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I Don't like the Talking Part: the Use of Videogames to Facilitate Grief Therapy for Adolescents with Autism Spectrum Disorder

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UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

I DON'T LIKE THE TALKING PART: THE USE OF VIDEOGAMES TO
FACILITATE GRIEF THERAPY FOR ADOLESCENTS
WITH AUTISM SPECTRUM DISORDER

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

Kyle Brent Johnson

College of Education and Behavioral Sciences
School Psychology

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This Dissertation by: Kyle B. Johnson

Entitled: *I Don't Like the Talking Part: The Use of Videogames to Facilitate Grief Therapy for Adolescents with Autism Spectrum Disorder*

has been approved as meeting the requirements for the Degree of Doctor of Philosophy in College of Education and Behavioral Sciences in Department of School Psychology

Accepted by the Doctoral Committee

Robyn S. Hess, Ph.D., Research Advisor

Michelle S. Athanasiou, Ph.D., Committee Member

Jeffrey A. Rings, Ph.D., Committee Member

Robin D. Brewer, Ed.D., Faculty Representative

Date of Dissertation Defense _____

Accepted by the Graduate School

Linda L. Black, Ed.D.
Associate Provost and Dean
Graduate School and International Admissions

ABSTRACT

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Adolescents with Autism Spectrum Disorder often experience difficulties interacting with peers and expressing their emotions, characteristics that may complicate their grief experiences. This qualitative study was designed to explore the experiences of four adolescents with ASD who participated in grief therapy facilitated through the use of videogames. Each participant engaged in 10 weekly grief counseling sessions. Participants and caregivers were interviewed prior to counseling, mid-way (participants only), and after completion of therapy. All counseling and interview sessions were video- or audio-recorded, and transcripts were created from these recordings. All data were analyzed and coded through the lens of the different periods of grief according to Lamb's (1988) process theory. These codes were analyzed for themes, and a cross-case analysis was completed.

Results from this study indicated that adolescents with ASD experience grief in a manner similar to their neurotypical peers, though on a longer timeline. The use of videogames seemed to facilitate participants' exploration of grief and death through the use of different characters in the game. The incorporation of videogames into more traditional therapy may assist adolescents with ASD to process their emotions associated with bereavement. Although these results are promising, additional research is needed to establish whether the use of videogames is a beneficial technique for use with adolescents who are experiencing grief over the death of loved one.

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CHAPTER I

INTRODUCTION

A few years ago, I had the pleasure of working at my university's counseling clinic where I first met Luke. Luke was a 14-year-old boy who was grieving the death of his grandfather. To make the counseling process a bit more complicated, Luke also had autism. During the intake, I found out that Luke had been having a lot of difficulty in school because he struggled to interact with other kids and control his anger. While Luke had been in counseling for a while, he was still having a lot of trouble, and his mother was not sure what to do, nor did I.

During my first meeting with Luke, I sat across from him, trying to engage him in conversation. He was looking down at the floor and only reluctantly talked to me. As I sat across from him, feeling the tension between us, I wondered how I was going to engage this grieving adolescent with autism in the counseling process. At this point, I had been trained only in client-centered therapy, and I could see that this type of therapy was not going to work for Luke. It wasn't the way that he processed his thoughts and feelings. As I grappled with this conundrum, I asked him about his previous experiences in counseling. Luke told me he really liked all the different activities that he had done, especially the games he had played. When I asked about what he didn't like, Luke quickly responded with "I don't like the talking part." It was with this statement that I knew I had to figure out a different way to approach grief therapy with individuals with autism.

Autism Spectrum Disorder

The number of children with ASD has been rising over the past decade (Baio, 2012, 2014). The most recent report from The Centers for Disease Control and Prevention (CDC) stated that an average of 1 in 68 children is diagnosed with autism spectrum disorder (ASD) (Baio 2014). As the name implies, ASD represents a variety of symptoms, and individuals with this disorder are placed on that continuum based on the severity of the impact on daily functioning. The symptoms required for diagnosis of ASD are specific to social communication impairments and restricted, repetitive patterns of behavior (American Psychiatric Association [APA], 2013). However, there are a number of associated difficulties. Individuals who experience greater levels of impairment (e.g., severe language difficulties or intellectual impairment) are generally considered to be lower functioning, while those who have lower levels of impairment (e.g., average to above-average abilities) are considered to be higher functioning, sometimes referred to as High-Functioning Autism (HFA) (Beglinger & Smith, 2001).

Regardless of whether individuals with ASD are considered to be higher or lower functioning, there are a range of difficulties that impact both their social interactions and social communication. Individuals with ASD experience difficulties with repetitive/stereotypical behaviors, social communication, and social understanding. The criteria for a diagnosis of ASD include deficits in social communication and social interaction (i.e., social-emotional reciprocity, nonverbal communication, and developing, maintaining, and understanding relationships) and restrictive and/or repetitive behaviors, interests, or activities (i.e., stereotyped or repetitive motor movements, insistence on sameness, inflexible adherence to routines, ritualized patterns of behavior, restricted

fixated interests, and hyper/hyporeactivity to sensory input) (APA, 2013). Adolescents with HFA experience these difficulties as well, though the difficulties tend to be manifested differently (e.g., poor understanding of emotions and social cues as well as limited ability to engage in social language) (Simpson & Myles, 2011).

Individuals with ASD also exhibit a restricted range of behaviors and/or interests (Buron & Wolfberg, 2008) and, consequently, experience difficulty adapting to change and transitions. Thus, many mental health professionals specializing in ASD focus on helping these individuals to cope with life transitions and to develop better adaptive skills (Baghdadli et al., 2012; Chang, Lung, Yen, & Yang, 2013; Giarelli & Fisher, 2013; Lawrence, Alleckson, & Bjorklund, 2010; Wehman et al., 2012). In fact, the need for sameness and the difficulty with understanding social situations have been shown to increase when adolescents with HFA are under stress (Chalfant, Rapee, & Carroll, 2006; Groden, Cautela, Prince, & Berryman, 1994; Kuusikko et al., 2008). For those who already have difficulty with adaptation and transitions, what could possibly be a greater transition in an adolescent's life than the death of a close friend or family member and the accompanying feelings of grief?

Grief and Loss in the Neurotypical Population

The experience of losing someone you love is a universal and unavoidable life event. Although all forms of loss are impactful, the death of a family member or close friend is an intense loss that can lead to the experience of grief, or the emotions associated with significant loss, and the process of dealing with these emotions (Bowlby, 1960; Lamb, 1988). It is estimated that in the United States approximately 2.5 million people die every year, leaving an average of five people (per deceased individual)

experiencing profound grief and bereavement (Shear, Frank, Houck, & Reynolds, 2005). Furthermore, according to the Social Security Administration (2000), 4% of children lose a parent before reaching the age of 18. Children and adolescents are not immune to the losses associated with the death of a loved one (Webb, 2011), but they conceptualize and process grief differently from adults, depending on their age and level of cognitive development (Silverman, 2000).

To gain understanding about an adolescent's grief, it is important to address the different terminology associated with grief. Bowlby (1960) defined grief as "the sequence of subjective states that follow loss and accompany mourning" (p. 11). The definition proposed by Kastenbaum (1998) for bereavement is very similar, but also includes that individual's experience of physical, psychological, and/or social stress due to the death of someone close. Researchers often refer to bereavement as the time period in which someone is dealing with the death of a significant person to the survivor, whereas grief refers to the emotional state of a survivor after the death of a loved one (Bowlby, 1960; Lamb, 1988; Stoebe, Hansson, Schut, & Stoebe, 2008).

The emotional states experienced after the death of a family member or friend can have a detrimental impact on children and adolescents. Individuals who experience grief at an early age (i.e., before age 18) are at risk of experiencing numerous social, emotional, developmental, and behavioral problems. Moreover, adolescents who have lost a parent are more likely to engage in criminal or careless behavior, demonstrate lower academic achievement, and perform lower on tests of cognitive functioning (Kastenbaum, 1998). Importantly, it is during the first two years following the death of a

loved one that children and adolescents are at highest risk for behavior problems and/or other psychiatric problems (Cerel, Fristad, Verducci, Weller, & Weller, 2006).

Higher levels of psychiatric problems is a common reaction experienced by grieving adolescents. For example, Worden (1996) reported that individuals under the age of 18 who have experienced the death of a family member have higher levels of anxiety and feelings of fear than do their non-bereaved peers. Adolescents who are experiencing grief reported difficulties in concentration, sleep disturbances, difficulty eating, uncontrollable crying, and headaches (Balk, Zaengle, & Corr, 2011). A study by Cerel et al. (2006) found that in the two years following a parent's death, the grieving child (aged 6 to 17) had higher levels of depression than did those in a non-bereaved control group. Although the bereaved group did not have levels of depressive symptoms as high as the depression control group, the bereaved group was at-risk for several psychological disorders including depression and anxiety. The risk of these psychological disorders was increased when the child and the child's surviving parent were under other stresses including low socioeconomic status, poor living conditions, and having feelings of guilt in the parent and child that were associated with the death.

Grieving adolescents, in particular, viewed their own academic performance and behavioral conduct as inferior to their peers (Worden, 1996). Worden (1996) also found that grieving adolescents believed that they had greater difficulty getting along with others than did their non-grieving peers. In addition, in their exploration of adolescents (ages 14 to 16 years old) coping after death of a loved one, Rask, Kaunonen, and Paunonen-Ilmonen (2002) found that the death of a family member or close friend sometimes leads to changes in adolescents' perspectives of themselves, others, their

relationships, life, death, and higher powers. This change in perspective can cause difficulty in maintaining current social relationships and creation of new relationships (Silverman, 2000) and may lead to withdrawal and/or engagement in risk-taking behavior (e.g., drug and alcohol use, criminal acts, and violence towards self or others) among adolescents (Noppe & Noppe, 2004).

Certainly, the negative effects associated with grief (i.e., lack of concentration, peer difficulties, risk-taking behaviors, or affective disorders) can increase the stress experienced by adolescents in the school setting. In recent years, there has been an increased focus on mental health in schools and an increase in the number of students receiving mental health service in schools (Colorado Department of Education, n.d.; National Association of School Psychologists [NASP], n.d.). School psychologists play an active role in the delivery of these mental health services (NASP, 2010), and school systems can provide significant support for not only grieving students, but also for their families, peers, and community (Heath, Nickerson, Annadale, Kemple, & Dean, 2009; Openshaw, 2011). With the focus on consultative services in the training of school psychologists, systemic support for grieving students is another area of mental health services that a school psychologist can provide (Merrell, Ervin & Gimpel, 2006; NASP, 2010).

Grief Support for Neurotypical Adolescents

As mentioned above, school psychologists are in the position to assist adolescents who are grieving and provide them with needed supports. To do this, they need to be aware that unresolved grief experienced in childhood may create emotional, social, and/or behavioral difficulties that can exist for years after the death of a loved one (Jones,

2001). Because it is impossible to protect adolescents from the stress, pain, and grief that accompany the death of a loved one as well as the disruption of their everyday lives they will experience in bereavement (Silverman, 2000), it is recommended that adolescents experiencing grief participate in some type of intervention (Jones, 2001). The most common interventions include different counseling techniques that give an adolescent the opportunity to confront issues surrounding the death and the emotions associated with grief, including group therapy, bibliotherapy, and play therapy.

Because those who are grieving often experience heightened levels of isolation and loneliness, grief counseling often takes place in a group counseling setting. This format is especially prevalent for adolescents receiving counseling services in school (Balk et al., 2011; Openshaw, 2011). Group counseling services have been found to be an effective means of helping adolescents cope with the stress of grief and to feel less ostracized and/or isolated (Burns, 2010; Chemtob, Nakashima, & Hamada, 2002; Finn, 2003; Jaycox et al., 2009; Salloum & Overstreet, 2008; Stubenbort & Cohen, 2006).

A technique that does not require a group setting, but that can help with feelings of isolation is bibliotherapy. Bibliotherapy is the use of books and/or stories to help individuals experiencing emotional or mental distress (Jones, 2001). Bereaved adolescents are encouraged to explore grief through a character in a story and, eventually, to safely express their own feelings (Berns, 2003; Lucas & Soares, 2013). This technique allows adolescents who are hesitant to share their own feelings about death and grief to talk about the character's emotions, rather than their own, and establishes a safe environment for the exploration of their own emotions associated with death and grief (Berns, 2003; Lucas & Soares, 2013).

Another technique to help children cope with grief and one that is increasing in its use with adolescents is play therapy (Carroll, 1995; Riviere, 2005; Webb, 2011). Play therapy is based on the belief that play is the language of children, especially at times when they are not able to verbally express themselves. It is a highly adaptable therapeutic technique that gives children the opportunity to use play to express their feelings, thus allowing them to have fuller expression than if they were required to discuss their feelings (Kottman, 2011). In their comprehensive review of the play therapy research, Bratton and Ray (2000) found evidence for the effectiveness of this modality on a myriad of different issues including: social maladjustment, conduct disorder, anxiety, autism, schizophrenia, self-concept, physical disability, learning disability, speech/language problems, sexual abuse/domestic violence, depression, post-traumatic stress disorder, attention deficit hyperactivity disorder, locus of control, divorce, and alcohol/drug abuse. Though more research was indicated, play therapy was shown to be effective in helping children in the areas of self-concept, behavioral change, cognitive ability, social skills, and anxiety (Bratton & Ray, 2000). More recently, a meta-analysis of 93 controlled outcome play therapy studies conducted by Bratton, Ray, Rhine, and Jones (2005) supported the effectiveness of play therapy and indicated that humanistic or non-directive approaches were more effective than directive treatments. The authors hypothesized that the significantly higher number of humanistic treatments used for this meta-analysis might have accounted for these apparent differences. The results of this study also indicated that play therapy was equally effective across gender, presenting issue, and age.

While the majority of research studies on the effectiveness of play therapy included younger children as participants (Bratton & Ray, 2000; Bratton et al., 2005), play therapists are beginning to use their techniques to help adolescents (Milgram, 2005). For adolescents, play regularly occurs and can be seen in their participation in sports or arts, computer and videogames, and card and board games (Milgram, 2005). The use of play as a form of communication allows adolescents to freely express and gain acceptance of emotions associated with grief (Reddy, Files-Hall, & Schaefer, 2005) which gives them an opportunity to develop a personal understanding of death and the loss they have experienced (Ayyash-Abdo, 2001; Webb, 2000). By allowing adolescents to direct their grief work and not evaluating this grief, a play therapist gives the individual the unconditional acceptance to fully process and progress through grief (Carroll, 1995; Webb, 2011).

Grief Reactions and Supports for Adolescents with Autism Spectrum Disorder

In contrast to the literature base for supporting neurotypical adolescents, there are relatively few studies that are specific to grief support services for adolescents with ASD. Few researchers have examined this topic, and those who have conducted research with this population have provided mainly anecdotal information (Allison, 2007; Forrester-Jones & Broadhurst, 2007; Hull, 2011). Adolescents with ASD have difficulties in areas that may cause them to have different reactions to grief than might be expected by a parent or mental health professional. That is, adolescents with ASD might have difficulty expressing their sadness or reaching out to others for support. Although this assumption seems to be a reasonable conclusion, currently there are no studies that examine the grief process in individuals with ASD. The possible differences that are experienced by

adolescents with ASD who are grieving should be taken into account when developing a plan to help them cope with grief.

The most effective techniques for helping adolescents with ASD deal with the stress, anxiety, and sadness associated with grief needs to be explored. One of the emerging areas of research includes an investigation of different ways of using stereotypical interests of adolescents with ASD in a therapeutic manner (Golan et al., 2009; LeGoff & Sherman, 2006; Wainer, Ferrari, Dautenhahn, & Robins, 2010). By using stereotypical interests that are linked to the client's restrictive and repetitive behavior, counselors are better able to facilitate and maintain a therapeutic relationship and are seeing an increase in the positive outcomes in therapy with adolescents who have ASD (Golan et al., 2009; LeGoff & Sherman, 2006; Wainer et al., 2010).

Many adolescents, both those with and without ASD, enjoy playing videogames (Ceranoglu, 2010; Hull, 2009). Given this nearly universal interest, the use of videogames as a therapeutic tool began in the 1980s, but, only recently have researchers started to focus on the potential benefits associated with the use of videogames in therapeutic sessions (Ceranoglu, 2010; Enfield & Grosser, 2008; Hull, 2009; Salonious-Pasternak & Gelfond, 2005; Yoon & Godwin, 2007). There is a growing body of research on possible uses of videogames in therapy, and preliminary results have demonstrated the effectiveness of this approach in helping children with disease management and social/emotional growth, increasing their awareness of the consequences of their behavior and choices, managing aggressive urges, and decreasing symptoms of emotional disturbance (Ceranoglu, 2010; Enfield & Grosser, 2008; Hull, 2009; Yoon & Godwin, 2007). Videogames may hold special promise as a technique for

working with youth with autism because they often represent an area of special, or stereotypical, interest.

Mental health practitioners generally consider the therapeutic use of videogames as a form of play therapy (Ceranoglu, 2010; Hull, 2009, 2011). In the present study, the videogames were used as both play therapy and as bibliotherapy because they followed the story and adventures of Harry Potter, a highly popular character in a series of novels. The themes of grief presented in this story provided a framework for the therapeutic process during the counseling sessions. It was believed that this framework would allow for adolescents with ASD to explore grief through the experiences of the characters and relate those experiences to their own. By adding the videogame aspect, it a level of interest was added to the counseling sessions, allowing for more interaction with the adolescent with ASD.

While counselors are beginning to understand the need for specific counseling techniques to be used with grieving adolescents with ASD, there is a significant lack of research on this topic. A search of PsychINFO and ProQuest research databases, leading sources for peer-reviewed journals in the field of psychology, found no published research studies examining effective therapeutic techniques that specifically focused on children or adolescents with ASD who were grieving. With the dramatic rise in the number of individuals diagnosed with ASD over the past decade (Baio, 2012, 2014) and the likelihood that these individuals will experience the death of a loved one before age 18, it is important to examine ways of helping them through this process. It is especially important when one considers the added difficulty that many adolescents with ASD experience with communication and sharing their emotions (Helbert, 2013).

Theoretical and Conceptual Framework

This study examined the use of videogames and bibliotherapy as mechanisms for delivering grief counseling to adolescents with ASD who were experiencing grief due to the death of a close family member or friend. Research on interventions for individuals with ASD indicated that those that use technology, incidental teaching, and/or play-oriented methods show promise as empirical intervention strategies (National Autism Center, 2009). In addition, there is research showing support for the use of bibliotherapy and/or play therapy techniques to help support children and adolescents struggling with grief (Berns, 2003; Reddy, Files-Hall, & Schaefer, 2005). This study combined these promising intervention techniques to examine a potential intervention for adolescents with ASD who are experiencing grief.

Because there is limited supporting research on how adolescents with ASD experience grief, I employed a qualitative research method. Qualitative research methods are used when a researcher is using an inductive, rather than deductive, process (Merriam, 2009). An inductive method enables the researcher to create theories or hypotheses from the collected data, which is an important feature when an existing literature base is not available. Furthermore, at any given time, there are only a few adolescents with ASD who are actively grieving, which, again, suggests the need for a more individualized approach to understanding their process.

While there are several specific methodologies within the purview of qualitative research, I used the collective case study methodology for this research. The purpose of a case study is to examine a bounded system or systems over time to gain a rich understanding of the experiences of the participants (Creswell, 2007). This process

allowed me to examine a phenomenon within its own context through a myriad of different lenses, developing a richer understanding of what was happening (Baxter & Jack, 2008). Case studies can be classified into different types, including: explanatory, exploratory, descriptive, intrinsic, instrumental, multiple-case, and collective (Stake, 1995; Yin, 2014). For this study, I used an exploratory collective case study design because of the limited amount of previous research and the ability of the collective case study design to provide rich detail about the experiences of the participants.

Statement of the Problem

There is a lack of knowledge about effective counseling techniques for adolescents with ASD who are grieving. With the increase of individuals under the age of 18 being diagnosed with ASD (Baio, 2014), it is likely that more adolescents who experience grief will also have a diagnosis of ASD. A number of studies have demonstrated strong support for services for adolescents with ASD to help them cope with life transitions, to understand their emotions, to self-regulate, and to develop coping skills (Baghdadli et al., 2012; Bauminger, 2002; Bauminger & Kasari, 2000; Giarelli & Fisher, 2013; Lawrence et al., 2010). Undoubtedly, these adolescents will experience the death of a loved one at some point in their lives and will need support to help with their acceptance of this loss. To date, there is a paucity of research related to how to help adolescents with ASD cope with this major change in their lives. Thus, further research in counseling techniques and strategies to help adolescents with ASD cope with the grieving process is necessary. Knowing the therapeutic techniques that are best suited to meeting the needs of youth with autism will allow school and clinic-based practitioners to effectively meet their needs. As noted, incorporating areas of interest such as

videogames and the character of Harry Potter may be especially relevant to grieving adolescents with ASD.

Purpose and Significance of the Study

The purpose of this qualitative collective case study was to describe the experiences associated with the use of a therapeutic technique for adolescents with ASD who are grieving. Specifically, the use of the videogames titled *LEGO® Harry Potter Years 1-4* (TT Games, 2010) and *LEGO® Harry Potter Years 5-7* (TT Games, 2011) (more discussion of the specifics will be addressed in Chapter III) were used as exploratory therapeutic tools to provide an opportunity for participants to engage in a form of grief therapy facilitated by the novels and videogames that accompany the Harry Potter stories. It was expected that this modality would reflect the specialized interests of many of the youth with ASD, that by focusing on the feelings of the character (i.e., Harry Potter), participants would be better able to identify the potential impact of grief and strategies for overcoming, and that this format for delivering therapy would allow adolescent participants with ASD to feel more comfortable in a therapeutic setting.

Research Questions

The primary research questions guiding this study follow:

- Q1 How do adolescents with ASD process their grief throughout the experience of grief therapy using the *LEGO® Harry Potter* videogames?
- Q2 What are the experiences of adolescents with ASD in grief therapy using the *LEGO® Harry Potter* videogames?
 - Q2a How do adolescents with ASD describe their experiences of exploring grief as facilitated by the *LEGO® Harry Potter* videogames?
 - Q2b What meaning do adolescents with ASD give to their grief throughout the process of participating in grief therapy using *the LEGO® Harry Potter* videogames?

Q2c What changes are observed in the behaviors of adolescents with ASD over the course of grief therapy using the *LEGO® Harry Potter* videogames?

Definition of Terms

Autism Spectrum Disorder is a disorder in which an individual demonstrates specific difficulty in the areas of social communication and repetitive/stereotypical behaviors. To be diagnosed with ASD, an individual must meet the following DSM-5 (APA, 2013) criteria: (a) deficits in social interaction and communication (i.e., failure of reciprocal communication, abnormal nonverbal communication, deficits in relationship building, and deficits in developmentally appropriate understanding of relationships); (b) engage in restricted and/or repetitive patterns of behavior (i.e., arm flapping, insistence on sameness, fixated interests, and sensory difficulties); (c) display of these behaviors and deficits during early development; and (d) evidence that these behaviors and deficits cause a significant impairment to the individual (APA, 2013).

Bereavement is the *situation* of dealing with the loss of someone significant through death. This time period is typically one of extreme stress for the surviving individual (Stroebe, Hansson, Schut, & Stoebe, 2008).

Bibliotherapy is a counseling technique using books and stories to help individuals who are experiencing emotional or mental disturbances (Jones, 2001). Bibliotherapy can be used to help children better understand their feelings, give them an opportunity to identify with characters experiencing similar situations, and increase a child's sensitivity to the feelings of others (Lesnik-Oberstein, 1994).

Grief, in this study, is defined as: (a) the emotional states that an individual experiences after a loss he or she considers to be significant; and (b) the process of

dealing with these emotional states, and coming to terms with life after the loss (Bowlby, 1960; Lamb, 1988).

Play Therapy is a counseling technique used with children of all ages. The tenets of play therapy state that play is a child's natural language, and it is through play that a child has the opportunity to better express her or his feelings and explore her or his personal emotional states. The purpose of play therapy is to provide a safe environment for a child in which to explore the difficulties and emotions she or he is experiencing, giving her or him the chance to develop insight, learn coping strategies, and experience healthy development (Kottman, 2011).

Videogames are a type of electronic game that is played using images on a video screen. These can be played using computers, consoles, or handheld devices. An important aspect of these games is that the individual uses controls such as a keyboard, hand-held control, or joystick to manipulate the images being displayed on the video screen. Examples of videogame systems include the Sony PlayStation 3, Microsoft XBOX 360, personal computers, and the Nintendo Wii (Videogame, n.d.a; Videogame, n.d.b).

Summary

The prevalence of individuals diagnosed with ASD has been increasing over the past few years (Baio, 2012; 2014). With this increase, the likelihood that some adolescents who have ASD will experience the death of a close family member or friend before the age of 18 is also becoming a more common experience. Adolescents who experience grief at an early age are at-risk for a variety of social, emotional, developmental, academic, and behavioral problems (Balk et al., 2011; Cerel et al., 2006;

Worden, 1996). Adolescents who have ASD may be at higher risk because of their difficulties in expressing themselves, connecting with others, navigating transitions, and using effective coping skills. Although many different therapeutic techniques (e.g., group counseling, bibliotherapy, or play therapy) have been used to help neurotypical adolescents who are grieving, there is very limited research specific to how these techniques might be modified and successfully used with adolescents with ASD (Forrester-Jones & Broadhurst, 2007). The purpose of this study was to describe and explore one such modified technique, the use of videogames and bibliotherapy, in the treatment of grief in adolescents with ASD. Specifically designed counseling sessions that incorporated the stories related to grief and loss within the *LEGO® Harry Potter Years 1-4* (TT Games, 2010) and *LEGO® Harry Potter Years 5-7* (TT Games, 2011) were used as the means of facilitating grief therapy with adolescents who have ASD.

CHAPTER II

REVIEW OF THE LITERATURE

In this review of the literature, I explore the literature related to the diagnosis of ASD with an emphasis on the experience of adolescents with ASD and different treatment approaches that have been used to address some of the social difficulties experienced by those with ASD. Understanding some of the challenges experienced by adolescents with ASD provides a framework for exploring the unique challenges of the grieving process among adolescents with ASD. This chapter ends with an introduction on the use of videogames as a therapeutic tool that may hold promise for facilitating the experience of grief.

Adolescent Experience of Autism Spectrum Disorder

Autism spectrum disorder (ASD) is characterized by impairment in the areas of social interaction and communication along with a restricted range of interests or behaviors (APA, 2013; Buron & Wolfberg, 2008). As the spectrum part of the name implies, ASD varies in presentation from individual to individual and ranges in severity (Newschaffer et al., 2006). Although researchers have intensely explored ASD over the last decade, very little is known about the causes of this disorder, though there does appear to be a genetic link (Newschaffer et al., 2006). Currently, there are no diagnostically informative biological tests for ASD, though research is being conducted into possible genetic testing (Herman et al., 2007; Lintas & Persico, 2008). The

diagnostic criteria of ASD are behavioral in nature, requiring observation and reporting of information for diagnostic assessment (Newschaffer et al., 2006). *The Diagnostic and Statistical Manual of Mental Disorders* (5th edition) (DSM-5) (APA, 2013) lists the essential diagnostic criteria of ASD as “persistent impairment in reciprocal social communication and social interaction (Criterion A), and restricted, repetitive patterns of behavior, interests, or activities (Criterion B)” (p. 53). The DSM-5 further explains that these symptoms must have been present during childhood and must cause significant difficulties or impairment in the individual’s everyday functioning (APA, 2013). To fully understand the diagnosis of ASD, it is important to look at the two main diagnostic criterion in the DSM-5 in detail.

Social communication and interaction difficulties are a required symptom in individuals diagnosed with ASD (APA, 2013). Specifically, an individual must experience deficits in the following three areas: (a) social-emotional reciprocity; (b) nonverbal communication; and (c) developing, maintaining, and understanding relationships. First, deficits in social-emotional reciprocity means that an individual has difficulty engaging in typical conversational patterns, has an awkward social approach/initiation, and rarely responds to the interests of others. Second, deficits in nonverbal communication include poorly coordinated use of verbal and nonverbal communication, lack of eye contact, lack of the use or understanding of gestures, and lack of facial expressions. Third, relational deficits may include one or more of the following: the inability to adjust one’s behavior based on social situation, lack of interest in peers, lack of understanding of typical relationships (e.g., not knowing why people

would be interested in being married), and difficulties engaging in developmentally appropriate social imaginative play (APA, 2013).

For adolescents with ASD, social deficits tend to occur in the areas of initiating social interactions and lacking understanding of others more so than in the areas of social sensitivity or interest (Bacon, Fein, Morris, Waterhouse, & Allen, 1998; Sigman & Ruskin, 1999). Adolescents with ASD frequently are in a spiral of wanting friends, but experiencing feelings of loneliness. These adolescents typically lack the social and emotional understanding and abilities to engage in relationship building to get themselves out of this spiral. Thus, this spiral may lead to feelings of depression (Bauminger, 2002; Bauminger & Kasari, 2000; Hobson, 1993; Wing, 1992).

The second key criterion in the DSM-5 diagnosis of ASD pertains to the restrictive interests and stereotypical behaviors seen in such children (APA, 2013). Although an individual does not need to meet all of these criteria, at least two must be present to a degree that it interferes with the daily functioning of the individual. Examples of these types of symptoms include: (a) stereotyped or repetitive speech, motor movements, or use of objects (hand-flapping, lining up of toys, echolalia, or stereotyped speech); (b) insistence on routines, inflexibility, or ritualized behavior (difficulties during transitions, changes causing distress, needing to eat the same thing in the same order, etc.); (c) highly fixated, restricted interests (knowing every make of washing machine ever made, focusing conversation exclusively on dinosaurs, etc.); and (d) hyper- or hypoactivity to sensory input or atypical interests in sensory stimulation (adverse response to textures or sounds, excessive touching or smelling of objects, atypical close examination of objects, etc.) (APA, 2013).

These types of behaviors can create more social difficulties for adolescents with ASD as they grow up (Bashe & Kirby, 2001; Klin & Volkmar, 2000; South, Ozonoff, & McMahon, 2005). For example, adolescents who display restricted interests often have difficulty talking to peers about any other subject. This consistent need to talk about their own interests to the exclusion of all other topics often annoys others and may lead to social conflict (South et al., 2005). Adolescents with ASD continue to have difficulty with social communication and understanding of nonverbal communication (Bauminger, 2002). As these forms of communication become more sophisticated in their typically developing peers, adolescents with ASD may be left behind and spend less time in peer interactions as they may not understand the more subtle aspects of the conversations (Bauminger, Shulman, & Agam, 2003). Studies have shown that adolescents with ASD report few, if any, friendships that include feeling close and the ability to share emotions (Howlin, 2003; Shattuck et al., 2007, Whitehouse, Durkin, Jaquet, & Ziatas 2009).

Adolescents who are severely impacted by this disorder are those who are experiencing the greatest impact to their daily functioning. These individuals may be completely nonverbal and have extreme difficulty in social situations. Adolescents in this lower range tend to withdraw from the world around them. They also frequently engage in repetitive and/or stereotypical behavior such as hand flapping or body rocking (D'Cruz et al., 2013). It is not uncommon for adolescents who are more severely impacted by ASD to also have an intellectual disability (ID). Comorbid rates of ID and ASD are estimated to be between 40% and 70% (Chakrabarti & Fombonne, 2005; Matson & Shoemaker, 2009; Yeargin-Allsopp et al., 2003).

On the other end of the autism spectrum are the adolescents who are considered to have high functioning autism (HFA). These adolescents are often very bright and have high-average to above-average intelligence. Unfortunately, they still experience difficulty with social communication similar to lower-functioning adolescents with ASD. Adolescents with HFA, while often highly articulate, tend to have difficulties understanding other people's beliefs and intentions (White et al., 2010) and engaging in the social aspect of communication (i.e., reading social cues, body language and facial expressions, reciprocity, and figurative language). Some research has shown that the social difficulties that individuals with HFA have increase during adolescence (Tse, Strulovitch, Tagalakis, Meng, & Fombonne, 2007).

Treatment of Autism Spectrum Disorder

Treatment of ASD tends to be focused on the increasing of social skills and decreasing repetitive or stereotyped behaviors that interfere with daily functioning. Other interventions include the development of social competence and coping skills though the treatment of these behaviors can be costly. It is estimated that children and adolescents with ASD cost 9 times more in healthcare expenses than neurotypical children and adolescents and 3 times more than children and adolescents with ID (Mandell, Cao, Ittenbach, & Pinto-Martin, 2006). Individuals with ASD typically require supportive services throughout their lifespan, possibly creating a financial burden for their families (Newschaffer et al., 2006). Many of these services include the use of behaviorally based education services. It is recommended that services address all core features and associated difficulties of ASD (National Research Council, 2001).

Intervention services can range from group work focusing on the development of social skills or the reduction of anxiety to discrete trial training (DTT) and functional communication training (FCT) to help develop more socially acceptable communication skills (Schmidt, Drasgow, Halle, Martin, & Bliss, 2013). Currently, there are no medical treatment options to reduce ASD symptomatology, but medication is used in the treatment of anxiety, hyperactivity/inattention difficulties, and aggressive and/or self-injurious behavior that all can be associated with ASD (Newschaffer et al., 2006). To better understand the effectiveness of these different interventions, the National Autism Center has developed a project to address the need for evidenced-based practices when working with individuals diagnosed with ASD (National Autism Center, 2009). Researchers examined a variety of intervention studies and rated the quality of the study as well as the effectiveness of treatment outcomes. Ratings for the interventions ranged from established, meaning that the beneficial intervention outcomes were supported by multiple well-controlled studies, to emerging, unestablished, or ineffective/harmful. Many of the established interventions were generally derived from the behavioral literature and included interventions that manipulated the events before a targeted behavior, ones that reduced problem behavior through basic behavioral principles, and interventions that incorporated applied behavior analysis techniques (National Autism Center, 2009).

Earlier efforts to establish the effectiveness of interventions for individuals with ASD (Simpson, 2005; Simpson et al., 2005) focused on categorizing the interventions into groups, depending on their focus: interpersonal relationship interventions and treatments; skill-based interventions and cognitive interventions and treatments;

physiological/biological/neurological interventions and treatments; and other interventions, treatments, and related agents. These interventions were then rated as either representing scientifically based practice, promising practice, practice for which there is limited supporting information, or not recommended. Scientifically based practices were those interventions that were determined to have significant empirical evidence of their efficacy (Simpson, 2005). Table 1 includes a list of all interventions evaluated by both the National Autism Center (2009) and Simpson et al. (2005) and their respective ratings (e.g., established or emerging evidence).

Table 1

List of Interventions by Designations

Established*	Scientifically Based Practice**	Emerging*	Promising Practice**	Unestablished/ Limited Supporting Evidence*	Not Recommended**
Antecedent Package	Applied Behavior Analysis	Augmentative and Alternative Communication Device	Play-Oriented Strategies	Academic Interventions	Holding Therapy
Behavioral Package	Discrete Trial Training	Cognitive Behavioral Intervention Package	Assistive Technology	Auditory Integration Training	Facilitated Communication
Comprehensive Behavioral Treatment for Young Children	Pivotal Response Training	Developmental Relationship-based Treatment	Augmentative Alternative Communication	Facilitated Communication	
Joint Attention Intervention	Learning Experiences: An alternative Program for Preschoolers and Parents	Exercise	Incidental Teaching	Gluten- and Casein-Free Diet	
Modeling		Exposure Package	Joint Action Routines	Sensory Integrative Package	
Naturalistic Teaching Strategies		Imitation-Based Interaction	Picture Exchange communication System	Gentle Teaching	
Peer Training Package		Initiation Training	Structured Teaching	Option Method	

Table 1 (continued)

Established*	Scientifically Based Practice**	Emerging*	Promising Practice**	Unestablished/ Limited Supporting Evidence*	Not Recommended**
Pivotal Response Treatment		Language Training (Production)	Cognitive Behavioral Modification	Pet/Animal Therapy	
Schedules		Language Training (Production & Understanding)	Cognitive Learning Strategies	Relationship Development Intervention	
Self-Management		Massage/Touch Therapy	Social Decision Making Strategies	Fast ForWord	
Story-based Intervention Package		Multi-component Package	Social Studies	Van Dijk Curricular Approach	
		Music Therapy	Pharmacology	Cartooning	
		Peer-mediated Instructional Arrangement	Sensory Integration	Cognitive Scripts	
		Picture Exchange Communication System		Power Cards	
		Reductive Package		Auditory Integration Training	
		Scripting		Megavitamin Therapy	

Table 1 (continued)

Established*	Scientifically Based Practice**	Emerging*	Promising Practice**	Unestablished/ Limited Supporting Evidence*	Not Recommended**
		Sign Instruction Social Skills Package		Scotopic Sensitivity Syndrome: Irlen Lenses	
		Social Communication Intervention		Art Therapy	
		Social Skills Package		Candida: Autism Connection	
		Structured Teaching		Feingold Diet, Herb, Mineral, and Other Supplements	
		Technology-based Treatment		Gluten-Casein Intolerance	
		Theory of Mind Training		Mercury: Vaccinations and Autism	
				Music Therapy	

Note: *As rated by National Autism Center;**as rated by Simon et al.

Interventions that were examined in these two studies were representative of a wide range of theoretical backgrounds (National Autism Center, 2009; Simpson et al, 2005), including behavioral, theory of mind, and developmental theories. As noted, the majority of interventions rated as established and/or scientifically based practice were based on behavioral modalities (National Autism Center, 2009; Simpson et al., 2005). One exception that was noted was naturalistic teaching strategies. This intervention was rated as established, but not based on behavioral theory. Naturalistic teaching uses stimulating environments, natural reinforcers, natural environments and activities, and child-directed interactions to teach functional skills (Cowan & Allen, 2007).

Within the categories of emerging and promising practices, there were many more diverse interventions. These designations were used to reflect interventions that showed positive outcomes, but did not have the scientific base to be considered established or scientifically based. Of specific interest to this study were those that included technology-based treatments (the use of computers or related technology to present instructional material), play-oriented strategies (interventions that use play to develop specific skills), and incidental teaching (interventions that provide instruction during activities that are tied to the participants' interests). These intervention strategies seemed to be a better fit for many adolescents with ASD because they meet individuals where they are and incorporate areas of interest to help keep them engaged in the therapeutic process. In addition, these interventions provide a model of support that is more conducive to working with an individual who is experiencing an emotional difficulty such as grief, rather than a behavioral deficit or excess.

Grief

Grief and loss are aspects of life that are universal and cannot be avoided.

Goodkin et al. (2001) defined grief by listing the cognitive states associated with it; “Grief includes depressed mood, yearning, loneliness, searching for the deceased, the sense of the deceased being present, and the sense of being in ongoing communication with that person” (p. 672). It is important to note that these definitions of grief use an inclusive format that describes the wide variety of different cognitive and emotional states that an individual can experience (Weiss, 2008). Grief is a very personal process, and people can react to it in a variety of ways (Fiorini & Mullen, 2006). While grief is individualized, different scholars have developed theories to give structure to the grief process.

Theories of Grief

There are many different theories and conceptualizations of the grief process. The most popular of these theories involves the work of Kubler-Ross, Wessler, and Avioli (1972) and is represented by Kubler-Ross’ five stages of grief (e.g., denial, anger, sorrow, bargaining, and acceptance). In the first stage of grief, denial, the central aspect is not a denial of the death, but more of a disbelief that the person who has died will not come home. The second stage, anger, emerges as the feelings of shock seen as the first stage begins to fade. This anger can present itself in many different ways. For example, an individuals can be angry at the person who has died, angry at themselves, or angry about not having enough time with the deceased. In experiencing the feelings beneath the anger, an individual enters into the bargaining stage, the third stage of the grieving process. During bargaining, an individual becomes lost in a sea of “what if” or “if only”

statements (e.g., What if I decided not to go to work that day?; If only I had one more day with them, I could tell them how much they meant to me.) (Kubler-Ross & Kessler, 2005). In moving from the bargaining stage to the depression stage, an individual transitions from thinking about the future to thinking about the present. It is during the depression stage that the underlying emotions that are covered by anger most acutely present themselves (Kubler-Ross & Kessler, 2005). The acceptance stage is the last stage in the Kubler-Ross five-stage theory of grieving. This stage is not about the individual embracing the death; instead, it is about accepting the new reality of life after the death (Kubler-Ross & Kessler, 2005).

Kubler-Ross' five-stage theory of grief is taught in medical schools and is cited by health experts as fact without empirical evidence for support (Prigerson & Maciejewski, 2008). Although this is a commonly accepted theory of grief, there are also other perspectives that may be beneficial to understanding the grief process. For example, Wolfelt (1983) stated that "grief is a process, rather than a specific emotion like fear or sadness; it can be expressed by a variety of thoughts, emotions, and behaviors" (p. 26). A process theory of grief was introduced by Lamb (1988) who conceptualized three periods of grieving that an individual goes through, beginning with the initial period.

During the initial period in Lamb's (1988) process theory of grief, an individual experiences a wide variety of cognitions and affect which, in turn, impact her or his behavior (Lamb, 1988). It is in this initial period that individuals experience feelings of shock, numbness, denial, anger, and crisis. These feelings allow an individual to experience the loss without being subsumed by the pain and sorrow involved; thus, this

period provides the time needed for individuals to develop coping mechanisms to help them deal with the meaning and implications of someone close dying (Lamb, 1998).

According to Lamb (1988), the purpose of the intermediate period of grief is to “experience actively the emotional states of grief” (p. 563). The emotional states of grief include: active grieving, intense searching, yearning, disorganization, and despair (Lamb, 1988). In this period, the individual experiences overlapping processes. First, one obsessively reviews the death. Individuals dwell and persevere on the circumstances surrounding the death of a loved one. Individuals develop many alternative hypotheses about what they could have done differently to create a more personally acceptable outcome. In conjunction with the obsessive recounting of the death, the intermediate period of grief brings an intense searching for meaning in the death or loss. For example, people may question their faith and look for answers to explain the death. They seek out new theoretical or theological perspectives, trying to make sense of the loss. Most individuals in this process continually put themselves in situations that trigger painful memories of their loved ones (Lamb, 1988), such as the constant revisiting of the site of a murder or car accident that resulted in the death. For many individuals, this period of the grief process is a time of low social support. Individuals typically try to limit contact with others and will spend time alone, actively experiencing the grief.

It is during the third and final period of the grief process that people begin to accept the loss of a loved one. Individuals make a conscious decision that there is no purpose or gain in dwelling on their loss. Individuals decide they must take active measures so that they will be able resume their life (Lamb, 1988). These active measures include self-renewal, self-recovery, and self-care. Individuals will reorganize and

reinvest in their continued life without the loved one. It is during this stage that individuals experience a return of their sense of humor, a return of enjoyment of activities avoided since the death, a development of new relationships and interests, and the ability to think about the loss without significant pain. There will also be a reduction in the amount of activity spent focused on the loss. This acceptance is not a process of moving on without the loved one or forgetting about them. It is a process of accepting the loss and processing the emotions that accompany it.

Although each of these theories (i.e., Kubler-Ross and Lamb) represents a slightly different perspective on the experience of grief, both view grieving as a process that changes over time. Furthermore, grieving is an experience that includes cognitions, behaviors, and emotions. For this study, Lamb's (1988) process theory was followed because it allows for a broader examination of the experiences of grieving, rather than focusing only on the specific emotions associated with grief which many adolescents with ASD may find difficult to identify, disclose, and discuss. When considering the grieving process in children and adolescents, there is another important element that guides the experience, and that is the developmental level of the individual. Depending on the children's age or developmental level, they might not be able to cognitively understand the meaning of death, they may not have the emotional vocabulary to express the loss, and they may struggle to find the supports needed to help rebuild their sense of self.

Grief in Adolescents

When discussing adolescents' grief, it is extremely important to consider their level of development. According to Shapiro (1994), "a child's attempts to absorb the loss and to adapt to the changes in the family system became interwoven with the developmental work of the child's stage of cognitive, emotional, and social development" (p. 101). Adolescents' current levels of cognitive and social/emotional development determine their ability to understand death and their ability to adjust in a positive manner. To gain a cognitive understanding of death, individuals must be able to realize the four aspects of death: universality, irreversibility, nonfunctionality, and causality (Aspinall, 1996). Universality is the idea that death happens to every living thing, and everyone eventually dies; it can happen at any time, with or without warning. Also, no matter what anyone does, death is permanent, irreversible. The nonfunctionality of death refers to the idea that once death has occurred, the body no longer functions. Finally, causality refers to an individual being able to accurately understand the causes of death and no longer believing in inaccurate causes (e.g., stepping on a crack will not break your mother's back, killing her).

Cognitive Development and Grief

Because an individual's cognitive developmental level affects her or his understanding of grief, it is important to consider the adolescent's current level of cognitive functioning. Several theorists have created theories explaining cognitive development including: Whorf's hypothesis, Quine's bootstrapping hypothesis, skill theory, sociocultural theories, core-knowledge theories, information-processing theories, and Piaget's theory (Berk, 2010; Fischer, 1980; Gentner, 2010; Lemerise & Arsenio,

2000; Nelson, 1996; Spelke & Kinzler, 2007). Although there is an abundance of theories of cognitive development, Piaget's theory is considered to be one of the most influential (Berk, 2010). Piaget's (1952) cognitive development theory explains how children's thoughts and abilities to reason change as they grow older. Piaget's theory has four stages: sensorimotor, preoperational, concrete operational, and formal operational. Most adolescents will be in the concrete operational to formal operational stages, and the relationship between these stages and grief are discussed below.

The third stage in Piaget's (1952) theory of cognitive development is the concrete operational stage and usually occurs between the ages of 7 to 11, but sometimes extends into early adolescence. During this stage, children's cognitive processes develop the ability to be much more organized, logical, and flexible (Piaget, 1952). They develop decentration (the ability to focus on several aspects of a problem, instead of just one) and reversibility. Children in the concrete operational stage also gain the ability to understand classification (hierarchical categories) and seriation (the ability to order objects based on quantitative attributes) (Hodges & French, 1988; Ni, 1998). While children have developed the capacity for organized, rational, and logical thought during the concrete operational stage of cognitive development, they are able to use these thought processes only with concrete, real-world information. Children in this stage of cognitive development usually do not work functionally with abstract ideas (Fischer & Bidell, 1991).

During the concrete operational stage, most children have developed the cognitive ability to fully understand death. They gain this understanding of death through exploration and asking questions (Webb, 2002). In this exploration of death, children are

able to express feelings about the potential positive gains they experience from the death (Silverman, 2000). Potential examples might be a girl who lost her sister and notes that now that she is an only child, she receives more attention from her parents or a child who has lost a grandparent is able to express relief that this individual is no longer in pain. Children at this stage will be able to identify these positive aspects, while still feeling grief over the loss. With their new knowledge about death and its full meaning, children in this stage of cognitive development speak about death in a more factual, rather than emotional way. They tend to comment on specifics regarding the death, versus their feelings of grief (Silverman, 2000).

In the beginning of adolescence, around age 11, children enter the formal operational stage according to Piaget's (1952) cognitive theory of development. During this stage, adolescents develop the ability to use scientific reasoning, understand abstract concepts, and systematically analyze thoughts and concepts (Venet & Markovits, 2001). One of the major developments in this stage is adolescents' ability to use hypo-deductive reasoning. This means that when adolescents are presented with a problem, they are able to solve it by first coming up with a hypothesis, and then isolating and combining appropriate variables to test the hypothesis (Berk, 2010). Adolescents also develop the ability for propositional thought, which is an individual's ability to examine and evaluate the logic of verbal statements without needing to reference the real-world circumstances that are associated with the statements (Osherson & Markman, 1975).

Adolescents in the formal operational stage of cognitive development have generally gained a full understanding of death and grief. They are able to talk more insightfully about their feelings. Adolescents are also able to hold and examine multiple

ideas and viewpoints at once, which allows them to better understand other people's behaviors during the grief process and how someone else might be acting differently while experiencing similar emotions (Noppe & Noppe, 2004; Silverman, 2000). While adolescents who are in the formal operational stage can fully understand death, grief during this time period can often affect cognitive development and current cognitive functioning. The experience of grief can create obstacles in an adolescent's transition to young adulthood (Balk, 1991). For example, a gifted teenager who experienced the death of a parent may become unable to complete simple academic assignments. Among youth who experienced the death of a parent, those whose loss occurred during early adolescence saw a more dramatic drop in their grades than did older adolescents (Gray, 1987). This type of cognitive regression has been observed by other researchers (Furman, 1974; Raphael, 1983). In addition, Balk (1991) stated that cognitive regression during grief experiences also affects adolescents' emotional and moral development, possibly creating long-term difficulties.

Social and Emotional Development and Grief

Though cognitive development is a key feature of an individual's overall development, it is also important to examine other areas of development. Erikson's (1950) psychosocial theory of development describes eight stages that a typically developing individual should pass through from infancy through late adulthood. Each of Erikson's psychosocial stages is defined by the crisis of two forces that are in conflict. During adolescence, an individual will typically be in the stage of psychosocial development called Identity versus Role Confusion (Erickson, 1950). During this stage, adolescents begin to be concerned with how others perceive them. Adolescents start to

consider what role they will play in adulthood, experimenting with different possible roles to create a lasting identity (Kroger, 2005). While adolescents have more cognitive skills than younger children do, the search for identity during this stage can undermine an adolescent's ability to think logically about death (Noppe & Noppe, 2004).

Adolescents' social and emotional development plays an important role in their understanding of and coping with the death of a loved one. During adolescence, individuals become better able to express feelings and discuss emotions of grief. Adolescents' ability to think abstractly allows them to explore relationships in deeper, more meaningful ways (Silverman, 2000). Also, adolescents tend to be social beings, they spend an increasing amount of time with peers, and the influence of their peers is greater (Mounts & Steinberg, 1995; Wentzel & Caldwell, 1997). Correspondingly, conflicts between parents and adolescents tend to increase, and time spent together decreases (Larson & Richards, 1991; Steinberg & Morris, 2001). While generally there is more conflict between parents and their children during adolescence, the death of a family member can create a vacuum in an adolescent's life (Silverman, 2000), causing withdrawal from others and/or engagement in risk-taking behavior (Noppe & Noppe, 2004). These behaviors can also be seen in adolescents who experience the death of a friend (Noppe & Noppe, 2004).

As children grow older and move into adolescence, the social focus of their world shifts from being on their parents to being on their peers. When adolescents experience the death of someone close to them during the Identity versus Role Confusion stage of development (Erickson, 1950), they may incorporate that loss as a key attribute of their identity (Markell & Markell, 2008). Experiencing grief and loss at this time in one's

social and emotional development makes an individual different from their peers. Being different in this way can be difficult for adolescents because they typically want to be like their peers. Adolescents separated from their peer groups can have difficulty moving through the grief process in an effective manner. They want to be a part of their peer group, but their feelings and thoughts about the grief experience separate them from their peers. This dichotomy may increase their levels of anxiety and isolation and, in fact, can be a form of “social death” for an adolescent (Noppe & Noppe, 2004, p. 154). Sterling and Van Horn (1989) suggested that adolescents experience the highest levels of anxiety about death during the peak of their struggle with identity creation.

People are social animals and look to others to learn socially acceptable behavior. Bandura’s (1977) Social Learning Theory explains that “most behaviors that people display are learned, either deliberately or inadvertently, through the influence of example” (p. 5), or modeling. Adolescents tend to use these models and combine them with their own cognitive process to determine what behaviors will most likely be rewarded in certain future circumstances (Bandura, 1977). Adolescents likely have little experience with the death of a loved one, so they look to their parents and other important adults to understand how to react (Berns, 2003). The model of grieving that adolescents learn from this social observation is typically the model they will use throughout adulthood (Shapiro, 1994).

Our social understanding and development allow us to create mutuality in close relationships. We use this mutuality to create socially adaptive selves that also maintain personal integrity. When a major stressor like the death of a loved one occurs, an adolescent’s ability to create this mutuality in relationships is impaired (Shapiro, 1994).

This can be a serious detriment to an adolescent's social and emotional development. In adolescence, the emotional reactions to loss can be devastating. Researchers have observed that grief reactions are significantly stronger in adolescents than in adults (Meshot & Leitner, 1993). Given the importance of social relationships in processing the loss of a loved one, it is important to consider how grieving occurs in individuals who have a limited ability to engage in these types of engagements with others.

The Grieving Adolescent with Autism Spectrum Disorder

Compared to their neurotypical peers, there is far less research on how adolescents with ASD grieve (Forrester-Jones & Broadhurst, 2007). Because of the limited research, it is important to consider the differences and difficulties adolescents with ASD may experience compared to their neurotypical peers. Adolescents with ASD have difficulty understanding social situations, have difficulty communicating effectively, and engage in stereotypical thoughts and behaviors. These difficulties may affect not only the individual's grief process, but also how other people view the adolescent during the grieving period. Although adolescents with ASD might experience grief differently, they generally proceed through the same process as an individual who is neurotypical, but on a different time table (Forrester-Jones & Broadhurst, 2007; Hull, 2011).

As mentioned previously, grief is a social process, and adolescents learn about grieving and the proper reactions to it through observations of the social world around them. Adolescents with ASD have greater difficulty picking up on social cues, including those of grief. Because of this, many people have long believed that individuals with ASD do not experience feelings (Conboy-Hill, 1992; Hull, 2011; Read, 2006). Of

course, this is not true, but these adolescents may not demonstrate or interpret social cues in the same manner that a neurotypical person might (Hull, 2011).

Adolescents who are neurotypical will often see how others around them are reacting to a death and attempt to behave in a similar manner, even though they might not understand what is going on. Adolescents with ASD, on the other hand, may have difficulty comprehending what is going on and may also have difficulty understanding appropriate ways of responding. Many adolescents with ASD experience mind blindness and alexithymia, or the inability to understand emotions and thoughts in others and emotions in themselves (Hull, 2011). Adolescents may become confused and fearful because of having to deal not only with their own grief and loss, but also with confusion about the social aspects of grief; thus, another layer of confusion is added, possibly increasing the amount of fear that the adolescent experiences (Hull, 2011).

Communicating about grief is difficult for both children and adults. Adults have difficulty expressing their feelings and also determining what they should share with a child about death (Webb, 2002). Adolescents often have difficulty expressing their emotions effectively, and the death of someone close to them is particularly difficult (Glazer, 1998). Adolescents who have ASD have difficulty communicating, in general, and in expressing and describing emotions, in particular (Helbert, 2013). Even though these adolescents are experiencing a wide range of turbulent emotions, they might appear to accept the death or not to care about it (Forrester-Jones & Broadhurst, 2007). Because of this outer exterior that appears to be calm, adolescents with ASD might not receive the support they need to help them deal with the emotions associated with grief.

Another feature of ASD is a certain rigidity in thoughts and behaviors. Thus, most adolescents with ASD do not handle changes in routine well and have difficulty adapting to new situations (Simpson & Myles, 2011). This rigidity has the possibility to make the grief process more difficult for them and generally increases the duration of the grieving period (Forrester-Jones & Broadhurst, 2007). Nationwide surveys of adolescents and adults with ASD conducted across England indicated that when individuals with ASD experience grief, they tend to experience an increase in the rigidity of their behavior as well as in their obsessions, fears, and resistance to change (Allison, 2007; Rawlings, 2000). Because the death of a loved one changes so many routines, an adolescent with ASD experiencing grief tends to cling tighter to any established routines that still exist. This behavior represents the adolescent's effort to have some sense of control at a time when he or she is feeling particularly vulnerable (Forrester-Jones & Broadhurst, 2007; Hull, 2011). While this type of coping mechanism is frequently seen with neurotypical adolescents, it is generally of greater intensity in adolescents with ASD (Helbert, 2013; Marston & Clarke, 1999).

Interventions Used with Neurotypical Adolescents Experiencing Grief

Adolescents who are experiencing grief can suffer from a wide range of negative consequences. They can experience detrimental effects in their adjustment, somatic complaints, lowered self-esteem, learning and concentration difficulties, and social difficulties (Dowdney, 2008; Kalter et al., 2002; Kaplow, Layne, Pynoos, Cohen & Lieberman, 2012). They will likely receive a variety of interventions from many different mental health providers, including schools, hospices, social service organizations, and individual practitioners (Rolls & Payne, 2003). Because of the

multitude of potential negative consequences of unresolved grief, therapists and counselors tend to use a variety of therapeutic techniques to help adolescents who are grieving (Rosner, Kruse, & Hagl, 2010). These therapeutic techniques often include bibliotherapy, group therapy, and play therapy (Rosner, Kruse, & Hagl, 2010; Webb, 2002).

Bibliotherapy

One common technique for grief therapy is bibliotherapy. Bibliotherapy has many definitions, but a common aspect of each of these definitions is the use of reading materials to bring about a change in the behavior or affect of an individual (Berns, 2003). Berns (2003) defines bibliotherapy as “essentially an interactive process whose goal is the understanding and expression of the self, utilizing the story as a vehicle to achieve that end” (p. 324). Bibliotherapy has also been described as the technique of using directed reading to guide individuals towards resolutions of personal problems (Howie, 1983). According to Garner (1976), an important aspect of bibliotherapy is the dynamic interaction between the reader and the text. This dynamic interaction is not a one-way interaction with the literature explaining concepts to the reader; rather, it is the interplay of the content and what the reader interprets. Readers have control over what they find important, and the literature is used as a guide (Garner, 1976).

Bibliotherapy has been shown to be effective in helping adolescents express thoughts, ideas, and feelings and to lessen feelings of isolation, increase a sense of companionship, gain insight into their own life situation, validate thoughts and feelings, and to develop creative and critical thinking (Berns, 2003). The use of bibliotherapy in grief therapy allows adolescents to use a third person (character in the book) as a vehicle

to discuss subjects that are uncomfortable (Berns, 2003). Reading stories about similar situations also allows adolescents to feel less isolated and fearful about their own lives (Pardeck, 1990; Timmerman, Martin, & Martin, 1989). In sum, bibliotherapy allows for identification (relating to characters in the story), catharsis (release of pent-up emotions), and insight (awareness of the adolescents' own difficulties and possible solutions for both themselves and the characters in the story), thereby aiding adolescents during the grieving process (Berns, 2003).

Peer Support Groups

Peer support groups, another grief counseling technique, can be used to help adolescents cope with feelings of grief and isolation from their peer group. Grief peer support groups are often used in school and clinical settings (Balk & Corr, 2001; Noppe & Noppe, 2004). A peer support group allows for feelings of acceptance and normalization of the emotions and thoughts associated with grief, especially in adolescents, allowing for a sense of belonging and identity with others who may be in a similar situation (Finn, 2003). Peer support groups have been shown to increase levels of self-esteem, which is an essential element in positive outcomes in a grieving adolescent (Balk & Corr, 2001).

In school settings, grief support groups are used for two different functions. The first is for an immediate response to trauma. Grief groups are created when a traumatic event has occurred that affects a large portion of the student body (e.g., school shooting, bus accident, tornado, etc.). The purpose of these peer support groups is to provide psychological first-aid quickly in response to a crisis (Balk et al., 2011; Openshaw, 2011). The second type of grief support group used in schools is the more traditional,

long-term group that allows adolescents to interact with others who have experienced similar trauma. Peer support groups focus on the strengths of the individual and the group, helping individuals to recover using natural support structures (Chen & Rybak, 2004; McNally, Bryant, & Ehlers, 2003).

Play Therapy

Play therapy is another counseling modality that uses natural interests and inclinations of children and adolescents and can be used to help these individuals cope with grief. While play therapy is traditionally used with young children, it is considered to be highly adaptable to the age or developmental level of children, their circumstances, and different treatment settings (Webb, 2011). While some mental health professionals may believe that adolescents are too old to engage in play therapy, there are a number of clinical reports that support the use of play therapy with this age group (Carroll, 1998; Cerio, 2000; Gil, 1996; Jernberg & Booth 1999; Ray, Bratton, Rhine, & Jones, 2001; Straus, 1999). The more relaxed play setting creates an ideal environment for developing a working relationship, especially with adolescents who are reluctant to participate in the therapeutic process or who do not want to talk about the difficulties they are experiencing (Milgram, 2005).

Play therapy can also be used to assess the adaptive functioning of adolescents. Adolescents' willingness to engage in therapy can be examined using imaginative play (e.g., sandtray), while their ability to express themselves can be explored using arts and crafts (Milgram, 2005). Games can reveal adolescents' social skills, power and control issues, feelings of self-esteem, and relationships with adults (Milgram, 2005), thereby generating information the therapist can use to make therapy more effective.

The techniques used in play therapy with an adolescent experiencing grief are varied. They can include the use of visual aids (e.g., empty bottle technique, pile of clay technique, and timelines), art (e.g., music, poetry, and photography), and expressive techniques (e.g., sandtray and drawing) (Kottman, 2011). Play therapy provides an opportunity for psychoeducation about death, release of emotions related to grief, and a nonjudgmental, safe relationship between the therapist and client. It allows for communication about grief and death in a nonthreatening way through the use of symbols, toys, and images (Reddy et al., 2005).

Grief Interventions with Adolescents with Autism Spectrum Disorder

Although the techniques listed above have been shown to be effective for neurotypical adolescents, there is limited research investigating how to help children and adolescents with ASD deal with grief (Forrester-Jones & Broadhurst, 2007). The information that is available comes from mental health practitioners' anecdotal evidence on what they have found helpful in their own practices (Forrester-Jones & Broadhurst, 2007; Helbert, 2013; Hull, 2011). Many of these reports have suggested the importance of working with adolescents at their developmental level which can be different than their same-aged neurotypical peers (Forrester-Jones & Broadhurst, 2007; Helbert, 2013; Hull, 2011).

Based on these clinical reports, a few important recommendations for working with individuals with ASD have emerged. The first of these is to make sure that mental health practitioners do not talk in abstractions (Forrester-Jones & Broadhurst, 2007; Helbert, 2013). Thus, it is important to use concrete phrases (e.g., "your grandpa died," not "you lost your grandpa"). The avoidance of euphemisms allows a mental health

practitioner to make sure that the adolescent understands that his or her loved one is dead. While these types of euphemisms can feel more comfortable to adults, they can be a source of confusion for children and adolescents with ASD (Forrester-Jones & Broadhurst, 2007; Helbert, 2013).

Another way to create clarity for adolescents who have experienced the death of someone close to them is to be truthful and factual about the death and the events surrounding it (Helbert, 2013). In her practice with adolescents with ASD, Helbert found that these individuals were better able to process the grief when they were told the truth about the death and felt free to ask questions. Also, adolescents with ASD should be allowed to express their thoughts and feelings about the death and the rituals or traditions associated with it (Forrester-Jones & Broadhurst, 2007; Helbert, 2013), thus, providing them the opportunity to feel they are a trusted and respected member of the family system (Forrester-Jones & Broadhurst, 2007; Helbert, 2013; Hull, 2011).

The use of stories is another recommended technique to use with grieving adolescents with ASD (Helbert, 2013; Hull, 2011). The stories can be either published stories (e.g., novels, short stories, and poems) or personal stories about the mental health practitioner's or caregiver's own experiences with death and grief (Helbert, 2013). The use of stories allows adolescents with ASD an opportunity to understand that both death and grieving are natural and normal. Stories can encourage conversations between the mental health practitioner and adolescents and questions from the adolescents which may help create a working relationship (Helbert, 2013).

When working with any adolescent, it is important to be patient while these individuals work to share their thoughts and feelings about death and grief. Rushing this

process can be particularly difficult for youth with ASD and can create stress and discomfort (Hull, 2011). If pushed too hard or too quickly, the emotions associated with grief can quickly overwhelm an adolescent with ASD. By being patient and empathetic and by creating a safe environment, practitioners can facilitate individuals' ability to feel comfortable to share their feelings and ask questions. Attention to pacing helps the mental health provider create an opportunity for adolescents to explore their own feelings and emotions about grief (Hull, 2011). A relatively new type of therapeutic tool, videogames, has been introduced and represents two of the modalities described above: play and story.

Videogames and Psychotherapy

A new method of giving adolescents these opportunities for exploration is videogame therapy. Videogames played on a console or on a computer are a relatively new form of media (Salonious-Pasternak & Gelfond, 2005). Even so, they have already established their importance in the everyday lives of many children and adolescents. Although some researchers are interested in the possible negative effects of videogames, there is a growing interest in how to use videogames to effectively relate to and teach individuals in a positive manner.

Videogames have been used to teach young people about medical procedures and have been incorporated into counseling sessions to help individuals in a myriad of different ways (Ceranoglu, 2010; Enfield & Grosser, 2008; Hull, 2009; Yoon & Godwin, 2007). With the increase in videogame play in youth, more mental health practitioners have been incorporating videogames into their work, though only a few have documented their experiences (Hull, 2009). Using videogames during therapy can help children

develop role play skills, imagination skills, self-regulation, emotional awareness, and create a better understanding of reality (Ceranoglu, 2010; Enfield & Grosser, 2008; Hull, 2009; Yoon & Godwin, 2007). Current research on the possible benefits of videogames in psychotherapy indicates that this approach can help mental health professionals develop working relationships with their clients (Ceranoglu, 2010). Many adolescents feel uncomfortable with traditional face-to-face psychotherapy. The use of videogames allows adolescents to assume a more comfortable position in therapy (sitting side by side, instead of facing the mental health professional) and may possibly decrease reticence (Ceranoglu, 2010).

Many adolescents including those with ASD enjoy playing videogames (Hull, 2011; Lenhart et al., 2008; Olson et al., 2009), and the use of the areas of interest of children and adolescents with ASD has been shown to be an effective therapeutic technique for a range of different issues (Attwood, 2007; Hull, 2011; LeGoff, 2004). The use of videogames may allow adolescents to connect their feelings, strengths, and weakness to a character, thus allowing a safe environment for the exploration of their grief (Hull, 2011). The possible benefits of the use of videogames in a therapeutic manner needs to be explored further using a more focused, empirical approach.

Summary

I began this chapter by discussing some of the difficulties of youth with ASD may experience during the adolescent period of development and the interventions used to help these adolescents navigate their social, emotional, and behavioral challenges. Although there are a number of interventions as related to treat the broad symptoms of ASD, there are few documented approaches specific to the treatment of grief in

adolescents with ASD. In fact, as I researched the general area of grief, I was surprised by the lack of recent studies, and the frequency of non-empirical writings about how individuals experience grief. However, using this existing literature and combining it with interventions that are commonly used with neurotypical adolescents experiencing grief, I have proposed that the use of a form of play therapy and bibliotherapy delivered through videogames might be used to help adolescents with ASD who are grieving the loss of a loved one.

CHAPTER III

METHODS

The purpose of this study was to explore the experiences associated with using videogames to facilitate grief therapy with adolescents with ASD. Because of the lack of research found on both how adolescents with ASD experience grief and the specific use of videogames by which to process their grief, a qualitative research design was chosen for this study. This approach allows for a deeper and more complete description of the experiences of each participant. This chapter provides a description of the research methods used for this study, the rationale for the chosen research design, my assumptions as a researcher including potential biases, as well as details related to participants, research procedures, instrumentation, and the data analysis plan.

Qualitative Research Design

Qualitative research is a broad term used to describe different methodologies that are employed to gain a deep and rich understanding of an issue, phenomenon, or experience. Van Maanen (1979) described qualitative research as “an umbrella term covering an array of interpretive techniques which seek to describe, decode, translate, and otherwise come to terms with the meaning, not the frequency, of certain more or less naturally occurring phenomena in the social world” (p. 520). Qualitative research focuses on gaining meaning and understanding through a rich description of the interaction of participants (Merriam, 2009). A main tenet of qualitative research is that it uses an inductive process, rather than deductive process. In other words, the purpose of

qualitative research is to gather data to create hypotheses and theories, rather than to use data to test established hypotheses and theories (Merriam, 2009).

Some of the most commonly used methodologies of qualitative research include narrative analysis, phenomenology, ethnography, grounded theory, and case study (Creswell, 2007). For my research, I used case study because I wanted to gain information about an issue that occurred within a bounded system. A bounded system can be a setting, a context, or a specific circumstance, as in this study—the experience of grieving. Creswell (2007) described a case study as:

A qualitative approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information (e.g., observations, interviews, audio/visual material, and documents and reports), and reports a case description and case-based themes (p. 73).

My purpose in carrying out this study was to explore the experiences associated with using videogames to facilitate grief therapy with adolescents with ASD. The focus on a specific population and specific counseling technique created a bounded system that was ideal to explore using collective case study methodology. In addition, the lack of research on how adolescents with ASD experience grief and how to help them through the grieving process also indicated the usefulness of a case approach because it would allow for a rich in-depth description of the experiences of the participants engaged in grief therapy as facilitated by videogames.

According to Crotty (1998), it is important for qualitative researchers to discuss their reasons for selecting the methodology and methods used in a study. Specifically, Crotty stated that researchers need to examine their theoretical structure, perspectives, and epistemology. In doing so, they have the opportunity to examine their assumptions

of the research project and how those assumptions might influence the current study. In the section below, I describe my research approach using Crotty's (1998) four elements of social research: (a) epistemology; (b) theoretical perspective; (c) methodology; and (d) methods.

Epistemology

Epistemology is the study of, and theories about, how individuals gain knowledge (Hofer, 2002). The epistemological framework used in this study was constructivism. As such, I believe that individuals create their reality and knowledge of that reality through their personal experiences in life. Our interactions with the world around us are the key points of learning and acquiring knowledge. As Crotty (1998) stated, "all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted with essentially social context" (p. 42).

Constructivism represented the best fit with my beliefs and understandings of how individuals gain knowledge of the world around them. In this study, I assumed that each adolescent had developed his own ideas about the meaning of death and the loss of his loved one. Further, the adolescent participants made their own meaning out of grief counseling using videogames. Finally, the interactions between adolescent participants and their families and with their counselors also resulted in unique experiences for each of the participants.

Theoretical Perspective

The theoretical perspective that I used is interpretivism and, more specifically, phenomenology. Interpretivism “looks for culturally derived and historically situated interpretations of the social life-world” (Crotty, 1998, p. 67). Phenomenology is the perspective of looking at “things themselves,” or as Crotty (1998) stated, “the phenomena that present themselves immediately to us as conscious human beings” (p. 78). He postulated that if researchers were able to lay aside their assumptions and basic understandings of the phenomenon, then a new understanding of the phenomenon would be possible or the former understanding could be authenticated.

I incorporated phenomenology as the theoretical perspective for this study because of the specific structure of grief, the way that individuals create their own meanings of grief, and the emotions associated with it. Phenomenology, as mentioned above, examines social interpretations of the world. Not only did this fit well with a constructivist epistemology, but it was also a good fit for this type of research because of the social nature of grief and the implications of being an adolescent diagnosed with ASD. The phenomenological theoretical perspective allowed for a detailed examination of the participants’ experiences. This perspective fit well with the purpose of this study, which was to gain greater understanding of the experiences of individuals with ASD in grief therapy using videogames.

Methodology

Collective case study was the methodology that I incorporated for this research study. Creswell (2007) described case study as “the study of an issue explored through one or more cases within a bounded system” (p. 73). This bounded system sets case

study apart from other methodologies. The bounded system is a setting or context that cannot be removed or manipulated by the researcher (Creswell, 2007). Stake (1995) referred to case study as a study of the specifics, details, and inherent complexity of a single case, the purpose of which is to understand what is happening within meaningful context and settings. Case studies can be divided into three different sub-categories: (a) instrumental case study; (b) intrinsic case study; and (c) the collective case study or multiple-case study (Creswell, 2007). According to Creswell, the collective case study methodology is used when the researcher is focused on a single problem, but chooses multiple cases to exemplify the problem. This allows the researcher the opportunity to describe different perspectives of the same problem. The amount of cases recommended to be used differs based on the data needed to gain a rich description and can range anywhere from two to hundreds of cases (Yin, 2014).

As mentioned, case study methodology allows for a deeper and richer understanding of a specific issue or problem within a bounded system (Creswell, 2007). The bounded systems that defined this case study were the specific use of participants that were adolescents with ASD and the specific counseling technique being explored, grief therapy using videogames and one set of games, in particular. By incorporating the collective case study methodology, I was able to gain a richer understanding of multiple experiences of bereaved adolescents with ASD through the technique, thus allowing for a deeper understanding of the problem as a whole.

Methods

The fourth and final element of social research are the methods. This element describes the details of what is happening during the study such as information about the selection of participants, sampling, research procedures, data collection, and data analysis. This element also details methods that are used to develop the trustworthiness of the study (Crotty, 1998).

Each of these components shaped my research interests in helping adolescents with ASD to process the death of a loved one. While the research approach described the “how” of my study, my personal experiences provided the “why.”

Researcher Statement

Grief and loss are very personal experiences that individuals work through in their own unique ways. Adolescents, especially, can react to grief in a myriad of ways. It was important that I remember this as I conducted this study and did not let my feelings or experiences with grief affect the results. When I was in high school, my father died. This event created strong feelings and beliefs about death, grief, and how to help adolescents through this process.

My father was diagnosed with carcinoid cancer when I was 8 years old. At that time, he was given six to eight months to live. I was unaware of this prognosis at the time because my parents wanted to protect me. My father was incredibly stubborn and, except for having many medical appointments all over the country, he showed no outward signs of having cancer. He appeared to be a very healthy man. Thankfully, the doctor’s prognosis was inaccurate, and my father lived for eight years after his original diagnosis.

For the first five years, my father showed no outward signs of the cancer and the damage it was doing to him. During that time, I would talk to peers about his cancer, but I would always frame it as something that was not a “big deal.” I had no idea that it was slowly killing him. I just thought cancer was something people sometimes had to deal with, but it was not something to worry about. During my freshman year in high school, he started to get worse.

As my father’s health deteriorated, my attitude toward school did as well. Throughout most of my high school years, I did the minimal amount of work to pass my classes. During that time, I would frequently miss school due to my own illnesses (e.g., flu, virus, and infections); I would also pretend to be sick. I did not get along well with my father during that time and frequently felt like nothing I could do would please him. During this time, my father participated in an experimental treatment as one of its first human participants. While the effectiveness of this treatment was eventually proven, my father’s cancer had already progressed too far for him to benefit. In the summer before my junior year in high school, my father’s doctor told us he would live for only another month or two. It was at this time that my mother engaged hospice services to help. My father died in October of my junior year.

The period of time after the death of my father was one that was incredibly chaotic for me. I was not interested in anything to do with school and did my best to avoid everything about it. My social relationships went through an upheaval; I withdrew from relationships with many individuals with whom I had been friends for years. Even though these individuals had been my friends before the death, I could not be around them after his death. My mother had me see a counselor once a week for individual

therapy to process my grief, but I was not ready to talk about anything and was very reluctant to engage in counseling. For the majority of the sessions, I would sit quietly, barely answering the counselor. I continually found reasons to miss the sessions until the counseling was canceled altogether.

In addition to individual counseling, I also received group counseling at my school. These sessions were attended by other students who had lost parents or siblings. Though I made jokes about the only reason I went was to get out of math class once a week, I found this technique to be a much better fit for me than individual counseling because of the lack of focus on me. This experience may have helped lead to my desire to find a more palatable individual grief counseling technique. The group counseling sessions were facilitated by the school psychologist who would lead us in discussions about different topics of grief. This experience also contributed to my pursuing a doctorate in school psychology. I wanted to help others as I had been helped.

During my graduate training, I had the opportunity to work with many children diagnosed with ASD, including those who are dealing with their own experiences with grief such as Luke, who was a student who I worked with during my graduate program. It is my experiences with Luke that helped me develop the idea for this research study. In addition, I have conducted interviews with parents, led social skills groups using LEGOs®, conducted ASD assessments, provided individual counseling, and have been a tutor/respite care provider. I have had fellowships working in autism assessment clinics, and was acting as a consultant on autism assessment and intervention for a large urban school district at the time of this study. I have spent hours individually interacting with

children on all ends of the autism spectrum. I greatly enjoyed the time I spent with them and plan to continue working with children who have ASD.

Because of these experiences, I have an understanding of some of the challenges experienced by individuals with ASD and their cognitive processes. That is, individuals with ASD sometimes see the world in black and white; they want to believe that there is one set of rules for how the world should be. While having background experience is important to any research study, I also needed to be aware of my own. I needed to be cognizant of how my previous experiences, both personal and professional, could shape the new information I was seeking. As noted, my personal theoretical perspective comes from a constructivist standpoint. I believe that each individual takes in information and, from that, they create their own truths about the world. Many adolescents with ASD would disagree with this perspective. They may believe in a rational truth, that there is only one correct answer. I needed to remain aware of this divergence in views and not try to let my perspective influence the information I gathered from the participants.

Methods

Participants

Using purposeful sampling techniques, efforts were made to recruit adolescents identified with ASD who were grieving over the death of a beloved person. According to Merriam (2009), “purposeful sampling is based on the assumption that the investigator wants to discover, understand, and gain insight and therefore must select a sample from which the most can be learned” (p. 77). I was able to successfully recruit four participants who ranged in age from 12 to 16 years old. All participants were considered to be in the adolescent period of development. In this stage, adolescents typically have

the ability to understand abstract concepts and to systematically analyze thoughts and concepts. Thus, it was expected that participants would have the ability to understand metaphor and relate their own experiences with grief to those experienced by characters in the videogame.

All four participants had received a previous diagnoses of ASD through the use of a comprehensive assessment including cognitive, social/emotional, behavioral, adaptive, and autism-specific assessment tools. All participants' guardians where asked to share with the lead researcher the results of this testing to evaluate its comprehensive nature. Most of these parents did not have easy access to the reports, and therefore the parent report of ASD plus the assessments given in making that identification were accepted as evidence of an ASD diagnosis. Information related to cognitive abilities was collected to assure that each participant had the capacity to understand the basic concepts of death and grief and were able to work with abstract ideas, thus, allowing them to be able to relate to the concepts that are typically a part of grief therapy. As cognitive testing is considered to be generally stable after early childhood (Burgaleta, Johnson, Waber, Colom, & Karama, 2014), individual cognitive tests after the age of 8 were accepted for this study.

In addition, all participants had experienced the death of a family member and each was perceived by their parents to be experiencing difficulty socially, academically, and/or emotionally beyond what they experienced as a result of their ASD. This difficulty had arisen since the death of the relative or when the participant found out about the impending death. Since grief occurs over time and is not something that an individual quickly resolves, I selected participants who were still experiencing the effects of grief, regardless of the timing of the loss.

Recruitment included a number of different strategies including providing detailed information about the study to local clinics that worked with individuals with autism, local counseling providers, local chapters of autism organizations (e.g., Autism Speaks), and parental support groups. The information given included my contact information, participant requirements, and basic information regarding voluntary participation. A sample letter to these organizations is shown in Appendix A, and a sample of the recruitment flyer is shown in Appendix B. All potential participants were contacted by the researcher, and an initial screening interview (see Appendix C) was conducted to ensure that each participant met all required criteria. To help increase retention in this 11-week therapy, participants' guardians received a \$10 gift card to a store of their choice at the end of the third, fifth, seventh, and ninth meeting and a fifth card at the end of the final meeting, for a total of \$50 in gift cards for each participant's family.

Videogame Intervention

I incorporated the use of LEGO® Harry Potter videogames (TT Games, 2010; TT Games, 2011) for this study for two reasons. The first was that the story of Harry Potter is filled with themes of death, grief, loss, and the power to overcome adversity (Rowling, 1997, 1998, 1999, 2000, 2003, 2005, 2007). The characters in the stories show that even though these situations are never easy, it is appropriate to talk about these experiences with one another and important adults. Because the characters are of similar age to Harry and his friends, they might serve as more relevant role models for the experience of grieving. The second reason I incorporated the Harry Potter videogames was that while the themes of death and grief are in the videogames, the games are not graphically

violent. When a character dies in the game, there is no explicit detail, and the LEGO® character just falls apart when killed (TT Games, 2010; TT Games, 2011). Each therapy room was set up with a television, Wii videogame console with a copy of both *LEGO® Harry Potter: Years 1-4* (TT Games, 2010) and *LEGO® Harry Potter: Years 5-7*, (TT Games, 2011), two controllers, drawing/writing material, and two chairs.

Procedures

After gaining approval from the University of Northern Colorado's Institutional Review Board (Appendix D), I began recruiting possible participants from the northern front range of Colorado and the Denver metropolitan area. Two participants were recruited through these methods. After exhausting sources in the northern front range of Colorado and the Denver Metropolitan area, I applied for approval from both the University of Northern Colorado's Institutional Review Board and the Baltimore City Public Schools (BCPS) Institutional Review Board to recruit participants in the Baltimore metropolitan area. After gaining approval from both agencies (Appendix D and E, respectively), I began recruiting by sending out emails and flyers to school psychologists working in BCPS (Appendix A and B, respectively). Two additional participants were recruited through this method.

Once I determined that a participant met the criteria for participation through the use of the screening interview (Appendix C), I set up an initial meeting in person with both the participant and the participant's guardian to complete the informed consent for research (Appendix D), the minor assent for research (Appendix E), and the initial semi-structured interviews. This meeting took place at the same time as the initial counseling session discussed below. The interview questions with the participant can be found in

Appendix F, and the interview questions with the participant's guardian can be found in Appendix G. Interview questions were developed with the input and review from an expert who specialized in working with children and adolescents with ASD and an expert in the field of play therapy and grief counseling. Interviews for the two Colorado participants were conducted by a research assistant who was an advanced graduate student in the field of school psychology. The interviews for the two participants in Maryland were conducted by myself. Both I and the research assistant had previous experience conducting semi-structured interviews through our graduate training and school/clinic-based experiences. After this part of the intake was completed, the counseling research assistant or I met with each participant and his guardian to discuss the counseling aspects of this project. Each interview was video recorded in order to create transcripts of the interviews for data analysis.

The intervention was delivered to each participant by one of three counseling assistants, and each was either a doctoral-level graduate student in the field of school psychology or counselor education or a practicing school psychologist. Each counseling assistant had a basic understanding of developmental disabilities, play therapy techniques, and working with individuals with ASD through doctoral-level classes or clinical/school experience. The counseling assistants all had demonstrated competency in beginning doctoral-level counseling courses or in their practice. The counseling assistants received training on the techniques to be used in this research study (discussed in detail in the Treatment Integrity section below). Each meeting with the counseling assistants was video recorded to create transcriptions for data analysis.

Because this research included a direct intervention, there were two levels of consent. Participants first agreed to be in the study (as described above) and then provided consent to conditions of the treatment as outlined in state statutes. The second half of the initial meeting focused on completing paperwork needed for counseling, including the approved permission forms that were consistent with the setting in which treatment would be delivered (e.g., HIPAA for clinic settings and FRPS for school settings). For each participant, the corresponding counseling assistant completed an intake with both the participant's guardian and the participant (Appendix H). This initial session provided them the opportunity to discuss with their participants an explanation of therapy and a typical session as well as to answer any questions.

During the explanation of therapy, counseling assistants discussed why the participant was coming to therapy and how these counseling sessions would concentrate on the use of videogames. The counseling assistants also used this time to discuss the format of a typical session. Two example explanations (one verbal and one using a pictorial explanation) of the sessions were developed, but only the verbal explanation was used and can be found in Appendices J. Throughout this initial meeting, the counseling assistants provided opportunities for the participants to ask questions about therapy in general and specific questions about the process.

The second meeting was considered to be the start of the grief therapy sessions. Each series of grief therapy session consisted of 10 50-minute sessions. The use of ten sessions was used after a review of the research determined that this was an average number of sessions. In addition, ten session was considered to be a good fit with the semester schedule of most public schools. The first therapy session started with the

counseling assistants transitioning the participants into playing one of the games. Which game to play and the specific section to play was decided by the counseling assistants using their clinical judgment based on the difficulties experienced by the participant and the period of grief. A sample of the matrix (Appendix K) of possible difficulties associated with grief in adolescence, related themes in the Harry Potter stories, discussion questions, and homework assignments were provided to each of the research assistants to facilitate their decision-making during counseling sessions. This matrix was organized by the three periods of grief as denoted by Lamb's (1988) process theory. The matrix lists different difficulties that an individual who is grieving might experience in each of these periods of grief. The matrix then gives a section of the Harry Potter story that relates to this difficulty. It then goes on to state the area of the videogames that correlates to this part of the story and some sample discussion questions and homework assignments that may be used to explore the difficulty that the individual is experiencing that is associated with grief. The information used for the creation of this matrix was gathered from resources on techniques for grief counseling with adolescents (Fiorini & Mullen, 2006; Helbert, 2013; Markell & Markell, 2008; Schonfeld & Quackenbush, 2010).

Once participants began playing the games, the counseling assistants used counseling skills (e.g., tracking, reflection of feelings, and paraphrasing) to comment on the play and the choices that were being made by the participant. During the videogame play, the counseling assistants also used the discussion questions provided in the matrix (Appendix K) to target specific grief issues. The discussion questions provided in the matrix were used as examples of starters that might be used to develop a dialogue

between the counseling research assistants and the participants. During videogame play, the counseling assistants also reflected on grief themes experienced by both the characters in the game and the participants. The videogame play was paused if more reflection or discussion time was needed on these themes based on the clinical judgment of the counseling assistants.

The last minutes of each session were devoted to a summary of the session and assignment of homework. Summary of sessions included a review of the important content from the current session. It was deemed important to conduct a summary of the session because it provides an opportunity to review progress and repeat important content to increase awareness in participants. A sample of possible homework assignments can be found in the counseling matrix in Appendix K and were linked to the themes explored during that week's grief therapy session. These homework assignments provided the participants with added time to reflect on the different themes of grief and death. Few homework assignments were actually completed by the participants, and counseling assistants often turned the homework assignments into discussion questions during the following session when homework was not completed.

Grief therapy sessions continued in this general format with the specific theme for the week having been selected by the counseling research assistant, usually based on the previous week or moving on to a new theme based on their clinical judgment. After the sixth meeting, a second participant interview was conducted. These were completed by either myself or the research assistant and consisted of the questions presented in Appendix F. At the end of the eighth meeting, after playing the videogame but before the summary/assignment of homework, counseling assistants were instructed to discuss the

ending of therapy with the participant. These discussions included an overview of how many sessions were left and about ending activities, ways to say goodbye to each other, and ways to tie the process all together during the final grief counseling session. A termination of therapy discussion also occurred in the tenth meeting during which counseling assistants worked with the participants to finalize their interest in types of ending activities.

The final meeting (11th), counseling session 10, began as the others had, with a review of the previous week's session. The counseling assistants and participants were then to engage in the ending activities upon which they had decided. The purpose of this activity was to create a remembrance of all that had been learned during the sessions and the progress the participant had made throughout the experience. It also provided a concrete ending for the counseling assistants and the participants, allowing them to work on any feelings of grief experienced by participants as related to the end of this experience. During the final meetings, all counseling assistants and participants choose to play the videogame, though the participants were allowed to choose the section to play, instead of being directed by their counseling assistant. During these final counseling sessions, the counseling assistants all discussed the progress made by their participant through the sessions and allowed the participants to discuss their feelings of the end of therapy.

Within two days after the final session, either myself or the research assistant attempted to meet with participants and their guardians to conduct a final interview (Appendix F and Appendix G, respectively). Only one participant's guardian was interviewed after this time frame. These interviews were conducted individually with the

research assistant or myself, meeting with the participant first and then meeting with their guardian. Interviews with the participants ranged in time from five to 20 minutes, while interviews with the participant's guardians lasted between 10 and 20 minutes. In addition to these interviews, interviews were conducted with the counseling assistants using the interview questions found in Appendix L. These interviews were conducted to gain an understanding of the counseling assistant's perspective of the therapy process and how the participants progressed through the sessions. These took place after the interviews with the participant and their guardians and lasted roughly 15 minutes each. Table 2 contains a summary of session foci, skills to be used during sessions, and indicators of when to switch to a different session focus. Table 3 contains reviews of the counseling and data collection activities completed during each meeting and the individuals involved.

Table 2

Session Summaries

Session	Focus	Skills	Indicators
Beginning sessions	Creating a working relationship. Themes of grief associated with initial period in the process theory of grief (see counseling matrix).	Attending behavior (i.e., active listening, attending body language; unconditional positive regard), tracking (i.e., what the participant is doing and what the characters in the videogame are doing), limit setting (e.g., if the participant is having difficulty transitioning away from the videogame), and restating content (i.e., paraphrasing participant statements).	Cognitions and behaviors that are impacting the behavior of the participant (e.g., shock, numbness, denial, anger, crisis, etc.).
Intermediate sessions	Themes of grief associated with the middle period in the process theory of grief (see counseling matrix).	Reflecting feelings (e.g., commenting on the emotions displayed by the participant), restating content, returning responsibility, interpretation, process comments, challenging, metacommunication (i.e., talking about the communication that is occurring), therapeutic metaphors (e.g., stories directly related to the participant's experiences), open-ended questions, teaching of new behaviors and/or skills through role-play, and facilitating understanding.	Intense searching, yearning, disorganization, despair, obsessive review, questioning of faith, purposeful triggering of painful memories, and isolation.
Termination	Themes of grief associated with the final period in the process theory of grief (see counseling matrix). Processing the termination.	Attending behavior, restating content, reflecting feelings, interpretation, tracking process, comments, metacommunication, open-ended questions, and facilitating understanding, making participant aware of how many sessions are left, processing participant's feelings about termination, creating an ending activity to provide closure to the participant	Acceptance, reinvestment in continued life, return of sense of humor, development of new relationships, and return of activities

Table 3

Meetings and Activities

Meeting Number	Counseling Activities	Research Activities	Individuals Needed
1	Counseling paperwork, Intake, and Explanation of Therapy	Research paperwork, and Initial Interviews	Participant, Participant's Guardian, Counseling Research Assistant*, and Research Assistant Conducting Interviews**.
2	First Grief Counseling Session	None	Participant and Counseling Research Assistant*
3	Second Grief Counseling Session	None	Participant and Counseling Research Assistant*
4	Third Grief Counseling Session	None	Participant and Counseling Research Assistant*
5	Fourth Grief Counseling Session	None	Participant and Counseling Research Assistant*
6	Fifth Grief Counseling Session	None	Participant and Counseling Research Assistant*
7	Sixth Grief Counseling Session	Mid-Point Interview with Participant	Participant, Counseling Research Assistant*, and Research Assistant Conducting Interviews**
8	Seventh Grief Counseling Session. Begin discussing the ending of therapy.	None	Participant and Counseling Research Assistant*
9	Eighth Grief Counseling Session.	None	Participant and Counseling Research Assistant*
10	Ninth Grief Counseling Session.	None	Participant and Counseling Research Assistant*
11	Tenth Grief Counseling Session. Engage in ending activities	Post-Intervention Interviews	Participant, Participant's Guardian, Counseling Research Assistant*, and Research Assistant Conducting Interviews**.

Note: *conducting counseling activities;**conducting research activities.

The counseling assistants who were not licensed received individual supervision from licensed psychologists. Supervision consisted of meeting with a licensed psychologist who had experience facilitating and supervising counseling sessions with adolescents and individuals with developmental disabilities. Supervision sessions consisted of bimonthly one-hour face-to-face sessions and occurred after the 2nd, 4th, 6th, 8th, and 10th meetings. During these sessions, the research assistants facilitating counseling and the supervisor discussed client progress, themes occurring in counseling, and future counseling plans.

Data Collection

The inductive nature of qualitative research demands the gathering of multiple sources of information using a myriad of different techniques (Creswell, 2007; Merriam, 2009). Collecting information from many different sources allows for triangulation, a strategy that compares and contrasts these different sources of information, methods, and/or perspectives of other investigators to increase the trustworthiness of the qualitative study (Denzin & Lincoln, 2005). According to Merriam (2009), the researcher is the main instrument for data collection and analysis during a qualitative research study. Through the use of interviews, direct observations, record reviews, documents, and artifacts, a researcher gains the data needed for qualitative analysis (Creswell, 2007). This research study used interviews, direct observations, and field notes. Data gathered from this research study was collected and stored in locked filing cabinets inside locked rooms at University of Northern Colorado's Psychological Services Clinic and Baltimore City Public Schools Central Office. All data collected in this study were accessible to myself and my research advisor. Different types of data were available to the various

assistants. For example, the counseling assistants had access to their therapy notes, but not the interviews. The research assistant had access to the interview data, but not the therapy notes. Finally, the two data assistants (doctoral students in school psychology) who transcribed sessions and interview in Colorado had access to all the video-recorded data for any particular case they were assigned. I transcribed the video-recording for the Maryland participants.

Interviews

Merriam (2009) classifies interviews into three groups (highly structured/standardized, semistructured, and unstructured/informal). The semistructured interview uses a series of predetermined questions to guide the interview process. These questions can be used in any order and should be open-ended. Although some of the questions might be asked of all participants to gain specific information needed for the study, the majority of the questions should be used as adaptable tools for exploration of the experiences of the individuals being interviewed (Merriam, 2009).

For this study, a research assistant or myself used a semi-structured interview method to gather information from participants, their guardians, and the counseling assistants. These interviews were video recorded. Participant interviews took place before starting the therapy sessions after the fifth counseling session, and after the final session (Appendix F). These questions were developed to gather information about their perspectives about the death they had experienced as well as their current experience of grief. They also provided insight to the participants' grieving process and their experiences in grief therapy using the LEGO® Harry Potter videogames (TT Games, 2010, 2011). Information from these interviews was used to understand the experiences

of participants before they started their grief therapy, during the sessions, and at the end of the sessions. By completing three interviews, I was able to explore the participants' progression through the therapeutic process.

Guardian interviews took place prior to the first session and after the last therapy session (Appendix G). These questions were also designed to gain an understanding about how the participants' behaviors had changed over the course of grief therapy using videogames. Interviews with the counseling research assistants occurred after the last counseling session (Appendix L). These questions were designed to gain another perspective on the experiences of the participants and their progression through the sessions.

Observations

Direct observations are a key aspect of data collection in a qualitative study. Observation as a research tool needs to be systematic, address a specific research question, and be subject to evaluation of trustworthiness (Merriam, 2009). In qualitative research, direct observations allow for triangulation of data collected in interviews and document analysis, provide an understanding of context, and describe behaviors that individuals are not comfortable discussing (Merriam, 2009). In this study, the counseling assistants observed the sessions as a "participant as observer," and I observed as a "complete observer" by the use of video recordings (Merriam, 2009, p. 124). According to Merriam, a "participant as observer" is an observer who is a member of the group being observed; their observation activities are known to the group, though these activities are subordinate to the responsibilities of being a group member. Merriam describes the "complete observer" as one who is not known to be observing by the

participants. Since the counseling assistants were also involved in the therapy sessions, their observations were recorded directly after each counseling session using the observation form in Appendix M. I reviewed each video recording of the sessions and used the same form (Appendix M). Observations from these sessions as well as the counselor assistant's observations were also used to confirm themes or to develop new ones as related to the guiding research questions.

The transcriptions were created by graduate-level students in the field of school psychology. The counseling assistants reviewed recorded sessions and completed play therapy session notes within 24 hours of the session. The play therapy session notes template were modified from the notes used by the University of Northern Colorado's Psychological Services Clinic. They were modified to create a document more in line with the use of videogames (for example, the removal of items associated with which toys the participant was choosing). A copy of the modified play therapy notes template can be found in Appendix N.

Field Notes

Field notes represent the information that was recorded directly after an observation session (Merriam, 2009). Field notes use the information and data that were recorded during an observation to create a detailed description of the session. It is recommended that these notes be both highly descriptive and reflective of the observer's experience (Merriam, 2009). Field notes in this study were used to gather further detail of the individual participants. Field notes were created by myself using completed observation forms (Appendix M) and video play therapy notes (Appendix N). Data from field notes further deepened the description of events and the feelings of observers.

Data Analysis

Data analysis is generally considered to be the least developed aspect of case study research (Yin, 2014). It is up to researchers to develop their own analytical strategy. Yin (2014) recommended that this strategy be developed using the “researcher’s own style of empirical thinking, along with sufficient presentation of evidence and careful consideration of alternative interpretations” (p. 133). To help researchers in developing their own analytical strategy, Yin (2014) provided four general strategies and five specific techniques that can be used. For the data analysis of this research study, I began by using the general strategy that Yin (2014) described as “developing a case description” (p. 139).

In the development of a case description, I created a descriptive history of each client’s grief process prior to the counseling sessions based on the interviews with their guardians and their own report. This descriptive history consisted of information gathered in interviews to create an understanding of the participant’s experiences with grief before the intervention. To further develop a thorough case description, I used a descriptive framework based on Lamb’s (1988) process theory of grief. A descriptive framework is a method of organization in case study that uses information from a review of literature to create a guide and structure for data collection and analysis (Yin, 2014). Each of the different periods of the grieving process was used to organize and categorize interviews, observations, and field notes based on how they “fit” into each of these stages. The initial stage of the grieving process, according to Lamb (1988), is associated with a variety of thoughts and feelings that allow the grieving individual time to develop coping skills, deal with implications of the death, and develop meaning. Data included in

this section included statements, reports, and observations of behaviors that indicated that the participant was feeling shock, was in crisis, was experiencing numbness, was in denial, and/or was protesting the occurrence of the death.

During the intermediate stage of the grieving process, an individual begins to actively experience the emotional states of grief (Lamb, 1988). Statements, reports, and observations that indicated that the participant was actively grieving were sorted into this section of the descriptive framework. This included feelings of yearning and depression, intense searching, obsessive review of the events associated with the death (“What could I have done differently?”), fantasizing about life without the loss, and disorganization. The final stage of the grieving process is marked by the decision to stop dwelling on the death and a beginning of resumption of life (Lamb, 1988). Data gathered into this section of the descriptive framework included statements, reports, and observations of behaviors that indicated that the participant was beginning to revive their sense of humor, reinvesting time and energy into activities previously ignored, focusing less on the death, experiencing a decrease in pain when thinking about the death, and a reduction of yearning, searching, and dreaming of alternatives.

To further develop the case description discussed above, I also created a timeline of events during the intervention process to develop a rich and deep case description. The descriptive history, descriptive framework, and timeline allowed me to gain a deep understanding of each of the individual cases. Once I had an understanding of the individual cases, I then moved on to the next stage of data analysis, which is the cross-case synthesis.

To start the cross-case synthesis section, I created word tables consistent with those described by Yin (2014). These are figures that “display data from individual cases according to one or more uniform categories” (p. 165). The uniform categories I used were based on my descriptive framework described above (i.e., Lamb’s (1988) process stages of grief). The word table incorporated the important aspects of each stage and allowed me to analyze these data for similarities and differences across cases. Through this process, I was able to develop over-arching themes.

The final step in the analysis was to take the themes found in the cross-case synthesis and examine all plausible rival interpretations and determine that all evidence was accounted for and attended to in the creation of these themes. It is important to examine as much data as are available to ensure the highest quality of data analysis (Yin, 2014). For this study, there was approximately 40 hours of video recording that were created into transcriptions, including intakes, counseling sessions, and interviews. In addition to attending to all available evidence, the detailed examination of rival interpretations also increased the quality of the data analysis (Yin, 2014). By including these two concepts in the data analysis, I increased the quality and trustworthiness of this research study.

Trustworthiness

Trustworthiness in qualitative research is demonstrated showing that the study has been conducted in a manner that generates valid data (Merriam, 2009). To accomplish this, a qualitative researcher must show through the depth of the information gathered, the methods used, and the methods of contending with the biased nature of the researcher to ensure that the study is of the highest quality. This can be accomplished in many

different ways including triangulation, expert review, peer review, and treatment integrity. Triangulation and peer review were used to increase the trustworthiness of the results of this study.

Triangulation

Triangulation occurred through gathering information from multiple sources including interviews of multiple participants, their guardians, and the counseling assistants, observations of the sessions, transcriptions of the sessions, and field notes. By gathering data from these different sources, I was able to gain a fuller understanding of the themes presented. By allowing for triangulation, I was able to see how new information fit with existing data. Another form of triangulation that was used for this study was multiple-case study design. By looking at the similarities and differences experienced by multiple participants undergoing the same therapy, I was able to determine if the results from one case were seen in the other cases.

Peer Review

Peer review was used in this research study to develop trustworthiness. Peer reviews, like expert reviews, provide outside viewpoints to ensure trustworthiness (Creswell, 2007). To effectively use peer reviews, Lincoln and Guba (1985) recommended that the peer reviewer challenge the researcher by asking difficult questions about methodology, interpretations, and meanings. By asking these difficult questions, the peer reviewer keeps the researcher on track and provides an outside opinion (Creswell, 2007). For this research study, I worked with one peer reviewer who was a recent doctoral graduate in the field of counseling psychology. This peer reviewer had knowledge about counseling theory and practice as well as qualitative research

practices. The peer reviewer received de-identified copies of the session transcripts to compare themes and interpretations with those of the researcher. I met with the peer reviewer during each phase of the data analysis for a total of three times. I kept journals of these meetings with the peer reviewer to follow changes in themes and interpretations.

Treatment Integrity

Because this research study included three different counseling assistants who provided the intervention, treatment integrity of individual sessions was assessed.

Treatment integrity refers to the concept that the intervention was carried out as intended and was comprised of three aspects: (a) adherence; (b) treatment differentiation; and (c) competence (Schoenwald et al., 2011; Waltz, Addis, Koerner, & Jackson, 1993; Yeaton & Sechrest, 1981). Adherence and treatment differentiation are closely related, with adherence meaning how well the counseling assistants followed the protocol of the intervention, and treatment differentiation describing the amount of difference between the intervention and other interventions. Competence refers to how skillfully the counseling assistants were able to carry out the intervention.

To help establish treatment integrity, each counseling assistant received training on the counseling techniques to be used during the grief therapy sessions. They met individually with the lead researcher to gain knowledge of the videogames being used, techniques used during grief therapy, the Harry Potter story, and the counseling matrix to be used in this study. During these meetings, they also engaged in role-play exercises to gain experience in using videogames as a therapeutic tool. To gain knowledge of the videogames being used, they spent time playing each game on each game system. They were given a tour of the game where different sections of the game were found and how

those sections aligned with the counseling matrix. The counseling matrix was reviewed and a description for how it should be used to help an adolescent process grief was provided. These training sessions lasted from two to three hours.

The counseling assistants also received access to resources to further develop their own understanding of grief therapy and the Harry Potter story. The counseling assistants received copies of *The Children who Lived: Using Harry Potter and Other Fictional Characters to Help Grieving Children and Adolescents* (Markell & Markell, 2008) to help them further develop their understanding of grief therapy for adolescents and the uses of stories to help adolescents process grief. To help increase their knowledge and understanding of the Harry Potter storyline, they were given access to the Harry Potter novels and movies, thus allowing them to research particular areas and themes as they related to the participants with whom they worked.

Observation of counseling sessions is considered to be one of the most common and beneficial ways to ensure treatment integrity. These observations are typically completed through the use of video recordings or observation through one-way glass (Schoenwald et al., 2011). To measure treatment integrity for this research study, I watched video files of each session and individually rated the treatment integrity using treatment integrity assessments created for the intake session (Appendix O) and the remaining sessions (Appendix P). The counseling assistant working with Bruce averaged a treatment integrity score of 86% per session. The counseling assistant working with Stephen averaged a treatment integrity score of 88%. The counseling assistant working with Wade and Peter averaged a treatment integrity score of 92% and 94%, respectively. The difference between the treatment integrity scores may have been due to the proximity

of the counseling assistant in Maryland to myself compared to the counseling assistants in Colorado.

Summary

This chapter provided an overview of qualitative research design and the specific elements of design used for this study including the epistemological framework, theoretical perspective, methodology, methods, and researcher stance. I provided personal and professional justifications for these choices. The methods used to provide the intervention and an outline of how counseling sessions progressed were reviewed. I provided details about data collection for this study and how treatment integrity was ensured.

CHAPTER IV

FINDINGS

This chapter provides a detailed description of four adolescents' experiences participating in grief therapy using videogames. Pseudonyms were developed and assigned for each of the participants. The pseudonyms were based on the secret identities of superheroes. In my counseling experience with adolescents with ASD, I often use a metaphor relating to superheroes, when the adolescent with ASD is having difficulty accepting their diagnosis and the difficulties associated with it. I tell these adolescents to think about superheroes and what makes them different from average people. We talk about how these differences are what makes them powerful. We then discuss what makes the adolescent different from their peers. I then relate these differences back to the differences of superheroes, discussing that the differences that the adolescents have can make them powerful, just like the superheroes. Each participant is introduced and his experiences are chronicled. This detailed examination of their experiences allows for the beginning of an in-depth understanding of each participant's personal process through the grief counseling sessions. The story of each participant's experience is given below.

Bruce

Bruce, a 12-year-old Caucasian male, was my first participant to complete grief therapy beginning on January 9 and finishing on April 24. He was diagnosed with ASD when he was a toddler and was currently attending a school that specialized in helping

students with this disorder. Bruce lived with his mother and brother. Bruce's father died in a motorcycle accident the summer before Bruce began his participation in this study. His mother expressed concerns about Bruce's lack of acknowledgement of his father's death and the increase in anger Bruce was displaying towards his mother and brother since his father's death.

Pre-intervention Interviews

Although the video recordings of the pre-intervention interviews malfunctioned, the research assistant's notes provided valuable information from his interviews with Bruce and his mother. The pre-intervention interviews took place at Bruce's school and were conducted individually by the research assistant. Both interviews were brief, with Bruce's lasting about 18 minutes and his mother's interview, 15 minutes. During his interview, Bruce displayed a great willingness to talk to the research assistant, especially about a topic of interest (Pokemon); however, he completely shut down when asked about his father's death. He refused to answer any questions related to death or his emotions. Bruce stated he "didn't want to talk about it," he "doesn't want to talk about death," and "I don't want to talk about Dad, I'm trying to forget him." At one point, he even ran out of the room to avoid talking about his father's death. Bruce's mother described the same behavior when she was asked about Bruce's response to his father's death. She told stories of displaying her grief and trying to engage Bruce in conversation about the accident. In response to these efforts, Bruce's response frequently was "Can you leave me alone?" His mother told another story about the Celebration of Life ceremony they had for Bruce's father. While Bruce came to the ceremony, he refused to stay for its entirety. Bruce left in the care of a school aide, saying he had to leave

because his preferred snack was not there. The way Bruce avoided talking about death and his spoken wish to forget about his father indicated to me that he was still in the initial period of grieving according to Lamb's (1988) theory. I viewed him as trying to hide and protect himself from his emotions in an effort to cope with his experience of grief.

Progression through Sessions

Beginning sessions (1 through 3). Bruce was seen by a male counseling assistant who was an experienced counselor, especially in the area of play therapy. He was a soft-spoken, friendly young man who spoke with a slight southern accent. Bruce was described by his counseling assistant as follows:

This client came to each session ready to play the videogame. He appeared to be more interested in playing the game than discussing the relationship of the game to his grief and loss. He treated much of the sessions as an extremely focused operation, where it was his sole duty to master the level or task presented to him. His interpersonal skills appeared off-putting at times, as I was not used to working with a child who was so transparent and bold. It took me a while to not allow his interpersonal skills and behaviors to personally affect me.

Bruce entered the counseling room at his school for his first grief therapy session very calmly and quietly. He wore baggy, comfortable clothes that were darkly-colored. His speech was relaxed, although he had an unusual intonation. Bruce started phrases at a higher pitch and then finished them with a lower tone and intensity. He had a pre-pubescent crack in his voice that would become more prominent as he grew excited or agitated. As I watched the first video recording of Bruce, my first impressions were that he seemed relaxed and emotionally flat, though that would change as the sessions progressed. He expressed interest in the activities, stating that playing a videogame "is a pretty good deal." When he began playing the game, more of his personality began to

emerge. He showed a strong desire to take control and frequently told the counselor what he should be doing at any moment in the game. Bruce did not seem afraid to let his thoughts, frustrations, or desires known. He was quick to grab the controller from the counselor assistant if he believed that this individual was doing something wrong, or worse yet, insult him if he was frustrated by something the counseling assistant had done. Within the first few moments of this first session, Bruce told the counseling assistant, “You need to listen to what I tell you to do because I am way smarter than you,” and “I am the boss of you.” This need for control and seemingly superior attitude would persist throughout the counseling sessions.

During the first counseling session, Bruce’s play and conversation seemed to be fairly task-focused. He explored the movement of the controls, the buttons, and the functions of each character. He talked about what he needed to do in the game and frequently told the counseling assistant what he should be doing. While this session was kept fairly surface-level, Bruce did display some play and conversation associated with the initial and intermediate stages of grief. For example, Bruce displayed behavior associated with a theme of avoidance and trying to forget about the death. Early in the first session, Bruce was asked how much he knew about the Harry Potter stories. He replied by telling the counseling assistant that he was very familiar, but when asked about more detail, Bruce replied by saying, “I remember the parents die, I am not telling you why because I forgot.” When asked about other aspects of the stories related to death or grief, Bruce responded by saying he forgot. At one point, he told the counseling assistant “I forgot that part, I forgot every part, except that one part.” This avoidance was also

noted in observations by the counseling assistant and myself. It seemed to me as if Bruce would do anything to avoid the subject of death.

As previously stated, Bruce was observed to be very controlling; he frequently told the counseling assistant what to do, that he was doing the wrong thing (in the game), or that "Bruce was the 'boss.'" This control was observed to happen more often and with greater forcefulness when the subjects of death or grief were brought up. During these times, Bruce seemed to speak louder, called the counseling assistant "stupid," or grabbed the controller out of his hand. Bruce's verbal assertions and aggression as well as his efforts to control the counseling assistant struck me as another way for him to avoid the subject of death. Furthermore, Bruce attempted to kill the counseling assistant's character. This type of play was not part of the game, but a choice made by Bruce. Bruce appeared to become frustrated when he realized he was not fully able to kill the counseling assistant's character, only knock him down. He said, "Why can't I kill you? I want to kill you." Bruce engaged in this type of aggressive play throughout this first session. I coded this play as part of the intermediate period of grief, because Bruce was actively engaging in play associated with death.

During the second and third sessions, Bruce continued to show behavior related to avoidance. He was observed to frequently ignore questions, redirect conversations by changing the topic, and did not respond to comments by the counseling assistant that were related to death, his own experiences with grief, and Harry's experiences. When asked a direct question related to the theme of grief, Bruce asked, "Why are we even talking about this?" "This is just weird," or "Do we really gotta keep talking about this?" Any attempts to get Bruce to talk about death or grief seemed to frustrate him to the point

where he finally responded by saying, “I hate everything! I just don’t KNOW!” While the majority of Bruce’s behavior during these sessions was related to the initial period of grief, he did display some play (e.g., killing play and saving characters) that might be associated with Lamb’s (1988) intermediate period of grief.

During the second session, Bruce continued to engage in death-related play by trying to kill the counseling assistant’s character or other characters in the story. Another play incident that occurred during this session was when Bruce made Harry Potter run off the screen. Once Harry’s character had gone out of view, Bruce began saying, “No, Harry’s missing, no, Harry’s missing.” He appeared distraught about the “missing” Harry and asked for help from the counseling assistant to “save” Harry. Bruce replayed this same sequence of events twice during the second session, and it was seen in other sessions as well. It was during this time that Bruce also admitted to relating to Harry, stating that they had things in common, though he had trouble expressing what they shared. This appeared to me as a preliminary way for Bruce to explore his experience with death in that he purposefully made a character disappear and then seemed distressed and wanted to save him (bring him back into the game).

During the third session, Bruce shared that he did not have anyone to talk to about death, nor did he want to talk about this subject. When asked about Harry’s ability to talk to someone about his parents’ death, Bruce said, “I don’t even remember him talking about his parents.” Bruce believed that Harry did not have anyone he could talk to when he was sad or when he wanted to talk about his parents. In addition, when his counseling assistant asked Bruce about who he has to talk to about his own experiences with grief, Bruce responded by saying, “How would I? I’m not talking about it. I’m never going to

talk about it.” Although his play seemed to match with behavior associated with Lamb’s (1988) intermediate period of grieving, his verbal interactions were marked by avoidance, lack of interest, and denial that he had anyone to talk to about his grief (through the character of Harry).

Bruce continued to try and control what was happening during the game throughout these initial sessions, and his responses were often verbally aggressive. He was observed telling the counseling assistant that he was “stupid” and an “idiot,” he asserted how much smarter he was than the counseling assistant, and he tried to control the counseling assistant’s moves within the game. Bruce became frustrated with the counseling assistant when he did not follow Bruce’s instructions exactly. At these times, Bruce grabbed the controller out of the counseling assistant’s hand so that he could accomplish the desired task on his own.

Middle sessions (4 through 6). During the middle sessions, Bruce began showing an increase in play and conversations associated with Lamb’s (1988) intermediate period of grief that surpassed those related to Lamb’s (1988) initial period of grief, especially during the fifth and sixth sessions. It was during these sessions that Bruce began to choose characters who were more associated with death. For example, during the fourth session, Bruce discovered that he was able to play the ghost of Harry’s father and said, “We get the ghost of Harry Potter’s dead pare . . . dad, that’s pretty cool actually.” In addition, it was during the fourth session that Bruce began playing as Voldemort, saying, “I’m going to be Voldemort; I’m being Voldemort, the person that killed Harry’s parents. I just think he’s pretty awesome.” Bruce was observed playing as

Voldemort or a Death Eater (person who supports Voldemort) for the remaining middle sessions.

In addition to increased amount of play associated with killing, Bruce began exploring themes of dying as related to his characters. For example, Bruce purposefully killed himself in the game (e.g., stepped off a cliff or allowed an enemy to hit him) and stated, "I've never been so excited to die." He also spoke of the characters in the Harry Potter story being "so excited to die." During the fifth counseling session, Bruce spent a majority of the session singing a song about stupid ways to die. He sang, "It's stupid, stupid, stupid; it is just a dumb way to die." During this session, he used this song to refer to the characters in the story, the people mentioned in the song, and at one point, his own experience. While singing about "dumb" ways to die, Bruce stopped singing and asked if love could hurt so bad that it would be a dumb way to die. In addition, Bruce seemed to refer to the manner of his father's death, saying, "an accident, a stupid way to die."

Though Bruce's play became more rooted in Lamb's (1988) intermediate period of grief, his conversation remained fixed in Lamb's (1988) initial period. Not caring or not knowing were frequent responses to the counseling assistant's questions related to death or grief. However, it was noted that Bruce seemed to become less aggressive in his resistance and avoidance. Instead of ignoring the counseling assistant or yelling at him, Bruce began to tell his counseling assistant that he either did not want or was not going to talk about death and grief and did so in a more respectful tone. During the sixth session, Bruce told the counseling assistant, "To be honest, I'm never talking about my dad's death." A similar transition was noted in his game play; Bruce continued to tell the

counseling assistant what to do, but his direction became less forceful. Bruce asked the counseling assistant to take certain actions more so than yelling at him. During these middle sessions, Bruce did not call the counseling assistant names, but did continue to tell him that he was not very good at these games.

These slight changes in his interactions with the counseling assistant seemed to suggest that Bruce was building a relationship in that he was engaging with him in a more appropriate manner. It was also clear that Bruce understood the purpose of the sessions and was overtly considering his participation. Although he said he was not willing to talk about his father's death, it was apparent that the ideas of death and loss were more at the forefront of his mind during these sessions. For example, during the fourth session, Bruce and the counseling assistant engaged in a conversation about talking to people when one is feeling sad. Bruce shared that when he was sad, he sometimes talked to his mother. Bruce also said that when he was sad, he "whines a lot. I whine, I whine." Although Bruce spontaneously shared his feelings of sometimes being sad, when the counseling assistant reflected that emotion, Bruce denied the feelings. Slowly, Bruce seemed to begin feeling more comfortable, and thus, became willing to explore vulnerable emotions, rather simply expressing anger, frustration, and impatience.

Ending sessions (7 through 10). As the sessions began to come to a close, Bruce's game play and interpersonal behavior seemed to revert back to the themes associated with Lamb's (1988) initial period of grieving. It is possible that this regression might have occurred due to a break in the sessions. Due to inclement weather and illness, there was a gap of two weeks between Sessions 6 and 7. Though Bruce had shown a slight increase in his willingness to speak of topics associated with grief and

death during Sessions 4, 5, and 6, in Session 7, Bruce seemed more reluctant to engage with his counseling assistant. Additionally, Bruce became somewhat verbally aggressive towards his counseling assistant again. He continued to deny any desire to talk about his father. In fact, after being asked about his father directly, Bruce indicated that he wanted to forget about him. The counseling assistant asked why he wanted to forget his father, and Bruce responded by saying, "Ahh, I don't want to; I'm NEVER GOING TO TALK ABOUT IT!" Bruce continued to tell the counseling assistant that he did not care about his father's death. At one point, when asked about what he would say to Harry about being able to talk to someone about death, Bruce responded by saying, "I would say, you know what . . . I actually don't care, I just, I just don't care about you, Harry, Mr. Potter." Despite this response, Bruce admitted that it was easier to talk about Harry's experiences with grief than his own. Bruce showed reluctance to talk about death and grief in a manner similar to earlier sessions.

Though the overt conversation associated with death and emotions such as sadness were reduced throughout these ending sessions, significant play behaviors associated with the intermediate period of grief were demonstrated. Bruce continued to engage in play associated with killing and frequently attempted to kill the counseling assistant's character. He was observed repeatedly to shoot the counseling assistant's character, and say, "I want to kill you." Bruce also continued to choose characters associated with death, with a specific preference given to Voldemort.

Although Bruce continued to emphasize his unwillingness to talk about grief and death, it was during these ending sessions that Bruce began to more appropriately express his general emotions. For example, during the seventh session, Bruce admitted that he

felt mad about having to watch introductory videos to the levels and the way the counseling assistant played the game. When the counseling assistant reflected these feelings of anger back to Bruce, he responded by saying, “Maybe it’s because . . . I’m not really angry with you, I just want you to drop out because, you actually kind of . . . I’m a little bit mad about the cut-away (introductory video).” Although Bruce still called the counseling assistant names when he believed he had done something wrong in the game, he also seemed to be making an effort to express his frustration appropriately and perhaps beginning to understand that his anger was about something other than the events in the moment. This recognition and expression of feelings was also seen more often in Sessions 8 and 9.

While Bruce had been displaying behaviors associated with the initial period of grief (e.g., avoidance) during Sessions 7, 8, and 9, he reverted back to death themes in his play, representative of the intermediate period of grief, in the tenth and final session. Bruce engaged in killing play and frequently attacked the counseling assistant’s character. At first, Bruce chose to play as Voldemort, but as the session progressed, he switched to playing as Harry Potter. This was the first time that, when given the choice of who to play, Bruce chose Harry.

Bruce’s demeanor changed dramatically during this final session from what had been observed in Sessions 8 and 9. During the previous three sessions, Bruce had frequently called his counseling assistant “stupid” and an “idiot,” averaging roughly 15 times or more per session. However, during the 10th session Bruce did not yell at or tell the counseling assistant he was stupid. In fact, Bruce called himself a “stupid idiot,” when something went wrong in the game. This was the first time Bruce faulted himself,

rather than blaming the mistake on another. For the majority of the session, Bruce's affect was one of subdued sadness, though he did become more agitated as the session end drew closer. He asked how much time was left and said, "How much time did I waste? I feel like I just wasted all my time." Additionally, Bruce often repeated "Is this the last session?" It seems as if he was talking not only about this session, but also of his time in grief therapy as a whole. He seemed more agitated with the game, but unlike in previous sessions, did not direct this agitation towards the counseling assistant.

Throughout all sessions, Bruce was observed to be highly interested in and focused on the game. He actively engaged in playing the game throughout each session and showed interest in talking about the game and the story, even though at times, the game seemed frustrating for him. Although he sometimes complained and said that he was going to quit, Bruce persevered through each section that frustrated him and refused to allow a puzzle in the game to beat him. As an example of how Bruce's engagement during sessions differed from his usual presentation, the counseling assistant was told by Bruce's school aide that he would need a break approximately every five minutes. Yet, Bruce fully participated in playing the game and did not once ask for a break during each of the 50-minute counseling sessions.

Mid and Post-intervention Interviews

Midpoint. After Session 5, a midpoint interview of about 16 minutes was conducted by the same research assistant who had conducted the initial interview, approximately six weeks prior. As with the pre-intervention interviews, this interview took place at Bruce's school. It was obvious during the midpoint interview that Bruce was still not willing to talk about death and grief. He got angry at the research assistant

every time he brought up the subjects of death and grief. At one point, Bruce yelled at him saying, "I JUST CAN'T DO IT ANYMORE! I AM NEVER TALKING ABOUT DEATH!" Though Bruce was uncomfortable talking about death, he did note that that he was changing. Bruce admitted that before the intervention began, he had been "more of an impatient jerk," both at home and school. This seemed like an important change from the previous interview where he had refused to talk about anything besides his areas of interest. Bruce admitted that his behaviors toward others were starting to change a little bit, but he had difficulty providing examples or details to the research assistant. He responded by saying that "I don't know" and "I'm a little bit of a complicated guy." Surprisingly, Bruce talked about his enjoyment of playing the game with the counseling assistant. He described the sessions as "going good" and "a little bit enjoyable." Bruce also mentioned that it was "pretty good" talking to the counseling assistant. However, he did point out that he was only frustrated when the counseling assistant did not know how to beat a level.

Post-intervention interviews. After the end of the entire counseling series, Bruce, his mother, and his counseling assistant were interviewed individually by the research assistant. These interviews lasted about 15 minutes each. Bruce was interviewed at his school directly after the last session. His mother was interviewed over the phone three days later, and the counseling assistant was interviewed in his home the following week. During this final interview, Bruce continued to express a need to avoid the topic of death and grief. In fact, he almost seemed proud of his ability to avoid talking about these topics. When asked about his thoughts on death, Bruce became angry and yelled at the research assistant, "You know what? I DON'T WANT TO TALK

ABOUT THAT!” He continued to avoid the other questions, or respond by saying, “I don’t want to talk about it.” At one point during the interview, Bruce said that “[counseling assistant’s name] just kept trying to talk about death, but I’d never do it.”

Although Bruce continued to show no interest in talking about death, he did describe himself as continuing to change. Bruce noted that he had been angrier before, but was noticing it less now. Bruce did not acknowledge that his anger was related to the death of his father, but did note that he had become increasingly angry shortly after his father died (although not in those words, simply in the offered timeframe). When asked about what had changed, Bruce said that he was less “aggressive” and not getting mad at other students at school as often. His counseling assistant noted during his interview, that although Bruce continued to show no interest in talking about death, as the sessions progressed, “[death and grief] were easier to bring up, it was easier, and it wasn’t this elephant in the room anymore.” He went on to note, “I could tell that there was a slight decrease in his resistance and anxiety towards the topic.”

During her phone interview, Bruce’s mother agreed that Bruce still did not want to talk about his father, but she also noted that his behavior was changing as well. She told the research assistant a story that had happened during the past week.

I found [Bruce’s father’s name]’s Sudoku book that he used to sit and do those puzzles for hours, and he loved them. And, I started crying, and sometimes it’s emotional and those kinds of things. And, Bruce was actually was sitting there with his headphones on and thought, didn’t think he could hear me, but he did, and he took his headphones off and said, “Mom, wait Mom. Are you crying?” And, I said, “Yeah, Buddy I am. I’ll be okay in a minute.” And, he said, “Wait, are you crying about Dad?” and I said, “Yeah, Buddy, I am. I’m sad. Look what I found.” And, I showed him the Sudoku book. I said, “Do you remember when Daddy taught you how to play Sudoku?” and he said, “Yeah.” And, he said, “Mom, I get it. I totally get it.”

This story represented the first time that Bruce had been able to engage in a conversation with his mother about his father's death. They were able to discuss what Bruce missed about his father. Bruce's mother went on to say, "I'm hoping to have more conversations like that." Bruce began grief counseling firmly in the initial stage of grieving according to Lamb's (1988) process theory. Even with his continued avoidance about talking about his feelings of grief, the story told by his mother gives support to the idea that Bruce was processing his grief and was in the intermediate stage of grief according to Lamb's (1988) theory.

Stephen

My second participant was Stephen, a 14-year-old Caucasian adolescent male. Stephen began grief therapy on June 12, 2015, and finished on August 18 of that same year. Stephen, who had been attending public school in a rural community, was on summer break at the time of this study. He was diagnosed with autism when he was 6 years old. He lived with his mother, stepfather, and younger brother. Three years earlier, Stephen experienced the death of a favored uncle who had killed himself. Stephen's family had not told Stephen about how his uncle died and, instead, said he had an illness that no one knew about and had died suddenly. Stephen's mother described his uncle as one of the few people Stephen allowed into his "bubble." Stephen's mother was concerned about his increasing anger as well as his continuing yearning and depression over the death of his uncle. Additionally, five months before starting his grief therapy sessions for this research project, Stephen's grandfather died. While Stephen and his grandfather did not get along very well, Stephen's mother was still concerned that this additional death was creating more difficulty for him.

Pre-intervention Interviews

The pre-intervention interviews took place at a day treatment school and counseling center, the same location where all counseling sessions occurred. Each pre-intervention interview was completed individually by the research assistant. Stephen's interview lasted for about 17 minutes. In watching the video recording of the interview, I was struck by how willing he was to talk with the research assistant about his grandfather and his feelings about his grandfather's recent death. Stephen told the research assistant about his grandfather's strength and how he was able to live with cancer longer than most people. Stephen also told the research assistant about how his grandfather was "secretly teaching me and [Stephen's brother], mainly me, for when he died I could help [take care of the farm]." When Stephen spoke about the lessons he learned from his grandfather, I was able to hear the pride in his voice. The way that Stephen spoke about his grandfather's life and death seemed to indicate that he was taking the death in and reorganizing his life around it, consistent with Lamb's (1988) final period in his process theory of grief.

Although Stephen appeared to be in the final period of grief in regards to his grandfather's death, he did not seem to be as far along in his grief for his uncle, even though that death had occurred further in the past. When asked about what it was like finding out about his uncle, Stephen said, "I lost myself and couldn't find myself. Wasn't pretty. I didn't know who I was, I didn't act like myself." Unlike his openness about his grandfather, Stephen only briefly mentioned his uncle, and only when directly asked about him.

Stephen's mother was interviewed for approximately 15 minutes while Stephen was meeting his counseling assistant. When his mother was asked about Stephen's reaction to his uncle's death, she said, "We dealt with a lot of anger in the beginning and a lot of crying, and Stephen doesn't normally cry. That one was pretty tough." She went on to comment that it was "Stephen, more to the extreme," referring to an increase in his behaviors associated with ASD. For example, Stephen continued to ask on an almost daily basis whether they had figured out how his uncle had died. She also noted that while Stephen grieved in similar ways to his younger brother, the grief was more extreme and had lasted for a longer period of time. His mother also mentioned that Stephen seemed to be trying to find a way of "being with his uncle" by attempting to keep all of his uncle's possessions, even though his cousin (the uncle's child) wanted them. Stephen displayed some reluctance to talk about the death of his uncle, but it appeared that he was actively grieving, and as such, seemed to be in Lamb's (1988) intermediate period of grief.

Progression through Sessions

Beginning sessions (1 through 3). Stephen was seen by a female counseling assistant who was a doctoral student in a school psychology program and had already completed an advanced degree in school psychology, both programs having included direct training and field experience in counseling children and adolescents. She was a friendly young woman who radiated calmness and spoke in a light voice. Her description of Stephen captured both his energetic presence and his lack of awareness of certain social norms:

Every session, the client charged in like a man on a mission. He would plop down on the couch and usually began with telling the counselor a random fact.

Sometimes he draped a weighted blanket across his legs for comfort or held a fidget in his hand, such as stress ball. Sessions were close to lunchtime, so the client often brought in food and chomped down a bag chips or sandwich, inattentive to the crumbs scattering about.

As I watched the video of his first session, I also was surprised by how Stephen entered the room as if he owned the place. He came in, told the counseling assistant that he could tell she had broken a piece of equipment, and threw himself down in a chair. My first impression of Stephen was that he was going to try to control the sessions, much as Bruce had done. Although in some ways he did control those early sessions, his approach was quite different. Very quickly, Stephen began telling elaborate stories about death that appeared to be fantasies that he had created. He shared them with his counseling assistant at any opportunity even though they were only sometimes related to what was going on in the videogame. For example, the counseling assistant reflected on how Stephen had told her that she had broken the equipment, and he responded by saying that he would never “call anyone out, because that is how you get killed in the street.” He went further, saying that gangsters killed people frequently, and he had witnessed it. He said that the gangsters “found a rope made into a hangman’s thing, and they hung him when he [random person on the street] wasn’t expecting it. Pushed him out towards the tree, put it around his neck, and hung it quick.” This was just one of the many stories about death that Stephen told during this first session, a theme that was raised throughout many subsequent sessions. These stories were coded as representing the intermediate stage of grieving in Lamb’s (1988) theory because they represented the acknowledgement of death.

Although the majority of the intermediate stage behaviors were based on this death-themed storytelling, Stephen also engaged in other conversations associated with

this stage of grief. He spoke about how Voldemort killed Harry's parents, of his grandfather's death, and about how Hagrid (a friend of Harry's) had been abandoned by his parents. As noted in my observations and the counseling assistant's observation notes, Stephen frequently brought up the subjects of death and abandonment during this first session. Although he never spoke about himself experiencing these feelings, his frequent mention of these topics left me with the impression that this was something he was actively experiencing and that he was searching for ways to explore these feelings.

During the second and third sessions, Stephen avoided the topics of death and grief in a manner that was consistent with Lamb's (1988) initial period of grief. Stephen told the counseling assistant many times that he didn't want to talk about these subjects. When asked what he might say to his uncle, Stephen responded by saying, "I don't know. I've never known." Although Stephen showed more resistance and avoidance than he had in the first session, the majority of his behavior, play, and conversations still seemed to represent the intermediate period of grief (e.g., exploring themes of death through play or story-telling).

Even though Stephen noted that he did not want to talk about his uncle, he did at times speak about the longing he had for him. At one point, Stephen remarked, "I wish I could just see him one last time when he was gone, but he died in his sleep, and I was at school." Stephen also raised the issue of not knowing how his uncle had died, saying "I don't know what happened to him, but it looked like something bad happened." Stephen's feelings about his uncle seemed to reflect loss, longing, and uncertainty. When asked about finding out that his uncle had died, Stephen said that it was "horrible" and that he felt "unhappiness," describing it as the "thing I hate." During the third session,

Stephen also mentioned that he believed that others could not help with his grief. He mentioned that no one could “help protect you” from grief and that “you had to handle that all by yourself.”

Middle sessions (4 through 6). Throughout the three middle sessions, Stephen wavered between avoiding the topic of death by saying things like, “I don’t like people asking those questions,” and exploring grief and death through his fantasy stories. In contrast to his earlier stories, his fantasy stories started to incorporate his family members rather than strangers as protagonists. He told stories about his great grandfather fighting Native Americans and dying in horrific ways, his family fighting off enemies, accidents involving his grandfather chopping off his foot, and his brother accidentally blowing off his limbs with a shotgun. During the fourth session, Stephen told a story about a spell in the Harry Potter world that would kill anyone who used it. Stephen said, “It is a horrible spell, if you do it till seven minutes, you die, after that seven minutes, you start screaming in agonizing pain.” He went on to say that if the spell was used by Voldemort, that “he [Voldemort] would explode. He would set off a non-stop magic around the world, around the univers[e].” This spell was a creation of Stephen’s imagination and not a part of the actual story. These stories seemed to be a way for Stephen to safely explore death and his grief. He appeared to use fantasy as a way to talk about death, without using his own experiences.

Through most of these middle sessions, Stephen appeared to be in the intermediate stage of grieving, though at times, he made comments that could be associated with the final period of grief. For example, Stephen said that one of Harry’s good memories was of his parents. He also spoke about how Harry’s uncle, “made him

tougher and together.” Stephen had difficulty talking about himself and his own experience, but was able to share insight into how Harry might have restructured his life around his own experiences with death. As with his fantasies, this use of Harry’s experience appeared to me as a way for Stephen to safely explore his own grieving process.

Although Stephen did engage in some behaviors and stories associated with the intermediate and final periods of grieving, his overall conversation and play related to grief and death was reduced for all three of these middle sessions. During the beginning sessions, Stephen engaged in conversation, play, or behavior associated with grief and death an average of 40 times per session, but during the middle sessions, his grief and death related behavior was coded at an average of 22 times per session. In fact, it appeared that the more the counseling assistant brought up the subjects of death and grief, the more he withdrew from these interactions.

Ending sessions (7 through 10). During the ending sessions, Stephen began to engage in more play and conversation associated with grief and death. He continued to share fantasy stories about death and, as before, these stories seemed like a way for him to explore death without directly confronting his own experiences. However, Stephen also described some of his own experiences during these final sessions. During the seventh session, Stephen told his counseling assistant about how he used to spend time with his grandfather and to help him in his work. While he told these stories, it was clear to both myself and the counseling assistant that his affect was different from his usual presentation. He had more emotion in his voice and appeared to be almost wistful, with small smile pulling up one corner of his face. These stories and his emotional affect

seemed to suggest that Stephen was becoming more comfortable with his life after the death of his grandfather. It is likely that because he understood why his grandfather had died and because he experienced the process of his grandfather living with cancer, growing weaker, and eventually dying, that he was better able to adjust and grieve. Conversely, his uncle's death had been sudden, and Stephen was closer to him, so the grieving process for his uncle seemed to create stronger feelings of grief.

Stephen appeared to have difficulty with not knowing how his uncle had died and was still searching for answers. Many times during these ending sessions, Stephen would mention how his family did not know how his uncle had died. For example, he said, "He actually died in bed for no reason. We don't know why." Additionally, he told different stories about how his uncle died, including one scenario that suggested the possibility of murder. "It's like someone came in and killed him. There's only one thing that could point to foul play, and it was on his neck." His conversations about his uncle seemed to suggest that Stephen was fixating on the lack of information, and without having the facts, he was creating his own story through fantasy.

During these ending sessions, Stephen also brought up feelings of depression. He described not caring about his future and that he believed his life was not going to happy. Stephen noted that, "It's [his life] already hell; I can tell." He also said that "I'm already caught up in the void", "There's no getting out of it once it catches," and "Emptiness is not good. It can destroy you. You just wait for your imminent doom." Stephen used these types of phrases in response to the grief he was experiencing over the death of his uncle and when speaking about his diagnosis of ASD. Entering into adolescence and

transitioning to high school also appeared to affect his feelings of depression and may have intensified how he was experiencing his grief and bereavement.

In the ninth session, Stephen told a long story about how black holes work. He said that “Black holes destroy the whole matter. It’s the end of your time. You know that they say black holes speeds up time. It doesn’t. It slows down time. It consumes the memory. It erases it.” Though, this could have been Stephen’s understanding of black holes from a television show or reading, his focus on the way that black holes destroyed memories seemed to be his own addition. Although a tentative observation in my field journal, I wondered whether this was Stephen’s way of expressing his desire to have the painful memories of his grief destroyed. It seemed as if Stephen was looking for a way for his pain to be removed, even if it meant that his memories would be “utterly destroyed” by a black hole.

In these final sessions, Stephen also brought up feelings of regret. He frequently mentioned how many special events his uncle and grandfather would miss. Stephen spoke about his graduation from high school, his first date, and other important events that they would not be able to see. While he had stated before that he did not care about his future, Stephen appeared preoccupied with a future that would not include his uncle and grandfather. To me, these expressed feelings of depression and regret appeared to be Stephen’s process of actively grieving for what he had lost. It also seemed that he was entering into the final stage of grieving in that he was thinking about how his life would play out without the presence of his loved ones.

In addition to Stephen’s themes of depression during these sessions, he also spoke about hope. Stephen shared that he felt that Harry’s uncle who died would tell Harry to

“keep on fighting” if he was able to come back. During the ninth session, Stephen was asked about who he would go to for advice, and Stephen responded by saying it would be his uncle. Stephen went on to mention that his uncle was always trying to teach him and give him advice to help him grow. He shared that one of the best pieces of advice his uncle had given him was “Don’t chew the gum when it has no flavor.” Stephen said that this saying meant that you should not keep doing something when it was not helpful. When Stephen spoke about his uncle and the advice he used to give him, he looked happy and content.

Stephen’s statements and behaviors related to death and grief decreased during the 10th and final session. Knowing it was his last session, Stephen appeared reluctant to engage in any activities, but did show some insight into the character of Voldemort. Stephen mentioned that Voldemort “wants to end the world to destroy his past experiences” and “He [Voldemort] wants to destroy the world. He doesn’t know that if he does, he’ll be the only one. He never thinks.” As before, Stephen appeared to be using Voldemort’s experience to relate to his own darker thoughts. With his conversation in Session 9 about the ability of black holes to destroy memory and Stephen’s theory about Voldemort wanting to destroy his pain and past experiences by destroying the world, it seemed as if Stephen was focused on ways of destroying his own painful memories of the past. The way Stephen chided Voldemort for “never think[ing]” might indicate that although Stephen wanted to be free of his own painful memories, he had thought about ways to destroy his memories and decided that it was not worth the consequences.

Mid and Post-intervention Interviews

Midpoint. Stephen was interviewed the day after his fifth counseling session by the research assistant. As with the first participant, it had been six weeks since Stephen had seen this individual. This interview occurred in the same room where the counseling was taking place and lasted for about five minutes. Stephen did not have much to say during the midpoint interview, and it was reported by his mother that he was “having a bad day.” He talked about how he liked the sessions with the counseling assistant and that he talked with her even though he did not want to. When asked about death, Stephen told the research assistant that he did not have any thoughts about death before starting his counseling and that this aspect had not changed. Compared to the previous interview, Stephen seemed very reluctant to talk to the research assistant during this interview and seemed agitated.

Post-intervention interviews. At the final interview after all of his counseling sessions had ended, Stephen was interviewed by the research assistant for about 18 minutes. As with the previous interviews, Stephen met with the research assistant in the same room where he was receiving counseling in the grief therapy. Although at first Stephen seemed reluctant to share his experiences, as the interview went on, he began to open up. During the post-intervention interview, Stephen was preoccupied by thoughts of the family dog that had died about three years ago. He repeatedly asked the research assistant if he knew how to find the dog’s ashes. He kept repeating his desire to have the dog’s ashes and said, “I want to bring him home, literally. I want him to be home with me to have a proper rest.” Stephen said that he feels, “rage and pain” when he thinks about death. Additionally, he said, “And a feeling, feeling that I’m lost, that something is

holding me back. Something powerful and something waiting for me. Something that wants me, something that I felt, simply around.” Stephen also brought up feelings of regret and the important moments in his life that his uncle would not see. During this interview, Stephen continued to show behavior associated with active grieving. He looked like he was withdrawing into himself as he talked about his dog and his uncle, curling up into a protective ball.

Stephen’s counseling assistant was also interviewed after the last session. According to her, Stephen started the sessions with a willingness to talk about death, though he simply seemed to be sharing the facts. The counseling assistant noted that “he wanted to tell all about his, the death of his uncle, and his grandfather, and was very focused on explaining to me how they died.” Additionally, during the beginning sessions, Stephen frequently asked the counseling assistant about her experiences with death. After a few sessions, Stephen seemed to lose interest in talking about death or grief. According to his counseling assistant, after a session or two of not wanting to talk about death or grief, Stephen opened up again and this time spoke about his feelings associated with the death of his uncle. She noted that his willingness to talk seemed to occur in “waves;” Stephen was reluctant to talk about death for a session or two, and then seemed eager to do so.

Stephen’s mother was also interviewed by the research assistant at the end of the final counseling session. As with Stephen, this interview took place at the day treatment and counseling center and lasted for about 10 minutes. When asked about differences seen in Stephen’s communication about death, his mother responded by saying that although he used to bring up his uncle every day, he had reduced the number of times that

he initiated this conversation. His mother believed that he was asking about him less, and when Stephen did bring up his uncle, it was about the pleasant memories he had with him such as having dinner at the house, creating sundae bars together, and telling others about his uncle's favorite things. Additionally, she noted that he appeared to be more focused on his current and future life. His mother said, "I don't think it's [in] the front of his mind, you know? Where he is thinking all the time," and "We just don't hear as much since he's done the program. I mean, we just, I think he's more okay with it." Stephen's behavior throughout the grief counseling sessions was mainly in the intermediate period of grief according to Lamb's (1988) theory, though the reduction in Stephen's perseveration on his uncle's death as reported by his mother indicated that he was beginning to move into Lamb's (1988) final period of grief.

Wade

Wade, a 14-year-old African American male, was my third participant and the first one recruited in Maryland. He began grief therapy on September 14, 2015, and finished on December 10, 2015. He was diagnosed with pervasive developmental disorder—not otherwise specified (now reclassified as having autism spectrum disorder) when he was 10 years old. Wade lived with his mother and brother, and was currently attending a public high school in an urban school district. Wade's grandmother died from cancer eight months before Wade began his participation in this study. Wade's grandmother lived with Wade and his family and spent most afternoons watching Wade and his younger brother. His mother expressed concerns about Wade's increased academic difficulty since his grandmother's death as well as his lack of acknowledgement of his grandmother's death.

Pre-intervention Interviews

Unlike the other two participants, Wade and his mother were interviewed prior to the intervention in two different locations. Wade's mother was interviewed at home for about 14 minutes the day before Wade's counseling sessions began, and Wade participated in a very brief interview (eight minutes) at school the morning before he started his first counseling session. I conducted both interviews and all subsequent interviews (i.e., midpoint and final). During his interview, Wade appeared to be withdrawn and was very hesitant to answer questions. He responded frequently with silence, subtle movements of his head, and one- or two-word answers. When asked about his grandmother, Wade responded by saying, "I like the fact that she liked buying me stuff." This was the most Wade spoke throughout the entire pre-intervention interview. He was able to express that he felt "shock" and "scared" when his grandmother died, saying that he "wasn't ready for it." Additionally, Wade stated that his life had become "more difficult" when asked how it had changed after his grandmother's death.

During her pre-intervention interview, Wade's mother spoke about how difficult the death had been for Wade. She noted that even though his grandmother had been sick for two years, Wade had been surprised by her death. Additionally, she noted how hard it was for Wade.

[Wade's grandmother] passed here in the house, and he just didn't take it well. He just shut down and cried. He just sat there with his head down and cried. Throughout the whole thing he just cried a lot. Even at the service, he couldn't sit up front with me. He had to sit towards the back because when he walked into the church, he just started . . . he just started . . . so had to, like, sat him back some so he wouldn't be so close.

Wade's mother spoke frequently about his lack of conversation about his grandmother's death. When asked if he had talked about her death, Wade's mother responded by saying

“No, not at all.” She later noted that if she specifically asked about his grandmother or her death, Wade would respond with one-word answers. Though the behavior described by his mother directly after the death and during his grandmother’s funeral indicated to me that at that time, Wade was actively grieving and in Lamb’s (1988) intermediate period of grief; his current inability to speak about the death, and his withdrawn behavior appeared to me to be more indicative of Lamb’s (1988) initial period of grief with its refusal to acknowledge what had happened.

Progression through Sessions

Beginning sessions (1 through 3). Wade was seen by a female counseling assistant who was a practicing school psychologist in an urban school district. She was a very friendly woman who presents as very open and willing to meet her clients at their level. Unlike previous participants, Wade’s counseling assistant was a different ethnicity than his own. According to her description, engaging Wade in detailed conversation was going to be tough:

My client, was not a Harry Potter fan, and seemed less than impressed with the videogame. Though he came to every session willingly, my client maintained a flat affect and quiet nature throughout the entire process. He did engage in the game, but rarely took initiative to try and figure out the tasks at hand or guide me through what needed to be done. He only replied to prompts and questions with one- to three-word phrases, often after long periods of silence, and sometimes did not respond at all.

As I watched the first session, I was struck by how withdrawn and subdued Wade appeared. He entered the room quietly, dressed in a hooded sweat shirt and baggy pants. He kept his hood up throughout all of the first session. Attempts to engage him in conversation were met with mostly silence, though he would at times answer with one- or

two-word responses or with nods and shakes of his head. When Wade did speak, it was in a very quiet voice, only scarcely louder than a whisper.

From my field notes and through discussions with my peer reviewer, we wondered whether Wade was using this silence as a method of passive control at times as most of his silence occurred in response to questions and conversation starters about death and grief. With this in mind, Wade's silence was coded as being part of the initial period of grief according to Lamb's (1988) process theory of grief. In total, Wade spoke roughly 85 words throughout his first 50-minute counseling session, and most of his interactions were not related to death or grief. However, he did respond to a few probes about his experiences with grief. At one point during the first session, when asked about how he talked to people about his grandmother's death, he mentioned that he didn't talk about her when she died. Though, with time, he was able to speak to some of his friends and family members about his grief. When asked by his counseling assistant if talking about his grandmother helped Wade deal with the grief, he said "yeah," but did not elaborate on how it helped.

During the second session, Wade's verbalizations were similar to the first session, though what he did say was more related to his feelings of bereavement over his grandmother's death. These descriptions were mostly coded as consistent with Lamb's (1988) intermediate period of grief. When asked about his grief, Wade responded by saying "I can't handle it." As I watched him say this, Wade appeared to withdraw into himself, bending over and covering his head with the hood of his sweatshirt. Shortly after, Wade expressed that he believed that no one could help him deal with grief. When asked about talking to his friends and family about his grandmother, he said that

“sometimes they can’t handle it.” He refused to explain his response any further, but both my observations and the counseling assistant’s therapy notes noted the degree to which Wade seemed to believe that he had to deal with his grief on his own. Wade also noted that he felt “sad” about his grandmother’s death and that he was angry that he did not know she was dying.

Between the second and third session, there was a break of one week because Wade was ill. For the third session, Wade seemed even more reluctant to talk and reduced the amount of words he used by half. Though Wade was much quieter, he did delve further into his anger and other feelings about his grandmother. Similar to the previous session, he described how angry he was about not knowing that his grandmother was dying. Additionally, Wade mentioned that it made him scared because he was afraid of other people he cared about dying. Both of these conversations were fairly one-sided, with Wade responding to his counseling assistant with nods, shakes of his head, or a whispered response. The longest that Wade spoke during the third session was when his counseling assistant asked him where he would go if he could use a magical train to go anywhere. Wade responded by saying “I would probably go to heaven to see my grandmother.” After his counseling assistant reflected this statement, Wade added, “And hug her.” His withdrawn demeanor, his conversation about his fear of others dying, and longing for his grandmother indicated to me that he was actively experiencing grief in a manner that was indicative of Lamb’s (1988) intermediate period of grief.

Middle sessions (4 Though 6). Between the third and fourth sessions, Wade’s counseling was again interrupted by his illness during one week and a power outage in his school the following week. During session 4, Wade spent the majority of his time in

silence, with roughly 50 words spoken throughout the entire session. When his counseling assistant asked what his grandmother might have done with a lucky potion, Wade stated that he thought she would use it to “stay longer.” Wade continued to appear to be in the intermediate stage of Lamb’s (1988) process theory of grief.

As Wade progressed into Sessions 5 and 6, his conversation increased, both in the general amount and in his conversations relating to death and grief. In both of these sessions, Wade spoke about his sadness over the death of his grandmother. He would mention this sadness if asked, but still frequently used single-word responses during conversations with his counseling assistant. Wade shared with his counseling assistant that his sad thoughts about his grandmother most frequently came to him when he was at home. During these middle sessions, Wade also mentioned that he had “nothing” to look forward to in the future. Additionally, it was during these sessions, that Wade began talking about how much he slept. He indicated that he was sleeping too much, both at home and at school.

Although some of his content was troubling, it was during these sessions that Wade began to engage more in the game. He appeared to relax more and uncurl from the protected sitting position he had favored during the earlier sessions. I also noted in my field notes that it seemed Wade’s connection to his counseling assistant was growing as he no longer appeared so flat in his affect and sometimes looked at her with a shy smile.

Ending sessions (7 through 10). Unfortunately, there was another break of a week in Wade’s grief counseling sessions between Session 6 and 7 due to his absence from school. It seemed that after each of these interruptions in counseling, Wade was quieter, and it was more difficult for him to express his thoughts and feelings. Session 7

was no exception. Wade appeared to be more reluctant to answer questions during this session and often responded by saying “I don’t know” or shrugging his shoulders when asked about his grief. During this session, Wade once again mentioned that he slept frequently and took “too many” naps.

Wade opened up again during Sessions 8 and 9. He spoke more frequently, and his body language was more open as well. As Wade’s comfort level increased, he seemed willing to talk to his counseling assistant. During these ending sessions, Wade shared more stories about his grandmother and his grief after her death. It was during these sessions that Wade began to talk about his grandmother and his relationship with her. He told his counseling assistant that his grandmother was always waiting for him after school with a snack and that his grandmother would “ask me about my day.” Wade indicated that he really enjoyed this time with her and that he shared things with her about which he would not talk to others. At one point, Wade was asked if he knew what she had been like when she was young. Wade responded with a shake of his head and then looked down. When asked what was he was thinking about, Wade looked up and with a sad look on his face, said that “I was trying to remember the things that I had asked her.” My field notes indicated that during this interaction, Wade seemed to be feeling regret. He also expressed other feelings associated with Lamb’s (1988) intermediate period of grieving, such as feeling sad about his grandmother’s funeral and generally feeling both sad and bad. It was during these ending sessions that Wade also began choosing to play as Lord Voldemort and engaging in other play related to death.

Up to this point, most of Wade’s conversation and play were related to the intermediate stage of grief, but he also began to express some ideas consistent with

Lamb's (1988) final period of grief. The most notable example was when Wade told the counseling assistant about how his grandmother was still communicating to him. Wade indicated that he still felt her presence around him and that at one point, she sent him a sign. Wade was asked when it had happened, and he said it was "when I missed a week of school, because I felt like I could not get up." This was roughly two months after the death of his grandmother. Wade went on to say that "I was feeling like I couldn't move, and she was saying that I needed to get up. It was like she was helping me to get moving." He went on to say that the idea of being watched over by his grandmother was "pretty nice."

During his 10th and final session, Wade seemed to have withdrawn again. His body language resumed the hunched-over protective stance that had been noted in earlier sessions, and he was more quiet than usual. It was possible that Wade was trying to protect himself from the experience of ending his counseling sessions. As with previous sessions, Wade's expressions were generally coded as being part of the intermediate period of grief according to Lamb's (1988) theory. Wade spent time playing as Lord Voldemort and introduced the play action of killing the counselor for the first time. He also expressed feelings of loneliness, saying "I don't have anyone to talk to." Even with the people in his life that he had previously noted that he talked to about his grandmother, including his mother, his counseling assistant, and his girlfriend, Wade seemed to believe that grief was something that he had to handle on his own.

Wade did volunteer one element that was coded as consistent with the final period of grief according to Lamb's (1988) theory. When asked about how his life had changed after the death of his grandmother, Wade mentioned that some of his relationships had

changed, especially the one with his girlfriend. He described that his grandmother's death "made me closer to my girlfriend." When Wade spoke about this change, he kept his head down, though he had a small smile on his face. According to my field notes, this exchange seemed to reflect a small action that represented the beginning of his restructuring his life after the death of his grandmother. His acknowledgement of a positive change based on the death of his grandmother and his belief that his grandmother was watching over him had possibly begun the first steps in his restructuring process.

Mid and Post-intervention Interviews

Midpoint. I met with Wade after his fifth counseling session at his school. Again, our conversation was brief, lasting only about nine minutes. It had been eight weeks since I had last met with Wade. When I came into the room, Wade was sitting quietly in his chair, looking at his lap. When I asked him to tell me about his experiences in the sessions, Wade said, "I like 'em." He followed that up with "I can talk about how I am doing and stuff like that." When asked about what it was like to talk about his grandmother's death, Wade responded that in the session "it's easier." A little later, Wade stopped answering many of my questions and sat in silence. At times, Wade would answer by nodding or shaking his head. Through the rest of the midpoint answer, I was able to find out that he was still sad over the death of his grandmother, and he noted that his heart "hurt."

Post-intervention interviews. The day after his final session, I met Wade at his school and interviewed him in the room where he had his grief counseling sessions. Compared to the other interviews, Wade seemed more comfortable with me, though he was still reluctant to talk. He appeared less withdrawn and looked at me more often than

he had during the other interviews. When asked about his experiences throughout the counseling sessions, Wade said, “it was all right.” As he was asked about his thoughts about death and his emotions associated with it, Wade responded with “I don’t have any thoughts” and had “no emotions.” As the interview was finishing, Wade was asked about how he had changed throughout the counseling sessions, and he responded by saying, “I am starting to talk a little bit more.” This entire interview lasted about 12 minutes.

Wade’s counseling assistant was also interviewed by myself briefly the day after all sessions had ended. When asked about the process with Wade, she remarked that “it was just a lot of patience, because he was not ready to talk” and “I found that I got the most conversation with him, walking to the office, but once we got in, he would shut down.” A change that was noted by his counseling assistant was though he did not talk very much during most of the sessions, his teachers noted that Wade was “always willing to come [to counseling] and that they saw more in the few interactions between us, than they get in class.” The counseling assistant also noted that Wade did appear more comfortable as the sessions progressed and seemed to engage more in the game, work more diligently to solve puzzles, and offer suggestions to the counseling assistant on how to solve them.

I had difficulty reaching Wade’s mother for her final interview. I was able to reach her 10 days after Wade’s final interview and scheduled an appointment to conduct her post-intervention interview over the phone. This took place the following morning for roughly five minutes. Even with a scheduled time, Wade’s mother seemed to be in a hurry, and our conversation felt rushed. Wade’s mother indicated that she had not noticed any change in his behaviors or conversations related to his grandmother’s death

saying, “We still haven’t talked about it, but that is [Wade]. He just doesn’t open up.” She went on to say, “Trying to get information from [Wade] is like literally trying to get your wisdom tooth out. He just don’t talk at all.” The subtle changes observed within the counseling sessions did not seem to be generalizing to his home environment. From beginning to end of the counseling sessions, Wade’s behavior appeared to be within the bounds of Lamb’s (1988) initial period of grieving, though he had begun demonstrating more behavior associated with the intermediate and final stages of grieving according to Lamb’s (1988) process theory during the half of his counseling sessions.

Peter

My fourth and final participant was Peter, a 16-year-old African American adolescent male. Peter began grief therapy on October 13, 2015, and finished on December 23 of that same year. Peter, who had been identified with autism when he was 9 years old, was in his sophomore year in a public school in an urban community. Peter’s 22-year-old brother had died from an illness in the fall of 2014. Peter and his brother had lived together until Peter was removed from his mother’s care and placed in foster care in the spring of 2014. His brother’s illness lasted for several months, but Peter did not know about it until his brother was in the hospital, unresponsive. Unfortunately, this was not Peter’s only loss. His mother had been in and out of his life and at the time of the grief therapy, was thought to be in a local hospital with a critical, possibly fatal condition. Peter was living with a foster family that consisted of his foster father, his foster father’s male partner, and another foster child. Peter’s foster father was concerned with Peter’s inability to talk about the death of his brother, his falling grades, and his increasing social difficulties.

Pre-intervention Interviews

I conducted Peter's pre-intervention interview at his school. This location was the same as where he would be participating in his grief counseling. Peter's interview lasted roughly 12 minutes. When asked to tell me about his deceased brother, using his name, Peter said, "To be honest, I don't have that much to talk about my brother. I can't really say that much about my brother because we really don't have . . . we have a complex relationship, but we do like each other." It was interesting to me that he spoke in the present tense, as if his brother was still alive. As I asked about Peter's thoughts about death, he told me that he "hates it." He also mentioned that he was "sad" about the death of his brother and that it made him "uncomfortable." He went on to say, "I try to think about other things so I don't have to worry about it. But, I still think about him when I am not distracted by anything else." Peter did not feel that he had changed since his brother's death, but life had changed "greatly, and not just for me." Peter said, "I feel uncomfortable with change," though he would not say how life had changed. At the end of the interview when asked what else he would like to share, Peter told me, "I wish I had hung out more. I wish I was nice to him [referring to his brother]." From this conversation, it seemed that Peter was wavering back and forth between Lamb's (1988) initial period (e.g., speaking about his brother in the present tense and trying to ignore the death of his brother) and the intermediate period (e.g., acknowledging his pain and sadness over the death of his brother).

Peter's foster father had been interviewed the day before Peter's interview, and this conversation took place at his house. This interview was fairly brief and lasted about 10 minutes. When asked how Peter reacted to the death of his brother, Peter's foster

father said, “He didn’t. He understood what it meant, but he wasn’t seeing . . . he wasn’t affected about it.” Peter’s foster father went on to say that “We didn’t see any visible crying, and he wasn’t . . . he wouldn’t talk about it. He didn’t want to participate in any conversations about it. It was uncomfortable.” Peter’s foster father mentioned that they did not see any anger or grief over the death, and it appeared that Peter just kept playing on his computer in much the same manner that he did prior to his brother’s death. When asked what else he would like to share, Peter’s foster father told me, “We are not sure about how he is processing it. We are not sure about how he sees it. We are not sure whether he is detached from it or if autistic kids process it totally different. We are not sure what his process for grief is.”

Progression through Sessions

Beginning sessions (1 through 3). Peter was seen by the same counseling assistant as Wade was seen, and as noted, she was a school psychologist in the same district as where both Peter and Wade attended school. These two participants did not attend the same school, nor did they know the assistant prior to their grief therapy. Her description of Peter contrasted sharply with how she had seen the previous participant (i.e., Wade):

My second client had very little background knowledge of Harry Potter, but quickly became interested in the characters and their stories—even reading the books on his own. He often sought me out to ask when his next session would be and became very invested in meeting on a regular basis. Though he was usually focused on the videogame, he would often use the controller for tactile stimulation. He became invested in the routine of the sessions, reviewing homework, playing the videogame, and then having a subject to discuss. He would often want to pause the videogame to concentrate on the discussion and made consistent effort to make eye contact, initiate positive physical contact, and discuss grief and death.

Peter entered the counseling room with a quiet energy. He was immediately drawn to the television screen and the game-start screen that was on it. Once he saw the screen, his eyes rarely wavered from it, and he smiled slightly. Peter picked up his controller, started moving it around, waved it in the air, and pressed the buttons on it, without a functional purpose. Peter spoke in a quiet monotone voice with a slight stutter. He mumbled frequently and was difficult to understand, both in the video recordings and in person. My first impressions of Peter were of a quiet adolescent who was friendly, though insecure or hesitant. He would check in with his counseling assistant, often asking if what he was doing was “okay.” As the session progressed, Peter sometimes asked to pause the game so that he could respond to the counseling assistant. I noted in my field notes that he appeared to have difficulty being able to talk and play at the same time. Peter appeared to put his entire focus into one or the other and was not able to switch easily between to the two.

Peter’s play and conversation seemed to be equally split between Lamb’s (1988) initial and intermediate periods of grief. Indicators of this initial period included Peter’s interspersed comments that he wanted to forget about the death of his brother. He told his counseling assistant, “I try to forget it” when she asked about his brother’s death. Later in the session, Peter told his counseling assistant that “I . . . I never talked about them. I never talked to them about it,” referring to his foster family. He went on to say that by not talking about his brother’s death, it made it easier for him to forget. Though Peter appeared to feel comfortable talking to his counseling assistant about his brother’s death, at different points he also said, “I don’t want to talk about it.” He tended to say something like this directly after he had described some aspect or feeling related to his

brother's death. Surprisingly, he sometimes continued on with stories about his grief right after he had said he didn't want to talk about his brother's death. It seemed to me that, though it was difficult for Peter to talk about his experiences with grief, he also wanted to speak to someone about it.

There was a certain regret or guilt in Peter's conversations about his brother. Peter expressed his wish that he had learned about his brother's death in a different manner and that he would have had more opportunities to connect with his brother. Peter told his counseling assistant that his mother let him know that his brother was dying when Peter went to see her; he believed it would have been better to learn this news directly from his brother when he went to visit him at the hospital. He also would have liked to have known sooner. Though his brother had been ill for a while, Peter did not learn about how seriously ill his brother was. By the time Peter went to see him, his brother was not able to talk. Peter stated, "I wish he would have called me." Peter implied that he wanted to know that his brother was in the hospital and might die. As he told his counseling assistant about these wishes, Peter looked down and lowered the volume of his voice. I noted that he looked to be actively grieving at this time. Peter mentioned how sad he was to hear that his brother had died, saying "then . . . I . . . I . . . I cry." While he was talking about these experiences, I made notes indicating that Peter seemed to be actively grieving and in the intermediate period of grief.

In Sessions 2 and 3, Peter continued to express play and conversation associated with both the initial and intermediate periods of grief. Peter continued to express feelings of trying to escape his grief by using his computer as a way of not thinking about his brother. Peter mentioned, "When I got on the computer, it didn't affect me that much."

He also told his counseling assistant that using the computer was a way to “forget about it [his brother’s death].” As seen in interviews with other participants, Peter also told his counseling assistant, “I don’t want to talk about it” at times when asked about his grief. Additionally, Peter described his difficulty understanding and expressing his emotions. Peter said, “I don’t know how I feel” in response to being asked about his grief. He later remarked, “I feel neutral. Pretty neutral.” When asked to explain further, Peter said, “I don’t have ways to talk about . . . how to make words and feel.” He went on to say that “I have never really . . . never really talked to anyone about this.”

Examples of Peter’s play and conversation that were coded as being in the intermediate stage included his reference to “strong sadness” and his engagement in killing play in the game. When he did talk about his brother’s death, he often said that he felt a “strong sadness” and that he still continued to feel this strong emotion. He mentioned that he tried not to feel that way, but that “it didn’t work.” It was during session three that Peter also began to engage in killing play. He started trying to kill his counseling assistant’s character and other characters in the game, which as noted earlier, is not part of the game. In another instance, when he could not figure out a puzzle, Peter offered the suggestion that “we could just kill ourselves” as way to solve the problem.

In session 3, Peter was asked by his counseling assistant what he would do if he knew of someone who was experiencing grief. Peter responded by saying, “I would try to comfort. I would try to feel sorry for them.” Peter appeared to know that this might be difficult for him, as I noted in my journal that he had a determined set to his face and a certain questioning quality to his voice. It was the stress that Peter put on the words “try” and other remarks he had made throughout sessions regarding his difficulty interacting

with other students that made me feel that he might have difficulty comforting somebody else throughout their own experiences with grief.

Middle sessions (4 through 6). During the middle sessions, there was a decrease in the amount of play and conversation that was coded as being part of Lamb's (1988) initial period of grief. Though it was decreased, Peter did display some behavior associated with this period. In particular, Peter denied any feelings of sadness saying, "I can't feel the emotions right now," even though in my observations I noted he looked very depressed while he was saying these things. Peter was looking down, talking very softly, and was curled into himself. When asked about how his homework had gone, Peter told his counseling assistant, "I can't write anything depressing. I am not sad right now." Additionally, Peter mentioned that he wanted to pretend that his brother had never died.

Though Peter did have those instances where he seemed to deny or avoid his feelings of grief or even that his brother had died, there was a notable increase in his play and conversation that was considered to be representative of the intermediate period of grieving. When looking at Peter's play, he increased the amount of times that he tried to kill the counseling assistant's character and other characters in the game. It was observed that he tried to kill characters multiple times per session during these middle sessions and even asked his counseling assistant for more time to attack her character.

Peter's conversations about death and grief also increased during the middle sessions. Peter talked to his counseling assistant about his belief that other people would not understand what he was going through, and therefore, would not be able to help. He said that "I try to explain it to people . . . like trying to explain something, but they won't

understand” when he was asked about who he could talk to about his brother’s death. His protective body language and low voice seemed to suggest to me that Peter was feeling very alone in his experience of his brother’s death.

While watching a scene in the game where characters were able to remove memories and Peter was asked if he had any memories that he would like to remove, he responded by saying, “my . . . my . . . my regrets. My embarrassments . . . and other stuff.” This statement was the lowest I had seen Peter. As he said it, he had a tear running down his face. He went on to explain that the regrets he had were mostly about not knowing his brother better, and his embarrassments where over the way he talked and how other students viewed him. As part of this conversation about regrets, Peter acknowledged that he often felt as if he would not be happy again and that sometimes it was as if “someone had taken my happiness.”

It was during these middle sessions that Peter began to engage in behaviors and conversations that might be viewed as being part of the final stage of grief according to Lamb’s (1988) theory. In Session 5, Peter began telling jokes. This happened once during Session 5 and three times during Session 6. The jokes were sometimes related to what was going on in the game, but not always. In Session 6, Peter told his counseling assistant that he had tried to be a web comic before his brother died and had created a few videos on YouTube. He went on to tell her that he was thinking about trying to create some more in the future. This plan seemed to represent a return to a previous interest, a behavior that is associated with the final period of grieving.

Ending sessions (7 through 10). As Peter moved into the ending sessions, he continued to increase the amount of play and conversation associated with the

intermediate period of grief and decreased those associated with the initial period of grief. Peter engaged in only three behaviors associated with avoiding, or denying his feelings of grief in Session 7, which was less than half of what was observed in previous sessions. In Session 7, Peter continued to explore his grief. Peter expressed thoughts about how sad he was over his brother's death saying, "I don't feel happy at all." Later in the session, Peter also mentioned that he did not like change and "I can't deal with it." As part of his exploration of his grief and feelings of unhappiness, Peter told his counseling assistant, "I don't know how to explain my feelings. I don't understand them. I don't understand myself. I don't know why I am not happy." According to observations and field notes, Peter appeared to be having difficulty understanding his grief and his reactions to it. It appeared to me that he was actively grieving, even if he did not know how to express it or completely understand what was going on. At the end of Session 7, Peter told his counseling assistant in reference to his brother's death, "I need to cope with it and deal with it, because it is not going to get better." This acknowledgement of his need to deal with his grief was coded as being part of Lamb's (1988) final period of grief.

Peter was absent from school on the day he would have had counseling session 8, and it was rescheduled for the following week. During this session, there was a decrease in behaviors associated with all three periods of grief in Lamb's (1988) theory, although Peter did share more about his relationship with his brother. He spoke about the things he and his brother had enjoyed and spoke about what his brother might want in a Room of Requirement (a magical room in the Harry Potter storyline that changes its dimensions and contents based on the needs and desires of the characters). He also mentioned how he used to fight with his brother. When talking about his brother, Peter was observed to

have a smile on his face, even when describing their fights. Peter looked happy, but went on to note that all he needed in his own Room of Requirements was videogames and his art because it was his “pure happiness.” In some ways, a statement like this might reflect that he was again attempting to avoid the topic of his brother’s death, that he didn’t need others, or that he was simply feeling better and describing things that he enjoyed. His meaning was not clear.

With Session 9 continuing as scheduled, Peter demonstrated another slight increase in the amount of behavior associated with the intermediate stage of grief. Peter engaged in more killing play during Session 9 than was seen in any of the previous sessions. He was observed to be more comfortable with his counseling assistant and reached out to her at times for physical contact. Peter told his counseling assistant that he was having “dark thoughts” about his brother. He later explained that these “dark thoughts” were of his sadness about not being able to talk to his brother. Peter mentioned that he would like an opportunity to talk to his brother to “find out how the afterlife is doing and what happened to him.” Peter appeared to have difficulty not knowing the circumstances of his brother’s death beyond knowing that he was sick. His conversation and play associated with the final period of grief also increased. It was during session 9 that Peter chose to play as Harry Potter when given an opportunity. Peter chose to play Harry and asked his counseling assistant to be Voldemort. Peter was insistent that Harry and Voldemort needed to work together. This was an interesting point in his play where he had a character that represented life and survival engage in some kind of action with a character that represented death. During this play, Peter was very engaged with his counseling assistant in both conversation and in body language. He frequently spoke to

her and looked at her to check in with what she was doing. It was in Session 9 that Peter also mentioned that he had support for the first time. Peter told his counseling assistant that he “has friends and family to not feel lonely.”

As Session 10 began, Peter entered the counseling room with a bounce to his step. He appeared excited and happy. Peter told jokes during the first half of the session. Many of these jokes were about death. He seemed to be making fun of some of his own experiences as well. One of the jokes was about having cancer. Peter got very quiet and whispered, “I am going to die in two days” and then later, “I have cancer.” When his counseling assistant asked him about it, Peter laughed out loud and said, “I have Sonic [a favorite videogame character of Peter’s] cancer.” He then went on to say, “Sonic cancer makes me play Sonic games all day till I die,” and “I’m just joking!” As the session progressed, Peter began engaging in death play again. He would attack the counseling assistant’s character or try to make her fall off a ledge to die. Peter used this play as a subject for his jokes, saying “Oh, no! You are getting close to the edge, I better help you. Whoops! You died! I’m joking [laughing].” In the second half of the session, Peter’s counseling assistant introduced a conversation about the future and what Peter wanted. Peter told her that the “future scares me” and “I try to avoid thinking about it.” He also told her some of the things that he would like to do, such as going to college, getting better at drawing, and becoming a web comic. When asked if there was anything else that he might be looking forward to, Peter responded by saying, “I am going to say, I guess . . . I guess . . . trying to move on.” Clearly, Peter had started to enter into the final stage of grieving.

Mid and Post-intervention Interviews

Midpoint. Peter was very willing to talk to me at his midpoint interview. It took place after his counseling session 5 in the same room where Peter's sessions were held. The interview lasted about 10 minutes. When asked about his experiences in the counseling sessions, Peter said, "I have been a little awkward. No, not like awkward, more like . . . Don't really know how to describe the feeling to you. I guess better since I can talk about my feelings." While talking with Peter, I was able to clarify that he meant that, although it was awkward for him to talk about his feelings, he also believed it was helping him. When asked about how his thoughts had changed about death, Peter responded by saying, "It changed a little bit. I have started to think less about it. I think less about my brother's death and stuff. It has helped more for the rest of the day sometimes" and that he felt "normal. I don't get that sad about it." At the end of the interview, Peter was asked if he had anything that he wanted to share, and in response, he said, "I will say this right here. They help me. Talking about my brother's death, and I hope for some more smile! To be serious, it did help me a little bit. Thank you for allowing me to have this session." At this interview, Peter appeared to be in the final period of grief according to Lamb's (1988) theory.

Post-intervention interviews. Peter was briefly interviewed (eight minutes) directly after his last counseling session. Peter seemed quieter during this interview and appeared less interested in talking to me than he was at the midpoint interview. I noticed that included with the school books he was carrying were four of the Harry Potter books. Peter expressed interest in the ability to talk to someone about his feelings, but he admitted he preferred other videogames. When asked about how he had changed, Peter

said, “I like doing comedy stuff to make the death funny” and that “I like being more humorous now.” It seemed that Peter was ready to enter into the final stage of grieving, but still might be figuring out how to appropriately do so.

The interview with Peter’s counseling assistant was conducted right after Peter’s interview and in the same place. She noted that Peter “came alive during these sessions.” She described Peter as having difficulty talking to others outside of the counseling session, but with the routine of session, he seemed better able to share what he was thinking. His counseling assistant noted that Peter began using “more adjectives and more feelings words to talk about death.” She also noted that Peter had begun to use some of the words and phrases used in the counseling sessions with both his foster parents and teachers to explain his feelings. Additionally, Peter’s counseling assistant noted that as the counseling sessions progressed, Peter’s familiarity with her and his interest in physical contact increased as well. When asked what else Peter’s counseling assistant might want to share about Peter’s process through the counseling session, she responded with the following statement:

I think this was a home run for him. I think that without it [grief counseling], he still would have been making progress on his IEP goals, but [with it], I just have seen him turn into a much more well-rounded and socially and emotionally aware student during sessions, and he is generalizing it into the classroom. I really do think that this has made a big difference in his life, and I want to keep doing it with him in the future.

Peter’s foster father was interviewed at his home for roughly seven minutes.

When asked about how Peter’s behavior might have changed throughout the time spent in the counseling sessions, he responded with “Nothing significant. Though, when we bring it up, you can see the appropriate reaction. He is looking sad, but after that, he goes on.”

His foster father noted that Peter was not really talking about his emotions, though he

could see the emotions on his face at times. His foster father said, “I see emotions that he is experiencing that he is not expressing, but we try to help.” This was somewhat different than what he talked about in the pre-intervention interview where he had described a lack of visible emotions. Information gathered from the post-intervention interviews made me feel that Peter was mostly in the final period of grief, though he was still feeling the emotions (e.g., strong sadness and confusion) associated with the intermediate period grief.

Discussion of Process

As a qualitative researcher, it is important to reflect on the process of the research project. This study changed my perspectives on research, grief, and adolescents with ASD. In this study, I had many different roles to play. I worked as a complete observer in regards to all the counseling sessions and as a participant observer for only the interviews of two of the participants. Additionally, I transcribed the video recordings for the participants in Maryland. In each role, I needed to focus on the specific actions required, and limit my own biases. By removing myself from the counseling aspects of this study and focusing only on the research aspects, I increased the distance between myself and my participants, thus providing some objectivity. However, something also seemed to be lost, and I thought about ways that I might have responded or integrated myself more deeply into counseling. I felt a strong desire to become more involved in the counseling process. Even with this distance, I still became attached to each of these participants, their stories, and their ways of coping with grief and loss.

Bruce, Stephen, Wade, and Peter all reminded me of the need to look at each individual with ASD as a unique person and, as such, to recognize that they expressed

their grief in different ways. Bruce was angry at everything and everyone, Wade was quiet in his grieving process, Stephen told elaborate stories to escape his loss, and Peter attempted to make jokes. Although the researcher in me wanted to see each one show significant progress through their counseling and their interaction with the videogame, they also each had their own pace for moving through Lamb's (1988) periods. Each one of these adolescents tried different techniques to deal with their grief, some adaptive, others less so. They all had experienced truly devastating experiences with death, and each was handling his loss in the best way they knew how in order to survive this experience. Observing their different processes affirmed my belief in the theory of constructivism and the way individuals structure their world.

There are established theories that try to explain the reactions we experience when someone we love dies. Through this study, I have attempted to understand the experiences of these four young men, using the framework of Lamb's (1988) process theory of grief. Although I believe this theory provides a reasonable overview of how people might grieve, it, like all the others, misses out on the finer details. By conducting this study, I have come to believe that there is so much more to understand about the overarching periods and reactions to grief that can only be accessed by working with individuals. A constructivist framework promotes the idea that we each make meaning based on our experiences, and this is also true for grief. Each death and corresponding grief experience is unique, and each of us will react in unique ways. This study further confirmed my belief and recommendation for the use of stereotypical interests during interventions with individuals with ASD. Bruce, Stephen, Wade, and Peter all became engaged in the videogame, even though some felt that the game was "not the best." The

videogame appeared to take away some of the stress and pressure that some adolescents experience in traditional talk-based therapy, just by changing the focus from each other to what is happening in and during the game.

Summary

In this chapter I provided a detailed recounting of the process as experienced by the participants and myself. I described each participant's experience through the use of a timeline and the themes associated with Lamb's (1988) process theory of grief. Throughout the counseling sessions, Bruce expressed many feelings of anger and the need to avoid the topic of his father's death. As the sessions progressed, he appeared to become more comfortable and began engaging in more behaviors associated with Lamb's (1988) intermediate period of grief. During his time in grief counseling, Stephen frequently told elaborate stories about death and violence. Through observation, it appeared that Stephen was further along with his grieving process in regards to the death of his grandfather, but was still struggling with his uncle's death, even though his grandfather's death was more recent. Though Wade was very quiet throughout his experience in grief counseling, he became more open and willing to talk as the sessions progressed. Peter was the most willing of the participants to talk about his experiences with grief and bereavement and was the participant that expressed the most themes associated with Lamb's (1988) process theory of grief. Though the experience was different for Bruce, Stephen, Wade, and Peter, through cross-case analysis, I was able to find overarching themes that were common to each participant. These themes are discussed in the next chapter.

CHAPTER V

DISCUSSION

When adolescents lose a family member, the process of grieving may elevate the risk that they will develop behavioral and/or mental health problems. Adolescents who have pre-existing disorders, such as ASD, may be especially at risk because of their difficulties expressing emotion and obtaining support from important others. Currently, there is limited research into the ways to help adolescents with ASD through the transitions and emotions associated with bereavement. This study was designed to provide an in-depth exploration of the experiences of four adolescents with ASD in grief therapy using videogames. Each participant had experienced the death of a close family member and, in some cases, had experienced other types of loss as well and were experiencing difficulties beyond those associated with their ASD. Although their difficulties varied slightly, they were noted to be experiencing anger, depression, withdrawal, failing grades, and difficulty talking within anyone about their loss. In consideration of their stories, their participation and progress in videogame therapy, observations, and interviews, the following themes emerged: (a) progression, (b) isolation, (c) avoidance, (d) regret, (e) depression, and (f) playing as death.

Collective Cross-case Analysis

Progression

“I need to cope with it and deal with it, because it is not going to get better.”

In different ways and at different rates, Bruce, Stephen, Wade, and Peter showed progress through Lamb's (1988) periods of grief. No one individual worked through these periods in a linear manner, moving seamlessly from one period to the next. Instead, each participant exhibited behaviors associated with Lamb's (1988) different periods interchangeably during each session (e.g., from intermediate to initial and back to intermediate) and from one session to the next. However, each participant demonstrated an increase in behavior associated with the intermediate period of grief (e.g., increased death play and greater time engaged in conversation about emotions associated with grief) as the counseling sessions progressed. Additionally, all participants increased the amount of behavior associated with the final period (e.g., chose to play as character representing survival and life and returning to activities of enjoyment) during their ending sessions. Though all showed progress, it was Peter who showed the greatest increase in verbalizations and behaviors associated with Lamb's (1988) final stage. This was somewhat surprising because of the many other losses in his life (e.g., living in foster care and potentially losing his mother). This difference might be in response to Peter actively trying to increase his social network. At the time of counseling, Peter had begun actively seeking out new peer relationships, social interactions, and adult support at school.

In addition to the increase in behavior associated with the intermediate and final periods of grieving, Bruce, Stephen, and Peter also displayed a decrease in the amount of

behaviors associated with the initial period of grieving (e.g., less avoidance of the topic of grief and less expressed anger). Wade was the exception as he actually increased his verbalizations associated with the initial period, but this might have been an artifact of Wade's general increase in conversation with his counseling assistant. Initially, he spoke so little it was difficult to categorize his verbalizations or play; however, as he began to interact more in these ending sessions, his current grieving process became more apparent.

Disruptions in the counseling sessions were observed to be difficult for participants, and each "break" was followed by a reduction in their willingness to engage with their counseling assistant. In many cases, participants returned to a behavior seen in earlier sessions (e.g., aggression for Bruce and withdrawal for Wade). Having more than a week between sessions seemed to disrupt the trajectories of these three participants. All participants except Stephen had to postpone at least one of their counseling sessions. Stephen's sessions proceeded as scheduled, and he did not appear to experience a regression to earlier behavioral states; however, he did start to decrease his play and conversation associated with the intermediate period of grief. This change appeared to be related to Stephen's identification of other concerns in his life (e.g., transition to high school) that were not related to grief. However, the fact that he was focusing on his role as a high school student does support that he was progressing toward the final stage in Lamb's (1988) theory.

It was interesting to note that both Bruce and Stephen seemed to reduce their grief behaviors in their final sessions. They appeared to have difficulty with the impending termination of sessions and changed their behaviors in response. Bruce frequently spoke

about “wasting time,” wondering how much time he had left, while Stephen just seemed to reduce the amount of behavior and conversation associated with grief and death. Neither Wade nor Peter demonstrated this abrupt change and in fact, increased their discussion associated with grief and loss in their final sessions. They appeared to be more accepting of the upcoming termination of grief counseling. It is unclear why the differences during the termination sessions occurred but it may have been because of the level of relationship-ending that would occur. That is, Bruce and Stephen would not have the opportunity to see their counseling assistants again while Wade and Peter knew that their counseling assistant would be available since this person worked in their school. If either of them wanted to follow up with their counseling assistant, they would be able to do so.

Increased positive social interaction. Bruce, Wade, and Peter all displayed more positive social interactions with their counseling assistants as the counseling progressed. Bruce became less aggressive and reduced the number of times he called his counseling assistant names. As mentioned previously, Wade began to talk more with his counseling assistant and to use longer sentences, rather than single-word responses. Peter began to look toward his counseling assistant more; he also began to tell her jokes and look for her reaction. He also sought more physical support such as reaching out to touch her, asking if she would hold his hand, or giving a hug. As these three participants became more comfortable with their counseling assistants, they displayed slight increases in prosocial behavior. Stephen’s social behavior did not really change through the sessions, although he may have increased his trust for his counseling assistant. He was

soon to begin attending high school and wanted to talk to his counseling assistant about this transition.

Some research, based on Kubler-Ross's stage theory of grief, indicated that feelings of anger may reduce after four months, depression may decrease after six months post-death, and acceptance may rise steadily throughout the grieving process and peak at around 24 months post-death (Maciejewski, Zhang, Block, & Prigerson, 2007). In this study, Bruce began grief therapy almost seven months after the death of his father, and he was still expressing high levels of anger well after the expected peak according to Maciejewski et al. (2007). In addition, both Wade and Stephen seemed to be experiencing symptoms of depression well after the six month mark, with Wade's loss occurring a year earlier and Stephen's, more than three years in the past. This elongation of the grieving process appears to corroborate with the anecdotal evidence given by others (e.g., Forrester-Jones & Broadhurst, 2007; Hull, 2011), suggesting that adolescents with ASD may experience a longer grieving process than their neurotypical peers, although the trajectory is similar. Conversely, Peter seemed to be on a typical trajectory as he seemed to be entering the final stages at one year after his loss and despite all of the other changes in his life.

Isolation

“I had to handle it all by myself.” At different points throughout the counseling sessions, each participant mentioned a feeling of isolation or not having anyone to talk to about their feelings of grief. Whether this situation was real or a perception, for each participant it seemed as if they did not believe anyone could understand their experiences. For Bruce, he introduced this theme by describing how Harry Potter was isolated. Bruce

mentioned that “I don’t even remember him [Harry] talking about his parents.” When asked about who he thought Harry would be able to talk to about the death of his parent’s, Bruce forcefully stated that Harry had “no one” to talk to. As he was asked more about it, Bruce said, “No. He [Harry] can’t talk to anyone.” When his counseling assistant went on to ask Bruce about who he had to talk to about his own experiences with grief, Bruce responded by saying, “How would I? I’m never going to talk about it.” Bruce remained adamant throughout all counseling and interview sessions that he would not talk about grief. Yet, at her post-intervention interview, Bruce’s mother described how Bruce was able to share about the things he missed about his father and show empathy toward his mother’s grief. Although a small step, Bruce may have been looking to remove some of his self-imposed isolation.

Stephen also shared his feelings of isolation through a conversation about how Harry’s mother’s love for him protected Harry from Voldemort (the evil character). When he was asked about who he thought had protected him when his uncle died, he stated that “No one did. I had to handle it all by myself.” Stephen’s sense of isolation went beyond the event of his uncle’s death to include a perception of separation from others in the future as well. He alluded to not having someone to go to for advice since his uncle’s death as he was the one person Stephen confided in. Although Stephen readily talked about his uncle’s death, he did not seem able to move beyond trying to understand how and why it had occurred. His sense of isolation from others was more about losing the “one person that he had let into his bubble,” as described by his mother.

Wade’s minimal communication, both before and after his grandmother’s death, seemed very isolating. If asked, Wade said he could talk to friends or his girlfriend, but

he also acknowledged that he was not always able to talk to them about his grief, saying, “Sometimes they can’t handle it.” Like Stephen, Wade had lost one of the few people he could talk to. When he came home from school, it was his grandmother whom he would talk to and share stories about his day. As his counseling reached the final session, Wade shared that he had few people to talk to about his grief, saying, “Sometimes I don’t have anyone to talk to.” In my field notes, I observed that he appeared to miss the opportunity to share his stories with his grandmother and, although he could sometimes talk to others (e.g., his girlfriend or friends), it did not seem to fill the void of his loss.

Peter brought up feelings of isolation and feelings of no one to talk to during multiple sessions. He mentioned that no one would talk to him about the death of his brother, yet he also noted that he had not tried to talk to his foster family saying, “I . . . I never talked about them. I never talked to them about it.” In the second session, after briefly talking about his grief, he stopped and looked down, sharing, “I have never really . . . never really talked to anyone about this.” Peter’s isolation seemed to be partially related to his perceived inability to explain himself or for others to understand him, “I try to explain it to people . . . like trying to explain something, but they won’t understand.” However, he also noted, “I have friends and family to not feel lonely.” Similar to the other participants, there was a sense that even with others around him, he could not always talk to them, and he was not sure whether people would understand his feelings.

This theme of isolation and believing that there is no one to talk to is similar to the grieving process of neurotypical adolescents. Elkind (1967) described grieving adolescents as often believing that no one can understand how they feel. This sense that others are not able to understand their grief can often lead to feelings of isolation and a

retreat into themselves (Cheifetz, Stavrakakis, & Lester, 1989; Worden, 1996). In fact, only 30% of adolescents had discussed grief and death with their family members after experiencing a loss (Justin, 1988). Increased feelings of loneliness was also noted by Murphy (1987) in adolescents who reported fewer grief responses. The findings of this study were similar, as each participant in this study had difficulty talking about their feelings of grief and their sense of isolation and not being understood.

When looking at a theme of isolation in adolescents with ASD, it is important to understand what the impact of having ASD might have on their experiences of grief. In general, adolescents with ASD struggle with social communication and interaction (APA, 2013), and these difficulties may contribute to higher levels of both social and emotional loneliness more so than in neurotypical peers (Bauminger et.al., 2003). Adolescents with ASD report few, if any, friendships that include the ability to share emotions (Howlin, 2003; Shattuck et al., 2007; Whitehouse et al., 2009). Although a sense of isolation and having no one to talk to is common among grieving adolescents, this perception may be even stronger in adolescents with ASD because of their social and communication difficulties. For example, three of the guardians expressed concerns over participants' increased difficulties with social interactions since the death of the family member. Bruce's and Stephen's mothers indicated that each of these young men had an increased anger toward others, and Peter's foster father noted that Peter was having more difficulty interacting with peers since his brother's death. Wade was the only participant who did not appear to be having more difficulty with social interactions since his grandmother's death, although his mother described him as "very closed off", so any changes may not have been evident.

Reconnection

“It made me closer to my girlfriend.” As part of a theme of isolation, there was a subtheme of reconnecting with others. Though there were indications that Bruce might have been moving away from his feelings of isolation, Peter was the only participant who expressed that he was trying to decrease his loneliness and that he had ways of combating these feelings. In addition, he was the only participant who appeared to be furthest along on his way to restructuring his life after the death (i.e., final period). According to Lamb’s (1988) process theory, it makes sense that those who are in the final period would be the ones most likely to want to reconnect with others. Though Peter was the only participant who provided specific examples about how he was trying to overcome his loneliness, Wade and Bruce also showed that they were trying to reconnect with others. In Wade’s case, he spoke about how the death of his grandmother was something that brought him closer to his girlfriend and Bruce’s mother shared about her conversation with Bruce. These reconnections might be an effect of being given an opportunity to explicitly speak about death in a safe environment. By openly discussing the topic of death, it was no longer the “subject that shall not be named” (Markell & Markell, 2008). Just as talking about Voldemort removed some of his power and ability to cause fear in the Harry Potter storyline, talking about death with the counseling assistants lessened the fear and power of the subject over the participants.

Avoidance

“I AM NEVER TALKING ABOUT DEATH!” All four participants engaged in avoidance behavior during their sessions, though each did it in different ways. Out of all the participants, Bruce was the most vocal in his desire to avoid the topics of death

and grief. He frequently shouted at his counseling assistant, declaring, "I don't want to talk about it!" Though the majority of Bruce's grief avoidant statements seemed hostile, as the sessions progressed, he began expressing his need to avoid the topic of grief more appropriately. For example, he asked not to talk about these topics, instead of demanding, and he used a much calmer voice, suggesting the emotionally charged aspect of his avoidance was somewhat diminished. However, this acceptance was brief and, after a short break between sessions, Bruce went back to a more forceful method of avoidance, yelling, "I'M NEVER GOING TO TALK ABOUT IT [death]!" Other participants also told their counseling assistants that they did not want to talk about their own experiences with grief, including Stephen and Peter, though neither of them used the forcefulness that was common with Bruce's avoidance.

Stephen also told his counseling assistant multiple times, "I don't want to talk about it" or "I don't like when people ask me those questions." When Stephen told his counseling assistant that he did not want to talk about his experiences with grief, he also expressed his wish to avoid the topic with a firmness that made it clear that he would not talk about this subject. So too, Peter told his counseling assistant, "I really don't want to talk about that" at times during his sessions. In contrast to the others, Peter was almost apologetic, as if he felt bad that he did not want to talk about his experiences with death and grief. Furthermore, he tended to proceed discussing whatever topic that the counseling assistant had brought up. Both Stephen and Peter made statements about not wanting to talk about a subject related to their experiences with grief and death every few sessions with no recognizable or changing pattern across the course of therapy. Wade did

not ever state that he wanted to discuss these topics, though with his tendency to stay silent, he did not need to state it explicitly.

In addition to their overt reluctance to share, participants engaged in other methods of avoidance during sessions as well. For example, they sometimes ignored direct questions asked of them by their counselors. This was particularly true of Wade, although he often did not respond to questions or comments on any topic, not just those related to grief or death. Participants also commonly avoided topics by changing the subject to something that was less threatening or to a preferred conversation like Pokémon or a favorite sports team for Bruce, videogames or art projects for Peter, and imaginative stories for Stephen. Of all the participants, Peter used this method of avoidance the most.

Another way that Bruce, Stephen, and Peter avoided the topics of death and grief was to say that they had forgotten, or wanted to forget, their grief. In one session, Bruce said, “I’m trying to forget my dad” and later, “I’m actually just trying to forget about my dad.” He also used this subtheme of forgetfulness when his counseling assistant tried to use the experiences of the Harry Potter characters to talk about grief, saying, “I forgot that part.” Stephen occasionally said “I don’t remember” when talking about his grief or when talking about the experiences of the characters in the Harry Potter story. This was a notable change because his counseling assistant described how Stephen enjoyed showing how much more he knew more about the Harry Potter story than she did. Additionally, Peter spoke of his desire to forget about his grief. Shortly into the counseling process, Peter told his counseling assistant “I try to forget” when asked about his deceased brother. He went on to say, “It makes it easier.” Peter also mentioned how he would use

the computer as a way to help him forget about his feelings, “I want to pretend it never happened.”

Avoidance in grief has been associated with a maladaptive coping through the bereavement process (Field & Sundin, 2001; Fraley & Bonanno, 2004; Ho, Chan, Ma, & Field, 2013). Avoidance has also been associated with complicated or prolonged grief (Holland, Neimeyer, Boelen, & Prigerson, 2009) and poorer adjustment over time through the bereavement process (Fraley & Bonanno, 2004). In fact, a recent study by Boelen and Eisma (2015) demonstrated avoidance, whether due to anxiety or depression, is significantly correlated with symptoms of prolonged grief disorder, depression, and post-traumatic stress disorder. Stephen provided an example of acceptance vs. avoidance during grief. He was almost always willing to talk about his grandfather’s death and had appeared to have already processed his grief over that death. On the other hand, when asked about his uncle, Stephen more often engaged in telling fantasy stories to avoid the subject. Though his grandfather’s death had occurred more recently, Stephen seemed more avoidant as related to his uncle’s death and clearly was stuck in the grieving process.

Adolescents with ASD often display task avoidance and social avoidance (Cihak, Kildare, Smith, McMahon, & Quinn-Brown, 2012; Ohtake, Kawai, Takeuchi, & Utsumi, 2013; Taylor, Ekdahl, Romanczyk, & Miller, 1994). Social avoidance becomes more prevalent in adolescents with ASD as they begin to understand their difficulties interacting with their peers (Bashe & Kirby, 2001; Klin & Volkmar, 2000; South et al., 2005). The avoidant behaviors observed in my participants appeared to be a mixture of both grief avoidance as well as a general feature of their ASD. For example, Wade often

refused to talk, no matter the subject. Additionally, both Bruce and Peter avoided tasks in the game if they were not interested in doing them, especially if they were having difficulty with a particular puzzle. Talking about grief is a task that participants experienced as difficult, both because of the painful memories they experienced and also because of the social interaction required. The fact that they were able to spend some time discussing these issues might have been a result of combining a task that the participants wanted to avoid (talking about their experiences with grief) with a preferred activity (playing videogames). This pairing has been shown to increase the participation in non-preferred activities with adolescents with ASD (Hull, 2011).

Regret

“All the things I regretted them not seeing.” Stephen, Wade, and Peter all brought up feelings of regret through their experiences in grief therapy using videogames. They expressed a wish that they had been there for the death or seen the deceased right after. When talking about his uncle’s death, Stephen said, “I wish I could just see him one last time when he was gone, but he died in his sleep, and I was at school.” For Wade, regret seemed to be about his choice not to be with his grandmother as she died. Peter regretted not being able to talk to his brother before he became so incapacitated by his illness. Of these three, Stephen’s regret appeared to be more intense than the others in that he perseverated on not knowing or not believing the cause of his uncle’s death. Some of his comments included, “I don’t know what happened to him, but it looked like something bad happened” or “He [his uncle] died in bed for no reason. We don’t know why.” His lack of information about his uncle’s death appeared to greatly trouble Stephen and perhaps delayed his grieving process because he felt somehow responsible

for figuring out this “mystery.” His mother also noted that he regularly brought up his uncle’s passing prior to starting therapy.

Although his grieving for his grandfather was more typical, Stephen expressed that he would regret all the occasions that his grandfather and uncle would miss including birthdays and his graduation. It may also have been Stephen saying that he would miss not being able to have these important individuals at his celebrations. It seemed as if, in some way, each milestone for him was one more thing to grieve because of who would not be there. Similar to Stephen, Peter brought up regrets over his brother’s death and “not getting to know my brother better.” Though he had lived with his brother and his brother had helped raise him, Peter did not feel that he had taken the opportunities to get to know him, and realized that there would be no more chances in the future. Unlike the other participants, Bruce did not acknowledge any feelings of regret. This might have been due to the circumstances of his father’s death (a sudden accident) or his insistence on not talking about the death. In fact, he almost seemed to take a certain pride in his ability to “not” talk about his father’s death.

Feelings of regret or guilt can be an integral part of the bereavement process (Stroebe et.al., 2014). Many adolescents believe that they should have done something differently or that they should have lived up to the expectations of the deceased (Stroebe et. al., 2014). Research has shown that greater feelings of regret correlate with higher levels of grief symptoms (Holland, Thompson, Rozalski, & Lichtenthal, 2013). Studies specific to Japan have reported similar findings in both adolescents and adults, noting that high levels of regret are related to psychological distress during the bereavement process (Akiyama, Numata, & Mikami, 2010; Mizota, Ozawa, Yamazaki, & Inoue, 2006).

Additionally, feelings of regret during bereavement have been linked to higher levels of depression (Torges, Stewart, & Nolen-Hoeksema, 2008). A study examining the differences in disappointment and regret between adults with ASD and a control group found that individuals with ASD experience less intense feelings of regret than the control group. Furthermore, the study indicated that individuals with ASD might have difficulty distinguishing regret from other similar feelings (Zalla et al., 2014). Therefore, more research may be warranted to better understand whether statements that seem to indicate “regret” reflect the experiences of grieving youth with ASD.

Depression

“It’s already hell, I can tell.” All the participants brought up feelings associated with depression during their sessions. Both Stephen and Wade specifically described their lack of interest in their respective futures. Stephen told his counseling assistant, “I don’t care about my future,” and Wade told his counseling assistant that he had “nothing to look for in the future.” Both of these participants appeared worried about their future (one was transitioning to high school, and the other had just made that transition) and seemed somewhat hopeless about what the future might hold. This transition appeared daunting to both of them, and each brought up fears about high school at least once during their sessions. Peter did not specifically talk about his future, but he did mention, “I feel like I won’t be happy ever again.” Unlike the others, Bruce did not bring up his future and what it might entail. His loss was the most recent, and he might not have been able to think about his future without his father.

When speaking about his feelings of depression, Stephen frequently used metaphors and fantasy. When talking about his life, Stephen mentioned, “It’s already

hell, I can tell.” He also spoke about an “emptiness” and a “void” when bringing up feelings of depression. Stephen related this back to his grandfather’s advice, saying that he was told “there’s no getting out of it once it catches [you]” and you just “wait for your imminent doom.” Stephen went on to say, “I’m already caught up in the void” and that “Emptiness is not good. It can destroy you.” These statements seemed to be Stephen’s way of sharing his feelings of despair after the death of his uncle and grandfather and that he had not yet figured out how to manage these feelings. Like Stephen, Peter also described his feelings of despair using metaphor. While playing a level with Dementors (magical creatures that suck the happiness out of people), Peter told his counseling assistant, “I feel like someone has taken a piece of my soul and happiness.” When asked more about it, Peter acknowledged that this was due to his brother’s death. In Peter’s case, it was clear that the game helped him to talk about the emptiness he felt after his brother’s death. It was more difficult to make that connection with the other participants.

Wade commented that he had “nothing” to look forward to. This was his only specific statement about feelings associated with hopelessness and depression, although he also shared the degree to which he was sleeping more than in the past. Wade told his counseling assistant, “I take too many naps” during multiple counseling sessions and admitted, “I go to sleep when bad thoughts come up.” Wade appeared to be using his sleep as an escape from his thoughts and feelings about grief. None of the other participants mentioned any somatic complaints, though it was noted in play therapy notes that both Wade and Peter would at times ask to leave the counseling room to go to the restroom. These occurrences all happened when they were discussing feelings of

depression, so it could have been related to somatic issues (e.g., gastrointestinal discomfort) or might have linked back to avoidance.

As stated above, Bruce did not mention feelings of depression like the other three participants, though he did display many incidences of anger and irritability, which can be symptoms of depression, especially with younger individuals (APA, 2013).

According to his mother, Bruce had displayed more aggression and anger ever since the death of his father. Further, he noted that he had become more irritable and impatient with others. In sessions, Bruce showed a high level of verbal aggression towards his counseling assistant and the interviewer, often yelling at them and calling his counseling assistant names. Though Bruce never acted physically aggressive, when he became angry with his counseling assistant, he would sometimes say, "I'm going to beat you." During a couple of play interactions, Bruce also played at the idea of disappearing by running his Harry Potter character off of the screen. It is difficult to know whether this was an exploration of his father's disappearance, consideration of his own non-existence, or simply checking out the parameters of the game.

Bereaved individuals often experience feelings and symptoms of depression (Harrison & Harrington, 2001). These symptoms may be considered a normal aspect of grief without understanding the possibility of developing a clinical level depression (Turret & Shear, 2012). When these depressive symptoms are at high levels, they have been associated with prolonged grief disorder (Shear, 2015). In the normal course of adjustment, these feelings and symptoms of depression are expected to decrease (Parkes, 1996). Adolescents with ASD may be prone to feelings of depression (Ghaziuddin, Ghaziuddin, & Greden, 2002) due to the conflict between their desire to connect with

others and their difficulty developing and maintaining relationships (Bauminger et al., 2003). In this study, it seemed that the participants who had experienced the death of someone they confided in, felt closest to, or offered a piece of themselves to (e.g., Bruce's father, Stephen's uncle, and Wade's grandmother) also described the most about depressive symptoms. Both Stephen and Wade appeared to not only be grieving the death of their respective loved one, but also the loss of the relationship to someone with whom they connected.

Playing as Death

“All I care about is destroying you in this game.” One of the notable aspects of this study was the degree to which each participant explored death using the videogame. Each of them was observed to attempt to kill characters, kill their own character, or to assume the role of a character who brought death as a way of exploring death, without the need to confront their own experiences with death. For Bruce, this play started out as aggression towards his counseling assistant's character and other non-combative characters in the game. Bruce frequently attacked, saying, “I want to kill you” or “I want to destroy you!” Though with less-aggressive verbalizations, Stephen and Peter also engaged in play trying to kill their counseling assistants' characters. Stephen usually did not say anything to his counseling assistant when he engaged in this play, instead allowing her to track his play. Peter would talk to his counseling assistant during this play, tracking himself, or tracking his character. He would often laugh during this play, saying, “Oh, no! Harry is going crazy!” Wade did not engage in this type of killing play at all during his grief counseling.

All four participants chose to play as characters related to death. When able to choose which character to play, all four repeatedly picked Voldemort or a Death eater, one of the characters that supports Voldemort and often kills other wizards in his name. This pattern was particularly seen in Bruce as he declared, "I'm going to be Voldemort, I'm being Voldemort, the person that killed Harry's parents. I just think he's pretty awesome." At times, he appeared to relish playing these characters and when he would, Bruce would attack his counseling assistant more frequently. Peter also engaged in more killing play when playing as Voldemort. For these two participants, it appeared as if they were using the characters of Voldemort and the Death eater as ways to role-play having the power over life and death as related to others. Wade did not choose to play as a character representing death until his counseling was nearing the end, which was different than the other participants who engaged in this type of play throughout their sessions.

Storytelling. In addition to playing at death as discussed above, Bruce, Stephen, and Peter also engaged in storytelling that was associated with death. Stephen's storytelling was the most striking example as he engaged in storytelling about death throughout many of his sessions. Stephen told fantastic stories about gang members killing people, his great grandfather fighting off Native Americans for his land, accidents involving gruesome injuries, and other stories about death, killing, and violence. Bruce used a song to tell his stories about death. He spent the majority of one session singing about "dumb ways to die." He used this song to explore different ways that people die, both realistic and fantastical. Peter's storytelling involved alternative universes. For example, Peter told a story where the character roles were reversed, and Harry was the

antagonist of the story. He also declared, “Oh, no, Voldemort has taken over the game!” and then told a story in which Voldemort had control of everything happening in the game as well as Peter and his actions in the game. As with the killing play, these stories appeared to be ways for the participants to explore death and its power over others without needing to address memories and feelings associated with their own experiences.

Play is considered to be the natural mode of communication for children (Green, Fazio-Griffith, & Parson, 2015; Kottman, 2011; Scarlett, Naudeau, Saloni-Pasternak, & Ponte, 2005). Though play therapy has typically been associated with young children, there has been growing support for use with adolescents because it provides the opportunity for creative and individual expression (Bratton, Taylor, & Akay, 2014). Children and adolescents often act out in play those feelings, thoughts, and experiences that they believe are too threatening to discuss verbally (Kottman, 2011). With this in mind, it was no surprise that the participants in this study all chose to play as death, and some chose to take up death’s mantle in order to engage in attempts to “kill” others. A videogame such as this allows adolescents that opportunity to adopt and enact these powerful roles as “deatheaters” in a safe environment. In this way, the videogame allows the participants to explore death and grief without having to confront their own experiences. The theme of playing as death and its subtheme of storytelling are the final themes that were observed through my cross-case analysis.

Summary

Through this study, I found themes across participants that provided details on how adolescents with ASD experience grief and the ways that they create meaning from a death. Through Bruce’s, Stephen’s, Wade’s, and Peter’s experience during this study, I

found that each progressed through Lamb's (1988) process theory of grief in their play, discussion, or both. The time frame for this progression appeared to be longer than what is expected of a neurotypical adolescent. I also found that those participants that communicated less verbally (e.g., Wade), or who were avoidant (e.g., Bruce), could explore their feelings of grief and bereavement through Harry Potter's experiences or by playing with aspects of death in the game.

When asked about their experiences, the participants described their counseling as mostly playing a game. Many of them expressed enjoyment of the game, even if they mentioned that they would rather have played a different one. Wade and Peter each expressed enjoyment of the sessions themselves, explaining that they believe it was helpful. All four felt the game made it easier to talk about death by focusing on Harry's experiences (e.g., Bruce) or by creating opportunities for conversation (Stephen).

No participant expressed a personal meaning of grief during this study, but that was not unexpected when working with adolescents with ASD. Instead, they voiced feelings such as isolation, regret, and depression which may be a reflection of the meaning they gave to their loss. Additionally, most participants engaged in avoidance of the topic of their own grief. Though avoidance was common, at differing points Bruce, Stephen, Wade, and Peter all chose to explore death through their play. As therapy progressed, observations indicated many changes in their behavior throughout the counseling sessions. Each was seen to become more engaged in counseling and to seek out more of a connection with their counseling assistants.

One of the goals of this study was to understand how playing a videogame with death themes facilitated the grieving process in adolescents with ASD. Two of the

participants expressed feelings of disinterest or annoyance with the game. During his midpoint interview, Bruce was asked about the game itself. He said, “It’s okay, I guess” and went on to say, “I like other games better.” Peter also told his counseling assistant many times about how he disliked the game and saying, “Can’t we play something else? Like Mario?” Neither Stephen nor Wade specifically mentioned a dislike or disinterest in the game, though Wade’s counseling assistant noted that Wade’s interest in the game changed. Originally, he appeared disinterested in the game, but as the sessions progressed, he became more interested and put forth greater effort to complete levels. This pattern seemed to occur for most of the participants with each spending more time focused on the screen, sitting forward, and reacting quickly to changing events in the game. By the ending sessions (7 through 10), the participants all appeared to be engaged and attempted to complete the objectives of the game. Specifically, although the counseling assistant for Bruce had been cautioned that he would need to provide breaks every five minutes, Bruce was able to participate in all sessions for the full time without needing to take a break during any of his sessions.

All the changes described throughout sessions and across participants must be considered with some caution. Parents and caregivers noted little change in the participants. If they did note a change, they attributed it to development rather than the therapeutic intervention. Stephen’s mother was the only person who credited the changes she saw in her son to the treatment. Although participants’ guardians often mentioned that they did not notice any change in their children, change in the participants was sometimes noted later during their stories (e.g., Bruce’s mother). Further changes in behavior were noted by myself and the counseling assistants during our observations of

the sessions. It may be that the changes were so subtle that they were not noted by others or that participants chose to discuss their ideas related to grief and loss only within the safety of the counseling room.

Many guardians expressed a feeling of not understanding how their sons were processing the deaths of their loved ones. Peter's foster father, Bruce's mother, and Stephen's mother all expressed confusion about the seeming lack of sadness or interest in talking about the person who had died. Even Wade's mother seemed somewhat perplexed by how closed off he was in relation to his grandmother's death. Each of these guardians seemed unsure of how their adolescent was coping with the death or the kinds of things they could do to support their sons. Unfortunately, because there is limited information on this topic (Allison, 2007; Forrester-Jones & Broadhurst, 2007; Hull, 2011), practitioners are not able to provide guidance.

Implications of Findings

All participants in this study were experiencing feelings of anger, depression, or isolation well after what would be expected from research completed on neurotypical individuals (Maciejewski et. al., 2007). This study, in conjunction with evidence provided by other mental health practitioners (Forrester-Jones & Broadhurst, 2007; Hull, 2011), suggests that when providing grief therapy to adolescents with ASD, it is important to consider that their grief process is similar to neurotypical youth but they may be going through the process at a slower pace. Therefore, when working with families of students with ASD who have experienced loss, it might be helpful to inform parents about a more realistic trajectory of their child's grieving process. It might also be important to help them understand that their child with ASD will likely have more

difficulty processing the various emotions that come with grief and loss. Many of the parents in this study were surprised by the lack of conversation and the limited emotions that were shown by their sons in reaction to the death of a loved one. By giving parents information about the timeline, they may be better able to support their grieving adolescents.

Feelings of isolation are frequently targets of intervention when working with adolescents who are grieving. To reduce this sense of isolation, group therapy is a recommended method of intervention for adolescents who are grieving (Bonanno, Boerner, & Wortman, 2008; Currier, Neimeyer, & Berman, 2008; Jordan & Neimeyer, 2003). Group therapy provides an environment for grieving adolescents to talk about their feelings and understand that they are not alone and others have experienced similar situations (Ayyash-Abdo, 2001; Rice 2015). For youth with ASD, a traditional group therapy setting requiring intensive sharing and social interactions with a number of different group members might be more stress-provoking than comforting. However, it might be helpful to use the Harry Potter videogame with a small group of adolescents with and without ASD (e.g., two to three participants) who are grieving the loss of a loved one. This type of setting might allow for that interaction and understanding that others are going through a similar experience, but the focus on verbal interaction is somewhat buffered by the videogame.

None of the participants expressed a great love of the Harry Potter videogames suggesting that no one videogame will likely meet the needs of all participants. However, this particular game was chosen because it had several themes of death and loss incorporated throughout, it represented a character in popular culture, and it incorporated

play and storytelling as a way to explore these themes of loss. In fact, all participants became more engaged in the videogame play over time and it may have allowed participants to engage in relatively uncomfortable discussions. All of the counseling assistants remarked on their participants' engagement in the videogame, and two specifically mentioned how the videogame provided a structure to the counseling sessions and allowed death to be explored in a more comfortable way for the participants. Some mental health practitioners are concerned that videogames detract from counseling and that the positioning (i.e., side by side) may interfere with the development of a therapeutic relationship (Ceranoglu, 2010). Though this is a concern in working with adolescents with ASD, this positioning may actually be beneficial as it creates a structure for the interaction and reduces some of the intensity of the interaction.

Most mental health approaches to processing grief place an emphasis on the need to talk and to share one's emotions about what has happened. For younger children, there is recognition that this emotional expression may occur through play, but with adolescents, it is much more likely that verbal expression will be expected. Through Bruce's experiences in this study, it seemed that despite his insistence on not talking about death or his emotions, he was still processing his bereavement. By the end of his grief counseling sessions, he was able to show empathy for his mother's sadness and share his feelings in a manner that he had not prior to therapy. Therefore, continued exploration of other ways to incorporate play in various forms may offer a strategy for keeping students with ASD engaged in their treatment.

Limitations

A limitation of this study was the use of three different counseling assistants. There were many aspects of the counseling assistant that varied such as gender, ethnic match to the participants, level of experience, and personal characteristics. It is not possible to determine the degree to which these person variables might have played a role in developing rapport, engagement in sessions, or other aspects of the therapeutic relationship. Though each counseling assistant had experience working with individuals with ASD, none of the counseling assistants had previous experience in the use of videogames as a therapeutic tool and only one was knowledgeable about the Harry Potter story.

As the lead researcher of this study, I was required to work with a variety of individuals to complete this study. This study was conducted in two different states almost 1,800 miles from each other. As noted, three different counseling assistants provided intervention in four different locations. Two counseling assistants worked with participants in Colorado and the same counseling assistant worked with the Maryland participants. It was difficult to keep abreast of everything that was going on in each location and, at times, I felt removed from the research. This disconnection was at odds with the views of some qualitative researchers who believe that it is important to be directly involved in each aspect of the study, including the delivery of the intervention (Jansen, Foets, & de Bont, 2010; Stange, Goodwin, Zyzanski, & Dietrich, 2003). My use of assistants for much of the data collection and treatment allowed a certain neutrality, but also limited my direct connection to my participants. However, the lack of direct interactions with the participants (except to interview two of them) allowed me to be

more of an observer and to remove some of the bias that is associated with being a participant observer.

To enhance the fidelity of the therapeutic approach, I attempted frequent contact with all assistants engaged in the research but it was much easier for me to do this with the counseling assistant in Maryland. There was a lag between when sessions occurred and when I was able to review them for the Colorado participants. Therefore, I was not able to provide feedback to counseling assistants regarding their adherence to the matrix or other aspects of fidelity. Therefore, these sessions had less treatment integrity than those that occurred in Maryland where I could review sessions weekly (or nearly so) and provide frequent feedback and guidance around the model to the counseling assistant. For counseling assistants in Colorado, the majority of my communication was through phone calls or video chats, as compared to the frequent in-person conversations with the counseling assistant in Maryland.

Future Research

In any research project, it is important to consider the need for future research in order to advance the findings of the current study. With this in mind, I believe that more research is warranted as related to aspects of the delivery of this type of counseling. For example, studies might be directed toward exploration of the number of grief sessions that might be most beneficial to adolescents with ASD who are grieving. In this study, although participants made progress with 10 counseling sessions, but not all of the participants were able to fully engage in the final period of grief according to Lamb's (1988) theory. As seen as a result of this study and in the review of research, adolescents with ASD may experience the negative feelings and emotions associated with grief for

longer periods of time. To fully process their grief, adolescents with ASD may benefit from more counseling sessions, or they might benefit from having the sessions more often than once a week. By allowing for more grief counseling sessions or the use of multiple weekly sessions, adolescents with ASD might make more progress in their bereavement. Another area that could be explored in future research is the use of pre-sessions to help the counselor and the adolescent build rapport before exploring the adolescent's experience with grief.

The participants in this study were all male. Since males are more frequently diagnosed with ASD than females (Baio, 2014), the resulting sample was not unexpected. However, future researchers may want to explore the use of videogames to facilitate grief therapy with female adolescents with ASD to see if there is a difference in their grieving process, and if videogames help facilitate grief therapy. The age range of these participants was also fairly narrow so future research might be directed toward understanding how the use of videogames facilitates outcomes with participants who represent a wider age range. This study focused on the experiences of adolescents with ASD but similar studies might be directed toward neurotypical youth who are grieving.

Generally, more effort towards understanding the most effective forms of treatment for youth with ASD is needed. Although traditional theories and modalities provide a foundation, further research is needed on how to adapt grief therapy techniques to better suit the needs and abilities of adolescents with ASD. These individuals experience difficulties with social interactions and may struggle to engage in traditional modalities (e.g. group therapy). By examining ways of adapting traditional techniques of

grief therapy for individuals with ASD, mental health professionals can be better prepared to meet their needs.

Consistent with that recommendation, more research is needed to prepare service providers to support grieving adolescents with ASD. This study provided evidence that indicates that these individuals experience grief on a different trajectory than their neurotypical peers. The parents and caregivers in this study frequently expressed that they were unsure of their child's grieving process. Future researchers might explore the best ways of supporting not only grieving adolescents, but also their families.

Although there is research on the topic of grief therapy with typically developing youth, more needs to be done to better understand the effectiveness of the techniques used. Specifically, the incorporation of areas of interest should be explored as a method for enhancing the effectiveness of grief therapy. Many children and adolescents have difficulty talk about death and grief. By pairing these conversations with areas of interest, young client might be able to improve their participation in grief counseling.

Another potential avenue for future research could focus on other types of videogames within grief therapy. The videogames used for this study were specifically chosen for their limited violence and the high levels of grief and bereavement themes found in the Harry Potter storyline. There are other Harry Potter videogames that could be used for this purpose or potentially other videogames. A matrix was developed specific to the Harry Potter videogames and this structure seemed to facilitate the progression of therapy for both the participants and counseling assistants. Therefore, if other games were used it is recommended that a similar guiding matrix be used so that the videogames serve a facilitating purpose rather than a distracting one.

Bereavement is a time sensitive phenomenon and often changes as youth mature. By looking at the experiences of grieving adolescents years after the intervention has been implemented, we could gain more insight into these individual's grieving process. Therefore, the use of longitudinal studies may be beneficial in understanding the grief experiences of adolescents with ASD.

Conclusions

With the dramatic rise in the diagnosis of ASD and the estimated number of students who will experience the death of a close friend or family member, it is critical for mental health practitioners to be prepared to provide grief counseling services to adolescents with ASD who are experiencing difficulty based on their reaction to grief. This study explored the experiences of four adolescents with ASD through a potentially beneficial method of providing grief counseling. Through this study, I found evidence that adolescents with ASD experience grief similarly to their neurotypical peers, though on a potentially slower timeline. The use of a videogame seemed to enhance engagement and possibly allowed participants to process their feelings, even if they were not expressing them verbally. Even though each participant displayed a variety of different behaviors as related to their experiences with death, they all showed some progress by attempting to reconnect with others, being more willing to discuss their experiences, or demonstrating empathy towards others.

The use of videogames and their potential benefit to children and adolescents has been an area of controversy in the research (Ceranoglu, 2010). This study, like others (Hull, 2009, 2011), has provided information that the use of videogames may help enhance the engagement of adolescents with ASD in therapy and allow them to explore

their feelings. Through the use of videogames, adolescents were provided an opportunity to explore themes associated with difficult emotions including grief and bereavement but could do so through the characters in the videogames. The experiences of Bruce, Stephen, Wade, and Peter, provide preliminary support for the use of videogames as a beneficial tool to help adolescents with ASD in grieving process.

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APPENDIX A
SAMPLE RECRUITMENT LETTER



Dear _____,

My name is Kyle Johnson, and I am a doctoral candidate in school psychology at the University of Northern Colorado. I am conducting a study exploring the experiences of adolescents with ASD in grief therapy. I am interested in attending one of your parental support groups in hopes of recruiting participants for this study. I am requesting a chance to speak to your group for a 10 minutes at the beginning or the end of one their sessions. If this is a possibility, please contact me through email or phone (listed below). Thank you for your time and consideration in this matter. This study has been approved by UNC IRB.

Sincerely,

Kyle Johnson
Doctoral Candidate
Dept. of School Psychology
University of Northern Colorado
205-999-1726
John2756@bears.unco.edu

APPENDIX B
SAMPLE RECRUITMENT FLYER

DO YOU HAVE AN ADOLESCENT WITH ASD WHO EXPERIENCED THE DEATH OF A FRIEND OR FAMILY MEMBER?

We are looking for adolescents to participate in a research study exploring the use of video games as a therapeutic tool for grief therapy.

PARTICIPANT REQUIREMENTS:

Adolescents ranging from 11 to 17 years of age with a diagnosis of Autism, Asperger's Disorder, PDD-NOS, or ASD. Participants must have experienced the death of a close friend or family member. The participants must be experiencing difficulty socially, academically, and/or emotionally.

PARTICIPATION:

Participants will receive weekly one hour grief counseling sessions lasting for 10 weeks. Participants' guardians will receive five \$10 gas cards spaced throughout the counseling process. All services are provided at no cost to the participants or their families.

FOR MORE INFORMATION:

KYLE JOHNSON -- JOHN2756@BEARS.UNCO.EDU

THIS RESEARCH PROJECT HAS BEEN APPROVED BY
THE UNIVERSITY OF NORTHERN COLORADO IRB



UNIVERSITY of
NORTHERN COLORADO



APPENDIX C
SCREENING INTERVIEW

SCREENING INTERVIEW

Guardian Name: _____

Date: _____

Participant Name: _____

Phone Number: _____

1. How old is your child?
2. What is your child's Diagnosis/identification?
3. What assessments were used for used for this diagnosis?
4. What is your child's current level of cognitive functioning?
5. Has your child experienced difficulty interacting with peers or family members since the death that is not typical?
6. Has your child experienced difficulty at school since the death that is not typical?
7. Has your child had difficulty regulating their emotions since the death that is not typical?
8. Would your child have an aversion to playing *LEGO® Harry Potter Years 1-4* or *LEGO® Harry Potter Years 5-7*?
9. Would your child prefer to play these video games on a Nintendo Wii, an Xbox 360, or a PlayStation 3?

Is the Guardian interested in going forward: YES or NO

Did the participant meet all requirements: YES or NO

Date scheduled for intake: _____

APPENDIX D

UNIVERSITY OF NORTHERN COLORADO
INSTITUTIONAL REVIEW BOARD
ACCEPTANCE LETTER

UNIVERSITY of
NORTHERN COLORADO



Institutional Review Board

DATE: July 29, 2015

TO: Kyle Johnson
FROM: University of Northern Colorado (UNCO) IRB

PROJECT TITLE: [631840-5] I Don't Like the Talking Part: The Use of Video Games to Facilitate Grief Therapy for Adolescents with High Functioning Autism

SUBMISSION TYPE: Continuing Review/Progress Report

ACTION: APPROVED

APPROVAL DATE: July 22, 2015

EXPIRATION DATE: July 22, 2016

REVIEW TYPE: Expedited Review

Thank you for your submission of Continuing Review/Progress Report materials for this project. The University of Northern Colorado (UNCO) IRB has APPROVED your submission. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of July 22, 2016.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Sherry May at 970-351-1910 or Sherry.May@unco.edu. Please include your project title and reference number in all correspondence with this committee.

APPENDIX E

BALTIMORE CITY PUBLIC SCHOOLS
INSTITUTIONAL REVIEW BOARD
ACCEPTANCE LETTER

BALTIMORE CITY PUBLIC SCHOOLS

Stephanie Rawlings-Blake
Mayor, City of Baltimore

Marnell A. Cooper
Chair, Baltimore City Board of
School Commissioners

Gregory E. Thornton, Ed.D.
Chief Executive Officer

July 31, 2015
0000224

Kyle Johnson

School Psychology Intern/Doctoral Candidate

Baltimore City Public Schools/University of Northern Colorado

7885 Popular Grove Road

Severn, Maryland 21144

Dear Mr. Johnson:

IRB# 0000224

TITLE OF PROPOSAL: *I Don't Like the Talking Part: The Use of Video Games to Facilitate Grief Therapy for Adolescents with High Functioning Autism*

This is to notify you of the approval of your project by the Office of Achievement and Accountability (OAA) Institutional Review Board (IRB) for the Protection of Human Subjects. It's the opinion of this Board that you have provided adequate safeguard for the rights and welfare of participants selected for this study. Your proposal seems to be in compliance with OAA's Federal Wide Assurance 00008794 and DHHS Regulations for the Protection of Human Subjects.

Date of Review: 07/30/15

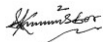
Your approval is valid until 07/30/16. Please note that the assigned IRB number must be displayed on the Informed Consent Form and copies of that form should be submitted to OAA IRB. All research members of this project who will have any interactions with students must be fingerprinted by City Schools Human Capital Office.

This project should be conducted in full compliance with all applicable sections of the IRB Guidelines. The IRB should be notified immediately of any proposed changes. You should also

report any unanticipated problems involving risks to participants or others to the IRB. For projects that continue beyond one year from the starting date, the IRB will request continue review and update of the research project. Your study will be due for continue review as indicated above. The investigator must also advise the IRB when this study is completed or discontinued.

If you have any questions, please contact the IRB Chair at (443) 642-4032, or by email at idiibor@bcps.k12.md.us. Thank you for your interest in City Schools.

Respectfully,



Ike Diibor, Ph.D.

IRB Chair

C: Theresa D. Jones, Chief Achievement and Accountability Officer.

APPENDIX F
INFORMED CONSENT FOR RESEARCH



CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH

UNIVERSITY OF NORTHERN COLORADO

Project Title: The Use of Video Games to Facilitate Grief Therapy in Adolescents with High Functioning Autism

Researcher: Kyle Johnson, B.A., Department of School Psychology

Phone Number: (205) 999-1726 E-mail: john2756@bears.unco.edu

Research Advisor: Robyn Hess, Ph.D., Department of School Psychology

Phone: (970) 351-1636 E-mail: robyn.hess@unco.edu

My name is Kyle Johnson and I am a doctoral candidate in the field of school psychology. I am researching the use of video games to facilitate grief therapy when working with adolescents with autism spectrum disorder. Participation in this study is voluntary. You may decide not to allow your child to participate in this study and if (s)he begins participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are

otherwise entitled. If you grant permission and if your child indicates to us a willingness to participate, you and your child will engage in several activities.

The first of these activities will include interviews. You will be interviewed about your child's experiences with grief and the services provided at the beginning and the end of the counseling meetings. Your child will also be interviewed at the beginning meeting, middle meeting, and at final meeting. The interviews with your child will focus on their own experiences with grief and their experiences in the counseling sessions.

As mentioned above, your child will engage in grief counseling as part of this research study. The counseling services will be provided at no cost to you or your family. Your child and counselor will meet for weekly grief counseling sessions at the University of Northern Colorado Psychological Services Clinic. These sessions will last for approximately 50 minutes and will continue for eleven weeks.

You will also meet with a research assistant during the first counseling session and during the last counseling session to conduct interviews with both you and your child. The grief therapy sessions will consist of directive play-based therapy using the LEGO® Harry Potter video games on the Nintendo Wii, PlayStation 3, or Xbox 360 console. As part of the grief therapy sessions your child will be asked to complete counseling homework assignments.

There are other activities to be conducted as part of this research study that will not require any time on your or your child's part. These include an interview with the counselor conducting the grief therapy sessions. This interview will focus on the counselor's observations of the counseling experiences of your child. We will additionally video record the interviews and counseling sessions and create

transcriptions of these video recordings for research purposes. Be assured that these recordings will be kept private.

To further help maintain confidentiality, computer files of adolescent's counseling sessions will be created and their names will be replaced by pseudonyms. The names of subjects will not appear in any professional report of this research. Only my advisor, the research assistants, and myself will have access to the information gathered in this research study. I foresee no risks to subjects beyond those that are normally encountered during grief therapy. Please feel free to call me if you have any questions or concerns about this research and please retain one copy of this letter for your records.

Thank you for assisting me with my research.

Sincerely,

Kyle Johnson
Ph.D. Candidate in School Psychology
University of Northern Colorado

Having read the above and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact the Office of Sponsored Programs, Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1910.

Child's Full Name (please print)

Child's Birth Date (month/day/year)

Parent/Guardian's Signature

Date

Researcher's Signature

Date

APPENDIX G
MINOR ASSENT FOR RESEARCH



ASSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH

UNIVERSITY OF NORTHERN COLORADO

Hi!

My name is Kyle Johnson and I'm a student at the University of Northern Colorado. I do research on grief and loss. That means I study the way people grieve and ways to help them. I would like to help kids deal with grief. If you want, you can be one of the kids I work with.

If you want to work with me, I'll ask you about the death you experienced. I will also talk to you about death and grief. We will also do a lot of different activities to help you feel better.

Working with me could help you feel better, but it could also have you remember sad times. Your parents have said it's okay for you to work with me, but you don't have to. It's up to you. Also, if you say "yes" but then change your mind, you can stop any time you want to. If you have any questions for me about my research, please let me know.

If you want to participate in my research and work with me, sign your name below and write today's date next to it. Thanks!

Participant

Date

Researcher

Date

APPENDIX H
PARTICIPANT INTERVIEWS

PARTICIPANT INTERVIEWS

ID # _____

DATE: _____

Pre-Intervention Questions

1. Tell me about _____ (the person who died)?
2. Tell me about the death of _____?
3. Tell me about your thoughts about death?
4. What was it like when you found out _____ died (or was going to die)?
5. Will you tell me about the feelings and emotions you have had about the death?

Please explain.

6. Many people change in how they act around others or at school/ work after experiencing a death? In what ways do you think that you act differently since the death?
7. How has your life changed since the death?
8. What do you think happens when people die?

Participant Interview Mid-Point and Post-Intervention Questions

1. Tell me about your experiences in your sessions so far.
2. Tell me how your thoughts about death have changed since you began attending these counseling sessions.
3. When we met before I asked you how you might have changed around others or at school/work. Tell me about these changes since you have been coming to sessions.
4. Tell me about the feelings you are having about _____'s death right now.

APPENDIX I
GUARDIAN INTERVIEWS

GUARDIAN INTERVIEWS

ID # _____

DATE: _____

Pre-Intervention Questions

1. We're talking during this interview about a time when your child experienced the death of someone close to them that resulted in his/her experiencing grief. Will you tell me about that experience?
2. Please tell me about how your child reacted to this death.
 - a. Can you give me a specific example?
3. Give me an example of what _____ talked about in the hours, days, and weeks following the death?
4. How did _____'s behavior change after the death, and in what way?
5. Do you think _____'s reaction to the event was unique from what you would expect of a child without ASD?
 - a. In what ways?
6. Are there aspects of _____'s grieving process that you found particularly difficult because of ASD? Please explain.
7. Were there aspects that you believe were easier because of ASD?
8. Are there questions that _____ asked about death after it happened?
 - a. Can you give me a specific example?
9. Does _____ talk about emotions and feelings they experience that are associated with the grieving process?
 - a. Can you give me a specific example?

- b. Are there emotions and feelings he or she appears to be experiencing that they do not talk about?

10. What else would you like to share about your child's grief?

Questions added for guardian interview post-intervention

1. How has _____'s behavior changed regarding the death since taking part in this intervention?
2. How has the way that _____ talks about death changed since taking part in this intervention?
 - a. Can you give me a specific example?
3. Have there been changes in the emotions, behaviors, and/or conversations related to _____'s grieving process since they took part in this intervention?

APPENDIX J
CHILD INTAKE FOR COUNSELING



Psychological Services Clinic

Please fill out this form as completely as possible and feel free to ask if anything is not clear to you. If some of the questions do not apply to your situation, please write "N/A" in the blank. Feel free to write on the back sides of the paper if you need more room. Thank you.

A. Identification

Person(s) completing this form: _____

Today's Date: _____

1. Child's name: _____

Birth date: _____ Age: _____

Address: _____

Telephone: _____

2. Mother/Female Guardian: _____ Age: _____

Address: _____

Cell Phone: _____

Home Phone: _____

Occupation: _____

Biological mother Adoptive mother

Grandmother/aunt/other _____

3. Father/Male Guardian: _____ Age: _____

Address: _____

Cell phone: _____

Home phone: _____

Occupation: _____

Biological father Adoptive father

Grandfather/uncle/other _____

4. Parents are currently: Married Divorced Remarried

Never married Other: _____

If divorced: Joint custody Sole custody – mother Sole custody – father

Custody resolved Custody evaluation in progress Custody being contested

Other: _____

5. Stepparents name(s): _____

Age: _____

Address: _____

Cell Phone: _____

Home Phone: _____

Occupation: _____

6. Child is currently living with: Both biological parents
 Mother Father Fostercare Friend Other: _____

B. Family History

Please check all items which apply and explain (i.e. who [mother, father, extended family], when, circumstances, etc.)

- Previous counseling _____

- Current counseling: _____

- Inpatient mental health treatment: _____

- Suicide history and attempts: _____

- Depression and anxiety: _____

- Learning disabilities: _____

- Physical or sexual abuse: _____

- Drug and/or alcohol abuse: _____

- Serious illness/injuries: _____

- Legal difficulties: _____

- Other: _____

C. Siblings

Child's name Date of birth Description of relationships – how do they get along?

D. Developmental History

1. Pregnancy and delivery

Problems during pregnancy? _____

Mother's age during pregnancy? _____

Father's age during pregnancy? _____

Did mother: Smoke? (number of cigarettes per day: __) Drink alcohol? (number of beers/drinks per day/week: __) Use drugs? (what drug and how much: _____) Experience illness during pregnancy? (_____) Was child premature? (by how many days? _____) Labor induced?

Length of labor? _____

Any other birth complications or problems? _____

2. Early development

Any problems with... Feeding Allergies Sleeping Medical Birth defects PersonalityAny delays in... saying single words Crawling Walking Talking Toilet training Fine-motor**E. Health**

List all childhood illnesses, hospitalizations, medications, allergies, head traumas, significant accidents and injuries, surgeries, periods of loss-of-consciousness, convulsions/seizures, and other medical conditions.

Condition	Age	Treated by whom	Consequences

F. Residences

1. Homes Dates From → to	Location	Living with whom	Reason for Moving	Any problems

2. Residential placements, institutional placements, or foster care

Dates	Location From → to	Living with whom	Reason for Moving	Any problems

G. Schools

School name and district	Child's age	Grade	Teacher

Significant academic problems: _____

Special education Retention (grade: _____) Speech/language therapy
OT/PT IEP Plan

Significant behavior problems Detention Suspension Expulsion

Organized sports: _____ Extracurricular activities: _____

Which subjects and activities does this child enjoy most? _____

Which subjects and activities are most difficult for this child? _____

List and describe any school special services in which this child has participated (resources, individual or group counseling, speech, etc): _____

May I call and discuss this child with his/her current teacher? _____

General description of child's social interactions: _____

H. Special Skills or Talents of Child

List hobbies, sports, recreation, TV, toy preference, etc: _____

I. History of Abuse

Describe any history of neglect, verbal, emotional, physical, or sexual abuse: _____

What actions were taken? _____

J. Previous Psychological Concerns and Counseling History

Please describe: _____

Name(s) of previous counselor(s): _____

Dates and types of therapy (e.g. individual, family, etc): _____

Impact/outcome/results of therapy: _____

K. Current Psychological Concerns

Describe all current psychological, emotional and behavioral problems and concerns: _____

Describe your current relationship(s) with this child: _____

L. Treatment

What would you like to achieve through therapy for this child? _____

How do you hope therapy might change things for you? _____

What would you like to achieve through therapy for the family? _____

What concerns do you have regarding therapy? _____

What questions do you have about therapy? _____

M. Other

What else might be important to share that might not appear on this form?

APPENDIX K
EXPLANATION OF THERAPY

Explanation of Therapy

I wanted to take a moment to talk to you about counseling and what our meetings will look like. You are coming here because of your experiences with the death of _____. During our time together we will talk about your thoughts and feelings related to these experiences. In many typical counseling sessions we would spend the majority of time talking about what is going on. Our time together is going to be a little different. To help us talk about death we will spend time playing Harry Potter video games. In this story, Harry has a lot of different experiences with grief and death. As we play the video game we will use Harry's experiences to talk about your own experiences, feelings, and thoughts. Every meeting will start with a review of our last meeting. Then we will play the game and talk about grief and death. Playing the game will take up most of our time together. At the end of each meeting we will have a review of what we did and talked about and then we will talk about activities for you to do at home before our next meeting. What questions do you have?

APPENDIX L
SAMPLE OF THE COUNSELING MATRIX

Period in Process Theory of Grief	Difficulties that the Participant Might be Experiencing Due to Grief	Corresponding Storyline Points in Harry Potter Novels	Location in the Video Game	Discussion Questions	Homework and Activities
Initial	The participant is not interested in talking about themselves or the person who died.	<p>The story has a variety of characters from young to old, brave to afraid, magical to non-magical, good to evil.</p> <p>The sorting hat and which house the characters belong to.</p> <p>Different quidditch team positions and being part of a team.</p>	<p>Game: Both: Able to choose all the different characters from the book.</p> <p>Game: Years 1-4: Video 9: The sorcerer's Stone-Hogwarts Intro</p> <p>Game: Years 1-4: Year 1: A Jinxed Broom</p>	<p>Which character is most like you (the person who died? you relate to the most? wish you were more like?)? Tell me about that.</p> <p>What house do you think that the sorting hat would place you in? What is it about you that the hat would sense to make it choose that house? Is this the house you would want to be in?</p> <p>If you were going to be on your chosen house's quidditch team which position would you play? What is it about that position that makes you want to play it?</p>	<p>Take an online test that sorts people into different houses and then have the participant discuss the results. (www.personalitylab.org/tests/ccq_hogwarts.htm)</p> <p>Create a poem/song about which house the sorting hat would place you or the person who died.</p> <p>Draw a picture of the character you most identify with and which you think the person who died would identify with</p> <p>Draw a picture or write a story of you and the person who died playing quidditch</p>

APPENDIX M
COUNSELING ASSISTANT INTERVIEW

COUNSELING RESEARCH ASSISTANT INTERVIEW

ID # _____

DATE: _____

1. What did the process look like for the participant?
 - a. What similarities and/or differences did you see across participants?
2. How did the participant's conversations about grief change though the session?
3. What changes in behavior of the participants did you notice throughout the sessions?
4. What did you notice about the participant's creation of meaning of the death did you notice throughout the session?

APPENDIX N
OBSERVATION FORM

Observation note ID #	
Name of Participant	
Location	
Name of Observer	
Observation date	
1. Observations of the affect of the participant	
2. Observations on the amount and content of conversation by the participant related to grief	
3. Observations on participant communication, both verbal and nonverbal	
4. Behavioral observations of the participant	
5. Other Relevant Observations not covered by 1, 2, and 3	
6. Information acquired through conversations with the participant's guardians	
7. Personal comments	

APPENDIX O
VIDEOGAME THERAPY NOTES

Date/Session # _____ / _____ Child/Age _____ Presenting Concerns _____

Counselor _____ Supervisor _____

I. Subjective (Feelings Expressed) Underline all that Apply (including capitalized words). Indicate predominate feeling(s) by circling _____

HAPPY: relieved, satisfied, pleased, delighted, excited, surprised, silly CONFIDENT: proud, strong, powerful, determined, free

SAD: disappointed, hopeless, pessimistic, discouraged, lonely HESITANT: timid, confused, nervous, embarrassed, ashamed

ANGRY: impatient, annoyed, frustrated, mad, mean, jealous CURIOUS: interested, focused

AFRAID: vulnerable, helpless, distrustful, anxious, fearful, scared, terrified FLAT: restricted, contained, ambiguous

II. Objective _____

A. SIGNIFICANT VERBALIZATIONS CH= Child initiated CO = Counselor initiated

B. LIMITS SET: Write limit set beside the category & indicate # of times limit set. (Ex: threw controller against wall/set once). If ultimate limit was set, describe.

PROTECT CHILD (HEALTH/SAFETY):

PROTECT ROOM/TOYS:

STRUCTURING:

REALITY TESTING:

SOCIALLY UNACCEPTABLE BEHAVIOR:

III. ASSESSMENT: General Impressions/Clinical Understanding _____

A. DYNAMICS OF SESSION: Rate (0=Low, 10=High): Child's play/activity level: _____
Intensity of play: _____ Inclusion of therapist/level of contact: _____

Destructive	1	2	3	4	5	6	7	8	9	10	Constructive
Messy/Chaotic	1	2	3	4	5	6	7	8	9	10	Neat/Orderly

SENSATION

SOMATIC COMPLAINTS
BREAKS

_____ Headache
_____ Stomach Ache
_____ Pain _____
_____ Discomfort with Clothing _____

TACTILE STIMULATION

_____ Toy
_____ Clothes
_____ Controller
_____ Other

SUBSTANCE ON:

_____ Self
_____ Counselor
_____ Objects

BATHROOM

_____ Urination
_____ Bowel

B. Benedict Themes: (developed by Helen E. Benedict, Ph.D., Baylor University, 2000 and 2002)

<u>AGGRESSIVE</u>	<u>ATTACH/FAMILY</u>	<u>SAFETY</u>	<u>EXP/MASTERY</u>	<u>INTERPERSONAL</u>
_____ G>B	_____ CON	_____ BUR	_____ EXP	_____ COOP
_____ AGG	_____ SEP	_____ BURY	_____ MAS	_____ COOP-
_____ JD	_____ SEP-R	_____ BR	_____ FAIL	_____ COMP
_____ POW	_____ NUR+	_____ BR-S		_____ SHAR
_____ SEEK	_____ NURS	_____ BR-H	<u>SEXUALIZED</u>	_____ HELP
_____ D-AG	_____ NUR-	_____ FX	_____ SEX-O	_____ PRO
_____ D-N	_____ NUR-A	_____ SFX	_____ SEX-T	_____ IND
_____ DEV	_____ NUR-N	_____ BRG	_____ CUR	_____ CNT
	_____ NUR-S	_____ FALL		_____ IM-CNT
<u>P-CODES</u>	_____ SLE	_____ CLN	<u>NON-PLAY</u>	_____ IM
_____ D/U	_____ STO	_____ MESS	_____ ART	_____ BND
_____ STG	_____ AD	_____ SOR	_____ GAME	_____ BND-
_____ ROLE		_____ DAN	_____ T-A	_____ FUS
_____ DIS		_____ SAF-C	_____ X	_____ AFF
		_____ SAF-P		_____ ANG
		_____ SAF-RES		_____ SAD
		_____ ESC		_____ REJ
				_____ PCON
				_____ RUF
				_____ TEA

D. OVERALL CHILD'S BEHAVIOR/AFFECT WAS:

Sad/Depressed/Angry	1 2	3 4	5 6	7 8	9 10	Happy/Content/Satisfied
Anxious (Fearful)/Insecure/Hesitant	1 2	3 4	5 6	7 8	9 10	Confident/Secure
Angry/Low Frustration Tolerance	1 2	3 4	5 6	7 8	9 10	High Frustration Tolerance
Dependent	1 2	3 4	5 6	7 8	9 10	Autonomous/Independent
Immature/Regressed/Hypermature	1 2	3 4	5 6	7 8	9 10	Age Appropriate
External Locus Of Control	1 2	3 4	5 6	7 8	9 10	Internal Locus of Control(self-control)
Impulsive/Easily Distracted	1 2	3 4	5 6	7 8	9 10	Purposeful/Focused/Curious
Inhibited/Constricted	1 2	3 4	5 6	7 8	9 10	Creative/Expressive/Spontaneous/Free
Isolated/Detached	1 2	3 4	5 6	7 8	9 10	Connected/Sense of Belonging
Flat Affect	1 2	3 4	5 6	7 8	9 10	Animated Affect

E. CONCEPTUALIZATION OF PARTICIPANT AND PARTICIPANT'S PROGRESS:

IV PLANS/RECOMMENDATIONS: (include talking with parent/school – requesting records, etc.) _____

Research Assistant's signature with credentials

Date

APPENDIX P
TREATMENT INTEGRITY MEASURE FOR
INTAKE SESSION

1. Did the Research Assistant go over *Consent to Treat a Minor* form?
YES NO
2. Did the Research Assistant go over *Minor Assent* form?
YES NO
3. Did the Research Assistant go over *Client Rights Disclosure Statement* form?
YES NO
4. Did the Research Assistant go over HIPAA Agreement?
YES NO
5. Did the Research Assistant conduct intake using the intake form?
YES NO
6. Did the Research Assistant discuss typical therapy with participant?
YES NO
7. Did the Research Assistant discuss why the participant was coming to therapy?
YES NO
8. Did the Research Assistant discuss the differences and similarities between traditional therapy and the current therapy?
YES NO
9. Did the Research Assistant discuss the format of the therapy sessions?
YES NO
10. Did the Research Assistant provide opportunities for questions by both the participant and their guardian
YES NO

APPENDIX Q
TREATMENT INTEGRITY MEASURE FOR
THERAPY SESSIONS

1. Was the room set up correctly?
YES NO
2. Did the review of previous session and assigned homework take place?
YES NO
3. Did this last for 10-15 minutes?
YES NO
4. Was the participant invited to play one of the video games?
YES NO
5. Did the Research Assistant have a preplanned section of one of the video games
picked out to start on?
YES NO
6. Did the Research Assistant use appropriate counseling skills as based on the
participants current level of functioning in the session?
YES NO
7. Did the Research Assistant use discussion questions provided in counseling
matrix during game play?
YES NO
8. Did the Research Assistant reflect on grief themes experienced by both the
characters and the participants in game play?
YES NO

9. Did the Research Assistant use the last 10-15 minutes of the session to conduct a session summary?

YES NO

10. Was important content of the session reviewed during the summary?

YES NO

11. Was any progress made by the participant stated in the summary?

YES NO

12. Was homework assigned?

YES NO

13. If assigned, was homework discussed with the participant?

YES NO