($n = 8$) and one with parents of children with autism ($n = 5$). Researchers focused on the purpose of supporting children in grades K–3 through the death of a loved one or pet.

Focus group participants discussed their perceptions of how this special population of children grieves and how to support them following a significant loss, such as the death of a loved one or beloved pet. After reviewing selected resources (supportive stories), participants offered their impressions regarding the appropriateness and potential effectiveness of the resources. Focus groups were audiotaped and later transcribed. Transcriptions were carefully reviewed and discussed by two individuals to identify and summarize themes. After summarizing the information from the transcriptions and organizing the information, one individual served as a quality check, to verify the accuracy of the findings. Additionally, a member check was offered to participants to assure accuracy in the typed transcripts (for intended meaning and content). The following information and recommendations are presented based on the input from the focus group participants.

Three overarching themes were identified in this study, as well as some specific cautions and warnings. Participants emphasized the importance of individualization in the selection of stories for children with autism. Readers should be aware of the child's specific needs and circumstances when they are selecting a story. The stories should be developmentally appropriate and should help support the child through the specific type of death or loss that has occurred. Participants also discussed the importance of selecting books that are concrete, simple, and structured. As children with autism often have difficulty with abstract concepts, the topic of death and loss should be approached in a concrete and literal way. Books that present information in this manner will best help the child to understand their experience.

Practitioners who use bibliotherapy to support children with autism through a death or loss should be sensitive to family beliefs. Open communication should be used with the child's family in order to select a book that best fits that child's needs. Children with autism will also benefit from stories that help to normalize their experience and that help them to understand the emotions that they or their family and friends may experience. Future research is recommended to further explore the use of supportive stories in aiding a child with autism through the grief and

loss process. It is important to examine how children with autism respond to the selected stories and to understand how effective the stories are in their coping and understanding process.

Keywords: grief, death, loss, children with autism, bibliotherapy

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CHAPTER 1

Introduction

Every living organism has a lifespan. Death may occur at any point across the projected lifespan. For some individuals, due to illness or injuries that cannot be cured or healed, death occurs much earlier than would be anticipated (Helbert, 2013). When faced with the death of a loved one, individuals experience a variety of strong emotions associated with grief. These strong feelings are an inevitable part of the human experience. Although there are some common emotions associated with grief (Kübler-Ross, 1969; Wolfelt, 2002; Worden, 2008), each person's grief is unique (Wharff, 2015).

Childhood Grief

Loss is defined by Chavis and Weisberger (2003) as the absence of someone or something of importance within an individual's universe. The emotional response that follows loss is known as grief (Bartolini, 2015; Stroebe, Stroebe, & Hansson, 1993).

The manner in which children grieve differs from how adults may grieve. For children, this may be their first encounter with loss and subsequent grief. They may lack the experience and ability to understand death, to clearly communicate their questions, and to express their emotions. Their limited life experiences may not prepare them for coping with grief in constructive ways (Berns, 2004).

Grief does not follow a specific trajectory across the life span (Wolfelt, 2002). Emotions associated with the death of a loved one may come and go as children enter new developmental stages and as their life experiences bring increased understanding and context to their grief (Wolfelt, 2002). With maturity, their understanding of death and their perceptions of loss change.

Grief is manifested in children's emotions and behaviors (Himebauch, Arnold, & May, 2008). Children may experience a variety of grief reactions in four major areas of functioning: behavior, feelings, thinking, and relationships (for detailed descriptions of these grief reactions, see Heath et al., 2008, p. 261).

Loss is omnipresent. Loss is no respecter of persons. Regardless of our gender, race, religion, class, or any characteristics, we all face death and loss (Bartolini, 2015). Despite this fact, minimal research has investigated the effects of grief on individuals with cognitive or developmental disabilities (Sormanti & Ballan, 2011). Until recently, it was assumed that those with cognitive disabilities were incapable of grieving. Contrary to this belief, individuals of all developmental levels are capable of grief, regardless of their ability to cognitively understand the details about death and loss (Bartolini, 2015; Brickell & Munir, 2008; McCoyd & Walter, 2016).

Grief and Children with Autism

Although the experience of loss for children with autism is somewhat similar to that of their typically developing peers (Helbert, 2013), children with autism generally have certain characteristics that increase their vulnerability following loss. In particular, understanding and regulating emotions are more challenging for children with autism. These social and emotional deficits make it difficult for them to navigate through their grief and to respond appropriately to others' emotions (Bartolini, 2015).

Sudden changes in routines are difficult for individuals with autism (American Psychiatric Association, 2013). Death and loss are often accompanied with significant changes in routine. For children with autism, changes in routine are unsettling and highly stressful. Rather than focusing on the loss, children may focus primarily on the need for structure. They may become demanding and volatile. Difficulties in communication and socialization may cause

children with autism to exhibit these problem behaviors when their routines are interrupted or when unexpected schedule changes occur (Banda, Grimett, & Hart, 2009).

Communication problems are a common experience for children with autism (Moseley et al., 2015). When communicating with these children, it is best to use concrete rather than abstract language, as individuals with autism often have difficulty comprehending language involving metaphors, double meanings, or implied meanings (Mesibov, Shea, & Schopler, 2005). Metaphors and euphemisms are often used when discussing death and loss. Instead of saying that someone has died, adults might explain that the deceased individual “went to heaven.” For a literal thinker, this could be perceived as a person leaving and then coming back at some point, much like going to the store or going on a vacation. Children expect loved ones to return home.

Communication difficulties and social awareness difficulties also add to the complication of grief for children with autism (Ozonoff, Dawson, & McPartland, 2002). If parents or teachers overlook signs of grief, children may feel isolated and disconnected from their peers and family (Bartolini, 2015). It is important to remember that children with autism are individuals who may react differently to situations and that generally effective approaches that may work with typically functioning children may not work with children with autism (Koehler, 2016).

Supportive Resources

Bibliotherapy has been used to support children through the grief and loss process (Berns, 2004; Heath, Sheen, Leavy, Young, & Money, 2005). Stories can help individuals to navigate the painful feelings and memories that they might experience, allowing them to better understand their emotions and learn ways to cope with their experience (Haine, Ayers, Sandler, & Wolchik, 2008; Heath et al., 2005). For children, stories can additionally help them to understand that they are not alone in their grief, and they can help to normalize the child’s experience (Haine et al.,

2008; Malchiodi & Ginns-Gruenberg, 2008). When discussing death and loss with children, they often benefit from more concrete language, and it is best to avoid selecting stories that have too many euphemisms. It is also beneficial to understand each child's specific circumstances in order to select books that will be the most beneficial for that individual child (Malchiodi & Ginns-Gruenberg, 2008). Prior to reading the supportive story to the child, it is important for the reader to preview the book in order to make sure that it will be appropriate and beneficial for that individual child.

To address the social-emotional needs of a child with autism, it is important to provide the child with information about what the death means (Forrester-Jones & Broadhurst, 2007). Storytelling has been used as a therapeutic strategy for children with autism, and it can be personalized to each specific child, in order to help them learn how to model appropriate social behaviors. The perceptions and needs of the child should be taken into account, allowing the story to be made more relatable to the child (Del Valle, McEachern, & Chambers, 2001). Over the years, books have been made specifically to help children through a variety of losses, including death and dying (Gray, 2003).

CHAPTER 2

Literature Review

Each of us will experience the death of a loved one or the loss of an important relationship. We will each experience the grief associated with death and loss. Death and loss are inevitable parts of life. Although children may not show grief in the exact way that adults show their grief, children have similar reactions to loss (Long, 2005; Vida & Grizenko, 1989).

The timing of death is difficult to predict. It is not possible to specifically identify when someone will die, even if we know that they are in the process of dying. A person might have the knowledge that someone will die from illness or injury, but they are not able to predict the exact moment of death. Their feelings can be difficult to understand and questions may arise that the person has a hard time putting into words. The topic of death can make some people uncomfortable and they may not like to think or talk about it. It is okay for a person to feel afraid, worried, uncomfortable, or confused when someone that they care about and love has died (Helbert, 2013).

The emotional and psychological effects of grief and loss were relatively unknown before the 1960s (Forrester-Jones & Broadhurst, 2007). Prior to the 1970's, parents often wondered whether or not they should inform children of a death or let them be involved in death related rituals (Gray, 2003).

Children's Grief

The manner in which people approach death, dying, and grief are all shaped by both familial and cultural expectations (Lipsky, 2013). Various factors can affect the way a child reacts to loss, including their age, personality, gender, the closeness of the relationship with the deceased person, and whether or not the loss was sudden or anticipated (Long, 2005). Due to

limited life experiences, children might not be prepared for coping with grief in constructive ways on their own (Berns, 2004). Children manifest grief through their emotions and behaviors (Himebauch et al., 2008). Common reactions and emotions that children may experience include sadness, anger, guilt, anxiety, shame, acceptance, and relief (Heath et al., 2008; Mitchell et al., 2006). Bereaved children also have an increased risk for developing diverse psychological and behavioral health problems, which may include depression, anxiety, posttraumatic stress reactions, substance abuse, conduct disorder, and functional impairment (Griese, Burns, Farro, Silvern, & Talmi, 2017).

Death can be extremely confusing for children, especially those between the ages of three to seven (Gray, 2003). Following a death, families often experience changes that they might not be adequately prepared for, and these new stressors can be destabilizing for a child. Children often benefit from reestablishment of this sense of security through effective family, professional, and community-based supports (Griese et al., 2017). Confusion can be eased by thoughtful guidance from caring adults. When discussing death with children of this age range, adults should try to best describe their own thoughts and feelings, which will help the child learn that it is okay to express feelings, quite possibly negative, thoughts and feelings. The language used in these discussions should be clear and honest, but aimed at the child's current level of understanding (Gray, 2003).

Some typical behaviors, as methods of coping with the loss, include substitution, aggression, and withdrawal. Following the loss, the child may try to replace the lost person with a surrogate, becoming strongly and quickly attached to this person. The child may begin acting out in ways that are not typical for their personality; or they might lose interest in activities that

they were previously invested in and they may become apathetic and socially isolated (Long, 2005).

Childhood Grief and Bibliotherapy

As research investigates specific details about childhood grief, it becomes more apparent that resources are needed to help children through this process. The use of bibliotherapy can be beneficial for children experiencing grief (Berns, 2004). Throughout time, people have connected with characters in stories and with the themes within the story itself. This proclivity has led to the usage of books in therapy, as the right story can provide an example to model behavior after. Individuals are able to learn methods of coping for real life situations. For those who have gone through a traumatic event, this can help them navigate through painful feelings and memories. For a child, books can help them understand that they are not alone in their grief and can provide developmentally appropriate explanations to questions they may have (Malchiodi & Ginns-Gruenberg, 2008). When selecting stories pertaining to grief for children, it is best to avoid books that have euphemisms, such as “passed away.” Using these bibliotherapy and specific story making techniques with children can be an effective way to help children process traumatic events. It is helpful to understand the circumstances of the event and the developmental level of the child in order to select books that will be the most helpful (Malchiodi & Ginns-Gruenberg, 2008).

When using bibliotherapy effectively with children experiencing grief, it is important to preview the books prior to the child reading them, to ensure that the book is appropriate and helpful, and that it matches the child’s developmental needs. Books and stories should be an appropriate level for the child developmentally, and should match the child’s vocabulary and reading skills. The relevance of the book or story to the child’s situation is also an important

consideration. When the child is presented with the book, they should be provided with an explanation as to how the book pertains to their situation. The selected books and stories should gently reassure and comfort the child. They can offer the child hope and confidence through characters and themes. Children are easily able to identify with others who have experienced similar events, and being able to identify with others can also help them to have more confidence. It is ideal for the books and stories to offer both coping and self-soothing strategies (Malchiodi & Ginns-Gruenberg, 2008).

Children with Autism

In 1943, the child psychiatrist Leo Kanner, used the term *autism* as a descriptor of behavior. This term stems from the Greek word *autos*, which means “self” (Wing, 1997). Autism was used as a general diagnosis before it was recognized that there are different types and different levels of severity within the broader condition of autism. Instead of being a narrowly defined condition, autism contains a spectrum (Ozonoff et al., 2002). Autism is characterized by delayed or abnormal developments in social, behavioral, cognitive, communication, and potentially motor skills. Restricted, repetitive patterns of behavior and interests may appear in repetitive motor movements, an insistence on the maintenance of routines or ritualized patterns of behavior, restricted and fixated interests, or hyper- or hypo-reactivity to sensory input (American Psychiatric Association, 2013).

Routines. Individuals with autism tend to be very routine-oriented. They might have an inflexible adherence to these routines or to ritualized patterns of both nonverbal and verbal behaviors (American Psychiatric Association, 2013). They often benefit from having advanced preparation for changes that may disrupt their routines. It is helpful for them to understand what to expect in different situations and social interactions, as sudden or unknown situations can be

difficult for them to handle (Wharff, 2015). Children with autism often struggle with transitions. This can lead to a variety of problem behaviors, which can include aggression, tantrum, and noncompliance. The difficulties in communication and socialization that children with autism face can contribute to these problem behaviors when routine or unexpected schedule changes occur (Banda et al., 2009).

Communication difficulties. Individuals with autism are often overly focused, which means that they struggle to listen and look at the same time. This can cause them to miss information and to have a harder time grasping the full picture of an event or interaction, which can make the world feel confusing and unpredictable. For someone with autism, this can mean that they misinterpret situations and those around them, leading to feelings of frustration, anxiety, and anger (Forrester-Jones & Broadhurst, 2007, p. 22).

Individuals with high-functioning autism often experience difficulties with social interactions, due to deficits in social-emotional reciprocity, nonverbal communicative behaviors in social interactions, and in the development, maintenance, and understanding of relationships. They might have unusual approaches to social interactions or difficulty engaging in back-and-forth conversations, sharing interests with others, or with initiating and responding to social interactions. Other difficulties may arise in the ability to make eye contact with others or in the understanding and use of gestures (American Psychiatric Association, 2013). For some children, if others approach them, they will engage in conversation, but they are not as likely to go out of their way to begin a conversation. Other children with high-functioning autism have a greater interest in others and seek out involvement. However, due to a limited knowledge of how to behave in social situations, the ability to communicate successfully with others can be limited. By not following what are perceived as general rules for social interaction, they might come

across as rude or disinterested. For an individual with high-functioning autism, looking at the person they are talking to or smiling during conversation to show that they are listening might not be things that come naturally. They can accidentally violate social conventions about when and how to share opinions and when and what questions are appropriate to ask.

For children with autism, the ability to understand another person's feelings or another's point of view is often delayed or may never develop (Ozonoff et al., 2002). In individuals without autism, empathy begins emerging at a very young age. A toddler may show interest in how another is feeling or a baby may begin crying when another baby cries. For children with high-functioning autism, it is difficult to understand one's own emotions, as well as another's feelings. If the child notices the feelings of another, they may misunderstand what these feelings mean. These difficulties with relating to other children's emotionally states can cause children with autism to feel lonely and socially isolated (Bauminger & Kasari, 2000; Ozonoff et al., 2002).

One common and noticeable feature of autism is the communication difficulty that the person faces. *Delayed echolalia* is when the child memorizes things that they have heard either from people or from dialogues and phrases used in media and books. The child may repeat the phrase when it has been associated with something else, such as a type of food or article of clothing, even though the association does not make sense to others. Another type of communication problem that children with autism might experience is called *literal interpretation*. The child is not able to recognize the meaning of a person's words when there is a disparity between a statement and the context in which it is used. For example, the child may have a hard time recognizing sarcasm. The way in which a child with autism speaks is also considered a form of communication problem. Their vocal level might not match what would be

appropriate in certain situations or their speech may display an unusual rhythm. Despite these differences being easily noticed by those around them, children with autism are often unaware of the difference themselves (Ozonoff et al., 2002).

When communicating with a person with autism, it is helpful to remember not to expect a response to questions or comments immediately, to speak in the most literal and concrete manner possible, and to provide information and communication tools (Faherty, 2008). Children with autism often have difficulties with understanding the emotions of others as well as their own emotions. When those around them are hurt or sad, they have trouble recognizing this and knowing when or how to offer comfort (Ozonoff et al., 2002).

Behaviors. Some behaviors displayed by children with autism are also more noticeable to those around them. The child's interests may be very focused and repeating the same activities over and over again does not become boring. Which many children will have specific interests and pastimes that they particularly enjoy, a child with autism will often focus on solely that interest and forego attention to anything else. This intense focus, and often the topic of the interest itself, can lead to social isolation from peers, as the other children find their behavior peculiar. Despite devoting so much time and attention to these interests, the child may not have good commonsense knowledge about the topic. They might demonstrate a great aptitude for knowing facts about the topic, but they can have difficulty with understanding more abstract concepts. Likewise, when a rule is given to a child with autism, they may have trouble generalizing the rule to other situations. When a problem arises, the child may want to use the exact same methods to resolve the problem every time and will feel frustrated with they do not get the desired outcome or when potential new solutions are introduced (Ozonoff et al., 2002).

Because parents and teachers need effective ways to manage children's behavior, certain strategies have proven beneficial in addressing challenging behaviors associated with autism. Social scripts are particularly helpful. A social script is essentially written prompts or guidelines for how to behave and what to say in certain social situations. Most people have social scripts for various situations, such as what they will say when they order food or when they answer the telephone. Children with autism most often will need assistance in creating social scripts, because this type of communication does not come naturally to them. Providing them with a script and then practicing it can be beneficial in preparing them for handling different situations (Ozonoff et al., 2002).

Another useful tool for children with autism are Social Stories™. These are written stories that provide information about a social situation, and they are less directive than social scripts. Carol Gray developed Social Stories™, and they help the child reader to learn critical information about the situation. They highlight what social cues to look for, why other people are acting a certain way, and they explain why it is important for a child to do or say what they are told to do or say. By providing rationale as to why they should behave a certain way, the child is able to better understand why the social behavior is important. Social Stories™ should contain more informative statements than directive statements. These stories provide individuals with autism with access to social information and an understanding of how to accurately interpret social cues (Gray, 1993). It is more important to explain the social cues and reasons for behaviors to the child than it is to tell them exactly what to do and say. Directives included in stories should be positive and include “do this” statements rather than “don't do this” statements (Gray, 1993; Ozonoff et al., 2002).

Grief and Children with Autism

While it was not until the 1960's that society began to take into account the effects of grief in general, it has taken even more time for the recognition of how grief affects those with autism (Forrester-Jones & Broadhurst, 2007; Long, 2005). Until recently, it was thought that people with ASD were not in a position to truly comprehend death, so explaining the situation and the concepts associated with it did not seem necessary (Faherty, 2008). These individuals do grieve, and they have the right and the capacity to do so (*Loss and Bereavement in Autism*, 2010). Although they similarly experience grief, coping with a death or loss can be more difficult for a person with autism. Death often means change, it very emotionally charged, and is something that is abstract and intangible (*Coping with Death*, n.d.).

More recent research indicates that those with autism truly do grieve (Bartolini, 2015). However, there is still much uncertainty about how to help guide a child with autism through the death or illness of their loved ones. Caregivers can feel overwhelmed by the reactions they already see from children with autism over what are seen as smaller day-to-day losses, causing them to worry about the reactions they might due to greater losses (Gray, 2003).

Death is a struggle that most people encounter at some point throughout their life, and it is a more abstract and non-tangible aspect of life. This is often troubling to those with autism (Faherty, 2008). There are expectations and unwritten rules in western culture about the death experience. Expectations are further affected by religious and environmental upbringings and can lead to sensory, cognitive, and social challenge for a child with autism (Lipsky, 2013). As grief in individuals with disabilities has not been thoroughly researched, these individuals will not have had access to adequate forms of support. They are often excluded from various loss related rituals, such as funerals. These individuals are often not prepared for losses, are not

given support to help them understand their emotions, and are sometimes not told about the loss. In recent years, the importance of providing support through the grief process for children with disabilities has been recognized (Gilrane-McGarry & Taggart, 2012).

When supporting a child with autism through bereavement, it is important to remember that they are individuals and that not every approach will work universally. They will likely express and demonstrate their grief differently than neurotypical children. Their routines will likely be even more important, making disruption in routines a dominant feature of coping with a loss. The child may also have a greater desire to be alone and they might have increased sensitivity, which could lead to outbursts (Koehler, 2016).

Much like neurotypical children, children with autism need to have their grief recognized and understood. In William Worden's (2008) model of grief, there are four tasks presented. The first task is the acceptance of the reality of the loss. For a child with autism, it is incredibly important to use proper terminology and to answer their questions in an honest and timely fashion. It is also important to help them understand the events that follow a death and to then allow the child to make informed decisions about how and in what ways they want to participate. The second task is working through the pain and grief. For a child with autism, the ability to access and recognize emotion is much more difficult, and for those around them, it can be difficult to watch them fail to display the expected emotions. Communication difficulties can make discussions about the loss between the child and family or friends less opportune. The third task is adjusting to a new environment that does not include the deceased person. This type of change is particularly hard for a child with autism, making the need for honest and precise information for the child even more important. The fourth task is finding a lasting connection with the deceased and moving forward in life. For some neurotypical children, keeping a

connection with the deceased can be helpful. Children with autism might not be ready for this task at first. They tend to focus more on the present rather than the future. This task can be later revisited when the child has had time to understand and deal with the death (Koehler, 2016).

Routines. Often times, individuals with autism have difficulty adapting to change, and the death of someone they care about can be an enormous change in their life. The period of time following a death can be described as “chaotic,” causing disorder, confusion, and uncertainty. It can be considered scary by many individuals to not know what emotions they will encounter and when, and this is completely normal. It is important for the individual to remember that they will not feel this way forever. During times such as this, it is important for children to be able to talk about potential changes with parents or caregivers (Helbert, 2013). The routines and rituals that a person with autism has help give them a sense of order in a world that they perceive as chaotic. Following a death, the first thoughts that a person with autism will likely have will revolve around whether the death will alter or interrupt their established routines. When these routines are interrupted, those with autism may have strong emotional reactions (Wharff, 2015).

The need for maintaining predictability that people with autism feel can dominate their thoughts, which causes them to appear to be indifferent emotionally to what is happening around them. Instead of focusing on how they feel, those with autism will focus more on solving the problem and allowing them to return to their normal routine. The change in routine can lead to an emotional outburst and a sense of panic and anxiety for the individual. For someone without autism, his or her initial inclination will likely be to attempt to soothe and calm the person with autism who is having an emotional outburst. By offering logical solutions or options to the problem, and then dealing with emotions afterwards, there is likely to be more success.

However, when the emotional outburst is due to the death of a loved one, there is no immediate solution to the disruption of routines. According to Lipsky (2013), the only and the best way to handle such situations is to have a script and a plan already in place before and after the death occurs. Another option is to focus on restoring predictability by restoring a routine or by creating a replacement. Due to grief and worry, people without autism often want to reassure loved ones that all will be well. This concern that they have can overshadow the need to deal with what is inevitable. Expecting an individual with autism to show a desire to provide this reassurance is not practical, as they do not tend to embrace sudden changes. By instead giving them more notice and helping them to prepare, they are better able to make accommodations in their routines (Lipsky, 2013).

Shock can overwhelm a family after a death, leading to feelings of confusion and bewilderment. The intense focus on funeral preparations may lead to an overshadowing of the special needs of a person with autism. A child with autism will not handle disruptions to routines and planned events as graciously as a person without autism would (Lipsky, 2013). Due to a desire to maintain routines and a feeling of sameness, the grief process can lead to feelings of great distress when it causes an interruption in the child's life (Hume, Regan, Megronigle, & Rhinehalt, 2016). Helping to honor routines can be of benefit for the child. Minimal interruption to the student's routine can help them to cope with the loss (Faherty, 2008). The stress of the loss combined with the stress of an altered routine could exasperate the child's grieving process (Lipsky, 2013). Allowing students to be included in rituals and ceremonies is another strategy. One would expect children with ASD to be included in rituals, although this inclusion may change based on their preferences (Hume et al., 2016).

The initial thoughts of a person with autism immediately following a death might be focused on whether or not this event will create an immediate interruption of their routines. This attention to routines rather than to the news of the death can seem unsettling and can come across as “insensitive” to those without autism. This perceived insensitivity further creates the image of those with autism being disconnected from their emotions and to the situation (Lipsky, 2013).

Reactions to grief. The different and unpredictable ways in which children with Autism Spectrum Disorder respond to bereavement can lead to a misperception that the death does not affect them (Koehler, 2016). Individuals with autism express their grief due to loss through anger, pain, sadness, confusion, and anxiety (Forrester-Jones & Broadhurst, 2007). Children with autism often have responses that are similar in content to their peers, but that differ in intensity or frequency. Their responses may be more exaggerated than those of their peers. They may feel the same curiosity, concern, and compassion that their typical peers demonstrate, but their atypical qualities can overshadow this. The child may show increased or decreased intensity of emotions or endless repetition in questions and behaviors, which can irritate or frustrate those around the child. Their reactions can seem disarmingly out of place and may seem to be in contrast to what others are experiencing (Gray, 2003). Due to communication and comprehension difficulties, other challenging behaviors may manifest while the child is grieving. These challenging behaviors can include aggression and disruptive behavior (Gilrane-McGarry & Taggart, 2012). When the death is of a significant person in the child’s life, anxieties and difficulties for the child can arise. There is now a loss of the functions that the deceased individual once performed (Rawlings, 2000).

In autism, individuals typically experience a delayed emotional reaction. This can occur anywhere from days to months or even a year after the death of a loved one. Generally, certain

triggers will precipitate sadness, despair, longing, and obsessing over the deceased. To help a person with autism process death emotionally, it is helpful to allow them to engage in their self-soothing techniques (Lipsky, 2013). What is sometimes viewed as a lack of “nostalgia” is often due to a desire to not dwell on the loss. Reminders of the deceased person can create a longing to restore the routines that were held with the deceased, leading to feelings of frustration. When the loss is still fresh, it is best not to force a person with autism to embrace sentimentality (Lipsky, 2013).

Grief does not manifest as only emotional feelings. Rather, people can experience grief physically, cognitively, mentally, and spiritually. This can be potentially extremely confusing and distressing for a person with ASD and can lead to an increase in symptoms of ASD (Helbert, 2013). Children with autism will experience a range of symptoms of grief. It is important to understand that, even if the child or teen is not talking, they are still grieving, that displays of emotion, or the lack thereof, do not accurately measure how much the child is grieving, and to allow the child to make decisions about how they handle the grief process (Helbert, 2013).

One mannerism that those without autism often find hard to understand is the apparent need of those with autism to be isolated. For a person without autism, support from others is often much needed in times of grief and stress, and knowing that they aren't alone helps to bring them comfort. Likewise, when someone that they know is experiencing a loss, their natural inclination is generally to offer support to that person and reassure them that they are not alone. However, for a person with autism, isolation may be much preferred. Interacting with others during this time can increase the chances of a cognitive overload, possibly leading to a meltdown. Agitation causes senses to be heightened for the person. Touching, talking, and visually looking at something can all become too over-stimulating on a sensory level. Being

near others who are experiencing and displaying powerful emotions can be sensory triggers for a person with autism, and may cause them to seek isolation in a sensory deprived environment. Engaging in activities alone is emotionally and mentally soothing, and provides an escape from the overstimulation (Lipsky, 2013).

The experience of grief can sometimes cause people to react in ways that are not usual for them. When a person has an “opposite” stress reaction, they display feelings that do not truly represent the actual emotions they are experiencing. For example, they might cry or laugh when they are feeling anxious or upset (Helbert, 2013). Those with autism tend to become more solitary when faced with overwhelming, stressful situations, choosing to seek refuge in what they consider to be safe. When those without autism experience painful situations such as grief, they tend to seek solidarity with others. It is often falsely believed that those with autism lack empathy and that they do not have a connection to their emotions. Displays of behavior during stressful events that are not considered conventional often reinforce this belief. While people with autism may not grieve in the same five-stage manner that is embraced in western society, they do still feel grief and the pain that it brings (Lipsky, 2013).

The ways in which a person with autism and a person without autism approach problems are usually opposite. Those without autism are more deeply connected with their emotions and what these emotions mean during times of stress. They also generally seek out others to share the information with and to find solidarity with, allowing them to connect with others. They may seek ways to not feel alone and to feel more secure. Children learn to model their grieving process from the actions and behaviors of the adults in their lives. There are many unwritten rules about how people should act when confronted with death. These are subjective and are often based on external factors and the mindset of people (Lipsky, 2013).

Following a death, the frequency of meltdowns will usually increase. The person with autism will begin to feel the emotional effects of the loss after they have been able to process the logical side of the death. This will usually present as anger and can present at times that do not seem logical or related to the death. These meltdown reactions can increase over what normally are perceived as non-issues, and their frustration levels can increase due to the significant changes that have resulted from the death. Trying to reassert and maintain existing routines from any deviations can feel mentally draining and can lead to an increase in meltdowns, which then become an emotional outlet to express the powerful emotions that a person with autism feels and doesn't understand (Lipsky, 2013).

Children with autism are also more likely to have comorbid anxiety and depression (Mazzone et al., 2013), which can further manifest and cause even more stress on the grieving child due to their limited coping abilities (Jahromi, Meek, & Ober-Reynolds, 2012). When stressed or anxious, a child with ASD might react in a way that is perceived as unusual. Their behaviors may come across as insensitive or inconsequential. Individuals with ASD often have a hard time identifying and describing words dealing with emotions, and they can also have trouble mirroring and perceiving these emotions in other people (Moseley et al., 2015).

Some children and teens with autism may seem to be drawn to the topic of death, which people may find to be unnerving. However, this special interest in death is not due to any form of mental derangement, as some believe it to be. Rather, those with autism have a strong preference for facts and they seek to find answers to unanswerable questions. Death is a complex subject, which may cause a child or teen with autism to want to explore it in depth. This exploratory practice allows them a vent for their repressed emotions and helps to stem fear of the unknown (Lipsky, 2013).

Emotional vocabulary. Some common struggles that children with autism often face include problems with understanding abstract language and concepts (Mesibov et al., 2005). Those working with the child should be careful in their selection of vocabulary and should be sure to use analogies that help translate abstract concepts into more concrete terms. Individuals with autism are very literal thinkers, and are likely to gravitate towards what is more observable and concrete. This is especially important to consider when helping a child with autism through a death or in preparing them for one. The emotions of all involved are generally more increased during this time, as are demands on time, causing everyone involved to experience more exhaustion than usual. Pre-thinking explanations can be helpful during this period of time. The same vocabulary and phrases should be used they should not be abstract. To help bridge between concept and comprehension, analogies can be used. They can add an element of fun and interest into the introduction of concepts that the child may not understand. However, they should not be used with every child, as some children with autism may not be able to understand and use analogies. If the child does not have the capability to understand representation and consider two pieces of information at the same time, they may not be ready for the use of analogies (Gray, 2003).

It is important to help the child know whether a loss is a temporary one, such as a teacher leaving on maternity leave, of a permanent loss, such as the death of a teacher. When the loss is permanent, the use of metaphors and abstract phrases should not be used with the child, as they can create confusion (Hume et al., 2016). Clear and direct language should be used in order to avoid this (Faherty, 2008). While confirming that the person has died and will not be returning, it can be comforting for some children to be reminded that they will always have their memories of the deceased and that they can reflect on these at any time (Faherty, 2008).

Euphemisms such as “passed away” can be confusing for a child with autism, as they benefit from the use of concrete and literal information. If a deceased individual is described as having “gone to heaven,” the child could become confused and think that the person will return, just as they would if they had gone to the store (Wharff, 2015). There are many expressions within the English language that involve mention of the heart, relating to emotional aspects rather than physical ones. For example, when someone is sad or hurt, they might say that their heart is “broken.” This does not mean that their heart has literally broken and stopped functioning. Rather, it means that they are so sad that they can feel a physical pain. Or when someone says that their heart is “full,” they do not mean that their heart has physically been filled with something. They mean that they are feeling more than one emotion at once, like gratitude and love. Especially at times when someone has died, a person might feel multiple emotions at one time, which can lead to feelings of confusion and stress (Helbert, 2013).

When communicating with someone with autism about death, it is best to be blunt and direct and not to try to ease into the conversation slowly. Being forward and addressing the death at the beginning of the conversation will help to prevent chances for misinterpretations about the news. It is helpful to have options of solutions for the affected routines when going into the conversation. Being consistent in the information presented, such as phrasing of what has happened to the deceased, is also important in order to avoid confusion and to prevent cognitive meltdowns (Lipsky, 2013).

In society, the topic of death is often viewed as taboo, and euphemisms are utilized rather than direct terminology. This can be confusing for children, particularly those with autism. They often have trouble understanding non-verbal communication as well. If a child with autism sees someone crying, they might be able to recognize that the person is feeling sad. However,

more subtle indications of sadness might be more difficult to identify (Koehler, 2016). The child's ability to connect with other students during the grieving process can also be affected, as children with autism often have difficulty with empathizing with others and recognizing emotions. These deficits within their social skills can affect and limit the child's ability to express their emotions, which could lead to their missing out on a community of support (Hume et al., 2016).

Communication. Children with autism benefit from having time to process information and being given the opportunity to verbalize their fears and feelings. Their grieving process can be impeded by difficulties with communication, cognition, and social interaction, which can lead to a failure to grieve following a loss or a delayed reaction to the loss. The bereaved individual may not fully grasp or understand that death is irreversible or might be uncertain about what appropriate responses to death are. Bereaved children with autism may display disruptive or aggressive behavior, as it is the only way they are able to express their grief. The child can be unsure of how to request help, causing them to be unlikely to ask for support during times they feel anxious, depressed, or unhappy, and they are unlikely to seek out activities that can aid in the grieving process (*Loss and Bereavement in Autism*, 2010).

It can be helpful to make a list of the people that an individual can talk to when they need someone to listen to them. There are several methods of communication that a person can use, and they include talking, writing, sign language, body movement, and other art forms. Whatever type of communication is selected, in order for it to be successful, the person who is receiving the communication should understand what it is that is being communicated. Sometimes, people with autism can have a difficult time with communication, which can lead to the feeling of being misunderstood. There may be times when they do not understand what others are trying to

communicate or times when they think they understand, only to find that they were wrong, leading to feelings of frustration. Beyond simply verbal communication, people with autism can have problems with the body movement type of communication, meaning that they might have difficulty understanding body language or facial expressions. This can lead to time-consuming attempts to decipher what people are communicating with these body movements. Other times, it can be others who misunderstand the body movements of those with autism. People with autism sometimes have body movements or facial expressions that do not convey the intended message, and this is exacerbated by additional stress (Gray, 2003).

It is important to have good, effective communication. Without it, it is not possible for others to know how a person is thinking or feeling. Being understood and being able to understand those around you helps an individual lead a more peaceful life. Understanding others can lead to the discovery of new information, including differences, similarities, and shared likes or dislikes. During the grief process, it is especially important to feel understood, because the experience of grief can feel very isolating otherwise. Every person's experience is different and their own, but there are ways that others can relate and empathize with the situation (Helbert, 2013).

When telling a person with autism about the death of a loved one, it is useful to have an existing plan in place, preferably one that they have been involved in creating. By involving them, it helps prepare them for what to expect when the event occurs and it allows them to contribute what they would find helpful. This also presents an opportunity to discuss the finality of death. Having separate plans for both expected and unexpected deaths can also be beneficial (Lipsky, 2013). After breaking the news of a death to a child with autism, it is good to be prepared for blunt questions about the nature of the death, questions about interruptions to

routines, and, if the death was unexpected, possibly expressions of fear about the same even happening to the child as well. For example, if the loved one died in a car accident, the child may fear being in or near cars. In situations such as this, it is important to use facts rather than reassuring facts in order to alleviate fear (Lipsky, 2013).

The ability to understand what others are thinking in order to predict and explain their behaviors is often referred to in literature as “theory of mind.” Those with autism may display “mind-blindness,” which is the trouble that children with ASD have in understanding their own minds and the minds of others (Baron-Cohen, 1995). This includes the ability to emotionally respond to mental states appropriately (Baron-Cohen, 2002). “Mind-blindness” can cause the child to fail to understand why others act and feel the way that they do, different ways in which others can help them, and how their own behaviors might appear to those around them (Koehler, 2016). Children with ASD often have a difficult time taking pieces of information and simultaneously putting them together. This can cause them to have trouble understanding the relationship that events and ideas have (Barnes & Baron-Cohen, 2012). They will also often have some type of language problem, ranging from minor trouble with using language socially to an absence of functional verbalism (Koehler, 2016). When a child with autism reacts or speaks in a way that could be interpreted by others as insensitive, this could be a sign of their feelings of unease, nervousness, or being overwhelmed. It is important to remind them and others of this in order to help them understand the response (Blackman, 2008).

Supporting Children with Autism Through Grief

Grief causes a person to have a variety of different feelings, and these feelings can change over time. While the degree of sadness may lessen over time, the person will still remember their loved one who has died. Some days, especially birthdays and holidays, can be

especially hard, but there are ways to remember the loved one, such as creating scrapbooks, listening to the loved one's favorite music, or planting trees or flowers (Helbert, 2013).

Those teaching children with autism about death should also remember to affirm the child's feelings. Just as it is important to acknowledge and validate the importance of a typical child's feelings. A child with autism may not have a fluent command of how they express their emotions, in terms of body movements, voice, and facial expressions. This can make it more difficult to interpret what they mean or how they feel. By utilizing visual materials and supports, the child could be able to more clearly identify and express their feelings. Representative scales, such as *The Incredible 5-Point Scale*, facilitate communication and help the child alert parents or teachers to feelings of discomfort or stress (Buron & Curtis, 2003). It is also important to help the child make connections and associations between past and present experiences. By assisting them in associating what they know about the life cycle to the current situation can help them frame their experience with death (Gray, 2003). It is important to know the child with autism and to be familiar with their sensory and cognitive triggers in order to avoid forcing them to extend beyond their coping limits (Lipsky, 2013).

Although it can be hard or uncomfortable at times to talk about people who had died or about the topic of death, it is still ok to do so. It is up to the individual to decide whom they want to talk to and when they want to do so. Creating, planting, writing, or cooking are all ways that one can remember their loved ones who have died (Helbert, 2013). It is often helpful for many children with autism to gain a better understanding about the death of a loved one and the experiences that may accompany it. Those working with these children should encourage conversation, questions, and togetherness, as it helps to affirm that death and grieving are a natural part of life (Helbert, 2013).

The supports of empathetic listening, counseling, and advanced preparation should be applied to students with autism as well as students without autism. One strategy to support children with autism through grief is to build a team. Having a team approach for supporting students through grief is essential, and the team can then develop a plan of action, which will allow them to share the news of a death in a consistent manner (Lawhon, 2004). When assisting a child with autism in handling cultural expectations, it can be helpful to have a plan designed or to utilize a script. While not always possible, it is helpful to have this prepared in advance of the death (Lipsky, 2013).

Children with autism can benefit when visual materials are used to help explain and enhance meaning, when there is structure in activities and the child's role in the activity, and when instruction is personally relevant (Gray, 2003). These children may have receptive language deficits (Mody et al., 2013), and can therefore benefit from information in multiple formats. Social narratives, which are stories that help the reader to understand social situations and give examples of possible appropriate responses, can be beneficial for aiding a student with autism (Wong et al., 2014). These were developed to help students learn information about a death, to reassure them about their own safety, and to provide the students with both insight and assurance about their feelings. These stories were further developed to help students learn ideas of how to cope with sadness and overwhelming grief. They can be used in print form, video, or PowerPoint and are able to be modified to match the student's level of comprehension (Lipsky, 2013).

Another strategy to help children with autism through grief and loss is teaching them to utilize coping and calming skills. When working with a child with autism, it is important to provide instruction on how to cope, self-manage, and take care of oneself. When a child already

has learned these skills prior to a death, they can fall back on these known techniques to aid them through the loss. Following a loss, team members should reiterate the importance of these skills, when and how to use them, and should work with students on practicing them. This will help to ensure that students are easily able to access calming activities during their process of grief. Individuals with autism may not find extended periods of “downtime” relaxing, and having access to these calming activities can be beneficial (Lipsky, 2013). Resources such as *The Incredible 5-Point Scale* (Buron & Curtis, 2003) and *How Does Your Engine Run?* (Williams & Shellenberger, 1996) can be modified to address emotions involved in grief, such as sadness and anger (Hume et al., 2016).

Supportive Books and Stories for Children with Autism

Advanced preparation for death is of great benefit to children with autism, and it is helpful to talk and teach about the subject beforehand. Doing so allows the child to ask questions and gives them time to process information before emotions become involved (Wharff, 2015). Regardless of whether this occurs before or after the death, it is important for those with autism to receive information about what death means and the finality of the event (Forrester-Jones & Broadhurst, 2007).

The experience of a loss can feel like an unexpected assault for a child with autism. New faces and routines can increase the potential for the child to make social mistakes. When helping teach a child with autism about loss, it is important to abandon assumptions. The focus should be on helping the child find ways to identify and work through perceptions and feelings. Instead of just focusing on the topic of the loss, there should also be focus on the emotions surrounding it as well. It is also important to have advanced notice, when possible. Books and Social Stories™ can both help in this, and can help the child to prepare for the ramifications of the death of a

loved one. The child may have previously experienced death, in the form of plants or small pets, but the focus should be on whether the child has learned from this experience. It is advised by experts that once a serious illness, accident, or death is known, children should be told. By providing this advanced notice to the child, they can be offered an explanation about what the death means and how it will affect the life of the child. It is helpful to assist the child with accommodations in vocabulary and analogies as well (Gray, 2003).

To help a child with autism through confusion about the death of a loved one, children's literature can be beneficial. Books and stories can address a variety of topics and specific situations, including but not limited to the death of a parent, a sibling, a pet, or a friend. Funeral homes sometimes have children's libraries available for bereaved families to use. By providing the child with a tangible vehicle for identifying and expressing their feelings about the death, the parent or caregiver can help meaningfully affirm their experience.

A therapeutic strategy that has been used to aid children with autism includes the use of storytelling. Stories can be told in a manner that reflects the child's unexpressed feelings as well as helping to encourage the child to contribute to the story. One variation of this mutual storytelling approach is narrative therapy, which involves telling stories concerning people and their problems in life. This aids the child in structuring, predicting, and understand the world they are living in. The stories can be personalized, which is beneficial for children with autism in showing how to model appropriate social behavior for the given situation (Del Valle et al., 2001). Children with ASD may benefit from the use of Social Stories™ when preparing for events such as death. The stories can be personalized and should help explain facts and events, explanations about other people's behaviors, and the thoughts and feelings that others may have. The child is able to learn more about death in a less emotionally charged atmosphere, and the

Social Stories™ can increase their social understanding. The use of visual and physical examples can also be helpful in explaining death. For example, explaining the process of the death of a plant to the child (Koehler, 2016). Stories can be used to introduce new routines and changes, describe appropriate responses in social situations, and teach appropriate social skills, explain what appropriate and inappropriate interactions are.

Bibliotherapy is an extremely useful tool in helping not only typical children through the grief process, but in helping children with autism as well. Books have been made specifically for helping children through various types of loss, including significant losses, death, and dying (Gray, 2003). Books can be used to help children with autism to build confidence in regard to what is appropriate after a loss. Books can help the child to know what is appropriate to say or do.

In regard to books about death, not only can books discuss and explain the basic concepts of life and the life cycle, such as in the book *Lifetimes* (Mellonie & Ingpen, 1983), but books can also be focused on specific types of deaths, such as the death of a parent, sibling, or pet. For example, *When a Pet Dies* by Fred Rogers (1988) details the experience of being a pet owner and the variety of emotions a child might feel after the death of their pet (Gray, 2003).

Research Questions

Although children with autism may benefit from books about death that are written for younger readers (Center for Autism Research, n.d.), parents' and teachers' perceptions of selecting grief-themed books have yet to be explored. This study examined the following research questions:

1. From parent's and teacher's perspectives, when supporting young children with autism who are coping with grief and loss, which selection factors should be considered when identifying grief-themed books and stories?
2. From parent's and teacher's perspectives, when supporting young children with autism who are coping with grief and loss, which of the pre-identified selection of books and stories are perceived as most helpful?

CHAPTER 3

Method

A phenomenological approach to focus group interviewing was used in this study. According to Creswell (2007), phenomenological research attempts to investigate the lived experiences of an individual or group of individuals, gathering information from participants' first-hand perspectives. Qualitative interviews are conducted to gather information from those who have experience in relation to the specific topic that is being investigated (Rabiee, 2004). In this study, the phenomenological approach allowed the researcher to listen and learn from teachers and parents of children with autism. More specifically, the researcher investigated how teacher and parent participants perceive and understand the needs of children with autism who struggle to cope with loss and feelings of grief.

An important aspect of conducting phenomenological studies, Hycner (1985) emphasized the process of audiotaping interviews and transcribing audiotapes following interviews. Hycner recommended that the researcher should first carefully listen to the recorded interview, then read and re-read the transcript numerous times to more fully understand participants' input. After removing redundant pieces of information, the researcher begins to cluster units of relevant meaning into themes. Summaries are written for the interview transcriptions, incorporating the themes elicited from the data. These summaries give context for the emergent themes. These themes are then modified, as needed, during the ongoing data evaluation process (Hycner, 1985).

The researcher carefully considers the transcribed interview themes, ultimately coming to a deeper understanding of the participants' lived experiences (Rabiee, 2004). Once the transcribed interviews are thoroughly investigated and understood, the researcher begins

addressing how the responses relate to the phenomenon being studied. Ultimately, participants' information increases the researcher's understanding of the identified research questions.

Focus Groups

This study utilized focus groups to gather data. According to Krueger and Casey (2001), focus groups should include selectively recruited participants, a comfortable environment, a skillful moderator leading the group, and a follow-up of systematic analysis, summarizing themes, and reporting the findings. The moderator should offer an open and safe atmosphere to encourage the participants' discussion.

Focus group discussions are most frequently semi structured with a prepared list of guiding questions (Rabiee, 2004). Individuals participating in focus groups should have the experience, knowledge, and characteristics required to provide commentary on the desired topic. It is important to avoid power differentials within the groups, and all participants should feel comfortable sharing their opinions in the group setting (Krueger & Casey, 2001; Rabiee, 2004). The location in which focus groups are held should be a familiar or neutral setting. Field notes should be taken to offer additional background information about the focus group setting, participants, and non-verbal communication (Hycner, 1985). Similar to Hycner's (1985) advice, Krueger and Casey (2001) also recommend that the focus group discussions should be recorded for later analysis.

When developing questions for focus groups, the goal is to ask questions that will address the purpose of the study. Good questions focus on getting information that will directly relate to the objectives of the study (Krueger & Casey, 2001). Questions should allow for open discussion between participants. Focus groups work best when participants are able to talk to one another and are able to build on each other's comments. Participants should be engaged and

the focus group should facilitate discussion. The semi-structured focus group protocol used in this study is included in Appendix A.

Participants

Participants were recruited from a pre-selected charter school specializing in education for children with autism. Convenience sampling was used to select eight teachers of children (K–3rd grade) with autism and five parents of children (K–3rd grade) with autism. Participants filled out a list of demographic questions (listed in Appendix B). Based on the information provided by participants, they ranged in age from 25 to 59 ($M = 38.31$). Each of the 13 participants self-identified as White or Caucasian. All eight teacher participants were female, and four parent participants were female and one parent participant was male. Selection criteria of teachers and parents were based on whether children were verbal and of average or above average intelligence (as described in assessment records). Additionally, the children with autism were verified to have autism diagnoses by way of the Autism Diagnostic Schedule (ADOS) or the Autism Diagnostic Schedule, 2nd ed. (ADOS-2) as recorded in assessment reports within educational files.

Additionally, the parent and teacher participants were selected because of their experience interacting with children with autism. Their years of experience with children who have autism ranged from 2 to 20 years ($M = 9.31$ years). Participants also expressed an interest in using books and stories to aid children with autism through the grief process. Those who accepted the invitation to participate each signed the Informed Consent Form (included in Appendix C).

Compensation

Participants received compensation for taking part in the study. At each focus group, a light meal was provided to participants. This was done in order to make the environment more comfortable and to ease the participants' ability to participate in the focus groups. If interested, they were also compensated by receiving two books of their choice from the selection discussed at the focus groups in order to provide them with the opportunity to use the books as future resources with their children and students. The form that participants filled out in order to receive these two books is included in Appendix D. Following the focus groups, the books were mailed to each participant who elected to receive this compensation. The books were either mailed to the participant's home or to the school, based on each individual participant's preference. Additional compensation included \$20 per participant to thank them for their time and participation. Each participant chose whether or not to accept the books and the \$20. The participant consent forms that contain this information are included in Appendix D. These teacher and parent consent forms were part of the application submitted to and approved by Brigham Young University's Institutional Review Board (IRB). The approval letter from the IRB is included in Appendix E. A slight amendment to offer the participants two books and a \$20 gift certificate was approved by the IRB and their approval of this slight change is included in Appendix F.

Benefits to Subjects and Society

As a direct result of the focus groups they were a part of, participants were exposed to resources that could possibly be used with children of autism who experience a significant loss or the death of a loved one or pet. Participants shared their thoughts and opinions on books and were provided with the opportunity to hear the opinions of others. Due to these discussions and

the complimentary resources they were provided with (the two books as compensation), they may have the benefit of being able to use these resources in the future. A list of which materials were identified as being the most beneficial for children with autism experiencing grief and loss was distributed to parent and teacher participants following the completion of the study.

While the effects of grief and loss on children as a general subject has been researched in the recent past, the effects on children with autism is still an under-researched area. There has not been much research done on the use of bibliotherapy with this particular group, and there is a lack of information on how to properly select books that will be the most beneficial. This research will contribute to the scientific knowledge of what selection criteria are important when choosing books to be used to support a child with autism who has experienced a significant loss or the death of a loved one or pet. The completed research will benefit both professionals and parents, as it will provide a list of resources that are currently available.

Potential Risks for Research Participants

One potential risk in focus group interviews is the prompting of memories that trigger sadness, grief, or emotional discomfort. Professor Melissa Allen Heath (licensed psychologist) supervised the study, and she made herself available to participants to discuss any concerns that they had during or following the study. Her contact information was provided to the participants at the completion of each focus group (via a business card).

As these focus group involved discussions of personal opinions, the research team took extra precautions to protect participant privacy. At the start of each focus group, the primary researcher began by asking the participants to agree to the importance of keeping the focus group discussions private. Only the primary researcher, co-investigators, and two undergraduate research assistants had access to the transcripts and recordings of the focus groups. Audio and

video recordings were deleted after participants had the opportunity for an accuracy check. Recordings will not be used in any future presentations. Typed transcripts of the focus groups will refer to participants with pseudonyms.

As student records are being accessed, there is a potential for a breach in confidentiality. There is also the risk of breach of confidentiality in terms of the potential identification of the student. As autism is not an extremely common diagnosis, it is possible that an individual might look at the school, age, and gender of the students of the teachers and parents and be able to identify them. Both parents and teachers have access to their student's records. Parents were given the option of either accessing their child's records themselves to provide the research team with the necessary information (e.g., verification of autism symptoms per ADOS) or of having their child's teacher access the student's records to provide the research team with the necessary information.

Procedures

Focus groups were used in the study to explore pre-identified topics and to get the views and opinions of selected parents and teachers. Participants agreed to take part in semi-structured focus group interviews asking about which children's books are appropriate for supporting children with autism through grief and loss, specifically books about the death of a loved one or pet. Additionally, the focus groups identified factors they perceived as being important in the selection of books and stories. The interviews explored which books are more appropriate, based on child's gender, developmental age, communication skills, and the type of death. The openness of the forums allowed participants to discuss their opinions and views regarding the preselected set of stories, books, and activities and how these resources may or may not support children with autism who are coping with a significant loss.

One parent group (five members) and one teacher group (eight members) participated in confidential, audio-recorded focus group discussions. Teachers and parents participated in separate focus groups in order to encourage participants to share their opinions with similar group members, avoiding pressure from members who have different responsibilities and expectations for children with autism. By having separate groups, teachers and parents were able to freely speak about their opinions without fear of judgment.

Both focus groups took place at the pre-selected school site in order to foster a familiar and comfortable atmosphere. The teacher group and parent group were held on separate days. The intent of the focus groups was to discern teacher and parent perceptions of the pre-identified selection of stories and books.

As participants entered the room for the focus group, they were provided with a copy of the consent form to sign (see Appendix C). At the start of the focus groups, the researcher began with a standard introduction that included a welcome message, an overview of the topic of the meeting, guidelines for the meeting (see Appendix A), and an initial question to start discussion. While in the focus groups, the researcher listened for vague or inconsistent comments and would probe for deeper understanding. Each session lasted approximately 1.5 hours.

The researcher served as a moderator and facilitator during the focus groups in order to observe participant interactions, provide promptings for discussions, and listen to conversations between participants. This allowed the researcher to probe for additional information related to the research questions. The researcher used controlled reactions to participants, both verbal and nonverbal, including head nodding and short verbal responses. Phrases that indicated approval or disapproval of participants' responses were not used in order to avoid influencing participants' opinions and responses. By being present during the focus group interviews, the researcher was

able to take note of participants' facial expressions and body language in order to gain more insight into the perceptions of the participants. During the focus groups, the researcher was also able to observe interactions between the participants.

The focus group guiding questions (see Appendix A) reiterated the research questions, probing to determine which factors should be considered when identifying grief-themed stories and books for children with autism and which stories and books were perceived as most helpful in comforting and supporting children with autism.

Fifteen pre-identified books and stories were selected based on subject matter and age-appropriateness. These books were also selected based on the Amazon ratings and based on books being frequently recommended as cited on library grief-themed book lists. In order to be beneficial to children with autism, books and stories with concrete and straightforward language were selected. The selection of materials was also reviewed by an autism expert, to ensure that sufficient options were provided. In particular, the book options were considered as potentially appropriate for children with autism. Considerations were made based on children with autism typically having significant language and communication delays.

In order to assure that the researcher's biases about the pre-identified books and stories did not influence the participants, the researcher refrained from contributing personal opinions. The researcher did not participate in discussions with participants beyond keeping them on topic and encouraging contribution from all participants involved.

Throughout the focus groups, the researcher utilized probes during pauses in the discussions. When a pause would last longer than five seconds, the researcher would provide a probing response such as "Would you explain further?" or "Would you give an example?"

When the researcher provided questions to the participants, open-ended questions were used in order to lead participants into discussion.

A second moderator was present during the interviews in order to provide another perspective on the discussions between participants and to ensure that the responses were interpreted accurately. The assistant moderator took careful notes and helped monitor the recording equipment. During the focus groups, taking notes was the primary responsibility of the assistant moderator. Other responsibilities included assisting in arranging the room and welcoming participants upon their arrival.

Note taking was done in a clear and consistent manner in order to allow for interpretation of the notes following the focus groups. The assistant moderator listened for notable quotes and phrases that were particularly interesting. The assistant also kept track of reoccurring key points and themes in discussions. Notes about emotions displayed by participants, body language, and non-verbal activity were also recorded. All observations and notes were recorded in electronic files and stored on password-protected computers.

At the end of each focus group, the researcher reviewed the purpose of the focus group interviews and asked if participants had anything further to add. Participants were asked to complete four forms at this point. These included a rating sheet (see Appendix G), a ranking sheet (see Appendix H), a demographic sheet (see Appendix B), and a compensation sheet (see Appendix D). The demographic form asked the participants to provide information about themselves in order to briefly learn about their background and their years of experience with children who have autism. The rating sheet asked participants to individually rate each of the 15 books on a Likert scale (1 to 5), indicating how effective each book would be in supporting a child with autism through a significant loss or the death of a loved one or pet. The ranking sheet

asked participants to rank order all of the provided books from 1 to 15, which 1 being the best choice and 15 being the worst choice, based on how effective the participant believed the books would be in supporting children with autism through a significant loss or the death of a loved one or pet. The compensation form provided participants with the opportunity to select two of the 15 books as a gift. They were asked to provide the titles of the two books they wished to receive, as well as the address to which they wanted the books to be mailed. Participants were provided with an additional copy of the consent form to take home, for their own reference. The researcher then thanked the participants and ended the meeting.

Qualitative Data Analysis

Immediately preceding and following the focus groups, the researcher checked the recording equipment to ensure that the recording device was working properly. After each group, the researcher and the assistant moderator debriefed and discussed notable themes, interpretations, and ideas from the discussions. Following the second focus group, the researcher and assistant compared and contrasted the two groups. Within a few hours of the focus groups, recordings were loaded onto a password-protected computer and made available to transcribers. Two undergraduate students transcribed the recordings of the de-identified focus group interviews.

Prior to transcribing the recordings, the undergraduate student transcribers successfully completed the University's Collaborative Institutional Training Initiative (CITI) ethics training. Additionally, the primary researcher trained the undergraduate student transcribers. Training consisted of a one-hour meeting, which included a brief overview of the study and directions for transcribing the focus group interviews.

Transcribers were encouraged to use headphones while listening to the recordings, in order to minimize background noise distractions and better focus on the participants' voices. In the transcriptions, statements made by the researcher were typed in bold print. Comments were typed word for word in the transcript. Once transcriptions were completed, the researcher listened to the audiotapes, reviewed the field notes, and read the transcriptions. Reading the transcriptions helped assure accuracy of the language recorded in the notes. Audio recordings were deleted after the primary researcher reviewed and checked the transcriptions for accuracy.

When analyzing the data from the focus groups, the researcher considered the words used by the participants, the meanings behind the words, the context of their comments in the discussion, how consistent participants were with their opinions throughout the discussion, how frequently topics were discussed and mentioned in comments, the intensity with which participants discussed topics, and the specific nature of participants' statements. After reading through the transcribed data, the researcher cited recurring ideas as key themes. This was done with the use of notes in the margins of the transcriptions. Key words and themes were compared in order to identify similarities, patterns, and differences. Additional categories were identified and developed as needed. Finalized matrices were created to provide a visualization of the relationships between the information pieces. Categories were used as headings in the matrices, and they included Book Characteristics, Sharing the Book with the Child, Helping the Child/Family, and Cautions/Warnings. Each category was defined to clarify its meaning. Information that was not relevant to the categories was either placed into new categories or was not used in the matrices. The researcher examined the data within the matrices for emergent themes.

The final check of the data involved a review by an auditor. This individual was familiar with conducting research with focus groups and was familiar with analyzing focus group transcripts. After this individual reviewed the transcribed data, she checked the analysis completed by the researcher and assistant. Corrections (if any) were noted and discussed with the researcher and assistant. A member check was conducted in order to provide participants with the opportunity to review the transcribed audio recordings from the focus group experience. Participants were provided an electronic copy of their focus group interview transcript. Out of the eight teacher participants, three teachers provided input indicating they supported the accuracy of the transcribed tapes. Out of the five parent participants, one parent indicated they supported the accuracy of the transcribed tape from the parent focus group. Of the four who reviewed the transcripts, all approved of the transcribed audio recordings' accuracy and made no recommendations for change. The use of member checking provided an indication that the transcribed audio recordings were an accurate representation of the focus group discussions. This check supported the researchers in moving forward to interpret and analyze the information contained in the transcribed data.

Quantitative Data Analysis

To supplement the qualitative data, participants also completed surveys that required them the rank order and rate the 15 grief-themed books. This information provided another mode of evaluating the participants' perceptions of the selected books.

Ranking books. After reading the 15 selected grief-themed books and completing the focus group, each participant completed a paper/pencil ranking sheet, included in Appendix H. Using numbers 1 (best choice) through 15 (worst choice), participating parents and teachers were instructed to rank order the 15 books. The number 1 indicated the grief-themed book that

they considered the most appropriate for sharing with a child identified with ASD. The number 15 indicated the grief-themed book that they considered least effective. All participants' ranking scores were then summed, and the books were ordered in the following manner: The book with the least points was the highest ranked, most favorite book; the book with the second-to-the-least points was ranked as the second highest, second favorite book, etc. The book with the highest summed score of rankings was considered the least favorite book.

Rating books. Along with ranking the 15 selected grief-themed books, each participant completed a paper/pencil rating sheet, included in Appendix G. Using numbers 1 (least effective) through 5 (most effective), focus group participants were instructed to rate the 15 books. The number 1 indicated that the participant felt that the grief-themed book would not be very effective in supporting a child with autism through the grief and loss process. The number 5 indicated that the participant felt that the grief-themed book would be very effective in supporting a child with autism through the grief and loss process. All participants' rating scores were then summed and averaged, and books were given average rating scores.

CHAPTER 4

Results

Five parents and eight teachers were invited to participate in two separate focus groups (one for parents and one for teachers). These groups included discussions related to how pre-selected materials (15 children's grief-themed picture books) would help support children with autism through the grief and loss process. Each participant had previous experience working with or parenting children with autism and they had also each expressed interest in the use of supportive stories in teaching and supporting children with autism through this process.

Overarching Themes

Participants in both focus groups identified similar elements about the book selection criteria that they recommended as supportive of children with autism. These elements and criteria have been grouped together into specific themes. Examples of participants' supportive comments are included to demonstrate the themes that emerged during the focus groups.

Books need to have specific characteristics. One common theme from both the parent and the teacher focus groups was that it is important for books to have specific characteristics. These characteristics allow a child with autism to connect to a story and will help them to further understand the concepts of grief and loss. There were five common characteristics that participants agreed upon: (a) Books need to be uplifting and instill hope; (b) Books need to be simple, concrete, and structured; (c) The quality of illustrations is important in teaching children about death and loss; (d) Stories should be engaging; and (e) Books should identify and teach about emotions and coping strategies.

Books need to uplift and instill hope. Participants cautioned against the use of books that are too real or morbid. One participant said, in regard to the *Dead Bird* book, "I think it is

just too much, almost.” They agreed that the stories do not need to be too directly graphic about the death, and that the stories should teach without it being too traumatic. There was a common consensus that the books should be uplifting. While it is important to teach children about death and loss, it is also important to refrain from selecting books that would be considered too *depressing*. Participants generally liked the stories to have happier endings that had a positive resolution or that ended in a positive manner. A parent participant shared, “I did like when they focus to the positive, because you’re trying to help them find meaning.” Finding meaning in what has happened can help the child to understand and cope with the event. Another participant shared that they felt that the stories should help the child to adapt to the loss and focus on moving forward, saying, “...whether it was getting another pet or you’re always going to love them, even though they aren’t with you, or, you know, whatever happens.”

Books need to be simple, concrete, and structure. In working with children with autism, it is important to keep information concrete and structured (Banda et al., 2009). Participants agreed that stories for children with autism should be predictable and structured. They also commented that stating information in “simple words” is helpful. Stories that include headings and titles and that have organized substructures, such as *When Your Grandparent Dies*, provide this sense of structure and predictability. Books that have simple language can be used with a wide range of children, particularly those who have developmental delays. Simple wording allows for additional interpretation, providing adults with the opportunity to expand on specific areas as needed. Also, participants shared the concern that if books were too *wordy*, the child could face an overload of information. This overload adds to their confusion as they are trying to learn and identify the important messages within the story. Providing information in small amounts helps avoid overwhelming the child. One participant warned against using stories that

were too abstract, saying, “One thing that worried me about a lot of the books is that the person is somehow in a lot of things, and, just the way it was phrased, it would worry the child. I think it is better to have it finalized and [absolute].”

Other participants also expressed concern about using abstract stories that could confuse the child. They indicated that readers would have to heavily filter these types of stories to avoid confusion. A common recommendation across focus groups was the need to provide children with autism with more “black and white” information when teaching about these sensitive topics. One comment from a parent concerned the layout of the words and the pictures, suggesting that the words and pictures be on different pages. This allows the child to focus on listening to the message when it’s on a “word page” and then turning the child’s attention to the picture when focusing on the “picture page.”

The quality of illustrations is important in teaching children about death and loss. A common concern amongst participants in both focus groups was the need for illustrations and pictures to be more current and updated. Despite how good the message was, participants shared that they would rate the book lower if the illustrations appeared outdated. The participants shared that pictures in a book need to be captivating in order to hold the attention of a child with autism. If language is a relative weakness for the child, strong illustrations can help the child to understand the message in the story. One of the teachers commented, “...language is difficult to understand, so you can talk about the pictures and they [the child] will often bring up things they see in the picture because they can understand them on their level.”

To help the child identify emotions, participants suggested having a picture of a face with the presented emotion, mentioning that it can be important for the child to receive repetition in seeing the emotion and making a connection between the situation and what emotions may be

present. Another common idea was that the child would connect with the story more if the pictures were more realistic or if the pictures were similar to those used in the classroom, such as Picture Exchange Communication System (PECS[®]).

Stories should be engaging. Participants, particularly in the teacher focus group, commented that the books should match the child's level and ability to focus. If a book is written for an attentive audience who needs to be deeply focused on the story, it might not be the best fit for a child who struggles with inattention. When discussing the book *Lifetimes*, a participant shared their opinion that the book didn't have much of a story and would therefore be harder for a child to follow along with. If the story is engaging and captivating, there is a better chance of capturing the child's attention, leading to them being more likely to take away from the story's message.

Books should identify and teach about emotions and coping strategies. When teaching a child with autism about the grief process, it is important to help them to identify what they are feeling. The child may benefit from assistance in understanding what feelings and thoughts they would possibly have in the given situation. The reader can explore the topics of both attachment and loss at this time with the child. This can also help the child to understand that, when presented with grief and loss, they might feel multiple emotions, and that this is to be expected. A person can feel sad about the loss while also feeling happy when thinking about fond memories with the individual that has died. One participant, in reference to the book *Jim's Dog Muffin*, said that having a story that could help explain another person's grief can be helpful. Beyond simply helping a child to understand what emotions they or others around them may experience, the stories should also help the child to learn ways to move forward and to learn coping strategies that can be used.

Certain selection criteria should be considered when identifying books on grief.

Another theme from the focus groups' discussion was the importance of certain criteria that parents and teachers should keep in mind when identifying and selecting grief-themed books for children with autism. This includes not only the specific story and illustrations that align with the child's experience and need to understand a specific aspect about death and grief, but the ability of the reader to individualize the story to the specific child. In particular parents and teachers mentioned the importance of selecting books that are sensitive to the beliefs and values of the child and their family.

Books should allow for individualization. When selecting a book for a child with autism, participants believed that it is important to keep that specific child and their individual needs in mind. Based on that specific child's needs, the reader may want to select books that focus on the specific type of grief needing to be addressed, the approximate age or gender of the character in the book, and what situations the book helps to explain. It can be beneficial for the child to be able to relate to the character in the book and for the child to be able to read the story through the perspective of the character experiencing the grief or loss. Depending on the type of death that has occurred or will be occurring, the child may benefit from having a story focused on that time of death, such as an expected death versus a sudden death. A child with autism may also benefit from having multiple emotions explained in the story, as individuals experiencing grief may encounter a multitude of feelings. By making the story more personal, the child is given the opportunity to relate to the provided information on a deeper level. One teacher participant said that she liked how the book "described what funerals are, because I feel like some of these kids don't know what funerals are, and it can be hard to understand some of these things." Books that allow some interpretation from the adult presenting the book to the child

could allow for more in-depth explanation, from the reader, of topics that are more relevant to the child. Participants also mentioned that it can be important to keep a child's culture and religion in mind during the book selection process, with one participant saying, "...you need to be able to adjust to your audience."

Books should be sensitive to family beliefs. Along with making sure that books are individualized for the child with autism, participants agreed that it is important to select books that are sensitive to the child and their family's needs. When selecting books, adults need to be aware of and consider the cultural or religious aspects portrayed in the book. Parents and teachers emphasized that death, grief, religious beliefs, cultural traditions, and rituals could not be separated, that these aspects are inherently intertwined. Descriptive details in the story must be aligned with the child's and family's beliefs. Participants commented on liking books that were broad and that talked about different cultures, sharing that they enjoyed that these stories allowed for diversity. One participant said, "...any family can have a child with autism, and whatever religion or beliefs they might have will be drilled into that child. So, you have to have multiple resources for that." By selecting books that can be adjusted to the audience, the child will be more likely to relate to the story. Teacher participants also shared that it is important to respect what both the parents and the school want shared with the child. If a teacher is sharing the story with the child, it is crucial to make sure to have an idea of how the parents want the subject approached. Participants also noted that it is important to be respectful and allow for different beliefs in life after death. During the parent focus group, one participant shared that she felt that in *The Tenth Good Thing About Barney*, there wasn't enough of this respect for beliefs about the afterlife. When discussing *When Your Grandparent Dies*, a participant shared that it would be important when considering a book to determine the family's preference, whether or

not the family wanted a story to mention Heaven. It is important to let the family of the child decide which religious beliefs should be shared with the child. Participants said that they would not want their own children taught about beliefs that they did not hold themselves. One participant said, "...if you are looking for one [a book] that is teaching the doctrinal beliefs, you go to a bookstore that specializes in your religion."

Books need to help the child/family. A third common theme from both focus groups was that the books should provide the adult reader with the opportunity to use the material to help the child and their family through the grief and loss process. Stories should help to prepare the child with autism with challenges that they might experience following the death of a loved one or pet, they should help to facilitate open communication between the child and the adult reader or their family, and they should help to normalize the emotions that the child may experience or that they may notice other experiencing.

Books should aid in preparation for challenges. When a child with autism is presented with a new experience, such as the death of a loved one or pet, it is important to help prepare them for the new experience. It can be beneficial for the story to provide the child with guidelines on how to act in various situations, such as during a funeral, and to help them know what to expect. Stories can also provide the child with information on what to expect prior to a death. If the death is expected, such as when a grandparent becomes gravely ill, stories could be used to introduce the child to the concept of death prior to it occurring. The stories can also help prepare the child with autism for eventual deaths that may not be immediate. When discussing *Saying Goodbye to Lulu*, one participant said, "I think a book would be a better way to prepare about another dog dying, rather than like your own dog is going to die..." Participants shared

that stories that prepare the child for a death can also help to prepare them for the lack of answers that sometimes accompanies death and loss.

Books should facilitate communication. In order to help a child with autism to understand grief and loss, participants agreed that it is beneficial to have a method of facilitating open communication with the child about the subject. Even if a book isn't focused on a specific type of death or if it has animals as the main characters, such as *Remembering Crystal*, a story can allow the adult sharing the book to begin a conversation with the child about grief and death. Books such as *Saying Goodbye to Lulu* the opportunity to broach the subject of animal death with a child prior to the death occurring. This not only helps to prepare the child for the eventual loss of a pet, but it opens the door for communication about the subject between the child and their caregiver. During the teacher focus group, participants discussed how often the topics of death or grief were mentioned in class, and common consensus was that these subjects were not often mentioned, as they didn't want the children to perseverate on death. They shared that it is important to keep communication with parents open so that school staff will know what avenue the parents want the teacher to take with their child. One teacher said, "...if you are going to have a class discussion, then making sure to let all of the parents know beforehand. And let them know what kind of things you will be talking about." Participants agreed that it was important to avoid books that might model behaviors that teachers and parents do not want the child to engage in.

Books should help to normalize what the child is experiencing. Stories should help the child with autism to understand that the emotions they experience are normal. One participant, during a discussion of *When Your Grandparent Dies*, that the book "...talked about crazy emotions and that being okay. It made everything very positive and reinforced that everything

you're feeling is normal and okay, but there is a better way of handling it." If the child with autism has never encountered the strong emotions that can accompany grief and loss, they might believe that what they are experiencing is "weird" or "not normal." By helping the child to further understand what they are feeling, the adult sharing the story can also help them to understand and learn appropriate ways of coping with these emotions.

Additional Noteworthy Themes: Cautions and Warnings about Book Selection

During the focus groups' discussions, certain special considerations about grief-themed books for children with autism were discussed. Participants shared cautions and warnings about the book selection process, which practitioners and parents should keep in mind when using a supportive story to help children with autism through the grief and loss process.

When discussing the pre-selected books and what would be most beneficial for supporting a child with autism through the grief and loss process, participants in both focus groups shared some cautions and warnings about book selection. There were three specific cautions and warnings that participants agreed upon.

Books should not focus on replacement of the deceased. A common caution shared by participants across focus groups was to make sure that the story doesn't focus on replacing the individual or pet who died. The concern mostly focused on the animal books that involved the replacement of a pet after its death. Participants were concerned that, for some children with autism, this might make them think that they could simply replace something that is dead with something else that is not dead. This would not allow them to truly process or mourn the loss of the loved one or pet who died, and it may lead them to focusing on finding a replacement figure. Participants shared that they didn't feel that replacement was always the answer following the loss of a pet, and therefore, there should not be a heavy emphasis placed on replacement.

There is a need for a wider variety of resources. When discussing the subject of individualization in regard to stories, participants expressed a desire to see a wider variety of books that are more inclusive in regard to the types of death portrayed. Many of the books focused on the death of a pet, and participants discussed the need for books that address various family member deaths in order to provide the child with ways to honor and remember the deceased. Specifically, participants mentioned wanting to see more books about the death of a sibling or the miscarriage of an unborn sibling. One of the parent participants shared that their child with autism had experienced the death of a sibling, and said that it would have been beneficial to have more resources for helping her child through the grief process, saying that, “...the way he dealt with it ended up not being very healthy.” It was also mentioned in both focus groups that books focusing on the death or loss of a friend would be beneficial. One participant shared, “...unfortunately, we don’t want to think about that, but it happens, and how do you help your child deal with the loss of a friend?” In the parent focus group, participants discussed a desire to have authors make books about death using characters that are meaningful to the children. One parent used the example of Pikachu, saying that, to her child, Pikachu is very real, and having a character such as this experience grief and loss would help her child to relate to the story even more. Participants also discussed Social Stories™ during this time, and said that a bigger selection of Social Stories™ focused on death would be beneficial for children with autism, as they are already familiar with this type of storytelling.

It is important to avoid overgeneralization. In book selection, the adult reader will want to avoid books that have overgeneralization of concepts. When discussing the book, *The Dead Bird*, participants were concerned that a child with autism who read this book would want to bury every dead thing they find, because the book shows an animal burial done by children.

One participant said, “There were some things that I feel like could’ve put thoughts in their heads like could’ve given them more reasons to be sad...” By a book portraying other children finding a dead animal, mourning the loss of that animal, and then burying it, participants worried that children with autism would feel that they need to mourn and bury every dead thing they find, possibly including dead insects. If this fixation occurred, it could begin interfering with the child’s daily life.

Results for 15 Pre-Selected Children’s Picture Books

As part of our research questions, we aimed to learn more about which selection factors, from parent and teacher perspectives, should be considered when identifying grief-themed books and stories and to learn what pre-selected books and stories were perceived by participants as being the most helpful in supporting a child with autism through grief and loss. Table 1 includes the titles and authors of the pre-selected books, as well as a summary of the participants’ rankings and ratings of the books. For the book rankings, participants were asked to consider and compare 15 pre-selected books, which were presented to them at the focus groups, and to then rank order the books from 1 to 15, with 1 being the best and 15 being the worst at supporting a child with autism through the grief and loss process. For the book ratings, participants were asked to rate how effective they believed the book would be in supporting a child with autism through grief and loss. The books were rated on a scale of 1 to 5, with 1 indicating that the book provided the lowest effectiveness and 5 indicating that the book provided the highest effectiveness. Table 1 also provides information on Amazon star ratings and the number of reviews each book had.

Table 1

Participants' Ratings and Rankings of Children's Picture Books that Support Children with Autism through a Significant Loss or the Death of a Loved One or Pet

Death/grief-specific book title	Author and date of publication	Participants' book ranking ^a	Participants' book rating ^b <i>M (SD)</i>	Amazon ratings and reviews ^c	
				Star rating	No. of reviews
<i>I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs</i>	Arlen G. Gaines & Meredith E. Polsky (2017)	1	4.58 (.90)	4.8	26
This book provides children with autism or other special needs with an explanation of death. It includes answers to questions that the child might have with straightforward text and clear illustrations.					
<i>I Miss You: A First Look at Death</i>	Pat Thomas (2000)	2	4.08 (.67)	4.4	226
This book provides children with information to help them understand death and to help normalize their experience with grief. The book can be used for the death of a close friend or family member.					
<i>Missing Mommy</i>	Rebecca Cobb (2013)	3	3.69 (1.18)	4.6	13
This book is about a child's experience following the death of their mother and the emotions that the child feels. It focuses on the recognition that the child still has their family's support and love.					
<i>I'll Always Love You</i>	Hans Wilhelm (1985)	4	3.75 (.97)	4.2	184
This book is about a boy's friendship with his dog and her eventual death. The story explores the grief of the family and the ways in which the boy copes with the death.					
<i>Saying Goodbye to Lulu</i>	Corinne Demas (2004)	5	4.00 (.71)	4.7	73
This book is about a young girl experiencing the death of her pet dog, Lulu, who was her best friend. The story explores their friendship, the time leading up to Lulu's death, the death of Lulu, and the ways in which the little girl remembers Lulu after her death.					

Table 1 (continued)

Death/grief-specific book title	Author	Participants' book ranking ^a	Participants' book rating ^b <i>M (SD)</i>	Amazon ratings and reviews ^c	
				Star rating	No. of reviews
<i>When Your Grandparent Dies: A Child's Guide to Good Grief</i>	Victoria Ryan (2002)	6	3.92 (1.04)	4.5	82
This book is about the death of a grandparent. It depicts the days before and after the death, explores the meaning of death and heaven, ways to stay close to the deceased grandparent, and questions for discussion.					
<i>Sam's Dad Died: A Child's Book of Hope about Loss</i>	Margaret M. Holmes (1999)	7	3.33 (.89)	4.5	4
This book is about a child's experience with the death of his father and the ways in which he copes with his loss to ease the pain.					
<i>Remembering Crystal</i>	Sebastian Loth (2010)	8	3.00 (.74)	4.7	7
This book is about the death of a friend, the grief process her surviving friend goes through, and ways in which friendship continues afterwards.					
<i>Jim's Dog, Muffins</i>	Miriam Cohen (1984)	9	3.15 (1.21)	3.1	5
This book is about the experience of first-grade students whose classmate (Jim) has experienced the sudden death of his dog. The story explores how the students try to help Jim and how they come to understand the grief process he's experiencing.					
<i>Always by My Side</i>	Susanne Kerner (2013)	10	2.77 (1.01)	4.8	24
This is a story about the death of a father and the experience of growing up without his presence. It explores the ways in which the father remains in the child's life and how they can always remember him.					
<i>Where Are You? A Child's Book About Loss</i>	Laura Olivieri (2007)	11	3.17 (.83)	4.4	58
This book is about a child who lost a parent, and wonders where they are now that they have passed. Different explanations are given as to where the father could be, and how he can still be a part of the child's life.					

Table 1 (continued)

Death/grief-specific book title	Author	Participants' book ranking ^a	Participants' book rating ^b <i>M (SD)</i>	Amazon ratings and reviews ^c	
				Star rating	No. of reviews
<i>Lifetimes: The Beautiful Way to Explain Death to Children</i>	Bryan Mellonie & Robert Ingpen (1983)	12	2.69 (1.25)	4.3	221
This book is about beginnings and endings in life. It provides children with an explanation of life and death, and it includes examples of the deaths of plants, animals, and people.					
<i>The Old Dog</i>	Charlotte Zolotow & James Ransome (1995)	13	2.77 (.93)	2.1	3
This book is about a child's friendship with his dog, the aging of the dog, and the dog's death. The story explores the boy's confusion and emotional pain following the death and the ways he comes to terms with his grief.					
<i>The Tenth Good Thing about Barney</i>	Judith Viorst (1971)	14	2.08 (.64)	4.4	118
This book is about the death of a pet cat. The child tries to remember good things about the cat and to accept the passing of his beloved pet.					
<i>The Dead Bird</i>	Margaret Wise Brown & Remy Charlip (1958)	15	1.85 (1.14)	3.8	18
This book is about a group of children who find a dead bird outside. Feeling sad about the bird's death, they decide to say goodbye and hold a funeral for the bird.					

^a Participants' ranking of books: 1= top ranked book; 15=lowest ranked book.

^b Participants' rating of books, based on a 1 to 5 scale: 5 = highest rating; 1 = lowest rating.

^c An average of online marketing Amazon's consumer ratings are based on a 1 (lowest rating) to 5 (highest rating). Information is also provided about the number of reviews each book received on the website [<https://www.amazon.com/>].

CHAPTER 5

Discussion

This study examined the perceived effectiveness of stories that could be used for bibliotherapy with children with autism to support them in the grief and loss process. This is an important issue to address, because children with autism often have social and emotional deficits that make it difficult for them to navigate through their grief and understand how to respond appropriately (Bartolini, 2015). Following a death or a loss, those affected generally experience significant changes in their routines, and individuals with autism experience difficulty with sudden changes in routine (American Psychiatric Association, 2013). These individuals may also experience difficulties with communication (Moseley et al., 2015). In communication with children with autism, they benefit from concrete and abstract-free language (Mesibov et al., 2005). If these communication and social difficulties are overlooked by parents or teachers, children with autism may feel isolated or disconnected from their peers and family (Bartolini, 2015). As children with autism are individuals who may have different reactions to situations in comparison to typical peers, it is important to keep their specific needs in mind (Koehler, 2016).

This study was conducted to learn what resources would be effective in supporting children with autism through the grief and loss process. Specifically, what selection factors, from parent and teacher perspectives, should be considered when identifying grief-themed books and stories and to learn what pre-selected books and stories were perceived by participants as being the most helpful in supporting children with autism through grief and loss.

From the overarching themes, as well as the cautions and warnings, identified in this study, there were some principles that we found especially interesting. The first was the need to individualize the use of supportive stories for each child. While participants agreed on selection

criteria that would overall be beneficial for children with autism, they emphasized that each child will have unique needs. This may include their developmental abilities, the types of pictures used in the books, and the manner in which death and possibly the afterlife is discussed. It is important to understand the child as an individual prior to selecting a story for them (Gray, 1992, 2003).

Participants identified having concrete, simple, and structured stories as an important selection criterion in the identification of supportive stories. For children with autism, it is important to avoid abstract themes within a book (Mesibov et al., 2005). Participants discussed the potential stress that children may experience if they did not understand the permanence of death. In both the wording of the stories and in the language that practitioners and parents use with children, it is vital to be straightforward and direct. Rather than using euphemisms or language that might be considered more “kind,” it is important to use direct and consistent language, such as “died” and “dead” (Mesibov et al., 2005; Sormanti & Ballam, 2011). Consistency and simplicity in language helps children gain a better understanding of what has occurred.

Another important principle is making sure that the selected stories are sensitive to family beliefs (Walker & Hathaway, 2013). Prior to selecting stories, the reader, if they are not a member of the child’s family, should assure that the book aligns with the family’s beliefs. When selecting books that mention the afterlife or what happens to a person after they die, readers should avoid stories that contradict family beliefs (Heath, Nickerson, Annandale, Kemple, & Dean, 2009). Participants further mentioned that if a family has a desire to provide their child with books that are more centered around their beliefs, it may be beneficial for them to look for these materials at a bookstore that specializes in that specific doctrine.

Another principle we found important is the need to help normalize what children are experiencing (Haine et al., 2008). As death is not an everyday experience for most, and since children with autism may experience difficulties in understanding their emotions, in the changing of their routines, or in communicating their experience, it is beneficial to help them understand that their experience is something that can be expected (Wolfelt, 2002). Ceremonial aspects of grief and death, such as funerals, may be a new experience for children with autism. Children may become distressed due to their own emotions or when observing others who are displaying strong emotions (Sormanti & Ballam, 2011). Because of this, children will benefit from learning about how others commonly express grief. Children who are not displaying emotions or who are delayed in their emotional processing will benefit from having this advance understanding. Discussing emotions and emotional expression in advance also helps to normalize the experience.

Additionally, we found the concern on focus on replacement of the deceased to be important. Participants expressed concern that books that focused on replacement may prompt the child with autism to believe that they can simply replace the person or pet that has died instead of allowing them to process and cope with the loss. Participants shared that a heavy emphasis on a replacement could lead a child with autism to fixate on finding a replacement figure for their deceased loved one. This caution was primarily focused on animal books with pet replacement, but may likely generalize to humans as well.

In the following sections, we explore the implications of this study as they apply to practitioners and teacher and to the parents of children with autism. We also address the possible limitations of this study. Following this, we will conclude by addressing possible implications for future research.

Implications for Practitioners and Teachers

One of the most important things for practitioners and school staff working with the child to keep in mind is to individualize treatment for every child with autism. As every child with autism is different and every experience with death and loss is different, it is vital for those working with these children to be aware of their individual needs. During the book selection process, the practitioners should be aware of the child's developmental level, in order to select a story that is developmentally appropriate for the child or to adapt the story in a way that the child will best understand it. This research has identified three main themes, each with subthemes, as well as cautions and warnings, for practitioners to utilize in the selection of books for bibliotherapy for children with autism. Practitioners can use these themes to guide their selection, however, they should also keep the child's unique situation and needs in mind during the selection process.

Communication between practitioners and families is also very important. In order to best help the child and their family, and to better understand the needs of both the child and the family, practitioners should maintain an open line of communication with the family about materials being used to support the child. Families may have certain beliefs or opinions about death and an afterlife, and it is important for the practitioner to verify that the information that is being shared with the child will not contradict these beliefs and opinions. If the story will be shared with more than one child, such as in a group or classroom setting, the practitioner should extend the line of communication to the other children's families as well, in order to respect and understand the desires of those families as well in regard to the type of information provided.

Practitioners should also bear in mind that their support of the child with autism should extend to not only helping them understand the death or loss they have experienced, but to help

them understand the emotions they or others around them may experience and how to cope with these situations. While the practitioner may only work with the child for a short period of time, the child may need continued support. The grief process is something that an individual may revisit throughout their lifespan (Worden, 2008). Due to this, practitioners may need to provide the child with support again in the future or refer the family for additional levels of support.

Appendix I includes a summary of this study's findings. Practitioners may use this information as a handout that can be provided to school staff and parents. The information provided may assist these individuals in the selection of books to support a child with autism through the grief and loss process.

Implications for Parents

It is important for parents of children with autism to understand that death and grief are topics that should be addressed and not ignored. While these are difficult topics to discuss, particularly with children with special needs, it is beneficial to support the child through the process. Children with autism may experience difficulty with communication or show a delayed or seemingly "inappropriate" response to the death or loss, and they would benefit from the support of their parents in navigating this new experience. Furthermore, if parents are themselves prepared for the challenges their child with autism will be experiencing, they will be more able to understand what their child responds the way that they do. One strategy that would be beneficial for parents is to read a carefully selected book with their child, allowing the child to prepare for these challenges, to learn about the emotions that they or others may experience, and to begin an open line of communication about death and grief with the child.

Having these communications with a child may feel uncomfortable to parents, as they may feel unsure about what to share with their child or how to talk with them about death and

loss. Prior to reading the supportive story to the child, parents could read through the material on their own. This would provide them with the opportunity to determine if the book can be individualized to meet the needs of the child. By pre-reading the stories, parents will also be able to think about questions that their child may have when reading the book and they may gain an understanding of how to approach the conversation with their child.

Limitations

This study had some limitations. One of these limitations was the availability of participants. The individuals who participated in this study were interested in the use of supportive stories to help a child with autism through the grief and loss process, but they did not have extensive expertise in the area of bibliotherapy or children's literature. Further, these participants did not have much prior experience in the utilization of supportive stories with children with autism as a teaching method. Our rationale for using this sample of participants was the fact that they each had experience working with children with autism, allowing them to provide insight into how a child with autism might react to the provided material, and they were interested in the use of bibliotherapy with these children.

The study was also limited by the researchers' limited knowledge concerning the functional abilities of the children who were associated with the participating parents and teachers. The school in which the focus groups were conducted serves children who exhibit a range of functional ability levels. Participants were not asked to share information related to the functional abilities of their children. Therefore, during the rating and ranking of the books, it is possible that participants made selections based on their children's specific needs and abilities. This is especially pertinent when considering selections that were made in relationship to the children's language skills and levels of functional communication.

Another limitation of our study was the small sample size. We elected to complete this study at a school that specializes in addressing the needs of children with autism. Recruitment information was sent to all Kindergarten through 3rd grade teachers to correspond with the use of picture books. From this, eight teachers volunteered to participate in the study. Focus group participation information was also sent to parents of Kindergarten through 3rd grade students. From this, five parents volunteered to participate in the study. Due to the small overall sample size of thirteen participants, the perceptions that are summarized in this study may not adequately or accurately represent the perceptions of all teachers and parents of children with autism.

During participation in the focus groups, group member influence may have influenced individual perceptions. Although participants were encouraged to share their thoughts and opinions about the books, the perceptions of one participant may have influenced the opinions of other participating members. Despite this possible limitation, focus groups have been shown to promote open and engaging conversations in which varying opinions are welcomed and expressed.

Implications for Future Research

This study did not address the actual use of children's books to support children with autism following or preparing for a death or a loss. Further research that involves using bibliotherapy with this population of children and the result of this use would be a valuable contribution to this subject. These future studies could benefit from using the identified stories from this study and using them to support children with autism who have experienced or may experience the death of a loved one or pet. This research could also examine how the use of these stories improves communication with the child, how they prepare the child for upcoming

challenges associated with the death or loss, and how they support the child in understanding emotions.

Another study that could be conducted would be a focus group with children with autism who have previously experienced the death or loss of a loved one. This would allow researchers to gain insight from an individual with autism on what would have benefited them during their experience, and to examine the differences between these individuals and the teachers and parents from our study on what aspects are important in the identification of supportive stories. Additionally, researchers may consider having both the individual with autism as well as their family members participate in the study, in order to see what family members may perceive as beneficial based on their child's previous experience. We now hope that other studies will be conducted that focus on using supportive stories for children with autism experiencing a death or a loss.

Conclusions

For any child experiencing grief, their limited life experience may not have prepared them for coping in constructive ways (Berns, 2004). This is especially true for children with autism, who have the additional challenge of social and emotional deficits that may cause them to experience difficulty in navigating through their own grief and in responding appropriately to the emotions of others (Bartolini, 2015). Bibliotherapy offers a cost-effective and research-based method of supporting these children through the death of a loved one or pet. It allows the reader and the child to have an open conversation on the subject of death and loss, and it allows the child to learn more about what they are experiencing. This study's findings will assist practitioners, teachers, and parents in understanding how to select supportive stories to help a child with autism through the death of a loved one or pet.

This is a subject that should be directly addressed with children with autism. If no action is taken and if the subject is not addressed, the child may experience further difficulty with understanding their experience. By providing supportive adults and children with these materials and with information about death and loss, both parties become better prepared to handle and face the challenges that will undoubtedly come with a death or loss. Facilitating conversations will also help the child to understand the experience of others, and it may allow the supportive adult to understand the child's experience. By promoting this process, the child can gain a deeper understanding of what has occurred and they will be able to begin moving forward in the healing and coping process.

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APPENDIX A

Semi-Structured Focus Group Protocol**Guided Discussion Questions****Pre-Discussion**

Establish rapport
 Provide meal
 Review research study
 Explain Consent Form
 Explain 4 Sheets to be completed after discussion
 Answer any questions

Signed consent form from participant _____
 (1 copy of Consent Form remains with participant)

Part A: Reviewing books

Start audio and video recordings
 Show empathy
 Express appreciation

Thank you so much for participating. I realize this topic isn't always the easiest to talk about. If at any time you need to take break, redirect questions that might be uncomfortable, or end participating in the focus group, please let me know. We can stop at any time, if needed.

Invite the participants to review the 15 children's books.

Present hard copies of the books and give the participants a chance to review them (approximately 50 minutes). Allow and encourage participants to take notes about the different aspects of the books that they believe would or would not make that item a good supportive resource for a child with autism who has experienced a significant loss or the death of a loved one or pet.

Our goal today is to have a discussion about these books. We would like to discuss the different elements in the books that make the book either a good choice or a poor choice for supporting a child with autism after a significant loss or the death of a loved one or pet. As you may not be familiar with these books the time is now yours to read and review each of these books. Please feel free to take notes on the paper provided on things you liked or did not like, etc., for reference during group discussion. You will have approximately 50 minutes to view the books before our discussion. Are there any questions?

Part B: Guiding discussion questions

Begin group discussion about the materials that have been reviewed (approximately 1 hour).

Let's start with a general question—

- *After reviewing these materials, are there any that you have used before?*
 - *What did you like about the material?*
 - *How did the child react to the book?*
- *Of all the materials reviewed, which do you think would be a helpful supportive resource for children with autism experiencing a significant loss or the death of a loved one or pet?*
 - *What are the strengths of these materials?*
- *Is there anything we should be cautious about when using a particular material?*
 - *Why/what would make you not use these materials?*

Think back over our discussion today—

- *Did you see any overarching themes? What features were common between the best materials for supporting children with autism through the grief and loss process?*
 - *Are there any books or materials that we have already discussed that you would like to make additional comments about?*
 - *Do any materials have strengths that were not previously mentioned?*
- Think back, are there any methods or activities you have previously used that were not talked about today that you have used to support children with autism through a significant loss or the death of a loved one or pet?*

Part C: Ratings, Rankings, Demographics, and Compensation

Following the focus group discussion, participants will complete 4 separate sheets.

- (1) They will individually rate each book on a Likert Scale of how effective the book would be in supporting a child with autism through a significant loss or the death of a loved one or pet.
- (2) They will rank all the books from 1-15, with one being the best choice and 15 being the worst choice material.
- (3) They will complete a demographic sheet.
- (4) They will complete the compensation sheet (optional) and provide a mailing address and indicate which 1 book will be sent following the study, as gratitude for their participation.

Ratings sheet from participant _____
(check for complete answers and legible handwriting)

Rankings sheet from participant _____
(check for complete answers and legible handwriting)

Demographic sheet from participant _____
(check for complete answers and legible handwriting)

Compensation sheet from participant _____
(check for complete answers and legible handwriting)

Wrap up

Ask the participant if they would be willing to review a transcript of the interview to ensure accuracy and make any corrections or modifications; if so, direct the participant to include their email address on bottom of the Informed Consent document.

Invite the participants to call and email with further comments or thoughts.

Thank the participant for their cooperation and remind them that we will be sending them 1 book in the mail, if they chose to receive that compensation.

APPENDIX B

Demographic Sheet

Please answer the following questions.

What is your age?

What is your ethnicity?

What is your gender?

What is your highest level of education received?

What county do you currently reside in?

What is your current occupation?

How many years of experience do you have with children who have autism?

Did you find yourself wishing we had more/different materials presented at the focus group?

Were there any materials that we did not discuss today that you have used/seen/think would be effective in supporting a child with autism through a significant loss or the death of a loved one or pet? If so, what are their titles?

APPENDIX C

Participant Consent Form**Consent to be a Research Subject**

Introduction

This research study is being conducted by Danielle Lewis (School Psychology Graduate Student) and Melissa Allen Heath (PhD, School Psychology Graduate Program Coordinator) at Brigham Young University to determine, through your knowledge and experience, what books best offer support to children with autism following a significant loss or the death of a loved one or pet. You were invited to participate because you are a teacher of children with autism or a parent of a child with autism and you have indicated interest in using bibliotherapy.

Procedures

If you agree to participate in this research study, the following will occur:

- you will verify that your child or student has been diagnosed with the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) by accessing student records (parents have the option of allowing their child's teacher to access the student records), and, if available, will provide the researchers with the student's IQ test scores, adaptive behavior scores, and communication/language scores
- you will participate in a focus group with four other participants (5 participants total) for approximately 2 hours discussing different materials and how much support you believe each would offer a child with autism following a significant loss or the death of a loved one or pet
- you will complete 4 sheets at the end of the focus group including a demographic questionnaire (asking about your background information such as age, gender, ethnicity, which county you reside in, and how many years of experience you have with children who have autism), a rating scale (asking you to rate the books discussed during the focus group on a 1 to 5 Likert Scale), a ranking scale (asking you to rank order the 15 books discussed), and an optional compensation form (offering you a gift of one book for study participation, which you can choose to have mailed to your home or to the school)
- the focus group will be audio and video recorded to ensure accuracy in reporting your statements
- a research assistant will take notes during the focus group to assist the data analysis process
- the focus group will take place in a classroom at the school
- you will be given the opportunity to review the transcripts of the focus group, which will take no longer than 30 minutes
- the total approximated time for the focus group and the completion of the forms is 2 hours total, and if you choose to review the transcripts, your total participation time will be 2.5 hours

Risks/Discomforts

Some focus group questions or discussion may prompt memories that trigger sadness, grief, or emotional discomfort. You may skip any question or discontinue participation at any time without penalty. Melissa Allen Heath (licensed psychologist) is supervising this study and is available to discuss concerns and referrals for counseling if desired. She will be present at the focus group and is available for you to contact following the focus group. Her contact information will be given to you (business card).



As discussion during focus groups will include personal opinions, extra measures will be taken to protect your privacy. The researcher will begin the focus group by asking the participants to agree to the importance of keeping information discussed in the focus groups confidential. She will then ask each participant to verbally agree to keep everything discussed in the room confidential and will remind them of this at the end of the group.

Sensitivity and caution will be used when discussing the topics of significant loss and death. Only the researcher team (primary researcher, co-investigators, and two undergraduate research assistants) will have access to the transcripts of the focus groups. The audio and video recordings will be deleted after all participants have been given the opportunity to check for accuracy (within three months of the tapes being transcribed). Hard copies and electronic copies of the transcripts and other data (contact information from the compensation, demographic questionnaires, and rating of the books) will be kept in a locked office inside a suite of locked offices. Any typed transcripts of the focus group and all other electronic data will be destroyed after three years.

Benefits

As a direct result of this research, you will have been exposed to resources that could possibly be used with children of autism who experience a significant loss or the death of a loved one or pet. You will have shared your thoughts and opinions on books and will have had the opportunity to hear the opinions of others. You may have the benefit of being able to use these resources in the future. A list of which materials were identified as being the most beneficial for children with autism experiencing grief and loss will be distributed to parent and teacher participants following the completion of the study.

Confidentiality

Names and other personal identification items will not be included in the transcribed portion of the focus groups or in any publications or presentations that result from this research. Unique pseudonyms will be used in order to protect confidentiality.

Electronic versions of the audio and video recordings and transcriptions will be kept on a password sensitive Google drive, only available to the primary researcher, co-investigators, and the undergraduate research assistants who are assisting with transcribing and data analyses. The audio and video recordings will be deleted after the participants have had a chance to check for accuracy (within three months of the tapes being transcribed). All other hard copy data (contact information from the compensation, demographic questionnaires, and rating of the books) will be turned into electronic data (through Excel and Word Documents), after which the hard copy data will be destroyed.

Transcriptions will be carefully reviewed by the primary researcher and the co-investigators. After the transcriptions have been carefully review, hard copies and electronic copies will be stored for three years.

Compensation

You will receive a light meal at the time of your participation in this study. You will also be compensated by receiving 1 book in the mail after the completion of your participation (optional). If you choose to withdraw from participation at any time during the focus group, you will still receive the book.



Participation

Participation in this research study is voluntary. You have the right to withdraw at any time or refuse to participate entirely without any impact to your child's education (for parents) or to your career (for teachers).

Questions about the Research

If you have questions regarding this study, you may contact Danielle Lewis at (970)646-2804 or daniellelewis_0913@msn.com or Melissa Allen Heath at (801)422-1235 or melissa_allen@byu.edu for further information.

Questions about Your Rights as Research Participants

If you have questions regarding your rights as a research participant contact IRB Administrator at (801) 422-1461; A-285 ASB, Brigham Young University, Provo, UT 84602; irb@byu.edu.

Statement of Consent

I have read, understood, and received a copy of the above consent and desire of my own free will to participate in this study.

Name (Printed): _____ Signature: _____ Date: _____

I agree to participate in a focus group. _____ (initial)

I agree to be audio recorded. _____ (initial)

Video can be studied by the research team for use in the research project. _____ (initial)

If you would like to review a transcript of the focus group to ensure accuracy of your statements and make any corrections or modifications please provide your email address:



APPENDIX D

Compensation Sheet

Thank you for your participation in this study! To show our gratitude for your participation today we would like to send you a gift of two books that were discussed at our focus group today. For parents, if you would prefer not to have the books mailed to you directly, you may choose to have the books sent to your child's teacher, and your child may bring home the book themselves. For teachers, if you would prefer not to have the books mailed to you directly, you may choose to have the books sent to you at your school address. *This is optional, you do not have to provide your name or address, and you do not have to receive any books.*

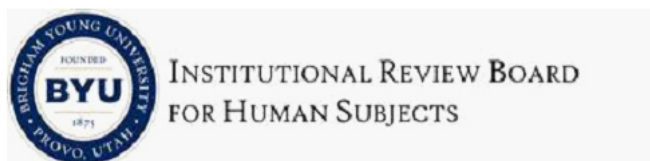
Please list the titles of the books you would like:

1. _____

2. _____

Please provide a mailing address to which we can send these books (or provide the name of the teacher who you would like the book to be sent to):

APPENDIX E

Institutional Review Board Approval Letter**Memorandum**

To: Danielle Lewis
Department: CP&SE
College: EDUC
From: Sandee Aina, MPA, IRB Administrator
Bob Ridge, PhD, IRB Chair
Date: September 27, 2017
IRB#: X17371
Title: *"Grief and Loss: Supportive Stories for Children with Autism"*

Brigham Young University's IRB has approved the research study referenced in the subject heading as expedited.

The approval period is from September 27, 2017 to September 26, 2018. Please reference your assigned IRB identification number in any correspondence with the IRB.

Continued approval is conditional upon your compliance with the following requirements:

1. A copy of the informed consent statement is attached. No other consent statement should be used. Each research subject must be provided with a copy or a way to access the consent statement.
2. Any modifications to the approved protocol must be submitted, reviewed, and approved by the IRB before modifications are incorporated in the study.
3. All recruiting tools must be submitted and approved by the IRB prior to use.
4. In addition, serious adverse events must be reported to the IRB immediately, with a written report by the PI within 24 hours of the PI's becoming aware of the event. Serious adverse events are (1) death of a research participant; or (2) serious injury to a research participant.
5. All other non-serious unanticipated problems should be reported to the IRB within 2 weeks of the first awareness of the problem by the PI. Prompt reporting is important, as unanticipated problems often require some modification of study procedures, protocols, and/or informed consent processes. Such modifications require the review and approval of the IRB.
6. A few months before the expiration date, you will receive a continuing review form. There will be two reminders. Please complete the form in a timely manner to ensure that there is no lapse in the study approval.

IRB Secretary
A 285 ASB
Brigham Young University
(801)422-3606

APPENDIX F

Institutional Review Board Amendment**INSTITUTIONAL REVIEW BOARD
FOR HUMAN SUBJECTS****Memorandum**

To: Danielle Lewis
Department: CP&SE
College: EDUC
From: Sandee Aina, MPA, IRB Administrator
Bob Ridge, PhD, IRB Chair
Date: August 17, 2018
IRB#: X17371
Title: *"Grief and Loss: Supportive Stories for Children with Autism"*

Brigham Young University's IRB has reviewed the amendment submitted on August 15, 2018. The IRB determined that the amendment does not increase risks to the research subject and the aims of the study remain as originally approved. The amendment has been approved. The revised consent statement has been approved and stamped for your files.

The approval of this protocol expires on **September 26, 2018**. All conditions for continued approval period remain in effect. Any modifications to the approved protocol must be submitted, reviewed and approved by the IRB before modifications are incorporated in the study.

IRB Secretary
A 285 ASB
Brigham Young University
(801)422-3606

APPENDIX G

Rating Sheet

Please individually rate each book on a Likert Scale (1 to 5), indicating how effective the book would be in supporting a child with autism through a significant loss or the death of a loved one or pet.

<u>Book Titles</u>	<u>1</u> (least effective)	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u> (most effective)
1. <i>Remembering Crystal</i> (Sebastian Loth, 2010)	1	2	3	4	5
2. <i>The Tenth Good Thing about Barney</i> (Judith Viorst, 1971)	1	2	3	4	5
3. <i>When Your Grandparent Dies: A Child's Guide to Good Grief</i> (Victoria Ryan, 2002)	1	2	3	4	5
4. <i>Saying Goodbye to Lulu</i> (Corinne Demas, 2004)	1	2	3	4	5
5. <i>The Dead Bird</i> (Margaret Wise Brown & Remy Charlip, 1958)	1	2	3	4	5
6. <i>Always by My Side</i> (Susanne Kerner, 2013)	1	2	3	4	5
7. <i>Lifetimes: The Beautiful Way to Explain Death to Children</i> (Bryan Mellonie & Robert Ingpen, 1983)	1	2	3	4	5
8. <i>I Miss You: A First Look at Death</i> (Pat Thomas, 2000)	1	2	3	4	5
9. <i>I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs</i> (Arlen Grad Gaines & Meredith Englander Polsky, 2017)	1	2	3	4	5
10. <i>Sam's Dad Died: A Child's Book of Hope Through Grief</i> (Margaret M. Holmes & Sasha J. Mudlaff, 1999)	1	2	3	4	5
11. <i>Where are You? A Child's Book about Loss</i> (Laura Olivieri, 2007)	1	2	3	4	5
12. <i>Missing Mommy</i> (Rebecca Cobb, 2013)	1	2	3	4	5
13. <i>I'll Always Love You</i> (Hans Wilhelm, 1985)	1	2	3	4	5
14. <i>The Old Dog</i> (Charlotte Zolotow & James Ransome, 1995)	1	2	3	4	5
15. <i>Jim's Dog, Muffins</i> (Miriam Cohen, 1984)	1	2	3	4	5

APPENDIX H

Ranking Sheet

Please rank order all of the books from 1 to 15, with 1 being the best choice and 15 being the worst choice material, based on that material being effective in supporting children with autism through a significant loss or the death of a loved one or pet.

Ranking	Book Title
_____	1. <i>Remembering Crystal</i> (Sebastian Loth)
_____	2. <i>The Tenth Good Thing about Barney</i> (Judith Viorst)
_____	3. <i>When Your Grandparent Dies: A Child's Guide to Good Grief</i> (Victoria Ryan)
=====	4. <i>Saying Goodbye to Lulu</i> (Corinne Demas)
_____	5. <i>The Dead Bird</i> (Margaret Wise Brown & Remy Charlip)
_____	6. <i>Always by My Side</i> (Susanne Kerner)
_____	7. <i>Lifetimes: The Beautiful Way to Explain Death to Children</i> (Bryan Mellonie & Robert Ingpen)
=====	8. <i>I Miss You: A First Look at Death</i> (Pat Thomas)
_____	9. <i>I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs</i> (Arlen Grad Gaines & Meredith Englander Polsky)
_____	10. <i>Sam's Dad Died: A Child's Book of Hope Through Grief</i> (Margaret M. Holmes & Sasha J. Mudlaff)
_____	11. <i>Where are You? A Child's Book about Loss</i> (Laura Olivieri)
_____	12. <i>Missing Mommy</i> (Rebecca Cobb)
_____	13. <i>I'll Always Love You</i> (Hans Wilhelm)
=====	14. <i>The Old Dog</i> (Charlotte Zolotow & James Ransome)
=====	15. <i>Jim's Dog, Muffins</i> (Miriam Cohen)

APPENDIX I

Summary of Study's Feedback

The following information summarizes feedback from the focus groups of parents of children with autism ($n=5$) and teachers of children with autism ($n=8$). Those who work with children with autism who experience a significant loss or the death of a loved one or pet may consider this feedback when they select books to best fit the child's needs.

Ranking of Children's Books

Considering books that helped to support children with autism experiencing the death of a loved one or pet, parents and teachers of children with autism ranked what they considered to be the "best" and "worst" books from a selection of 15 books.

Books rank ordered as best choices to support a child with autism through the grief and loss process

The following six books were ranked as the "best choices:"

1. *I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs* by Arlen Grade Gaines & Meredith Englander Polsky
2. *I Miss You: A First Look at Death* by Pat Thomas
3. *Missing Mommy* by Rebecca Cobb
4. *I'll Always Love You* by Hans Wilhelm
5. *Saying Goodbye to Lulu* by Corinne Demas
6. *When Your Grandparent Dies: A Child's Guide to Good Grief* by Victoria Ryan

Books rank ordered as the worst choices to support a child with autism through the grief and loss process

When compared to a selection of options (15 books), these books were cumulatively ranked as the "worst choices:"

1. *The Dead Bird* by Margaret Wise Brown & Remy Charlip
2. *The Tenth Good Thing about Barney* by Judith Viorst
3. *The Old Dog* by Charlotte Zolotow & James Ransome
4. *Lifetimes: The Beautiful Way to Explain Death to Children* by Bryan Mellonie & Robert Ingpen
5. *Where Are You? A Child's Book about Loss* by Laura Olivieri
6. *Always by My Side* by Susanne Kerner

Rating of Children's Books

Books rated individually on a 1 to 5 Likert scale

When rating books individually, and not comparing them to any other options, on a Likert Scale (1 to 5, with 1 being the lowest rating and 5 being the highest rating), the following list includes the books that were perceived as being effective in supporting a child with autism through the grief and loss process. This list includes the books with the highest cumulative ratings:

1. *I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs* by Arlen Grade Gaines & Meredith Englander Polsky
2. *I Miss You: A First Look at Death* by Pat Thomas
3. *Saying Goodbye to Lulu* by Corinne Demas
4. *When Your Grandparent Dies: A Child's Guide to Good Grief* by Victoria Ryan
5. *I'll Always Love You* by Hans Wilhelm
6. *Missing Mommy* by Rebecca Cobb

Focus Group Recommendations:

Important Things to Consider When Selecting a Book to Support a Child with Autism through the Grief and Loss Process

- Select books that will uplift and instill hope in the child
- Books should be simple, concrete, and structured
- The quality of illustrations in the book is important and the stories should be engaging
- Books should identify and teach about emotions and coping strategies
- Books should allow for individualization
- Be sensitive to family beliefs when selecting books
- Books should aid in preparation for challenges, facilitate communication between the child and the reader, and help normalize the child's experience
- Avoid books that focus too much on replacement of the deceased and books that overgeneralize information