Parent Experiences of Grief when Caring for a Child with a Diagnosed Mental Health Disorder

Christine L. Clark

Department of Psychology and Counseling, Georgian Court University

Author Notes

There are no conflicts of interest to disclose.

Acknowledgements

I would like to acknowledge the following people for their support throughout my dissertation writing process:

My Dissertation Chair- Dr. Theresa J. Brown: I am beyond grateful for all of the support which has been unending and invaluable from my undergraduate years through my doctoral dissertation. Thank you for believing in me and supporting me in each step of my education. Words cannot describe how truly grateful I am for all you have done.

My Dissertation Committee: Dr. Mancuso and Dr. Springer, I truly appreciate your support throughout my educational career at Georgian Court University. From the coursework to being on my committee, your knowledge and expertise was truly appreciated.

My Cohort: I appreciate each of you and your support over the past three years. Your support and encouragement both through our classes and in the dissertation writing process was the best.

My Participants: I appreciate your participation in my study. I extend my gratitude to you for your openness and willingness to share your experiences on such a personal topic. Your strength and perseverance is truly admirable.

My Mom, Ann Clark: Words cannot describe how grateful I am for all of your unending love, support and patience. Thank you from the bottom of my heart for being my number one cheerleader and support.

My Brother, Thomas Clark: Thank you for your support and humor which brought a smile to my face throughout my doctoral program.

My Grandfather, Walter A. Patterson Jr.: While you are no longer with us here on Earth, I know you are smiling from Heaven. Your support and excitement at the start of my doctoral program has been a motivation for me throughout the past three years.

Thank you all!

Abstract

Using the lens of the grief model, the purpose of the study was to gain a better understanding of the experiences of parents of children diagnosed with mental health disorders. In doing so, and to the best of the researcher's knowledge, this is the first study to examine a parent's reported current grief when caring for a child with a diagnosed mental health disorder. Participants ($N = 155$) were mothers and fathers recruited from national and regional mental health associations who support children with a mental health diagnosis and their families. Participants completed questionnaires to assess the study constructs. These included measures of parent-child relationship quality, mental health functioning, social support, and a demographic questionnaire. It was hypothesized that there would be a positive correlation between a parent's reported current grief, anxiety, depression, and stress. This hypothesis was supported. It was hypothesized that a parent's perception of available personal support would be predictive of a parent's reported current grief experienced with higher levels of personal support being predictive of lower levels of grief. The support of a significant other was predictive of a parent's reported current grief while the support of friends and family were not. It was hypothesized that poorer parent-child relationships would be predictive of higher levels of a parent's reported current grief. This hypothesis was supported. It was hypothesized that the number of diagnoses and the diagnosis of externalizing disorder would be predictive of a parent's current grief. These hypotheses were not supported. These findings are discussed in the context of the current research. Limitations include the use of an online internet survey which resulted in fewer participants completing the entire study and may have resulted in a participant sample that was not representative of the population. Future research should focus on parents from diverse cultural backgrounds and take into consideration alternate means of participant recruitment such using in-person surveys.

Table of Contents

Chapter One: Introduction

Statement of the Problem

According to the National Alliance on Mental Illness (NAMI) a mental health disorder is a condition which impacts an individual's emotions, behavior, and thoughts (2020). NAMI reported that one in five adults live with a diagnosed mental health disorder at any given time. The onset of mental health disorders usually begins in childhood with 50% of mental health disorders being diagnosed in children by the age of 14 and 75% diagnosed by the age of 24. This number is continuing to rise as more children are diagnosed with a mental health disorder now than in the past (Juhásová, 2015). Ambikile and Outerwater (2012) suggested that 20% of children globally have been diagnosed with a mental disorder. Here, the phrase mental health disorder will be used, although it is noted that phrases mental illness, mental health disorder, and behavioral health issues also appear in relevant research.

Different types of mental health disorders affecting children include anxiety and depressive disorders, substance use, attachment disorders, and behavioral disorders (e.g. Conduct Disorder) (Ambikile & Outerwater, 2012). One approach to conceptualizing mental health diagnoses is through their classification as either internalizing or externalizing disorders. Categorization as such is important, as each group of disorders impact the child and their family differently (Mazur & Mickle, 2018). Guzick et al. (2019) described internalizing disorders as those which result in a child either avoiding or withdrawing from those around them while experiencing heightened levels of anxiety, depression or a combination of the two. Externalizing disorders include symptoms such as problematic behaviors directed towards others and elevated levels of activity. Internalizing disorders include depression, anxiety and withdrawal while externalizing disorders include Conduct Disorder and Oppositional Defiant Disorder (de Voort et al. 2014: Guzick et al., 2019; Hser et al., 2013).

Several consequences result from when a child is diagnosed with a mental health disorder (Wu et al., 2018). Caring for a child with a mental health disorder may result in short- and long-term negative impacts for the entire family and most especially parents (Mazur & Mickle, 2018; Richardson et al., 2011). When caring for a child with a mental health disorder, parents face many negative side effects including emotional, social, financial struggles, and lack of support (Ambikile & Outerwater, 2012). Parents of children with diagnoses often face stigmatization by family and friends who believe they are responsible for the child's behaviors (Liegghio, 2017; Park & Seo, 2016). While there is stigmatization for mental illness overall, child mental health disorders hold greater stigmatization than do adult mental health disorders (Mukolo et al., 2010).

Purpose of the Study

Using the lens of the grief model, the purpose of the study was to gain a better understanding of the experiences of parents of children diagnosed with mental health disorders. Here, the focus is on parent's increased experience with negative emotions and anxiety, depression, and distress. Such symptoms are important as grief results in emotional side effects of decreased emotional regulation and increased levels of depression, stress and anxiety (Oreo & Ozgul, 2017). While literature supports the theory that parents play a key role in the efficacy and outcome for their child, there is a need to understand the support available to mothers and fathers (Chase & Peacock, 2017; Greenberg et al., 1997; Horwitz & Reinhard, 1995; Koren et. al, 2016). Dependent on the support parents feel is available to them, the magnitude of grief experienced may vary. Grief experienced by parents may be influenced by the responsibility and caregiver strain felt in providing care for their child.

Parent experiences of grief may also be dependent on their child's mental health disorder. Wiens and Daniluk (2009) suggested the variation in stress may be attributed to the types of behaviors children exhibit with more of the severe externalizing behaviors being more impactful than the internalized concerns of children with anxiety disorders. Further, while there is some debate in research, the overall consensus is that parents struggle more as the number of mental health disorders a child is diagnosed with increases. This may, in turn, influence parental grief experiences (Marmorstein & Ignacio, 2004; Weins & Daniluk, 2009; Yoo et al., 2009). When parents experience grief following their child's diagnosis of a mental health disorder there is greater strain in their quality of relationship with their child. This, in turn, may suggest that the quality of parent-child relationships may influence the grief experienced. Similar to the grieving process, it is believed a parent progresses through a series of stages following a child's diagnosis. As more time passes since the diagnosis, the grief experienced may change.

As discussed, parents face increased responsibility in providing care for their child and are the primary responders to their child's behaviors or emotional symptoms. In addition to providing additional care, the parent-child relationship tends to suffer and parents experience heightened emotional symptoms such as anxiety, depression, and stress. Through understanding a parent's perception of the parent-child relationship, emotional symptoms, and the child's mental health disorder, it may be possible to understand its contribution to the magnitude of grief experienced.

Chapter Two: Literature Review

Grief as a Theoretical Model

One way to understand the impact of raising a child with a mental illness is through a grief model (Bordere, 2017; Howarth, 2011; Mitchell 2018). Parents are often surprised when the child is diagnosed with a mental health disorder as many are not aware that their child’s behaviors or symptoms are atypical (Ward & Gwinner, 2014). Additionally, parents struggle when they realize that their hopes and dreams for their child may not come true (Hernandez & Barrio, 2015; Mendenhall & Mount, 2011). As differences between their child and other children become more apparent, negative emotions of sadness and grief intensify for parents (MacGregor, 1994; Richardson et al. 2011). A contributing factor to the grief felt is a parent’s loss of their former relationship with their son or daughter (Oreo & Ozgul, 2017). The more grief experienced by parents, the greater the strain in their quality of relationship with their child with a disability (Godress et al., 2005; Oreo & Ozgul, 2017).

A grief lens is beneficial as it provides structure to a multifaceted experience including responding to a change in normal daily functioning, strain the parent-child relationship, the restructuring of the family system, emotional and physiological responses as well as burden experienced with additional responsibilities and expectations (Godress et al., 2005; MacGregor, 1994; Richardson et al., 2011; Tessler et al., 1987). A benefit of using a grief model is the acknowledgement that what the individual experiences in response to a life changing event may be varied and different (Blau, 2008; Gilbert, 1996; Handsley, 2001). In providing structure to understanding the experiences of parents, it may be possible to better appreciate their experiences and provide support based on their needs.

Supporting the Use of a Grief Model

In support of the use of the grief model, Tessler et al. (1987) noted there is a staged approach to a parent's response to a child's mental health disorder. This nine-step process begins with the parent deciding to reach out to others to get their child help and the later acceptance of a child's diagnosis with the parents adapting to a new normal. In the first stage, parents develop insight that something is wrong, which is followed by the second stage where parents experience denial. As parents enter the third stage, called labeling the problem, they reach out for help and support. This is followed by the fourth stage where parents establish trust in mental health professionals providing care. The fifth stage involves crises both with the child's behavior and the internal response within the parent to the diagnosis, whereas the sixth stage involves developing an awareness for the long-term impact the child's diagnosis has on the individual and family. During the seventh stage, the focus is on mistrust parents and family develop towards those providing professional care. In the eighth stage parents develop a belief they are able to provide care for their child prior to reaching the ninth stage where parents become concerned for and aware of the need to plan for long term care (Tessler et al., 1987). These stages suggest that it takes time for parents to become aware of the widespread impact their child's diagnosis has both immediately and long term on the family.

Tessler et al.'s (1987) use of a grief model parallels the staged approach used in the traditional context of grief which is one of the most well-known approaches (Stroebe et al., 2017). The original staged approach to grief was developed by Kübler-Ross, and it focused on those facing terminal illness (Bergman, 2010; Kübler-Ross, 2014). In developing the theory, Kübler-Ross conducted a series of two hundred interviews with dying patients to understand the process they go through. Based on the interviews conducted, Kübler-Ross surmised that individuals go through a series of stages following learning their prognosis.

The original stages of grief developed by Kübler-Ross are: Denial, Anger, Bargaining, Depression and Acceptance. Kübler-Ross (2014) suggested the Denial stage does not last long and is immediately following the news of imminent death. Anger, the second stage, begins the acceptance of what is to come but deals with the realization of all that will not happen, especially regarding missed experiences. The Bargaining phase, while short in length, is an attempt made by the individual to change the outcome to get what they want and avoid dying. As symptoms progress, individuals enter the Depression stage and experience sadness. During the final stage, Acceptance, patients come to terms with what is happening and make peace with the situation (Kübler-Ross, 2014).

Kübler-Ross' (2014) stages were not originally intended to be applied to the family and friends of the deceased; however, there was some consideration for their grieving process. Specifically, Kübler-Ross (2014) spoke to the range of emotions loved ones experience and the lack of acceptance and understanding of others surrounding those feelings. Children are believed to experience increased difficulty with the grieving process, partially given their age yet may be attributed to the discomfort adults may experience in talking to them about the loss. In order to progress with their grief, Kübler-Ross (2014) supports family members talking to friends or relatives for support, especially someone else who knew their loved one. Since the initial development of the model in 1964, the stages of grief have been adapted and modified by other professionals in the mental health and medical fields to fit the unique needs of their field (Stroebe et al., 2017).

While the stages of grief are well known, this approach is not accepted by all mental health or medical professionals, and there is a debate as to how much or what role the stages should play in understanding the grieving process (Bugen, 1997; Calderwood, 2011; Holland et al.,2014; Holland & Neimeyer, 2011; Stroebe et al., 2017). Some researchers suggest that the stages are not the best approach to grief as they do not allow for a full understanding of what grief is while also acknowledging the lack of empirical evidence supporting its use and how the theory is incongruous when working with individuals with a religious background (Bergman, 2010; Calderwood, 2011; Corr, 2015; Corr, 2020; Stroebe et al., 2017). Another concern over the staged approach is that it might be harmful to those grieving. While the staged approach provides different benchmarks a person may go through, the theory does little to explain the entirety of the grieving process including changes to family structure, emotional and physiological experiences and coping with changes to normalcy (Bugen, 1997).

Instead of a staged approach, Zonnebelt-Smeenge and DeVries (2003) suggested that people should view grief as a series of tasks that must be accomplished for full healing to take place. At the beginning of the grieving process, individuals face the need to come to terms with the loss and accept a new normal (Currier et al., 2015; Zonnebelt-Smeenge & DeVries, 2003). A part of accepting a new normal is coming to accept a change and the loss of what can no longer be (Rodger & Tooth, 2004). Gilbert (1996) and Stroebe et al. (2017) note that one of the main purposes of grief is responding to the loss and the consequential adjustment a person experiences as they adapt to a new normal. As people adjust to a new normal, there is frequently a desire to remain connected to the person who passed away (Bouc et al., 2016). Affected individuals do not always need to focus on their grief or loss and that with time they learn to cope and continue on with life (Kenney, 2003). While grief does not need to remain the primary focus of a person's day to day life, Corr (2020) shared that people must face the loss and identify the areas in their life which were impacted.

A New Normal

Utilizing a grief model following a loss, people are tasked with adjusting to a new normal and reconstructing their view of themselves and the world (Neimeyer et al., 2014). Frequently following a loss, part of reconstructing their view includes the need to find a different purpose (Gilbert, 1996). In adjusting to a new normal, people often question their identity and who they are in relation to others (Neimeyer et al., 2014). Moos (1995) shared that a key part of grieving involves understanding and accepting a new identity as an individual and also as a part of a larger family system.

The diagnosis of a mental health disorder in a daughter or son results in a change in lifestyle and a development of a new normal. Following a child's diagnosis, a parent's experience with grief includes emotional symptoms, increased strain in the parent-child relationship, a change in the family dynamic as well as increased caregiver strain as a result of increased responsibilities in providing treatment support (Chase & Peacock, 2017; Drugli et al., 2010; Hernandez & Barrio, 2015; Masa'Deh, 2017; Tessler et al., 1987; Ward & Gwinner, 2014). One way in which parents experience a change is that they may experience judgment from family and friends (Barak & Solomon, 2005; Eakes, 1995; Eaton et al., 2016; Gavois et al., 2006; Hernandez & Barrio, 2015). Parents are aware that many judge them for their child's diagnosis, and the potential they will be blamed for what happened to their son or daughter. They may feel intense emotions (Eaton et al., 2016). Hernandez and Barrio (2015) suggested that mothers face the most judgment and are often viewed as the cause of their child's problems. Those who are providing care for a child with a mental health disorder have additional expectations placed on them than do parents of typically developing children (Mendenhall & Mount, 2011). The process of adjusting to a new normal and additional expectations does not start following the diagnosis, yet instead begins as a child’s symptoms emerge (Gavois et al., 2006; Tessler et al., 1987).

Emotional Symptoms

Emotional symptoms during the grieving process are similar to what parents experience following their child’s diagnosis. Emotional symptoms people experience while grieving include anxiety, distress, and depression, with the most commonly expressed emotion being depression (Bugen, 1997; Moayedooddin & Markowitz, 2015; Spuij et al., 2012). While the levels of depression and anxiety experienced vary by person and intensity throughout the grieving process, there are factors which influence the impact it has on functioning. For example, the use of legal and illegal drugs as well as alcohol to cope, either together or in isolation, is linked to greater difficulty in overcoming depressive symptoms experienced (Goldstein et al., 2019; Harper et al., 2014).

In addition to anxiety and depression, other common emotions include anger and fear (Moos, 1995). Following a loss and throughout the grieving process, it is expected that individuals will feel sadness, uncertainty and upset; however, anger and fear are not as frequently acknowledged (Howarth, 2011). Moos (1995) noted that when grieving, people may become hostile even if they had not been in the past. Bugen (1997) suggests that those who are grieving may feel upset and express anger as they think about the loss and how they could have prevented or changed the situation. Protective factors in grief responses are related to optimism and resiliency (Boelen et al., 2016).

A concept unique to grief, and not examined with parents of children with mental health disorders, is complicated grief. When depression, anxiety, anger, and other grief symptoms go unaddressed, it is possible that individuals will experience complicated grief (Smith & Ehlers, 2020). Lundorff et al. (2020) suggested that complicated grief is relatively common, impacting up to 15% of those dealing with a loss. Complicated grief refers to a longer lasting grieving process that impacts daily life, trouble accepting the loss, emotional numbness, a poor outlook on their own life and the future (Dillen et al., 2009; Eisma et al., 2019). Additionally, symptoms such as depression and anxiety are experienced with more intensity with complicated grief (Tomarken et al., 2008).

Complicated grief is more likely to occur when someone experiences multiple losses or feels intense guilt. Complicated grief may be situationally based such as with the loss of a child or following a violent accident. Personal factors including socioeconomic background and predisposition for depression further contribute to the likelihood for complicated grief (Boelen et al., 2010; Boelen, 2015; Goldstein et al., 2019; Kramer et al., 2010; Li et al., 2019; Maccallum et al., 2015; Neimeyer et al., 2010; Vegsund et al., 2019). Complicated grief may have societal repercussions through withdrawal from friends as well as mental health complications of distress (Eckholdt et al., 2018; Howarth, 2011; Salloum et al. 2011).

Similarly to those who grieve following a death of a loved one, parents of children diagnosed report negative emotional symptoms (Ambikile & Outwater, 2012; Koren et al., 2016; Hernandez & Barrio, 2015; MacGregor, 1994; Oreo & Ozgul, 2017). As those who are grieving a death, parents experience feelings of vulnerability, sadness, anxiety and depression. In addition to coping with a change in normalcy, parents caring for a child with a diagnosis face negative life experiences such as responding to behavior and aggression (Poon et al., 2018). While all parents experience stress when caring for a child, parents caring for a child with a mental health diagnosis experience higher levels of stress (2018). Further, parents experience stress and concern over managing and caring for their child's behavior (Ambikile & Outwater, 2012; Hall

& Graff, 2011). Many parents worry they do not have the skill set to care for their child or their needs related to the symptoms they present with, especially when a child presents with severe behaviors (Foroughe et al., 2018; Perez Algorta et al., 2018).

The importance of parent involvement in the outcome of a diagnosed child's treatment is widely researched, although the impact of providing extra care for a child on the emotional wellbeing of a parent is not (Koren et al., 2016**;** Mendenhall & Mount, 2011). Richardson et al. (2011) purported that parents suffer as a result of having to provide the majority of care for their child. Mendenhall and Mount (2011) also noted that the negative impact of caring for a child with a mental health disorder results in poor mental health of parents as well. The degree of impact is dependent on the role parents play which varies by child, their diagnosis, and its severity (Milliken & Northcott, 2003). While the degree of impact varies, almost all parents face caregiver burden when supporting their child (Koren et al., 2016 Mendenhall & Mount, 2011; Milliken & Northcott, 2003). The impact on a parent's life is multifaceted, impacting their own mental health, physiological wellbeing, career success, social interactions and connections to other family members, both immediate and extended (Mendenhall & Mount, 2011). The level of impact is also influenced by the child's age and severity of diagnosis.

The degree of stress reported by parents may vary by the severity and diagnosis a child receives. Diagnoses frequently presenting a combined presentation of internalizing and externalizing disorders, such as Schizophrenia and Bipolar Disorder are reported as more severe than internalizing disorders such as Major Depressive Disorder and diagnoses in the family of anxiety disorders (Masa'Deh, 2017; Wiens & Daniluk, 2009). The variation in stress may be attributed to the types of behaviors children exhibit with more of the severe externalizing behaviors being more impactful than the internalized concerns of children with anxiety disorders.

Alternatively, the presence of parent mental health disorders does impact the success of their child’s treatment plan (Schleider et al., 2014). Moreover, children with mental health disorders tend to come from families with greater levels of emotional disturbance (Marmorstein & Ignacio, 2004). The presence of emotional disturbance in the home not only impacts the treatment outcome for the child, but also how the family as a whole responds to the situation. Family relationships are an important factor and more positive relationships are beneficial in reducing future antisocial behavior in children (Haddad et al., 1991).

Ambikile and Outwater (2012) suggested the stigma of having a family member with a diagnosed mental health disorder alone results in a negative impact on a parent’s emotional well being. Eaton et al. (2016) suggested that when parents believe they are being stigmatized by others, they start to feel self-doubt and might self-stigmatize where they believe external negative perceptions and biases about themselves and their abilities. Further, parents report feeling discriminated against by extended family, friends and mental health professionals when a child is diagnosed (Liegghio, 2017).

The result of the stigma and discrimination is feelings of blame and higher levels of vulnerability (MacGregor, 1994; Pejlert, 2001). While parents are frequently blamed for their child’s diagnoses and behaviors, mothers and fathers may also engage in self-blame where they internalize their child’s behaviors as their fault. Eaton et al. (2016) suggested that when parents blame themselves, it frequently stems from the belief they are not good parents. When blame is examined more closely, mothers are more likely to develop self-blame especially after feeling stigmatized by those in their social circle or by professionals (Eaton et al., 2016).

There is a relationship between the level of grief experienced by parents and their emotional functioning with higher levels of grief being linked to poor emotional regulation (Oreo

& Ozgul, 2017). As feelings of sadness and grief intensify, parent self-care declines (Mendenhall & Mount, 2011). Parents may also experience social isolation as responsibilities for their child increase. Further, parents may experience frustration and depression related to caring for their child which results from providing care for their child (Eakes, 1995; Hernandez & Barrio, 2015). Similarly, many parents report feelings of isolation from peers and family who they cannot spend time with (Eaton et al., 2016; Ward & Gwinner, 2014). The compilation of sadness and isolation results in parents feeling a sense of loss in their own lives (Wiens & Daniluk, 2009). Many families report feelings of shock, or emotional numbness, especially when external support is not available (Gavois et al., 2006). Poon et al. (2018) purported that as parents adjust to their child's diagnosis and come to a point of acceptance, their overall mental wellbeing improves.

There is some research to suggest that a child's diagnosis may influence the symptoms parents experience (Park & Seo, 2016). In comparison to children with an internalizing mental health disorder, Perez Algorta et al. (2018) suggested that parents of children diagnosed with bipolar disorder report higher levels of emotional symptoms, stress and social withdrawal. Further, a child's level of functioning and their symptoms combined are most linked to parental stress and burden.

Many parents report a sense of helplessness, loss, and guilt with their child being diagnosed (Koren et al., 2016; Mohr & Regan-Krubinski, 2001; Ward & Gwinner, 2014; Wiens & Daniluk, 2009). Further, Oreo and Ozgul (2017) suggested that parents may avoid the child who was diagnosed as to not have to confront some of their negative emotions. This guilt may stem from upset in themselves for not being able to detect or identify early warning signs or symptoms.

Parent anxiety is related to the emotional and physiological distress experienced by mothers and fathers when caring for their child. Immediately following a diagnosis, parents may feel as though they are in a state of shock and will avoid reminders of their child's condition. To assist parents, it is recommended that they receive guidance on developing appropriate coping skills (Barker et al., 2012; Godress et al., 2005; Koren et al., 2016). In comparison to parents of typically developing children, caregivers report higher levels of distress and stress (Barker et al., 2012; Mazur & Mickle, 2018).

The stress that parents experience can have a physiological toll (Baker et al., 2012, Juhásová, 2015). Parents caring for a child with a diagnosis report poorer physical health and physiological wellbeing (Juhásová, 2015). This may be attributed to the elevated levels of stress and responsibilities parents hold. According to Barker et al. (2012), the physiological impact of stress may be seen through elevated levels of cortisol which increased after negative experiences at home with their child. The elevated cortisol levels remained in the parents' systems after the event was over. In these instances, parents need support to reduce levels of stress experienced.

There are varying factors which influence emotional symptoms experienced. While both mothers and fathers experience anxiety, Crissanti (2000) suggested mothers more so than fathers experience the highest levels based on their caretaking role. A protective factor for some parents may be level of education, with parents with higher levels of education reporting lower levels of stress (Cook et al., 1994). Additionally, younger parents experienced greater distress than did older parents. Environmental factors, such as pre-existing family stress, were linked to increased reports of problems related to their child's diagnosis (Haddad et al., 1991).

Parents also report anxiety related to the need to care for their child's mental health needs (Cook et al., 1994). In situations where parents reported feeling greater control over their situation, less distress was reported (Duchovic et al., 2009). The later the onset of the child's diagnosis, the more severe stress reported by parents (Ribe et al., 2018).

SUPPORT

The Need for Support

Under the grief model, support from friends, family or loved ones is considered important (Mitchell, 2018). Shear et al. (2011) and Smith and Ehlers (2020) noted that bereavement often does not require mental health support and resolves on its own when assistance from peers and family is provided. In more serious circumstances, especially for those with unresolved grief, support from a mental health professional may be beneficial (Shear et al., 2011). Support, when not provided by a mental health professional, is beneficial even if it is also provided by friends and family (Lundberg et al., 2018; Mitchell, 2018).

Alternatively, some individuals seek support from non-mental health professionals such as physicians or clergy (Bregman et al., 2019). When non mental health professionals provide care, Bergman et al. (2010) noted that they may not be able to provide the type of care individuals need.When approaching treatment or understanding a loss, it is important for the person receiving support to acknowledge the impact of the loss on all areas of their life (1981). Vegsund et al. (2015) purported that helping foster resilience through counseling is important for a healthy grieving process. Grief counseling is needed when working with families, especially those responding to trauma such as a medical illness or a severe accident (Jacobson & Butler, 2013).

In considering therapeutic approaches for the grieving process, de Groot et al. (2007) noted that cognitive behavioral therapy may reduce self-blame and guilt. Professional support provided within the first six months following the death is most effective in facilitating a healthy grieving process (Smith & Ehlers, 2020). Kochen et al. (2020) further suggested that when a loved one dies from an expected illness, families may benefit from support from the group or facility that provided care for their loved one. This may be especially beneficial as those who work for the facility already know the family and their loved one who passed away. It is important to note that families vary in their willingness to get outside support (Moos, 1995).

After a child receives a diagnosis, parents often struggle with their new role and additional responsibilities (Godress et al., 2005). When caring for a child with a mental health disorder, parents are likely to not only listen to the advice of mental health professionals, but seek feedback and support from peers and family as well (Honey et al., 2015). Getting support is not easy and is a continuous struggle for families with a diagnosed child (Gavois et al., 2006). Parent experiences are not always understood or accepted when treatment plans are developed by mental health professionals. As a result, parents may not feel valued or as though their concerns are considered by those developing treatment plans (Mohr & Regan-Krubinski, 2001; Tessler et al., 1987). Parents often receive minimal personal support, and this is further lessened when their child lives at home (Greenberg et al., 1997). Mothers, especially, feel their experiences and concerns for their child's behaviors are not considered or respected by professionals, reducing the likelihood of implementing treatment plans (Cirsanti, 2000).

A barrier to support for some parents is the fear of stigmatization. Liegghio (2017) suggested that parents feel judged by mental health professionals which resulted in discomfort from parents in sharing their concerns for their children. For example, mothers who sought extra help for their child at a hospital following serious behaviors, felt doctors judged them for not wanting to care for their son or daughter (Cirsanti, 2000). Based on the judgment experienced, mothers reported that their interactions with hospital based mental health professionals were not positive.

Stigmatization experienced may also be based on geographical location. This is especially the case in smaller or rural communities where there is a greater risk for dual relationships and a fear of confidentiality (Huscroft-D'Angelo et al., 2018; Mak & Cheung, 2012). While parents frequently try to find help for themselves as well as their child, they may lack trust in the process as they do not understand how the system works that their child is in (Davis et al., 2010; Koren et al., 2016; Mazur & Mickle, 2018). Understanding lack of trust and fear of stigmatization is important, especially in cases of working with diverse cultures and families from smaller communities.

When parents are able to access support, families still experience struggle with expectations in their role in providing treatment. Tessler et al. (1987) suggested families are not consulted adequately when treatment plans are developed, placing parents in a position where they struggle to provide care. The lack of involvement and stigmatization leaves families in a position where they want more support from mental health providers (Tessler et al., 1987). Based on the role parents are expected to play, Cirsanti (2000) noted that parents, especially mothers who tend to be the primary caregiver, should be included in the treatment planning process. Mothers of adult children who are hospitalized or receiving intensive care, do not feel they are receiving sufficient support (Cirsanti, 2000). Given parental experiences and expectations, it is important to provide support for the emotional symptoms and experiences faced (Oreo & Ozgul, 2007). To alleviate some of the struggle that parents experience, treatment programs frequently offer parent training to assist in understanding how to manage problematic behaviors at home (Chase & Peacock, 2017).

Psychoeducation

The majority of support offered to parents involves learning additional skills or methods in caring for their child (Ambikile & Outwater, 2012; Godress et al., 2005; Koren et al., 2016; Mendenhall & Mount, 2011; Ribé et al., 2018). Support for parents is often delivered in the form of psychoeducation which involves educating families on the diagnosis and fostering understanding of their child (Greenberg et al., 1997; Mendenhall & Mount, 2011; Ward & Gwinner, 2014). Psychoeducation assists parents with ways to manage behavior related to symptoms as well (Hall & Graff, 2012; MacGregor, 1994; Ribé et al., 2018). Interventions are often needed to promote a more positive parent-child relationship with sufferers based on the diagnosis (Godress et al., 2005). A benefit of psychoeducational support for parents is that it helps improve mother's and father's self-efficacy and coping skills in caring for their child's needs (Foroughe et al., 2018; Shor & Birnbaum, 2012).

Psychoeducational support is touted as being necessary to help the child overcome specific issues related to their diagnosis (Perales et al., 2017). While educational support groups may take different forms, including peer led and organizational led, those led by mental health professionals tend to be the most effective for educational purposes (Hoagwood et al., 2010). While the goal of psychoeducation and parent training shares a similarity of educating parents on a child's diagnosis, psychoeducation programs are more educational while parent training provides hands-on training in responding to behaviors and symptoms as a part of caring for their son or daughter. These interventions are most successful when implemented soon after the diagnosis (Möller-Leimkühler & Weisheu, 2012). A problem with parent training programs is that there is not always continuity with participation in training programs (Chase & Peacock, 2017). This may be attributed to differences in parent involvement in training and implementation of interventions within the home. Further research suggests that psychoeducational support might be most beneficial when mothers and fathers meet separately and learn skills to support their child (Hall & Graff, 2012).

Social Support

Caregiver burden and distress can be reduced through social support from peers and extended family (Ambikile & Outwater, 2012; Park & Seo, 2016; Ribe et al., 2018). Social support is important, and when provided by extended family members helps reduce the burden, distress, and isolation felt by parents (Ambikile & Outwater, 2012; Greenberg et al., 1997; Hoagwood et al., 2010; Horwitz & Reinhard, 1995, Masa'Deh, 2017; Shor & Birnbaum, 2012). The social connections parents previously held are often negatively impacted, as there is not the time to spend time or connect with friends and family. Social connections, when maintained, are a protective barrier against negative symptoms experienced (Mendenhall & Mount, 2011).

When parents are not able to connect with their pre-existing peer groups, self-help groups for parents of children with the same or similar diagnoses can be beneficial (Cook et al, 1999). Further, support groups are beneficial for parents who are in the beginning stages of providing care for a child with a diagnosis (Metz, Nicot & Bacque, 2018). Parents who participate in self-help groups were noted to have less pre-existing social support. Those who participate in the support groups tend to have higher levels of caregiver burden however reported lower levels of strain post group involvement (Cook et al., 1999). Through establishing connections with parents in similar positions, participants are afforded the opportunity to connect with peers for advice (Mazur & Mickle, 2018). Establishing connections for families from diverse cultural backgrounds is most important and, according to Sturm et al. (2017) assists in lowering stigmatization and isolation.

FAMILY DYNAMIC

A child's mental health disorder and presenting symptoms creates a shift in the family dynamic and results in the reallocation of time and attention parents dedicate to other children, friends, family and work responsibilities (Ambikile & Outwater, 2012; Foroughe et al., 2018; Kochanska et al., 2013; MacGregor, 1994; Ma et al., 2017; Pollio et al., 2001; Schleider et al., 2014; Sin et al., 2016; Wu et al., 2018). While the diagnosis alone does not influence how well a family will cope, it is associated with changes to the family dynamic (Pollio et al., 2001; Schleider et al., 2014). The changes to the family dynamic included increased challenges faced by the parents and siblings when working to provide optional care for the child with a diagnosis (Hernandez & Barrio, 2015). Sin et al. (2016) and Wu et al. (2018) purport that both parents and siblings of those diagnosed report increased levels of stress and decreased quality of life.

Similarly to those grieving the death of a loved one, when considering what influences a family's dynamic when a child has a diagnosed mental illness, it is important to consider the family as a unit as well as the relationships the individual has with each family member (Ma et al., 2017). At the family unit level, the child's diagnosis may result in increased stigmatization experienced by the child, parents and siblings (MacGregor, 1994).

The connection between parents and other children may become strained as well as the relationship between siblings. Siblings without diagnoses may report feelings of strain or being overlooked by their parents (Ma et al., 2017). Families as a whole may be afraid to talk about their experiences with one another, especially in front of the child with a diagnosis, given the fear of hurting their loved one's feelings (MacGregor, 1994). Pollio et al. (2001) suggested the child's commitment to treatment and taking medicine influences the family dynamic as a whole as well as their relationships with parents and other siblings. Further, symptom severity more so than symptoms themselves impact family functioning and emotional health (Hernandez & Barrio, 2015).

Parent-Child Relationship

The influence of parent-child relationships starts at an early age. Childhood relationships with both parents is important for the development of healthy personality types and traits. Positive parent-child relationships at an early age were linked to lower levels of anti-social problems in children later on in childhood (Kochanska et al., 2013). Parent involvement and fostering of sensitive traits is linked to lower levels of mental health disorders and fewer reports of externalizing behaviors. Although the involvement of both parents is important, research focuses primarily on the mother's role in caregiving. Marmorstein and Ignacio (2004) noted that conflict with mothers during adolescence was significantly related to gender, with higher levels of problems reported by mother-son relationships. Further, van der Voot et al. (2014) suggested that higher levels of emotional sensitivity from mothers is linked to more emotional security in adolescents and fewer severe symptoms.

The parent bond with their child impacts the outcome for their son or daughter's treatment plan (Godress et al., 2005). Parents who held a positive attachment with their child reported a more positive outcome post-treatment implementation. Lower levels of parent-child engagement were associated with higher levels of symptomatology associated with conduct disorder and other externalizing disorders. Perez Algorta et al. (2018) suggested that a child's perception of their relationship with their parent is important to consider, as the perception of poor attachment is linked to more emotional problems. Further, lower levels of attachment between a child and their mother is associated with increased behavioral and emotional problems with more severe symptoms being reported by fathers than mothers. Overall, a more healthy parent-child relationship is associated with lower distress in treatment and parent distress in caring for their child (Pickett et al., 1997).

Parents are responsible for putting in additional efforts and strategies to mediate inappropriate behaviors and actions of their children. Parenting styles impact the development of antisocial and externalizing behavior problems (Kochanska et al., 2013). The parenting style influences the outcome of their child's mental health disorder. Early childhood parent relationship interactions are influenced in later development of mental health disorders.

As mothers are often the primary caregivers, they are more likely to be the target of their child's negative behavior. When mothers provide care for a child who is emotionally or physically abusive, they are more likely to feel higher levels of helplessness and optimism for the future (Sporer & Radatz, 2017). The abuse that mothers experience from their child can be equated to those that experience domestic abuse from their partners (Sporer & Radatz, 2017). When mothers experience abuse, there is increased resistance to attempting to obtain help because of fear of retaliation from their child after visiting a mental health professional.

Demographic Considerations

Understanding the grieving process also requires consideration of demographic factors including age, gender and culture. Specifically, D'Antonio (2011) purported that while the grieving process is unique to each individual, how a person grieves is influenced by their cultural background, age and relationship to the person lost.

As with individuals grieving the death of a loved one, demographic factors including gender, age, culture and socioeconomic factors influence a parent's reaction to a child's diagnosis (Cook et al., 1994; Haddad et al., 1991; Möller-Leimkühler & Weisheu, 2012; Pearles et al., 2017; Sturm et al., 2017). Similar to research on those grieving a death, there is minimal representation of diverse groups in literature on families with children with mental health disorders. Sturm et al. (2017) suggest a family's unique cultural background influences the information shared with others in their community and this can be influenced by factors such as language skills and the ability to communicate with others.

Further, a family's religion, age, and cultural background influence how they respond to and view their child's diagnosis relating to treatment, openness to share experiences and the cause of the symptoms (Sturm et al., 2017). Families who come from diverse backgrounds may be less confident in accessing support based on language abilities and usually need assistance in accessing different resources to support their child (2017). Based on the role that culture plays, it is important to assist culturally diverse families in developing resilience and ways of communicating with mental health professionals.

Gender

When considering the grieving process, it is important to take into consideration a person's gender (Kenney, 2003). While the intensity of grief experienced is not dependent on gender, women and men respond to grief differently (Kenney, 2003; Lundorff et al., 2020). Men are more likely to experience guilt following a death, women are more likely to suffer long-term mental health impacts related to anxiety and depression (Kenney, 2003). Conversely, Chiu et al. (2010) and Liew and Servaty-Seib (2018) suggested that females are more likely to experience anxiety and distress following the death of a loved one while males experience fewer grief reactions.

Females, more so than males, are at a greater risk for developing a mood disorder when grieving (Aalbæk et al., 2017; Chiu et al., 2010). This may occur because of women's greater tendency to ruminate on the loss resulting in long term depression. Conversely, men are more likely to experience physiological symptoms including heart issues and potentially death (Kenney, 2003). For men, this may occur because of cultural and societal expectations that men need to internalize all feelings of grief (Kenney, 2003; Moos, 1995).

Religion

When considering religion and the grieving process, Frei-Landau et al. (2000) noted that individuals who hold a more positive and secure connection to their religious beliefs experienced a healthier recovery from their loss. Despite this, holding religious beliefs does not make the grieving process easier but religious practices govern immediate processes following a death giving structure to the grieving process (Feldman et al., 2017; Tooh, 2004; Walter, 2000).

A family's response to a child's mental health disorder is different when considering their religious background. A family's religious background may influence the likelihood to reach out for help for their child and their mental health disorder as well as how parents cope with the situation. Depending on a family's religious views, there may be varied perspectives on who parents will reach out to for support, with many preferring to reach out to a religious leader within their community instead of a mental health professional (Imran et al., 2016). Hernandez and Barrio (2015) suggested that it is important for mental health professionals working with Latino families to understand that religious beliefs frequently serve as a coping mechanism and should be incorporated in treatment plans. When working with more religious families, females more so than males are receptive to accessing support from mental health professionals (Imran et al., 2016).

Parent and Child Age

The type of burden and the impact it has on parents is dependent on caregiver and child age (Cook et al., 1994). Younger parents report more problems with a child's behavior. As children with a diagnosis become older, parents express more concern for their growing needs. Parents of older children and adults are sometimes unaware of how they will provide care as their child ages (Richardson et al. 2011). Upon entering adulthood, parents face barriers when providing care for an adult child especially as they are viewed as being legally independent by the state (Milliken & Northcott, 2003). As both parents and children age, there are additional concerns for caregivers based on the mental and emotional toll (Cook et al., 1994).

Summary

When a child receives a mental health disorder, their parents undergo a grieving process and experience similar changes to their life as does someone whose loved one passed away (Chase & Peacock, 2017; Drugli et al., 2010; Eakes, 1995; Gavois et al., 2006; Greenberg et al., 1997; Masa'Deh, 2017; Mendenhall & Mount, 2011; Pejlert, 2001; Tessler et al., 1987). Research indicates that parents struggle to adjust to a new normal as they consider their child's future and what they had hoped it might be and what it actually might be. Further, many parents grieve the loss of a positive parent-child relationship which is often tested and changed based on the child's presenting symptoms (Floyd & Gallagher, 1997; Pickett et al., 1997; van der Voot et al., 2014). Parents further struggle with understanding the additional expectations and responsibilities in providing care for their child (Axelrod et al., 1994; Milliken & Northcott, 2003; Park & Seo, 2016). The result of additional expectations and responsibility results in caregiver strain and heightened emotional symptoms including anxiety, depression, and stress (Hernandez & Barrio, 2015; Koren et al., 2016; MacGregor,1994; Oreo & Ozgul, 2017).

Following the deinstitutionalization movement, there has been an increase in expectations placed on parents to play a proactive role in their child's treatment plan (Cook et al., 1994; Horwitz & Reinhard, 1995; Onwumere et al., 2018; Shor & Birnbaum, 2012; Tessler et al., 1987). The increased responsibilities, coupled with changes to the family dynamic and parent-child relationships, can result in increased burden, emotional symptoms-including anxiety and depression, physiological reactions to stress and less support from social connections (Ambikile & Outwater, 2012; Hernandez & Barrio, 2015; Marmorstein & Ignacio, 2004; Mendenhall & Mount, 2011; Oreo & Ozgul, 2017; Ward & Gwinner, 2014). The resulting struggle parents experience is similar to those grieving and adjusting to a new normal (Chase & Peacock, 2017; Davis et al., 2010; Davis et al., 2017; Drugli et al., 2010; Gavois et al., 2006; Hernandez & Barrio, 2015; Masa'Deh, 2017; Mendenhall & Mount, 2011; Tessler et al., 1987). In reviewing the present research, it is important to understand parent's personal experiences surrounding child mental illness through a grief model.

Chapter Three: Hypotheses

The current study sought to understand a parent's reported current grief following a child's diagnosis of a mental health disorder and the factors that impact their experiences of grief. These factors include perceived availability of social support, reported quality of relationship with their child, and factors related to their child's diagnosis.

Hypothesis One

A parent's response to a child's diagnosis is similar to the grieving process as it is multifaceted and includes negative emotional symptoms. As noted by Godress et al. (2005) and Oreo and Ozgul (2017), the long-term impact of the grief can be negative with parents reporting increased feelings of depression, anxiety and stress. It was therefore hypothesized that there would be a positive correlation between a parent's reported current grief, anxiety, depression, and stress.

Hypothesis Two

Research reviewed here indicates that grief is impacted by support. Specifically, individuals who receive higher levels of support report lower levels of grief whereas those who receive lower levels of support report higher levels of grief (Horwitz & Reinhard, 1995; Tessler et al., 1987; Wu et al., 2018). As discussed earlier, support can take many forms including support from professionals or family and loved ones. Support from family and loved ones can be characterized as personal or social support. It is therefore hypothesized that a parent's perception of available personal support would be predictive of grief experienced with higher levels of personal support being predictive of lower levels of grief.

Hypothesis Three

When parents experience grief following their child's diagnosis of a mental health disorder, there is greater strain in their quality of relationship with their child. Positive parent-child relationships are important when there is a diagnosis of a mental health disorder, and is dependent on the availability of outside support to facilitate the connection. Overall, a more healthy parent-child relationship is associated with lower distress in treatment and parent distress in caring for their child (Pickett et al., 1997). It was therefore hypothesized that poorer parent-child relationships would be predictive of higher levels of a parent's reported current grief.

Hypothesis Four

The degree of stress reported by parents may vary by the child's diagnosis. Diagnoses frequently presenting a combined presentation of internalizing and externalizing disorders, such as Schizophrenia and Bipolar Disorder are reported as more severe than predominantly internalizing disorders such as Major Depressive Disorder and diagnoses in the anxiety disorder family (Masa'Deh, 2017; Wiens & Daniluk, 2009). Masa'Deh (2017) and Wiens and Daniluk (2009) suggest the variation in stress may be attributed to the types of behaviors children exhibit with more of the severe externalizing behaviors being more impactful than the internalized concerns of children with anxiety disorders. It was therefore hypothesized that diagnoses of externalizing disorders as compared to diagnoses of internalizing disorders would be predictive of higher levels of a parent's reported current grief.

Hypothesis Five

Although there is some disagreement in the literature, the majority of research suggests holding two or more diagnoses is more problematic for the child and their family (Marmorstein & Ignacio, 2004; Weins & Daniluk, 2009; Yoo et al., 2009). The impact on the family also grows as children's behavior and symptomology expands and impacts more areas of their life and that of their parents. When a diagnosis of Conduct Disorder or Oppositional Defiant Disorder is accompanied by a diagnosis of an internalizing disorder, such as an anxiety or depressive disorder, there is a greater likelihood that the diagnosis will remain with a child for a longer period of time (Drugli et al., 2010). It was therefore hypothesized that having a child with two or more diagnoses would be predictive of higher levels of a parent's reported current grief.

Hypothesis Six

Similar to the grieving process, it is believed a parent progresses through a series of stages following a child’s diagnosis. As parents progress through the stages, they accept the child’s diagnosis and the negative emotional symptoms experienced begin to decrease with time (Tessler et al., 1987). It was therefore hypothesized that the greater the length of time since the child’s diagnosis would be predictive of lower levels of a parent's reported current grief.

Chapter Four: Methodology

Research Design

Self-report questionnaires were used to measure parents' reported current grief as well as other study variables. The questionnaires included the *Burns Relationship Satisfaction Scale;* the *Depression, Anxiety and Stress Scale-Short Form* (DASS-21); *The Multidimensional Scale of Perceived Social Support* and the *Mental Illness Version of the Texas Inventory of Grief.* Participants also completed a demographic questionnaire created specifically for this study. This questionnaire included questions on the child's diagnosis(es) and time since diagnosis.

Sample

Participants were mothers and fathers who were recruited from national, regional and local mental health associations which provide support and education for children with a mental health diagnosis and their families. Organizations contacted included but were not limited to the National Association for Mental Illness (NAMI), the Depression Bipolar Support Alliance (DBSA) and the Children's Mental Health Network. All contact with the organizations occurred through email.

There were more female participants (n = 193, 91.47%) than male (n = 17, 8.07%) or participants who identified as other (n = 1, 0.46%) . The majority of the participants were married (n = 138, 65.71%). The remaining participants were single (n = 19, 9.05%), divorced (n = 32, 15.24%), in a civil union (n= 4, 1.9%), widowed (n = 13, 6.2%) or other (n = 4, 1.91%). The majority of participants reported to be White (n = 193, 91.47%). The remaining participants reported their ethnicity as Black (n = 7, 3.32%), Asian American (n = 1, 0.47%), Hispanic (n = 7, 3.32%) and Other (n = 3, 1.42%).

Participants were asked to report if their child with a diagnosis lives at home with them and if so, the frequency: full time, part time, or other. The majority of participants reported that their child lives at home (*n* = 146, 69.7%). Most parents reported their child lives at home full time (*n* = 131, 89.12%), while part time (*n* = 1, 0.68%) and other arrangements (*n* = 15, 10.20%) were less commonly reported.

Participants reported information on both their age as well as the age of their child. There was a wide range in age of parents participating (*M* = 54.3, *SD* = 10.16). There was a similarly wide range in child age (*M* = 19.99, *SD* = 9.91). The age of participants varied greatly and ranged from 18 to 91 years of age. The age of the child that the parents were supporting also varied greatly and ranged from 1 to 56 years of age.

Inclusion Criteria The primary inclusion criterion was having a child diagnosed with at least one diagnosis that is included in the *Diagnostic and Statistical Manual for Mental Disorders-5* (American Psychiatric Association, 2013).

Exclusion Criteria Non-parent caregivers were not included in this study. While their experiences are valuable to understand, all existing research examined surrounds parent caregivers and not nontraditional caregiving situations. Further, participants are excluded from the study if their child had a diagnosis which did not appear in the *DSM 5*. Participants were also excluded if they did not complete the *Mental Illness Version of the Texas Inventory of Grief*, the questionnaire assessing the dependent variable.

Measures

Burns Relationship Satisfaction Scale. The Burns Relationship Satisfaction Scale (BRSS) is a self-report measure of an individual's satisfaction with their relationships. The BRSS was developed to assess satisfaction with any relationship. The BRSS uses a six point Likert scale ranging from "strongly disagree" to "strongly agree". Individuals report their satisfaction on dimensions of relationships including communication and closeness. It should be noted instructions were changed slightly from “Place an (x) in the box to the right of each category that best describes the amount of satisfaction you feel in your closest relationship” to substitute child with a diagnosis for “closest relationship”. Participant scores range from zero to 42, with higher scores reflecting greater satisfaction in the relationship. A sample item from the BRSS is, *Degree of affection and caring*.

Psychometric information was provided by Steadman et al. (2007). Internal consistency is reported high (coefficient alpha= .94). In this study, internal consistency was reported to be high (.956). Evidence of construct validity was demonstrated by demonstrating high correlations on the BRSS with other scales assessing aspects of relationship quality including the Locke-Wallace MAT (r=.80), the Dyadic Adjustment Scale (r=-.89) and the Norton’s Quality of Marriage Index (r=.91). The BRSS appears in Appendix I.

The Depression Anxiety Stress Scale-Short Form. The Depression Anxiety Stress Scale-Short Form (DASS-21) is an abbreviated form of the Depression Anxiety and Stress Scale. The scale may be used to differentiate between the presence of significant levels of anxiety, depression and stress which often are manifested in ways which overlap. The DASS-21 is a self-report measure utilizing a three point Likert scale ranging from “Does not apply to me at all” to “Applies to me very much or most of the time”. The DASS-21 yields three scores, one for depression, anxiety, and stress. A sample item from the DASS-21 is, *I experienced breathing difficulty (eg. excessively rapid breathing, breathlessness in the absence of physical exertion).* The DASS-21 appears in Appendix I.

Psychometric information provided by Antony et al. (1998). The reliability and validity of the DASS-21 was assessed both in the general population as well as a clinical group, or those with a diagnosed mental health disorder. Cronbach's alpha for each of the three areas were in the acceptable range; for depression alpha was .94, for anxiety alpha was .87, and for stress alpha was .91. In the current study reliability was reported to be in the moderate to high range; for depression alpha was .91, for anxiety alpha was .79, and for stress alpha was .83. Further, concurrent validity was assessed through comparing DASS scores for each of the areas to related measures: Beck Depression Inventory, State Trait Anxiety Inventory-Trait, Beck Anxiety Inventory. Antony et al. (1998) provided the exact correlations for the DASS and not the DASS-21. Antony et al. (1998) noted there were similar findings for the DASS-21 when considering the length and magnitude of the study.

The Mental Illness Version of the Texas Inventory of Grief. The Texas Inventory of Grief- Mental Illness (MI-TIG) version is an adaptation of the original Texas Inventory of Grief. The original measure is used to assess an individual's grief response following the death of a loved one regarding their past behavior and emotional symptoms. The MI-TIG, was developed in 1990 to specifically examine parental grief responses to a child receiving a diagnosis of a mental health disorder. The MI-TIG consists of two self-report scales: one assessing reactions at the time of the diagnosis, containing eight items and a second assessing current grief symptoms, 16 items. A sample question from the MI-TIG is, *I used to cry about how he/she was before the illness*. The MI-TIG appears in Appendix I.

The MI-TIG utilizes a five point Likert scale ranging from “Completely False” to “Completely True”. Both scales mirror the original scale, the TIG, with the exception of changes in wording from “death” to “before he/she became ill”. Psychometric information for the MI-TIG was provided by Miller et al. (1990). Miller et al. (1990) provided the revised scale to experts in the field of grief to ensure the changed items did not alter the construct being measured.

Internal consistency for the two scales were reported, with the first scale reporting moderate to high consistency (.824) and the second scale reporting extremely high consistency (.92). In this study, initial grief was reported with moderate consistency (alpha = .697) and current grief was also reliable (alpha = .925). Information on the validity of this measure is limited. However, this is the only available measure of complicated grief in the context of mental illness.

The Multidimensional Scale of Perceived Social Support. The Multidimensional Scale of Perceived Social Support (MPSS) was developed by Zimet et al. (1988) in an effort to understand an individual’s perception of different forms of social support available to them. Three areas of social support are assessed: familial support, support from friends and support from a significant other. The MPSS is a self-report questionnaire consisting of 12 items. When completing the questionnaire, those responding report their responses using a seven point Likert scale ranging from “Very Strongly Disagree” to “Very Strongly Agree”. A sample item from the MPSS is, *There is somebody special around when I am in need*. The MPSS appears in Appendix I.

Psychometric information was provided by Zimet et al. (1988). Reliability and validity of the questionnaire as assessed through administering the scale to a group of undergraduate university students (n = 275). Females (n = 136) and males (n = 139) were evenly represented. Participants were traditional college aged students ranging in age from 17 to 22 years (M = 18.6). Reliability for each of the three scales was good: *Significant Other* (.91); *Family Support* (.87), and *Friend Support* (.85). Internal reliability was assessed through 69 of the participants completing the questionnaire again, 3-4 months following initial compilation. Strong internal reliability was for each of the subscales: *Significant Other* (.72); *Family Support* (.85); and *Friend Support* (.75). In the current study, reliability was reported to be high: *Significant Other* (alpha = .94), *Family* (alpha = .93), and *Friends* (alpha = .93).

Validity was assessed through the use of a correlational analysis comparing scores on the MPSS to the Hopkins Symptom Checklist (HSC). Zimet et al. (1998) reported that Family Support was negatively related to scores on both the Anxiety (r= -.24, p< .01) and Depression (r= -.18 p< .01) subscales of the HSC. With regard to the Friend Support, a significant correlation was reported for Depression only (r= -.24, p< .01). With regard to the Significant Other subtest, significant correlations were reported overall (r= -.25, p< .01) and for Depression (r= -.13, p< .01).

Demographic Questionnaire. A demographic questionnaire was created specifically for the study. Questions asked of participants included personal information, *what is your age?*, and information about their diagnosed child, "what is your child's diagnosis?". The demographic questionnaire appears in Appendix I.

Procedure

Approval for this study was obtained through Georgian Court University's Institutional Research and Review Board (IRRB). Further, consent to recruit participants was obtained from each organization where the research opportunity was posted. With organization approval, the research opportunity was either posted on the organization's website or shared through the organization's email list. No direct contact was made between the researcher and participants, instead it was mediated by the organization.

All participants, regardless of recruitment through a posting on a website or contact through email, were invited to complete the online survey by clicking on a link and being directed to the online survey. Upon reaching the survey and signing a digital informed consent, participants will complete the questionnaires listed in the measures section. Upon completion of the survey, participants were provided with a link to the American Psychological Association's Psychologist Locator should participation in the study result in feelings of distress. Copies of the IRRB Application, Informed Consent, and Debriefing Statements are in Appendix II.

Chapter Five. Analytic Strategy

Data were screened for missing data, multivariate outliers, linearity, normality and homoscedasticity. In addition, variables included in the multiple regression analysis were screened for multicollinearity. Next, descriptive statistics (e.g., means, standard deviations) for all study variables were calculated.

The tests of the study hypotheses were then conducted. Pearson's correlation analysis was to test Hypothesis 1. Hypothesis 1 stated that there would be a positive correlation between a parent's reported current grief, anxiety, depression, and stress. Hypotheses 2 through 5 examined the influence of social support, parent child relationship quality, type of diagnosis, and number of diagnoses, respectively, on a parent’s reported current grief. Here, social support, relationship quality, type of diagnosis, and number of diagnoses were the independent variables. These are also known as the predictor variables. Here, a parent’s reported current grief was the dependent variable. It is also known as the criterion. Simultaneous multiple regression analysis was used to test Hypotheses 2 through 5. To do so, each of the predictors were entered into a regression equation to determine if they forecast a significant amount of variation in the criterion, a parent's reported current grief. Hypothesis 6 which examined the influence of the time since a child’s diagnosis on a parent's reported current grief was tested with a Pearson’s correlation analysis.

A power analysis with a medium effect size assumed was conducted. The power analysis indicated that 98 participants were necessary to achieve a statistical power of .80. SPSS 27 was to conduct the analyses.

Chapter Six. Results

Data Screening

Scores for the dependent variable, a parent's reported current grief, were assessed for normality by examining the values for skewness and kurtosis (Mertler & Rinehart, 2017). The value for skewness was equal to 0.41 and the value for kurtosis was equal to -1.05. These values indicate scores on the dependent variable are normally distributed. Data were also assessed for multivariate outliers. Multivariate outliers are identified as an atypical combination of participant scores for multiple variables which separates the responses from the distribution of other responses (Mertler & Rinehart, 2017). As a result, 5 participant responses were identified as outliers and thus excluded from data analysis. Examination of the scatterplots for the dependent variable and all of the independent variables indicated that the assumption of linearity was satisfied.

Using criteria discussed by Mertler and Rinehart (2017), examination of the residual scatterplot indicated that there were no violations of the assumptions of normality, linearity, or homoscedasticity for the residuals. Data screening also indicated that the predictor variables included in regression analysis were not multicollinear. All tolerance values were greater than 0.1 and all values for the variance inflation factors (VIF) were less than 10. As discussed by Mertler and Reinhart (2017) tolerance values and VIF in these ranges are indicative of a lack of multicollinearity.

Descriptive Statistics

The BRSS was used to assess parent satisfaction in their relationship with their child. Scores range from 0-42, with higher scores indicating greater levels of satisfaction. The mean and standard deviation are reported in Table 3 which appears in Appendix V. Here, scores ranged from 0-42, with a mean of 22.56 (*SD* = 13.07). The mean score suggests most parents do not report high levels of satisfaction in their relationship with their child.

The DASS-21 was used to assess parent levels of depression, anxiety and stress. The DASS-21 yields three scores for Depression , Anxiety, and Stress. Scores for each index can range from 0-42, with higher scores indicating higher levels of depression, anxiety or stress. Here, scores for Depression ranged from 9-42; Anxiety from 0-34; and Stress from 0 to 42. The mean and standard deviation are reported in Table 3 which appears in Appendix V. Here, participants' mean scores for Depression were 16.48 (*SD* = 8.97), for Anxiety they were 7.76 (*SD* = 7.69) and for stress they were 13.37 (*SD* = 10.35). These scores are suggestive of moderate levels of Depression and Stress and relatively lower levels of Anxiety.

The MSPSS was used to assess parent perception of social support.The mean and standard deviation are reported in Table 3 which appears in Appendix V. Three forms of support were assessed through the MSPSS: Support from Family, Support from Friends, and Support from a Significant Other. Scores ranged from 4 to 28, with higher scores indicating greater satisfaction with a relationship: Family (*M* = 17.79, *SD* = 6.45), Support from Friends (*M* = 18.42, *SD* = 6.02) and Support from a Significant Other (*M* = 20.29, *SD* = 6.69). Here, mean scores for participants suggest moderate satisfaction in support from family, friends, and a significant other.

Parent's reported current grief was assessed through the MI-TIG. The MI-TIG yields scores for Initial Grief and Current Grief. Scores for Initial Grief can range from 8 to 24 . Current Grief is the dependent variable with scores ranging from 13 to 39. Here, scores for Initial Grief ranged from 8 to 24 and scores for Current Grief ranged from 13 to 39. The mean and standard deviation are reported in Table 3 which appears in Appendix V. Higher scores indicate higher levels of grief; Initial Grief (*M* = 16.39, *SD* = 3.50) and Current Grief (*M* = 26.37, *SD* = 7.02). Here, the mean scores reported by participants suggest higher than average Initial Grief and higher than average Current Grief.

Parents reported information on the number of mental health disorders their child was diagnosed with as well as the length of time since initial diagnosis. The mean and standard deviation are reported in Table 3 which appears in Appendix V. The number of diagnoses (*M* = 2.69, *SD* = 1.75) suggested most participants reported more than one diagnosis. The time since diagnosis (*M* = 11.81, *SD* = 8.40) suggested many participants have a child who was diagnosed many years prior to participation in the study.

Values for Pearson *r* appear in Table 4, Appendix VI. Because multiple correlations were conducted, a Bonferroni correction was applied. A *p* value of less than .007 was necessary to achieve statistical significance. As can be seen in Table 4, Appendix VI, satisfaction in the parent-child relationship (BRSS) is significantly related to a parent's reported current grief, *r*(140) = - .556, *p* < .001. As can be seen in Table 4, Appendix VI, support from family is significantly related to a parent's reported current grief *r*(140) = -.229, *p* = .002. As can be seen in Table 4, Appendix VI, support from friends was not significantly related to a parent's reported current grief, *r*(140) = -1.06, *p* = .091. As can be seen in Table 4, Appendix VI, support from a significant other was significantly related to a parent's reported current grief , *r*(140) = -2.36, p = .001. As can be seen in Table 4, Appendix VI, the presence of a child’s externalizing diagnosis was not significantly related to a parent's reported current grief, *r*(140) = .001, *p* = .489. As can be seen in Table 4, Appendix VI, the number of child diagnoses was not significantly related to a parent's reported current grief, *r*(140) = .093, *p* = .120.

Tests of Hypotheses

Hypothesis One stated that there would be a positive correlation between a parent's reported current grief, anxiety, depression, and stress. Hypothesis One was supported. Results indicated that stress was significantly correlated with a parent's reported current grief, $r(201) = .408$, $p < .001$. Depression was significantly correlated with a parent's reported current grief , $r(200) = .453$, $p < .001$. Anxiety was significantly correlated with a parent's reported current grief, $r(200) = .309$, $p = .001$.

As stated above, a multiple regression analysis was used to test Hypotheses 2 through 5. Here, perceptions of supports from others, which includes family, friends, and a significant other (Hypothesis 2); parent child relationship (Hypothesis 3); the presence of an externalizing disorder (Hypothesis 4); and the number of diagnosis (Hypothesis 5) were the independent variables. The result of this analysis indicated that the independent variables, as a set, predicted a significant amount of variation in a parent's reported current grief , the dependent variables, $F(9,145)= 11.16$, $p < .001$, accounting for 41% variance in a parent's reported current grief. A summary of the regression model may be found in Table 5, Appendix VII**.**

Hypothesis Two stated that a parent's perception of available personal support would be predictive of a parent's reported current grief experienced with higher levels of personal support being predictive of lower levels of grief. Hypothesis Two was partially supported. As seen in Table 5 given in Appendix VII support of family was not predictive of a parent's reported current grief. Here, the standardized regression coefficient was equal to .013, and the associated significance test indicated that it was not a significant predictor of a parent's reported current grief, $t(153) = .877$. As seen in Table 5 given in Appendix VII support of friends was not predictive of a parent's reported current grief. Here, the standardized regression coefficient was equal to .105, and the associated significance test indicated that it was not a significant predictor of a parent's reported current grief , t(153) = .226. As seen in Table 5 given in Appendix VII support of a significant other was predictive of a parent's reported current grief. Here, the standardized regression coefficient was equal to -.233, and the associated significance test indicated that it was a significant predictor of a parent's reported current grief, t(153) = 12.528, p = .012. Here, higher levels of support from a significant other were predictive of lower levels of a parent's reported current grief .

Hypothesis Three predicted that poorer parent-child relationships would be predictive of higher levels of a parent's reported current grief. Hypothesis Three was supported. As seen in Table 5 given in Appendix VII satisfaction in the parent-child relationship was predictive of a parent's reported current grief. The standardized regression coefficient was -.543, and the associated significance test indicated that it was a significant predictor of a parent's reported current grief, *t*(153) = -7.855, *p* = .001. Here, higher quality parent child relations were predictive of lower levels of a parent's reported current grief.

Hypothesis Four predicted that diagnoses of externalizing disorders as compared to diagnoses of internalizing disorders would be predictive of higher levels of a parent's reported current grief . Hypothesis Four was not supported. As seen in Table 5 given in Appendix VII a child’s diagnosis of an externalizing disorder was not predictive of a parent's reported current grief. Here, the regression coefficient was -.056, and the associated significance test indicated that it was not a significant predictor of a parent's reported current grief, *t*(153) = -.827, *p* = .409.

Hypothesis Five predicted that having a child with two or more diagnoses is predictive of higher levels of a parent's reported current grief. Hypothesis Five was not supported. As seen in Table 5 given in Appendix VII having a child with two or more diagnoses was not predictive of a parent's reported current grief. Here, the standardized regression coefficient was .015, and the associated significance test indicated that it was not a significant predictor of a parent's reported current grief, $t(153) = .226$, $p = .821$.

Hypothesis Six predicted that the greater the length of time since the child's diagnosis would be predictive of lower levels of a parent's reported current grief. Pearson's r was used to test this hypothesis. The result of this hypothesis test was not significant, $r(41) = -.186$, $p = .245$.

Additional Analyses

An independent t-test was used to determine the relationship between gender, Female or Male, on a parent's current grief. There was no significant effect for current grief $t(200) = 1.2$, $p = .88$, between females ($M = 26.37$, $SD = 6.70$) and males ($M = 24.13$, $SD = 6.79$).

An additional correlational analysis was conducted to determine the presence of a relationship between a parent's initial grief and a parent's current grief. Results indicated that a parent's initial grief was significantly correlated with a parent's current grief, $r(204) = .32$, $p < .001$.

Summary

In conclusion, a multiple linear regression was conducted to determine if parent-child relationship; perception of support from family, friends or a significant other; stress, anxiety, or depressive symptoms; the presence of an externalizing disorder; or the number of diagnoses were predictors of a parent's reported current grief. Following the screening of data for normality, linearity, and multicollinearity, responses from 155 participants were included in final analysis.

Three hypotheses were fully or partially supported. Through correlational analysis depression, anxiety, and stress were demonstrated to be correlated with a parent's reported current grief. Both satisfaction in the parent-child relationship and support from a significant other were predictive of a parent's reported current grief. Hypotheses about the support of family and friends, the number of diagnoses and types of diagnoses were not supported. The time since initial diagnosis could not be included in the analysis given the lack of participant response. Instead, a correlational analysis of time since diagnosis and a parent’s reported current grief was conducted. This hypothesis was not supported as there was no significant relationship between the time since diagnosis and a parent’s reported grief.

Chapter Seven. Discussion

Discussion

Using the lens of the grief model, the purpose of the study was to gain a better understanding of the experiences of parents of children diagnosed with mental health disorders. While literature supports the theory that parents play a key role in the efficacy and outcome for their child, there is a need to understand the support available to mothers and fathers (Chase & Peacock, 2017; Greenberg et al., 1997; Horwitz & Reinhard, 1995; Koren et. al, 2016). Previous research supports the belief that the magnitude of grief parents experience varies by the availability of support.

To the best of the researcher’s knowledge, this is the first study to examine a parent's reported current grief when caring for a child with a diagnosed mental health disorder. Hypothesis One stated that there would be a positive correlation between a parent's reported current grief, anxiety, depression, and stress. Hypothesis One was supported, as results indicated that depression, anxiety and stress were significantly correlated with a parent's reported current grief. This is consistent with previous research which supports that extended feelings of grief increase reports of depression, anxiety and stress (Godress et al., 2005; Oreo & Ozgul, 2017).

Hypothesis Two stated that a parent’s perception of available personal support would be predictive of a parent's reported current grief experienced with higher levels of personal support being predictive of lower levels of grief. Hypothesis Two was partially supported. The support of family and the support of friends was not predictive of a parent's reported current grief. However, the support of a significant other was predictive of a parent's reported current grief. Higher levels of support from a significant other were predictive of lower levels of a parent's reported current grief . While only the support of a significant other was an important predictor, the results are consistent with previous research which emphasizes the importance of social support while caring for a child with a diagnosis (Horwitz & Reinhard, 1995; Tessler et al., 1987; Wu et al., 2018).

Hypothesis Three predicted that poorer parent-child relationships would be predictive of higher levels of a parent's reported current grief. Hypothesis Three was supported as satisfaction in the parent-child relationship was predictive of a parent's reported current grief . This is to say, that higher quality parent child relations were predictive of lower levels of a parent's reported current grief. This is consistent with previous research which suggested a healthier parent-child relationship is associated with lower distress (Pickett et al., 1997).

Hypothesis Four predicted that diagnoses of externalizing disorders as compared to diagnoses of internalizing disorders would be predictive of higher levels of a parent's reported current grief. Hypothesis Four was not supported as the child's diagnosis of an externalizing disorder was not predictive of a parent's reported current grief. While child diagnoses and a parent's reported current grief have not been examined before, these results differ from previous research which has demonstrated a link between parent stress and a child’s diagnosis (Drugli et al., 2010; Masa’Deh, 2017; Wiens & Daniluk, 2009). The difference in results might be based on how internalizing and externalizing disorders are defined.

Hypothesis Five predicted that having a child with two or more diagnoses is predictive of higher levels of a parent's reported current grief. Hypothesis Five was not supported as having a child with two or more diagnoses was not predictive of a parent's reported current grief. The findings that multiple diagnoses is not predictive of a parent's reported current grief is somewhat consistent with previous research where there are varied findings in whether holding two or more diagnoses is more problematic for the child and their family (Marmorstein & Ignacio, 2004; Weins & Daniluk, 2009; Yoo et al., 2009).

Hypothesis Six predicted that the greater the length of time since a child's diagnosis would be predictive of lower levels of a parent's reported current grief. Given the lack of participant response to the survey question measuring length of time, this variable was not included in the regression analysis. Instead, a Pearson's *r* was used to test this hypothesis. The length of time since diagnosis was not correlated with parent's reported current grief. This is inconsistent with Tessler et al.'s (1987) staged theory of grief which purported that as parents progress through the stages of grief, they accept the child's diagnosis and the negative emotional symptoms experienced begin to decrease with time . To the best of the researcher's knowledge, this is the first study to address this question through a survey instead of an interview format, which may explain the difference between Tessler et al.'s (1987) theory and the results in the present study.

Implications

The results of the correlational analysis support that depression, anxiety, and stress are positively correlated with a parent's reported current grief. These findings suggest that parents who report higher levels of a parent's reported current grief are more likely to experience symptoms of depression, anxiety and stress. These findings suggest parents could be assisted through being provided support for their emotional symptoms. These findings are significant as it deviates from current support for parents which is based in psychoeducation and parent training (Ambikile & Outwater, 2012; Godress et al., 2005; Koren et al., 2016; Mendenhall & Mount, 2011; Ribé et al., 2018).

A multiple regression analysis supports the parent-child relationship and perception of significant others in predicting levels of a parent's reported current grief. The importance of the parent-child relationship has been discussed in previous research (Kochanska et al., 2013;

Marmorstein & Ignacio, 2004; Perez Algorta et al., 2018). These findings build on previous research which purports the positive outcome for a child's mental health treatment is influenced by the quality of the relationship with their parent (Pickett et al., 1997). The findings from the present study suggest that a parent's ability to cope with their current grief is also dependent on the relationship with their child. Previous research has also emphasized the importance of social support for parents coping with their child's diagnosis (Ambikile & Outwater, 2012; Greenberg et al., 1997; Hoagwood et al., 2010; Horwitz & Reinhard, 1995; Masa'Deh, 2017; Shor & Birnbaum, 2012). These findings suggest that parents who are in a committed relationship cope with their current grief more effectively when they are satisfied in the support they receive from a significant other.Taken together, these findings are significant as it suggests strengthening the parent-child relationship as well as support from a significant other would lower grief reported.

Collectively, the findings from the present study support a parent's report of current grief is correlated with the experience of symptoms of anxiety, depression and stress. Further, satisfaction in the parent-child relationship and the support of a significant other predict the current grief reported by parents. Based on these findings, interventions should focus on alleviating symptoms of depression, anxiety and stress as well as improving the parent-child relationship.

Limitations and Areas for Future Research

This study utilized a self-report survey which has both benefits and drawbacks. According to Kite and Whitley (2018), benefits of online surveys include the ability to reach more participants and assess an individual's feelings and opinions. Problems with self-reports include accuracy in reporting one's feelings, difficulty recalling previous events with clarity and the desire to respond to surveys in a positive way (2018). Further, online surveys have a higher rate of incompletion where participants drop out prior to ending the study. For this study, originally 354 participants provided consent to participate while only 155 completed enough of the survey for inclusion in the analysis.

Recruitment through online support groups and agencies may have limited the diversity and number of participants. This is supported by previous research which suggests that a parent's lack of trust in agencies or support groups often stems from stigmatization or fear of judgment, especially amongst culturally diverse populations (Davis et al., 2010; Gavois et al., 2006; Greenberg et al. 2017; Koren et al., 2016; Mazur & Mickle, 2018). Future research should focus on more diverse populations and should take into consideration alternate means of participant recruitment such as the use of in-person surveys.

Generalizability of the findings are limited based on demographic factors. The majority of the participants were White (91.5%) suggesting future research should focus on the experiences of parents from Black, Asian American and Hisapnic communities. The lack of diversity in participants may be attributed to different factors such as language barriers or lack of trust in the mental health care system. Further, all questionnaires utilized in the study were in English limiting who could participate in the study. Translating the questionnaires into other languages who have limited the reliability of the results. Previous research by Sturm et al. (2017) supports the idea parents from non-White backgrounds are more likely to be fearful of strigmatization and judgement from the mental health community.

The majority of the participants were female (91.5%), indicating further research should focus on the experience of fathers. A majority female sample is consistent with previous research (Crissanti, 2000; Hernandez & Barrio, 2015; Marmorstein & Ignacio, 2004; van der Voot, 2014). This may be attributed to the fact that mothers more so than fathers tend to be the primary caregiver (Crissanti, 2000; Marmorstein & Ignacio, 2004). While this study did not consider other demographic factors, future research should examine factors such as the number of other children in the family. The number of other children in the family would be beneficial to explore as research by Ma et al. (2017) suggests increased strain in relationships between parents and other children without a mental health diagnosis.

The majority of participants reported their child lived at home. These results are consistent with research stating that parents are primarily responsible for providing care for the child’s treatment (Cook et al., 1994; Horwitz & Reinhard, 1995; Onwumere et al., 2018; Shor & Birnbaum, 2012; Tessler et al., 1987). One factor this study sought to explore was the impact of the length of time since a child’s initial diagnosis on a parent's reported current grief. Out of the 340 participants who started the study, and the 155 participants included in the final analysis, only 34 responses for this question were recorded. Future research could explore this factor further. Previous research supports the impact of a child’s diagnosis on the entire family (Ma et al., 2017; MacGregor, 1994). Therefore, it would be beneficial to expand on current research to understand the experience of siblings following a child’s diagnosis.

The findings from the present study support satisfaction in the parent-child relationship and support from a significant other as being predictive of a parent’s current reported grief.Further research should also focus on parent-child relationships and the availability of support from a significant other. Research should focus on identifying which aspects of a parent-child relationship are the most meaningful as well as means of intervention. Similarly, further research should explore gender differences in support from a significant other and what support would be most meaningful.

Conclusions

To the best of the researcher’s knowledge, this was the first study to utilize a grief model to understand the experiences of parents of children diagnosed with mental health disorders. Previous research has documented the need to understand the support available to mothers and fathers when caring for a child with a diagnosed mental health disorder (Chase & Peacock, 2017; Greenberg et al., 1997; Horwitz & Reinhard, 1995; Koren et. al, 2016). To the researcher’s knowledge, this is the first study to examine emotional symptoms, relationship satisfaction, availability of support and factors related to a child’s diagnosis in relation to a parent’s current grief. Using a correlation analysis, both depression and stress were moderately associated with a parent's reported current grief while anxiety was not. These findings support the importance of providing parents with support in processing feelings of depression and stress when caring for their child.

A correlation analysis supported the relationship between depression, anxiety and stress on a parent’s current reported grief. Utilizing a multiple regression analysis, this study sought to understand whether depression, anxiety, and stress, the availability of personal support, satisfaction of the parent-child relationship, number of child diagnoses, the type of diagnoses, and time since initial diagnosis was predictive of a parent's reported current grief. Given insufficient participant response to the question of time since initial diagnosis, this variable was not included in analysis.

The support of family and friends, the number of child diagnoses, and the type of diagnoses were not predictive of a parent's reported current grief. Two factors were identified in predicting a parent's reported current grief: satisfaction in the parent-child relationship and perceived support of a significant other. These findings are important as it supports the importance of strengthening the parent-child relationship and the availability of support from a significant other in reducing a parent's reported current grief.These findings are also important as it identifies the support of a significant other as a predictive factor in a parent's reported current grief.

References

Aalbæk, F. S., Graff, S., & Vestergaard, M. (2017). Risk of stroke after bereavement-a systematic literature review. *Acta Neurologica Scandinavica*, *136*(4), 293–297. https://doi.org/10.1111/ane.12736

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Ambikile, J. S., & Outwater, A. (2012). Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam - Tanzania. *Child and Adolescent Psychiatry and Mental Health, 6*, 11. http://dx.doi.org.library.georgian.edu:2048/10.1186/1753-2000-6-16

Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment, 10*(2), 176-181. http://dx.doi.org.library.georgian.edu:2048/10.1037/1040-3590.10.2.176

Axelrod, J., Geismar, L., & Ross, R. (1994). Families of chronically mentally ill patients: Their structure, coping resources, and tolerance for deviant behavior. *Health & Social Work, 19*(4), 271-278. https://library.georgian.edu/login?url=https://www-proquest-com.library.georgian.edu/docview/618623278?accountid=27354

Barak, D., & Solomon, Z. (2005). In the Shadow of Schizophrenia: A Study of Siblings' Perceptions. *Israel Journal of Psychiatry and Related Sciences, 42*(4), 234-241. https://library.georgian.edu/login?url=https://www-proquest-com.library.georgian.edu/docview/621289418?accountid=27354

Bergman, E. J., Haley, W. E., & Small, B. J. (2010). The role of grief, anxiety, and depressive symptoms in the use of bereavement services. Death Studies, 34(5), 441-458. http://dx.doi.org.library.georgian.edu:2048/10.1080/07481181003697746

Blau, G. (2008). Exploring antecedents of individual grieving stages during an anticipated worksite closure. *Journal of Occupational and Organizational Psychology, 81*(3), 529-550. doi:http://dx.doi.org.library.georgian.edu:2048/10.1348/096317907X241560

Boelen, P. A. (2015). Optimism in prolonged grief and depression following loss: A three-wave longitudinal study. *Psychiatry Research, 227*(2-3), 313-317. doi:http://dx.doi.org.library.georgian.edu:2048/10.1016/j.psychres.2015.03.009

Boelen, P. A., Huntjens, R. J. C., van Deursen, D. S., & van den Hout, Marcel A. (2010). Autobiographical memory specificity and symptoms of complicated grief, depression, and posttraumatic stress disorder following loss. *Journal of Behavior Therapy and Experimental Psychiatry, 41*(4), 331-337. http://dx.doi.org.library.georgian.edu:2048/10.1016/j.jbtep.2010.03.003

Boelen, P. A., Reijntjes, A., Djelantik, A. A. A. M., & Smid, G. E. (2016). Prolonged grief and depression after unnatural loss: Latent class analyses and cognitive correlates. *Psychiatry Research, 240*, 358-363. doi:http://dx.doi.org.library.georgian.edu:2048/10.1016/j.psychres.2016.04.012

Bordere, T. (2017). Disenfranchisement and ambiguity in the face of loss: The suffocated grief of sexual assault survivors. *Family Relations: An Interdisciplinary Journal of Applied Family Studies, 66*(1), 29-45. http://dx.doi.org.library.georgian.edu:2048/10.1111/fare.12231

Bouc, A., Han, S., & Pennington, N. (2016). "Why are they commenting on his page?": Using Facebook profile pages to continue connections with the deceased. *Computers in Human Behavior, 62*, 635-643. http://dx.doi.org.library.georgian.edu:2048/10.1016/j.chb.2016.04.027

Bregman, L. (2019). Kübler-Ross and the Re‾visioning of Death as Loss: Religious Appropriation and Responses. *The Journal of Pastoral Care & Counseling*, *73*(1), 4–8. https://doi.org/10.1177/1542305019831943

Bugen, L. A. (1977). Human grief: A model for prediction and intervention. *American Journal of Orthopsychiatry, 47*(2), 196-206. doi:http://dx.doi.org.library.georgian.edu:2048/10.1111/j.1939-0025.1977.tb00975.x

Calderwood, K. A. (2011). Adapting the transtheoretical model of change to the bereavement process. *Social Work, 56*(2), 107-118. doi:http://dx.doi.org.library.georgian.edu:2048/10.1093/sw/56.2.107

Chase, T., & Peacock, G. G. (2017). An investigation of factors that influence acceptability of parent training. *Journal of Child and Family Studies, 26*(4), 1184-1195. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10826-016-0644-x

Chiu, Y.-W., Yin, S.-M., Hsieh, H.-Y., Wu, W.-C., Chuang, H.-Y., & Huang, C.-T. (2010). Bereaved females are more likely to suffer from mood problems even if they do not meet the criteria for prolonged grief. *Psycho-Oncology*, *20*(10), 1061–1068. https://doi.org/10.1002/pon.1811

Cook, J. A., Lefley, H. P., Pickett, S. A., & Cohler, B. J. (1994). Age and family burden among parents of offspring with severe mental illness. *American Journal of*

Orthopsychiatry, 64(3), 435-447. http://dx.doi.org.library.georgian.edu:2048/10.1037/h0079535

Cook, J. A., Heller, T., & Pickett-Schenk, S. (1999). The effect of support group participation on caregiver burden among parents of adult offspring with severe mental illness. *Family Relations: An Interdisciplinary Journal of Applied Family Studies, 48*(4), 405-410. http://dx.doi.org.library.georgian.edu:2048/10.2307/585248

Corr, C. A. (2015). Let's stop "staging" persons who are coping with loss. *Illness, Crisis, & Loss, 23*(3), 226-241. http://dx.doi.org.library.georgian.edu:2048/10.1177/1054137315585423

Corr, C. A. (2020). Elisabeth Kübler-Ross and the "Five Stages" Model in a Sampling of Recent American Textbooks. *Omega: Journal of Death & Dying*, *82*(2), 294–322. https://doi.org/10.1177/0030222818809766

Currier, J. M., Irish, J. E. F., Neimeyer, R. A., & Foster, J. D. (2015). Attachment, continuing bonds, and complicated grief following violent loss: Testing a moderated model. *Death Studies, 39*(4), 201-210. http://dx.doi.org.library.georgian.edu:2048/10.1080/07481187.2014.975869

D'Antonio, J. (2011). Grief and loss of a caregiver in children: A developmental perspective. *Journal of Psychosocial Nursing and Mental Health Services, 49*(10), 17-20. doi:http://dx.doi.org.library.georgian.edu:2048/10.3928/02793695-20110802-03

Davis, E. L., Deane, F. P., Lyons, G. C. B., & Barclay, G. D. (2017). Is higher acceptance associated with less anticipatory grief among patients in palliative care? *Journal of Pain and Symptom Management, 54*(1), 120-125. doi:http://dx.doi.org.library.georgian.edu:2048/10.1016/j.jpainsymman.2017.03.012

Davis, T. S., Scheer, S. D., Gavazzi, S. M., & Uppal, R. (2010). Parent advocates in children's mental health: Program implementation processes and considerations. *Administration and Policy in Mental Health, 37*(6), 468-483. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10488-010-0288-x

de Groot, M., de Keijser, J., Neeleman, J., Kerkhof, A., Nolen, W., & Burger, H. (2007). Cognitive behaviour therapy to prevent complicated grief among relatives and spouses bereaved by suicide: Cluster randomised controlled trial. *BMJ: British Medical Journal, 334*(7601), 994. http://dx.doi.org.library.georgian.edu:2048/10.1136/bmj.39161.457431.55

Dillen, L., Fontaine, J. R. J., & Verhofstadt-Denève, L. (2009). Confirming the distinctiveness of complicated grief from depression and anxiety among adolescents. *Death Studies, 33*(5), 437-461. http://dx.doi.org.library.georgian.edu:2048/10.1080/07481180902805673

Drugli, M. B., Larsson, B., Fossum, S., & Mørch, W. (2010). Five- to six-year outcome and its prediction for children with ODD/CD treated with parent training. *Journal of Child Psychology and Psychiatry, 51*(5), 559-566. http://dx.doi.org.library.georgian.edu:2048/10.1111/j.1469-7610.2009.02178.x

Duchovic, C. A., Gerkensmeyer, J. E., & Wu, J. (2009). Factors associated with parental distress. *Journal of Child and Adolescent Psychiatric Nursing, 22*(1), 40-48. http://dx.doi.org.library.georgian.edu:2048/10.1111/j.1744-6171.2008.00168.x

Eakes, G. G. (1995). Chronic sorrow: The lived experience of parents of chronically mentally ill individuals. *Archives of Psychiatric Nursing, 9*(2), 77-84. doi:http://dx.doi.org.library.georgian.edu:2048/10.1016/S0883-9417(95)80004-2

Eaton, K., Ohan, J. L., Stritzke, W. G. K., & Corrigan, P. W. (2016). Failing to meet the good parent ideal: Self-stigma in parents of children with mental health disorders. *Journal of Child and Family Studies, 25*(10), 3109-3123. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10826-016-0459-9

Feldman, D. B., Fischer, I. C., & Gressis, R. A. (2016). Does religious belief matter for grief and death anxiety? Experimental philosophy meets psychology of religion. *Journal for the Scientific Study of Religion, 55*(3), 531-539. http://dx.doi.org.library.georgian.edu:2048/10.1111/jssr.12288

Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations: An Interdisciplinary Journal of Applied Family Studies, 46*(4), 359-371. http://dx.doi.org.library.georgian.edu:2048/10.2307/585096

Foroughe, M., Stillar, A., Goldstein, L., Dolhanty, J., Goodcase, E. T., & Lafrance, A. (2019). Brief emotion focused family therapy: An intervention for parents of children and adolescents with mental health issues. *Journal of Marital and Family Therapy, 45*(3), 410-430. http://dx.doi.org.library.georgian.edu:2048/10.1111/jmft.12351

Frei-Landau, R., Tuval-Mashiach, R., Silberg, T., & Hasson-Ohayon, I. (2020). Attachment to God as a mediator of the relationship between religious affiliation and adjustment to child loss. *Psychological Trauma: Theory, Research, Practice, and Policy, 12*(2), 165-174. http://dx.doi.org.library.georgian.edu:2048/10.1037/tra0000499

Gavois, H., Paulsson, G., & Fridlund, B. (2006). Mental health professional support in families with a member suffering from severe mental illness: A grounded theory model.

Scandinavian Journal of Caring Sciences, 20(1), 102-109. http://dx.doi.org.library.georgian.edu:2048/10.1111/j.1471-6712.2006.00380.x

Gilbert, K. R. (1996). "We've had the same loss, why don't we have the same grief?" Loss and differential grief in families. *Death Studies, 20*(3), 269-283. http://dx.doi.org.library.georgian.edu:2048/10.1080/07481189608252781

Goldstein, R. D., Petty, C. R., Morris, S. E., Human, M., Odendaal, H., Elliott, A., Tobacco, D., Angal, J., Brink, L., Kinney, H. C., & Prigerson, H. G. (2019). Pre-loss personal factors and prolonged grief disorder in bereaved mothers. *Psychological Medicine, 49*(14), 2370-2378. http://dx.doi.org.library.georgian.edu:2048/10.1017/S0033291718003264

Godress, J., Ozgul, S., Owen, C., & Foley-Evans, L. (2005). Grief experiences of parents whose children suffer from mental illness. *Australian and New Zealand Journal of Psychiatry, 39*(1-2), 88-94. http://dx.doi.org.library.georgian.edu:2048/10.1111/j.1440-1614.2005.01518.x

Greenberg, J. S., Greenley, J. R., & Brown, R. (1997). Do mental health services reduce distress in families of people with serious mental illness? *Psychiatric Rehabilitation Journal, 21*(1), 40-50. http://dx.doi.org.library.georgian.edu:2048/10.1037/h0095344

Guzick, A. G., Cooke, D. L., McNamara, J. P. H., Reid, A. M., Graziano, P. A., Lewin, A. B., Murphy, T. K., Goodman, W. K., Storch, E. A., & Geffken, G. R. (2019). Parents' Perceptions of Internalizing and Externalizing Features in Childhood OCD. *Child Psychiatry and Human Development, 50*(4), 692-701. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10578-019-00873-w

Haddad, J. D., Barocas, R., & Hollenbeck, A. R. (1991). Family organization and parent attitudes of children with conduct disorder. *Journal of Clinical Child Psychology, 20*(2), 152-161. http://dx.doi.org.library.georgian.edu:2048/10.1207/s15374424jccp2002_6

Handsley, S. (2001). "But what about us?" The residual effects of sudden death on self-identity and family relationships. *Mortality, 6*(1), 9-29. http://dx.doi.org.library.georgian.edu:2048/10.1080/13576270020028610

Harper, M., O'Connor, R. C., & O'Carroll, R. E. (2014). Factors associated with grief and depression following the loss of a child: A multivariate analysis. *Psychology, Health & Medicine, 19*(3), 247-252. http://dx.doi.org.library.georgian.edu:2048/10.1080/13548506.2013.811274

Hernandez, M., & Barrio, C. (2015). Perceptions of subjective burden among Latino families caring for a loved one with schizophrenia. *Community Mental Health Journal, 51*(8), 939-948. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10597-015-9881-5

Hoagwood, K. E., Cavaleri, M. A., Serene Olin, S., Burns, B. J., Slaton, E., Gruttadaro, D., & Hughes, R. (2010). Family support in children's mental health: A review and synthesis. *Clinical Child and Family Psychology Review, 13*(1), 1-45. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10567-009-0060-5

Holland, J. M., & Neimeyer, R. A. (2010). An examination of stage theory of grief among individuals bereaved by natural and violent causes: A meaning orientated contribution. *Omega: Journal of Death and Dying, 61*(2), 103-120. doi:http://dx.doi.org.library.georgian.edu:2048/10.2190/OM.61.2.b

Holland, J. M., Thompson, K. L., Rozalski, V., & Lichtenthal, W. G. (2014). Bereavement-related regret trajectories among widowed older adults. *The Journals of*

Gerontology: Series B: Psychological Sciences and Social Sciences, 69(1), 40-47. http://dx.doi.org.library.georgian.edu:2048/10.1093/geronb/gbt050

Honey, A., Chesterman, S., Hancock, N., Llewellyn, G., Hazell, P., & Clarke, S. (2015). Knowing what to do and being able to do it: Influences on parent choice and use of practices to support young people living with mental illness. *Community Mental Health Journal, 51*(7), 841-851. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10597-015-9864-6

Horwitz, A. V., & Reinhard, S. C. (1995). Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses. *Journal of Health and Social Behavior, 36*(2), 138-150. http://dx.doi.org.library.georgian.edu:2048/10.2307/2137221

Howarth, R. A. (2011). Concepts and controversies in grief and loss. *Journal of Mental Health Counseling, 33*(1), 4-10. http://dx.doi.org.library.georgian.edu:2048/10.17744/mehc.33.1.900m56162888u737

Hser, Y., Lanza, H. I., Li, L., Kahn, E., Evans, E., & Schulte, M. (2015). Maternal mental health and children’s internalizing and externalizing behaviors: Beyond maternal substance use disorders. *Journal of Child and Family Studies, 24*(3), 638-648. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10826-013-9874-3

Huscroft-D’Angelo, J., January, S.-A. A., & Duppong Hurley, K. L. (2018). Supporting Parents and Students With Emotional and Behavioral Disorders in Rural Settings: Administrator Perspectives. *Rural Special Education Quarterly*, *37*(2), 103–112. https://doi.org/10.1177/8756870517750827

Imran, N., Ashraf, S., Shoukat, R., & Pervez, M. I. (2016). Mother's perceptions of child mental health problems and services: A cross sectional study from Lahore. *Pakistan Journal of Medical Sciences*, *32*(3), 778–781. https://doi.org/10.12669/pjms.323.9775

Jacobson, L., & Butler, S. K. (2013). Grief counseling and crisis intervention in hospital trauma units: Counseling families affected by traumatic brain injury. *The Family Journal, 21*(4), 417-424. doi:http://dx.doi.org.library.georgian.edu:2048/10.1177/1066480713488530

Kenney, J. S. (2003). Gender roles and grief cycles: Observations on models of grief and coping in homicide cases. *International Review of Victimology, 10*(1), 19-47. doi:http://dx.doi.org.library.georgian.edu:2048/10.1177/026975800301000102

Kite, M. E., & Bernard E. Whitley, J. (2018). Principles of research in behavioral science (4th ed.). Routledge.

Kochanska, G., Kim, S., Boldt, L. J., & Yoon, J. E. (2013). Children's callous-unemotional traits moderate links between their positive relationships with parents at preschool age and externalizing behavior problems at early school age. *Journal of Child Psychology and Psychiatry, 54*(11), 1251-1260. http://dx.doi.org.library.georgian.edu:2048/10.1111/jcpp.12084

Kochen, E. M., Jenken, F., Boelen, P. A., Deben, L. M. A., Fahner, J. C., van den Hoogen, A., Teunissen, S. C. C. M., Geleijns, K., & Kars, M. C. (2020). When a child dies: a systematic review of well-defined parent-focused bereavement interventions and their alignment with grief- and loss theories. *BMC Palliative Care*, *19*(1), 1–22. https://doi.org/10.1186/s12904-020-0529-z

Koren, E. V., Kupriyanova, T. A., Drobinskaya, A. O., & Khairetdinov, O. Z. (2016). Effects of mental disorders in children on parents in the context of differentiated approaches to psychosocial interventions in pediatric psychiatry. *Neuroscience and Behavioral Physiology, 46*(4), 394-399. http://dx.doi.org.library.georgian.edu:2048/10.1007/s11055-016-0248-3

Kramer, B. J., Kavanaugh, M., Trentham-Dietz, A., Walsh, M., & Yonker, J. A. (2010). Complicated grief symptoms in caregivers of persons with lung cancer: The role of family conflict, intrapsychic strains, and hospice utilization. *Omega: Journal of Death and Dying, 62*(3), 201-220. http://dx.doi.org.library.georgian.edu:2048/10.2190/OM.62.3.a

Kübler-RossE. (2014). *50th Anniversary Edition On death and dying : what the dying have to teach doctors, nurses, clergy and their own families*. Routledge.

Li, J., Tendeiro, J. N., & Stroebe, M. (2019). Guilt in bereavement: Its relationship with complicated grief and depression. *International Journal of Psychology, 54*(4), 454-461. doi:http://dx.doi.org.library.georgian.edu:2048/10.1002/ijop.12483

Liegghio, M. (2017). Our biggest hurdle yet: Caregivers' encounters with structural stigma in child and youth mental health. *Families in Society, 98*(4), 300-309. http://dx.doi.org.library.georgian.edu:2048/10.1606/1044-3894.2017.98.35

Liew, C. H., & Servaty-Seib, H. (2018). College student grief, grief differences, family communication, and family satisfaction. *Death Studies, 42*(4), 228-238. http://dx.doi.org.library.georgian.edu:2048/10.1080/07481187.2017.1334014

Lundberg, T., Forinder, U., Olsson, M., Fürst, C. J., Årestedt, K., & Alvariza, A. (2018). Bereavement stressors and psychosocial well-being of young adults following the loss of a parent—A cross-sectional survey. *European Journal of Oncology Nursing, 35*, 33-38. http://dx.doi.org.library.georgian.edu:2048/10.1016/j.ejon.2018.05.004

Lundorff, M., Bonanno, G. A., Johannsen, M., & O’Connor, M. (2020). Are there gender differences in prolonged grief trajectories? A registry-sampled cohort study. *Journal of Psychiatric Research*, *129*, 168–175. https://doi.org/10.1016/j.jpsychires.2020.06.030

Ma, N., Roberts, R., Winefield, H., & Furber, G. (2017). The quality of family relationships for siblings of children with mental health problems: A 20-year systematic review. *Journal of Family Studies, 23*(3), 309-332. http://dx.doi.org.library.georgian.edu:2048/10.1080/13229400.2015.1108994

Maccallum, F., Galatzer-Levy, I., & Bonanno, G. A. (2015). Trajectories of depression following spousal and child bereavement: A comparison of the heterogeneity in outcomes. *Journal of Psychiatric Research, 69*, 72-79. doi:http://dx.doi.org.library.georgian.edu:2048/10.1016/j.jpsychires.2015.07.017

MacGregor, P. (1994). Grief: The unrecognized parental response to mental illness in a child. *Social Work, 39*(2), 160-166. https://library.georgian.edu/login?url=https://www-proquest-com.library.georgian.edu/docview/618503474?accountid=27354

Mak, W. W. S., & Cheung, R. Y. M. (2012). Psychological distress and subjective burden of caregivers of people with mental illness: The role of affiliate stigma and face concern. *Community Mental Health Journal, 48*(3), 270-274. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10597-011-9422-9

Marmorstein, N. R., & Iacono, W. G. (2004). Major depression and conduct disorder in youth: associations with parental psychopathology and parent-child conflict. *Journal of*

Child Psychology and Psychiatry, 45(2), 377-386. http://dx.doi.org.library.georgian.edu:2048/10.1111/j.1469-7610.2004.00228.x

Mazur, E., & Mickle, C. L. (2018). Online discourse of the stressors of parenting children with mental health disorders. *Journal of Child and Family Studies, 27*(2), 569-579. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10826-017-0912-4

McDonald, T. P., Poertner, J., & Pierpont, J. (1999). Predicting caregiver stress: An ecological perspective. *American Journal of Orthopsychiatry, 69*(1), 100-109. http://dx.doi.org.library.georgian.edu:2048/10.1037/h0080385

Mendenhall, A. N., & Mount, K. (2011). Parents of children with mental illness: Exploring the caregiver experience and caregiver-focused interventions. *Families in Society, 92*(2), 183-190. http://dx.doi.org.library.georgian.edu:2048/10.1606/1044-3894.4097

Mertler, C. A., & Reinhart, R. V. (2017). *Advanced and multivariate statistical methods: Practical application and interpretation*. ROUTLEDGE.

Metz, C., Nicot, C., & Bacqué, M. (2018). Support groups for parents with an adult child suffering from bipolar disorder. *Psychodynamic Practice: Individuals, Groups and Organisations, 24*(1), 40-55. http://dx.doi.org.library.georgian.edu:2048/10.1080/14753634.2017.1421093

Miller, F., Dworkin, J., Ward, M., & Barone, D. (1990). A Preliminary Study of Unresolved Grief in Families of Seriously Mentally Ill Patients. *Psychiatric Services*, *41*(12), 1321–1325. https://doi.org/10.1176/ps.41.12.1321

Milliken, P. J., & Northcott, H. C. (2003). Redefining parental identity: caregiving and schizophrenia. *Qualitative Health Research, 13*(1), 100-113. https://library.georgian.edu/login?url=https://www-proquest-com.library.georgian.edu/docview/57706929?accountid=27354

Mitchell, M. B. (2018). “No one acknowledged my loss and hurt”: Non-death loss, grief, and trauma in foster care. *Child & Adolescent Social Work Journal, 35*(1), 1-9. doi:http://dx.doi.org.library.georgian.edu:2048/10.1007/s10560-017-0502-8

Mohr, W. K., & Regan-Kubinski, M. (2001). Living in the fallout: Parents' experiences when their child becomes mentally ill. *Archives of Psychiatric Nursing, 15*(2), 69-77. http://dx.doi.org.library.georgian.edu:2048/10.1053/apnu.2001.22406

Moos, N. L. (1995). An integrative model of grief. *Death Studies, 19*(4), 337-364. doi:http://dx.doi.org.library.georgian.edu:2048/10.1080/07481189508252737

Möller-Leimkühler, A. M., & Wiesheu, A. (2012). Caregiver burden in chronic mental illness: The role of patient and caregiver characteristics. *European Archives of Psychiatry and Clinical Neuroscience, 262*(2), 157-166. http://dx.doi.org.library.georgian.edu:2048/10.1007/s00406-011-0215-5

Neimeyer, R. A., Burke, L. A., Mackay, M. M., & van Dyke Stringer, Jessica G. (2010). Grief therapy and the reconstruction of meaning: From principles to practice. *Journal of Contemporary Psychotherapy: On the Cutting Edge of Modern Developments in Psychotherapy, 40*(2), 73-83. doi:http://dx.doi.org.library.georgian.edu:2048/10.1007/s10879-009-9135-3

Neimeyer, R. A., Klass, D., & Dennis, M. R. (2014). A social constructionist account of grief: Loss and the narration of meaning. *Death Studies, 38*(8), 485-498. http://dx.doi.org.library.georgian.edu:2048/10.1080/07481187.2014.913454

Park, K., & Seo, M. (2016). Care burden of parents of adult children with mental illness: The role of associative stigma. *Comprehensive Psychiatry, 70*, 159-164. http://dx.doi.org.library.georgian.edu:2048/10.1016/j.comppsych.2016.07.010

Pejlert, A. (2001). Being a parent of an adult son or daughter with severe mental illness receiving professional care: parents' narratives. *Health and Social Care in the Community*, *9*(4), 194–204. https://doi.org/10.1046/j.0966-0410.2001.00301.x

Perales, F., Johnson, S. E., Baxter, J., Lawrence, D., & Zubrick, S. R. (2017). Family structure and childhood mental disorders: New findings from Australia. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services, 52*(4), 423-433. http://dx.doi.org.library.georgian.edu:2048/10.1007/s00127-016-1328-y

Perez Algorta, G., MacPherson, H. A., Youngstrom, E. A., Belt, C. C., Arnold, L. E., Frazier, T. W., Taylor, H. G., Birmaher, B., Horwitz, S. M., Findling, R. L., & Fristad, M. A. (2018). Parenting stress among caregivers of children with bipolar spectrum disorders. *Journal of Clinical Child and Adolescent Psychology, 47*, S306-S320. http://dx.doi.org.library.georgian.edu:2048/10.1080/15374416.2017.1280805

Pollio, D. E., North, C. S., Osborne, V., Kap, N., & Foster, D. A. (2001). The impact of psychiatric diagnosis and family system relationship on problems identified by families coping with a mentally ill member. *Family Process, 40*(2), 199-209. http://dx.doi.org.library.georgian.edu:2048/10.1111/j.1545-5300.2001.4020100199.x

Ribé, J. M., Salamero, M., Pérez-Testor, C., Mercadal, J., Aguilera, C., & Cleris, M. (2018). Quality of life in family caregivers of schizophrenia patients in Spain: Caregiver characteristics, caregiving burden, family functioning, and social and professional support. *International Journal of Psychiatry in Clinical Practice, 22*(1), 25-33. http://dx.doi.org.library.georgian.edu:2048/10.1080/13651501.2017.1360500

Richardson, M., Cobham, V., Murray, J., & McDermott, B. (2011). Parents' grief in the context of adult child mental illness: A qualitative review. *Clinical Child and Family Psychology Review, 14*(1), 28-43. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10567-010-0075-y

Rodger, S., & Tooth, L. (2004). Adult Siblings' Perceptions of Family Life and Loss: A Pilot Case Study. *Journal of Developmental and Physical Disabilities, 16*(1), 53-71. http://dx.doi.org.library.georgian.edu:2048/10.1023/B:JODD.0000010039.14986.41

Salloum, A., Bjoerke, A., & Johnco, C. (2019). The Associations of Complicated Grief, Depression, Posttraumatic Growth, and Hope Among Bereaved Youth. *Omega: Journal of Death & Dying*, *79*(2), 157–173. https://doi.org/10.1177/0030222817719805

Schleider, J. L., Ginsburg, G. S., Keeton, C. P., Weisz, J. R., Birmaher, B., Kendall, P. C., Piacentini, J., Sherrill, J., & Walkup, J. T. (2015). Parental psychopathology and treatment outcome for anxious youth: Roles of family functioning and caregiver strain. *Journal of Consulting and Clinical Psychology, 83*(1), 213-224. http://dx.doi.org.library.georgian.edu:2048/10.1037/a0037935

Shear, M. K., Simon, N., Wall, M., Zisook, S., Neimeyer, R., Duan, N., Reynolds, C., Lebowitz, B., Sung, S., Ghesquiere, A., Gorscak, B., Clayton, P., Ito, M., Nakajima, S., Konishi, T., Melhem, N., Meert, K., Schiff, M., O'Connor, M., . . . Keshaviah, A. (2011). Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety, 28*(2), 103-117. http://dx.doi.org.library.georgian.edu:2048/10.1002/da.20780

Shor, R., & Birnbaum, M. (2012). Meeting unmet needs of families of persons with mental illness: Evaluation of a family peer support helpline. *Community Mental Health Journal, 48*(4), 482-488. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10597-012-9504-3

Smith, K. V., & Ehlers, A. (2020). Cognitive predictors of grief trajectories in the first months of loss: A latent growth mixture model. *Journal of Consulting and Clinical Psychology, 88*(2), 93-105. http://dx.doi.org.library.georgian.edu:2048/10.1037/ccp0000438

Sporer, K., & Radatz, D. L. (2017). Mothers of violent children with mental illness: How they perceive barriers to effective help. *Journal of Family Violence, 32*(7), 683-697. http://dx.doi.org.library.georgian.edu:2048/10.1007/s10896-017-9935-2

Steadman, P. L., Tremont, G., & Davis, J. D. (2007). Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of Geriatric Psychiatry & Neurology*, *20*(2), 115–119. https://doi.org/10.1177/0891988706298624

Spuij, M., Reitz, E., Prinzie, P., Stikkelbroek, Y., de Roos, C., & Boelen, P. A. (2012). Distinctiveness of symptoms of prolonged grief, depression, and post-traumatic stress in bereaved children and adolescents. *European Child & Adolescent Psychiatry, 21*(12), 673-679. http://dx.doi.org.library.georgian.edu:2048/10.1007/s00787-012-0307-4

Stroebe, M., Schut, H., & Boerner, K. (2017). Cautioning health-care professionals: Bereaved persons are misguided through the stages of grief. Omega: Journal of Death and Dying, 74(4), 455-473. doi:http://dx.doi.org.library.georgian.edu:2048/10.1177/0030222817691870

Sturm, G., Bonnet, S., Coussot, Y., Journot, K., & Raynaud, J. (2017). Cultural sensitive care provision in a public child and adolescent mental health centre: A case study from the Toulouse University Hospital Intercultural Consultation. *Culture, Medicine, and Psychiatry: An International Journal of Cross-Cultural Health Research, 41*(4), 630-655. http://dx.doi.org.library.georgian.edu:2048/10.1007/s11013-017-9538-7

Tessler, R. C., Killian, L. M., & Gubman, G. D. (1987). Stages in family response to mental illness: An ideal type. *Psychosocial Rehabilitation Journal*, *10*(4), 3–16. https://doi.org/10.1037/h0099599

Tomarken, A., Holland, J., Schachter, S., Vanderwerker, L., Zuckerman, E., Nelson, C., Coups, E., Ramirez, P. M., & Prigerson, H. (2008). Factors of complicated grief pre-death in caregivers of cancer patients. *Psycho-Oncology, 17*(2), 105-111. http://dx.doi.org.library.georgian.edu:2048/10.1002/pon.1188

Vegsund, H. K., Reinfjell, T., Moksnes, U. K., Wallin, A. E., Hjemdal, O., & Eilertsen, M.-E. B. (2019). Resilience as a predictive factor towards a healthy adjustment to grief after the loss of a child to cancer. *PLoS ONE*, *14*(3), 1–15. https://doi.org/10.1371/journal.pone.0214138

Walter, T. (2000). Grief narratives: The role of medicine in the policing of grief. *Anthropology & Medicine, 7*(1), 97-114. doi:http://dx.doi.org.library.georgian.edu:2048/10.1080/136484700109377

Ward, L., & Gwinner, K. (2014). "It broke our hearts": Understanding parents' lived experiences of their child's admission to an acute mental health care facility. *Journal of Psychosocial Nursing and Mental Health Services, 52*(7), 24-29. http://dx.doi.org.library.georgian.edu:2048/10.3928/02793695-20140324-02

Wiens, S. E., & Daniluk, J. C. (2009). Love, loss, and learning: The experiences of fathers who have children diagnosed with schizophrenia. *Journal of Counseling & Development, 87*(3), 339-348. http://dx.doi.org.library.georgian.edu:2048/10.1002/j.1556-6678.2009.tb00115.x

Wu, M. S., Hamblin, R., Nadeau, J., Simmons, J., Smith, A., Wilson, M., Eken, S., Small, B., Phares, V., & Storch, E. A. (2018). Quality of life and burden in caregivers of youth with obsessive-compulsive disorder presenting for intensive treatment. *Comprehensive Psychiatry, 80*, 46-56. http://dx.doi.org.library.georgian.edu:2048/10.1016/j.comppsych.2017.08.005

Yoo, J. P., Brown, P. J., & Luthar, S. S. (2009). Children with co-occurring anxiety and externalizing disorders: Family risks and implications for competence. *American Journal of Orthopsychiatry, 79*(4), 532-540. http://dx.doi.org.library.georgian.edu:2048/10.1037/a0017848

Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, *52*(1), 30. https://doi.org/10.1207/s15327752jpa5201_2

Zonnebelt-Smeenge, S., & DeVries, R. C. (2003). The effects of gender and age on grief work associated with grief support groups. *Illness, Crisis, & Loss, 11*(3), 226-241. http://dx.doi.org.library.georgian.edu:2048/10.1177/1054137303254313

Appendix I

Burns Relationship Satisfaction Scale

Place an (x) in the box to the right of each category that best describes the amount of satisfaction you feel in your relationship with your child with the diagnosis.

	0 Very Dissatisfied	1 Moderately Dissatisfied	2 Somewhat Dissatisfied	3 Neutral	4 Slightly Satisfied	5 Moderately Satisfied	6 Very Satisfied
Communication and openness							
Resolving conflicts and arguments							
Degree of affection and caring							
Intimacy and closeness							
Satisfaction with your role in the relationship							
Satisfaction with the other person's role							
Overall satisfaction with your relationship							

Depression Anxiety and Stress Scale (DASS 21)

For each statement below, please circle the number in the column that best represents how you have been feeling in the last week.

Statement	**Did not apply to me at all**	**Applied to me to some degree or some of the time**	**Applied to me a considerable degree or a good part of the time**	**Applied to me very much or most of the time**
1. I found it hard to wind down	0	1	2	3
2. . I was aware of dryness of my mouth	0	1	2	3
3. I couldn't seem to experience any positive feeling at all	0	1	2	3
4. I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5. I found it difficult to work up the initiative to do things	0	1	2	3
6. I tended to over-react to situations	0	1	2	3
7. I experienced trembling (eg, in the hands)	0	1	2	3
8. I felt that I was using a lot of nervous energy	0	1	2	3
9. I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10. I felt that I had nothing to look forward to	0	1	2	3
11. I found myself getting agitated	0	1	2	3
12. I found it difficult to relax	0	1	2	3
13. I felt down-hearted and blue	0	1	2	3
14. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15. I felt I was close to panic	0	1	2	3
16. I was unable to become enthusiastic about anything.	0	1	2	3
17. I felt I wasn't worth much as a person	0	1	2	3
18. I felt that I was rather touchy	0	1	2	3
19. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20. I felt scared without any good reason.	0	1	2	3
21. I felt that life was meaningless	0	1	2	3

Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
Circle the "2" if you **Strongly Disagree**
Circle the "3" if you **Mildly Disagree**
Circle the "4" if you **are Neutral**
Circle the "5" if you **Mildly Agree**
Circle the "6" if you **Strongly Agree**
Circle the "7" if you **Very Strongly Agree**

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Mental Illness Version of the Texas Inventory of Grief

Part I. Think back to the time this person was first diagnosed and answer all of these items about your feelings and actions at that time by indicating whether each item is Completely True or Mostly True, Both True and False, Mostly False or Completely False as it applied to you after this person was diagnosed . Check the best answer.

	Completely or Mostly False	True and False	Completely or Mostly True
I found it hard to get along with certain people	1	2	3
I found it hard to work well when I became aware of his/her mental illness	1	2	3
I lost interest in other family members, friends and relatives	1	2	3
I found a need to do things the way he/she used to do them.	1	2	3
I was unusually irritable.	1	2	3
I couldn't keep up with my usual activities for the first three months.	1	2	3
I was angry with him/her for the changes that were taking place.	1	2	3
I found it hard to sleep.	1	2	3

Part II. Now answer all of the following items by checking how you presently feel about this person's diagnosis. Do not look back at Part I.

	Completely or Mostly True	True and False	Completely or Mostly False
I cry when I think about how he/she used to be before the illness.	1	2	3
I cry when I think about how he/she could have been if not for the illness.	1	2	3
I get upset when I think about how he/she used to be before the illness.	1	2	3
I get upset when I think about how he/she could have been if not for the illness.	1	2	3
I very much miss the way he/she used to be.	1	2	3
It is painful to recall memories of how he/she used to be.	1	2	3
I am preoccupied with thoughts about how he/she used to be before the illness.	1	2	3
I hide tears when I think about him/her.	1	2	3
No one will ever take the place that he/she used to have in my life.	1	2	3
I can't avoid thinking about how he/she was before the illness	1	2	3
I can't avoid thinking about how he/she could have been if not for the illness.	1	2	3
I feel that it is unfair that he/she became mentally ill.	1	2	3
Things and people around me still remind me of the way he/she used to be.	1	2	3
I cannot accept his/her mental illness.	1	2	3
At points I still feel the need to cry for him/her	1	2	3

Demographic Questionnaire

Please provide the following information about yourself.

1. Gender: Female Male Other

2. Race/ethnicity: Black Asian American White
Hispanic Other

3. Age:__________________

4. Are you: Married Single Divorced In a Civil Union
Widowed Living with a Partner Other

6. What is the age of your child with a diagnosed mental health disorder?____

7. How many mental health disorders is your child diagnosed with?______

8. What is(are) your child's mental health disorder(s)?

9. How long ago was your child diagnosed with their mental health disorder? In the case of more than one disorder, when was your child diagnosed with the **first** disorder?_____

10. Does your child live at home with you?

11. If your child does live at home with you, does s/he live with you:
Full Time Part Time (e.g. on weekends) Other

Appendix II

Application for IRRB Approval
Part I: Request for Approval of Human Subjects Research
Georgian Court University · Institutional Research Review Board (IRRB)

1. Identifying Information:
    a. Your Name: Christine Clark
    b. Your Address: 900 Lakewood Ave. Lakewood, NJ. 08835
    And Telephone Number: 732.915.6028
    c. Project Title: Understanding Parental Experiences of Caring for a Child with a Diagnosed Mental Illness Utilizing a Grief Model
    d. If researcher is a student, faculty sponsor: Dr. Theresa Brown, Dissertation Chairperson
    And Telephone number: 732.987.2636
    e. Duration of project: from February 2021 – to December 2022

2. Give a brief description of the nature of the project.

To understand the role of emotional symptoms (depression, anxiety and stress), parent-child relationship quality and the child's diagnosis characteristics in relation to parental grief experienced.

Nature of Project: Online survey completed by the parents containing 6 self-report measures.

3. Give details of procedures that relate to participants' participation:

    a. Will the participants be recruited through an organization (school, hospital, prison, or other relevant organization)?

    ☐ No
    ☒ Yes (Specify) State and local chapters of NAMI, organizations for child mental illnesses (e.g. PACER), parent listservs

    Is the approval of another Institutional Review Board required?

    ☐ Yes ☒ No

    How are the participants recruited?

    ☐ Participants will be recruited verbally

☐ Participants will be recruited by poster
Where will the poster be placed?
☐ Participants will be recruited by letter
To whom will letter be sent?
☒ Participants will be recruited electronically. (I.e. social media or email)
What sites will be used for recruitment purpose? NAMI State and County Chapters, organizations for child mental illness groups, listservs for parents
☐ Other (describe) Click here to enter text.

b. What incentive is offered to participants to encourage participation?

☐ Course credit or extra credit
☐ Other (describe) Click here to enter text.
☐ Access to study results
☒ None

c. Salient characteristics of participants, please fill in boxes below:

How many participants do you intend to recruit? 250

What will be the sex composition of your sample?

☐ Male only ☐ Female only ☒ Male and Female

Will the participants be at or over 18 years of age?

☒ Yes ☐ No

Are the participants

☐ Patients? ☐ Prisoners?
☐ Mentally infirm persons? ☒ None of the above

d. What do participants do, or what is done to them, or what information is gathered?

Participants will complete an online survey containing the following questionnaires: the *Burns Relationship Satisfaction Scale*; *The Depression Anxiety Stress Scale- Short Form*; *The Mental Illness Version of the Texas Inventory of Grief*; *The Multidimensional Scale of Perceived Social Support* and a demographic questionnaire created by the researchers.

How many times will observations, tests, etc., be conducted? Participants will complete the survey one time.

4. List any assistants who will be working with you. Cite your and their experience with this kind of research. List any research classes you or your assistants have taken.

I will be conducting the research however Dr. Theresa Brown is my dissertation chairperson who will be overseeing the data collection process.

☒ PHRP Training submitted to IRRB for primary investigator and all research assistants (if certification was obtained after 2/7/2019

☐ NIH-Training submitted to IRRB for primary investigator and all research assistants (if certification was obtained before 9/26/2018

5. How do you explain the research to participants and obtain their informed consent to participate?

☒ Written consent from participant

☐ Implicit consent

☐ Written proxy consent from someone legally able to give consent on behalf of the participant (e.g. parent, legal guardian)

☐ Verbal assent from participants under 18 years of age

Is it made clear to the participants that they can quit the study at any time?

☒ Yes (Explain how) Prior to starting the survey, participants view the Informed Consent page where it states participation is voluntary.

☐ No (Explain why not)

Do you make provision for participants to obtain a copy of the results of the study?

☒ Yes (Explain how) Both on the informed consent page and upon completion of the study, participants are provided with the researcher's contact information.

☐ No (Explain why not) Click here to enter text.

6. Do participants risk any harm – physical, psychological, legal, social – by participating in the research?

☒ No: This is a minimal risk study.

☐ Yes

- Explain why the risks are necessary.
- What safeguards do you take to minimize risks? Click here to enter text.
- How are the risks explained to the participants? Click here to enter text.

7. Are participants deliberately deceived in any way?

☒ No:
☐ Yes

- ■ What is the nature of the deception?
- ■ Why is the deception essential to the research?
- ■ What explanation do you give to participants following their participation?

Click here to enter text.

8. Are data collected anonymously?

☒ Yes
☐ No

- ■ How is confidentiality assured?
- ■ Is identifying information removed from the data? At what stage?

9. All research data should be stored for at least five years after the completion of the study.

- ■ Where and in what format will research data be stored? (Check all that apply)

☒ Password protected computer file.
☐ Locked file cabinet.
☐ Other (please explain)

- ■ To what uses – research demonstration, public performance, archiving – might they be put in the future? The results could be used as the basis for future studies- this will be further determined based on the findings of the present study.

- ■ How is participants' permission for future use of their data obtained?

Participants will be made aware when signing informed consent that their data, stored anonymously, may be used in future research.

Part II: Expedited Category Self-Assessment

Research activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the following categories, may be reviewed by the IRRB through the expedited review procedure authorized by 45 CFR 46.110 and 21 CFR 56.110. The activities listed should not be deemed to be of minimal risk simply because they are included on this list. Inclusion on this list merely means that the activity is eligible for review through the expedited review procedure when the specific circumstances of the proposed research involve no more than minimal risk to human subjects.

The IRRB committee will make a final determination about whether a research project qualifies for expedited procedures; however, investigators are asked to complete the following self-assessment. Please select all that apply from the list below.

Research Categories

☐ (1) Clinical studies of drugs and medical devices only when condition (a) or (b) is met.

(a) Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required.

(b) Research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.

☐ (2) Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows:

(a) from healthy, nonpregnant adults who weigh at least 110 pounds or
(b) from other adults and children, considering the age, weight, and health or the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected.

☐ (3) Prospective collection of biological specimens for research purposed by noninvasive means.

☐ (4) Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves.

☐ (5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).

☐ (6) Collection of data from voice, video, digital, or image recordings made for research purposes.

☒ (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. This listing refers only to research that is not exempt.)

☐ (8) Continuing review of research previously approved by a full review from IRRB.

Part III - Exemption Category Self-Assessment

The IRRB committee will make a final determination about whether a research project qualifies for exemption; however, investigators are asked to complete the following self-assessment. Please select all that apply from the list below.

Note: Research projects involving prisoners or the collection of biological samples cannot be granted exemption.

☐ (1) Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as: regular and special education instructional strategies, or effectiveness or comparison of instructional techniques, curricula, or classroom management methods.

☒ (2) Research involving one or more of the following if the information is recorded in a manner that individuals cannot be identified (directly or through identifiers linked to the individual), OR if the information may be recorded in a manner that individuals can be identified (directly or through identifiers linked to the individual), but disclosure of the information could NOT reasonably place the participants at risk of criminal or civil liability or be damaging to their financial standing, employability, or reputation.:

i. Educational tests (cognitive, diagnostic, aptitude, achievement):
ii. Survey or interview procedures (this exemption category does not apply to research activities with minors/children):
iii. Observation of public behavior:
NOTE: For minors/children: Observation of public behavior of minors is eligible for exemption only if the researcher does not participate in the activities being observed.

☐ (3) Research (the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior) involving elected or appointed public officials or candidates for office, even when confidentiality cannot be maintained.

☐ (4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens:

i. If these sources are publicly available; OR
ii. If the sources are not publicly available, but the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

☐ (5) Research and demonstration projects that are conducted by or subject to the approval of federal department or agency heads, and are designed to study, evaluate, or otherwise examine public benefit or service programs, procedures for obtaining benefits or services under those programs, possible changes in or alternatives to those programs or procedures, or possible changes in methods or levels of payment for benefits or services under those programs.

☐ (6) Taste and food quality evaluation and consumer acceptance studies:

i. If wholesome foods without additives are consumed, OR
ii. If a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration or approved by the Environmental Protection Agency.

Signature of principal researcher Date

Signature of faculty advisor (if relevant) Date

INFORMED CONSENT STATEMENT

I am asking you to participate in a research study. This research is a part of my doctoral dissertation for Georgian Court University's Psy.D. program in School Psychology, under the direction of my Dissertation Chairperson, Dr. Theresa Brown, Georgian Court University.

This is a study investigating your experiences of caring for your child with a diagnosed mental health disorder . If you agree to participate in the study, you will be asked to complete six questionnaires which take approximately 20 minutes to complete. The questionnaires are multiple choice or fill in the blank.

There are no foreseeable risks for completing this study. Possible benefits of completing this study is a greater sense of awareness of your own feelings related to raising a child with a mental health disorder. Additionally, through completing this study, your contributions will help in developing a greater understanding of the needs of parents and what support can be provided to others in your position.

Your results will be completely anonymous. Nobody, including myself, will have access to any personal or identifying information. Your decision to participate (or not) should be completely voluntary. If you decide not to participate, you will not be affected in any way. Participation in the study is anonymous and no identifying information about you or your child will be collected.

We will be archiving the data from this study indefinitely (we are required to keep it for at least 5 years); we may use the data again in future research.

Should you have any questions about the study, please contact **Christine Clark, MA CAGS** (cclark@georgian.edu) or **Theresa Brown, PhD.** (tbrown@georgian.edu). If you have any questions or concerns regarding confidentiality, ethics, or the nature of this study, please contact IRRB Co-Chairs, Dr. Megan Sherman at msherman@georgian.edu or 732-987-2368, or Dr. Jean Parry at jparry@georgian.edu or 732-987-2370.

Statement of Consent

By clicking “Continue” you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered;
- you have been informed of potential risks and they have been explained to your satisfaction;
- you are 18 years of age or older;
- your participation in this research is completely voluntary;
- you may leave the study at any time; if you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

DEBRIEFING STATEMENT

Thank you for participating in this study. Here, we are examining parent experiences of caring for a child with a mental health disorder(s) in the context of grief experienced. Should you feel distress or upset with participating in this study, please consider using the APA Psychologist Locator to find someone to speak with: https://locator.apa.org/

We thank you for your participation. If you have any questions about this study, please contact Christine Clark, cclark@georgian.edu or Dr. Theresa J. Brown, at 732.987.2642 or brownt@georgian.edu.

Once again, thank you for participating!

Appendix III.

Table 1

Frequency Statistics: Demographic Information

	n	%
Gender		
Female	193	91.47
Male	17	8.07
Other	1	0.46
Marital Status		
Married	138	65.71
Single	19	9.05
Divorced	32	15.04
In a Civil Union	4	1.90
Widowed	13	6.20
Other	4	1.91
Ethnicity		
Black	7	3.32
Asian American	1	0.47
White	193	91.47
Hispanic	7	3.32
Other	3	1.42
Does Your Child Live at Home?		
Yes	147	69.7
No	64	30.3
If yes		
Full Time	131	89.12
Part Time	1	0.68
Other	15	10.20

Appendix IV.

Table 2

Frequency Statistics: Demographic Information

	n	Minimum	Maximum	Mean	SD
Parent Age	203	18	91	54.3	10.16
Child Age	202	1	56	19.99	9.91

Appendix V.

Table 3

Frequency Statistics: Predictor Variables and Dependent Variable

	n	Minimum	Maximum	Mean	SD
BRSS	155	0	42	22.56	13.07
Depression	219	9	42	16.48	10.35
Anxiety	219	0	34	7.76	7.69
Stress	221	0	42	13.37	8.97
Friends	15.5	4	28	18.42	6.02
Significant Other	155	4	28	20.29	6.09
Family	155	4	28	17.79	6.45
Initial Grief	155	8	24	16.39	3.50
Current Grief	155	13	39	26.37	7.02
Number of Diagnoses	178	1	15	2.69	1.75
Time Since Initial Diagnosis	45	1	38	11.81	8.40

Note: BRSS is the Burns Relationship Satisfaction Scale. Depression, Anxiety and Stress are variables on the DASS-21. Friends, Significant Other and Family are variables on the Multidimensional Scale of Perceived Social Support.

Appendix VI.

Table 4

Correlations for Study Variables

	1	2	3	4	5	6	7	8	9	10	11	12
1. Current Grief	1.00	-	-	-	-	-	-	-	-	-	-	-
2. BRSS	-.41**	1.00	-	-	-	-	-	-	-	-	-	-
3. Family	-.20**	.25**	1.00	-	-	-	-	-	-	-	-	-
4. Friends	-.08	.06	.51**	1.00	-	-	-	-	-	-	-	-
5.Significant Other	-.21**	.12	.58**	.62**	1.00	-	-	-	-	-	-	-
6.Stress	.41**	-.28**	-.11	-.02	-.07	1.00	-	-	-	-	-	-
7.Anxiety	.31**	-.14*	-.13	-.11	-.10	.70*	1.00	-	-	-	-	-
8.Depression	.45**	.21*	-.11*	-.22	-.17*	.79**	.65**	1.00	-	-	-	-
9.Externalizing Diagnosis	.00	-.06	.05	.04	.00	-.12	-.08	-.19*	1.00	-	-	-
10.Number of Diagnoses	.07	-.10	-.08	-.03	-.09	.08	.13	.04	.18*	1.00	-	-
11.Time Since Diagnosis	-.19	-.14	.06	.11	.11	-.09	-.09	-.15	.13	.88	1.00	-
12. Initial Grief	.32**	-.11	-.02	.01	-.01	.36**	.28**	.32**	.16*	.18*	-.12	1.00

Note: ** Correlation is significant at the .001 level

* Correlation is significant at the .05 level

Appendix VII

Table 5

Regression Model Assessing Relationship, Support Satisfaction, Emotional Symptoms and Child Diagnostic Factors on Parent Grief

	B	*SE B*	*β*	*p*	*t*
BRSS	-.54	.04	.48	.00	-7.86
Family	-.01	.09	.06	.46	.88
Friends	.11	.10	.08	.33	.23
Significant Other	-.23	.09	.22	.02	12.53
Externalizing Disorder	-.06	1.09	.01	.94	.23
Number of Diagnoses	.02	.26	.03	.63	-.83