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THE FUNCTION OF CONNECTION: A QUALITATIVE EXAMINATION OF SOCIAL-  
ECOLOGICAL SUPPORTS IN THE LIVES OF PARENTALLY BEREAVED YOUTH

by

Lauren M. Schaefer, M.A.

A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

Major: Clinical Psychology

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## **Dedication**

I dedicate this work to my mother. I have faced significant health challenges over the last 14 months due to acquiring COVID-19 and complications due to Post-Acute Covid Syndrome. In understanding the importance of this final year of internship and dissertation work, my mother moved to Georgia, where I was completing my internship, to care for me all year. This allowed me to focus my limited energy and resources on my internship and dissertation progress. This sacrifice on her part is just one example of the countless sacrifices she has made as a single mother over my lifetime. I absolutely would not be where I am today without her love, guidance, and support. Growing up, my mother modeled the importance of hard work, perseverance, excellence in giving your best effort to everything you do, the importance of kindness and compassion towards others, and going the extra mile to support those around you. These examples shaped who I am today and gave me the strength and perseverance I needed to keep going after the significant challenges I've faced during my doctoral training years. These last five years have been the hardest of my life due to trials I faced outside of my graduate work coupled with the demanding nature of doctoral training. My mother has been there for emotional support, daily phone calls that allowed me to vent and problem solve, and tangible instrumental support this entire year. I count myself so fortunate to have her as my mother. My research over the years has highlighted the critical importance of support in fostering resilience. My resilience amid the challenges of the last five years is no doubt largely due to my mother's support. This is for you, thank you for everything.

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## Abstract

**Background:** The present study qualitatively explored the roles of multiple social-ecological supports (i.e., spirituality, parent-child communication, therapist support via grief counseling) in the lives of parentally bereaved youth. The selected supports are theoretically grounded within the well-documented and highly cited Ecological Systems Theory and the buffering hypothesis of social support. **Method:** Reflexive thematic analysis was utilized to analyze 30 semi-structured interviews with parentally bereaved youth ages 8-17 ( $M_{age}=12.53$ ,  $SD=2.8$ ). Most participants identified as girls (63.33%) and the most frequently reported race was White (43.33%). **Results:** The reflexive thematic analysis resulted in 10 overarching themes or domains: (1) Positive and Active Role of Spirituality, (2) Little to No Role of Spirituality, (3) Stronger Spiritual Relationship Post-Bereavement, (4) No Change in Spirituality, (5) Questioning One's Faith and Abandoning Religion, (6) Open Communication about Deceased, (7) Avoiding Talking about Deceased, (8) Caregiver Directed Positively Valenced Communication about the Deceased, (9) Remain in Counseling, and (10) Choice to Discontinue Counseling. **Discussion:** The overarching themes and the content of their themes and subthemes highlight that these social-ecological sources of support serve varied and vital functions in the lives of parentally bereaved youth. Namely, the benefits of grief counseling and spirituality were overwhelmingly identified by youth as critical in facilitating their coping with the loss of a parent. Whereas parental communication regarding the deceased varied widely, highlighting the need for additional supports beyond the relational support offered by surviving caregivers.

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## **The Function of Connection: A Qualitative Examination of Social-Ecological Supports in the Lives of Parentally Bereaved Youth**

The death of a loved one is often world-shattering, and for youth, the impact of this loss on their worldview and functioning is especially significant (Keyes et al., 2014). Childhood bereavement of a parental figure has been described as one of the most traumatic life events that can be endured (Cerel et al., 2006; Keyes et al., 2014). Through parental bereavement, children are left to make sense of a world without the presence of a critically important caregiver. Despite the enormous impact on youth, childhood bereavement remains a relatively understudied topic in the research literature, with parental bereavement garnering even less empirical attention (Kaplow et al., 2014). Further, the predominant focus of study within bereavement research is adverse outcomes (e.g., prolonged or complicated grief, depressive symptoms, and maladjustment; Akerman & Statham, 2014; Prigerson et al., 2009; Van Denderen et al., 2015). However, the influx of the positive psychology field in recent decades has given rise to research examining factors that promote adaptation, coping, and resilient outcomes post-bereavement (Brown et al., 2007; Draper & Hancock, 2011; Eppler, 2008; Lin et al., 2004). Social support is one factor that may be especially impactful among bereaved youth, but minimal work has examined the role of specific social-ecological forms of social support or the protective role they may serve. Thus, the current study qualitatively explored the roles of spirituality, parent-child communication, and therapist support via grief counseling among parentally bereaved youth.

### **Parental Bereavement among Youth**

Estimated rates of childhood bereavement vary widely. Conservative national estimates suggest that between 3.5 and 5 percent of youth will experience the death of a parent by the age of 16 (Akerman & Statham, 2014; Parsons, 2011). More recent national data from the Childhood

Bereavement Estimation Model indicate that 6.99% of children will experience the death of a sibling or parent before reaching age 18 (Burns et al., 2020). That percentage equates to upwards of 5 million, or 1 in 14 children, who will experience parental or sibling bereavement in the United States (Burns et al., 2020). That number rises significantly when accounting for worldwide parental loss, where nearly 140 million children under age 18 experience the death of one or both parents (Burns et al., 2020).

Bereavement is defined as the objective circumstance derived from the death of a loved one (Neimeyer & Harris, 2015). It has been identified as the most common and most stressful type of adverse event among both young adult and adult samples (Layne et al., 2017). Bereavement experienced during childhood is considerably less normative than adulthood loss, and thus highly distressing and often traumatic, even more so when a parental figure dies (Keyes et al., 2014). Grief is a product of bereavement characterized by cognitive and affective responses that are distinct from mental health symptoms and can significantly impact functioning (Sandler et al., 2003). In turn, permanent separation from an important attachment figure, particularly a caregiver, can lead to significant difficulties for children. Parental loss has been associated with a diminished capacity to develop and maintain relationships, interference with developmental milestones, increased risk for behavioral and mental health problems (e.g., suicide, depression), reduced academic performance, and diminished ability to cope with life stressors that often accompany parental loss (e.g., changing schools, financial insecurity; Burns et al, 2020; Griese et al., 2018).

In the aftermath of bereavement, youth often display marked distress and increased anxiety, particularly regarding concerns of personal safety, fears about separation from their loved ones, and worries surrounding experiencing additional losses of other family members

(Akerman & Statham, 2014; Wolchik et al., 2009). While some distress is expected, a sizeable percentage (e.g., 10-20%) of bereaved youth will experience major depression, suicidal ideation, posttraumatic stress symptoms, anxiety, social withdrawal, behavioral problems, relationship issues, or academic challenges following the loss (Akerman & Statham, 2014; Burns et al., 2020; Cerel et al., 2006; Draper & Hancock, 2011; Griese et al., 2018; Wolchik et al., 2009). Although the array of responses to childhood parental bereavement is vast, most youths do not go on to develop psychopathology or prolonged grief (Kaplou et al., 2014). Yet, much of the research examining bereaved youth focuses on adverse outcomes rather than attempting to understand factors that promote positive functioning post-bereavement, such as social support.

### **Theoretical Models of Social Support**

Social support is often broadly defined and measured, but conceptual work has recommended assessing specific forms of support (i.e., family support, friend support, spiritual/religious support, and community support) rather than a global evaluation of this construct (Barrera, 1986). The theoretical framework that aligns with social support being conceptualized within specific domains is Ecological Systems Theory (Bronfenbrenner, 1977; 1994), which emphasizes the contribution of variables at different contextual levels or systems within the child's life, including the individual level, the relational level, and the community level. Within this model, individuals are embedded within a system of multiple interacting relationships that are represented by overarching categories. Bronfenbrenner's model highlights the importance of examining these varied levels of support, including support found within the individual (i.e., spiritual connection), relations in their microsystem (i.e., family), and community support via their exosystem (i.e., community resources such as grief therapy; Bronfenbrenner, 1977; 1994).

In order to understand the function of social support and how it might aid bereaved youth, the social support buffering hypothesis should be considered in conjunction with Ecological Systems Theory. This hypothesis suggests two mechanisms by which social support buffers negative outcomes post-bereavement: (1) a buffering mechanism and (2) supporting recovery effects (Cohen & Wills, 1985; Stroebe et al., 2005). First, social support may attenuate the stress response to bereavement by impacting the loss appraisal (e.g., I'm not alone in this, I have the support of caring others). Second, social support can assist bereaved individuals in inhibiting maladaptive responses and facilitating coping responses. Accordingly, even when the presence of social support is not strong enough to buffer the immediate pain of bereavement, over time it may promote more adaptive outcomes in youth by facilitating healthy coping strategies and inhibiting adverse behaviors (Cohen & Wills, 1985; Stroebe et al., 2005). Thus, this hypothesis posits that having an effective social support network can improve one's well-being, can facilitate coping through emotional and/or tangible support, and can be protective by serving as a buffer in the face of stress (Çakar, 2020; Cohen & Wills, 1985). The makeup of one's support network can be multifaceted, including one's family, friends, relatives, mentors, community members, counselors, support groups, or religious/spiritual resources (Çakar, 2020; Cohen & Wills, 1985).

The social support buffering hypothesis is well-researched in bereaved adults, with evidence to suggest that those with high levels of support recover faster and evince better outcomes than those with low levels of support (Stroebe et al., 2005). A recent quantitative analysis by Çakar (2020) utilized the buffering hypothesis as their theoretical framework to examine the role of social support among bereaved adolescents (of any loss type) ages 14-to-18 ( $n = 216$ ). As hypothesized, they found that social support fully mediated the association

between adolescent grief and well-being, highlighting that those with higher levels of social support more easily coped with their grief and had better well-being (Çakar, 2020). Although this study advances the literature, more nuanced research is needed to understand the role of different forms of support in youth adaptation and well-being post-parental loss. As these social support models remain largely theorized, rather than empirically examined; further research is essential to deepen our understanding of the nuanced role of varied forms of social support in the lives of parentally bereaved youth.

## **Social-Ecological Supports among Parentally Bereaved Youth**

### ***Individual Support Garnered from One's Spirituality***

In alignment with the ecological systems framework, spiritual support can be captured through the lens of the individual system, as the child's private spiritual relationship with a higher power. The connections one finds through their spirituality (e.g., with God, nature, etc.) have been shown to serve as a source of individual support (Hill & Pargament, 2003). While religiosity can encompass multiple levels of one's ecological system (e.g., individual and community), the term spirituality is used to denote the personal and subjective experience of connecting to a higher power (Hill & Pargament, 2003). Spirituality also extends beyond a religious experience, as one can identify as spiritual and not religious (Hill & Pargament, 2003). Accordingly, as spirituality represents the inward and emotional expression of one's belief system, it is most appropriate to be studied at the individual level of the social ecology (Hill & Pargament, 2003). Spiritual support is derived from the individual connection one experiences with their identified higher power (e.g., a close personal relationship with a higher power), their perceived support from this relationship (e.g., drawing upon their spirituality in times of stress), and their beliefs (e.g., my higher power is with me and will help me; Hill & Pargament, 2003).



Spirituality has shown promise as an effective source of support for youth in general, but it may have even greater potential among bereaved youth, through facilitating continuing bonds with their deceased parent and offering comfort in believing that they will one day be reunited (Rooney et al., 2020). Nevertheless, current research examining one's spirituality as a source of individual support in the lives of parentally bereaved youth is limited. Instead, spirituality is typically conceptualized and examined as a protective factor. In fact, findings from multiple studies suggest strong associations between high spirituality and positive youth development and/or absence of psychopathology (Bryant-Davis, 2012; Dill, 2007; James & Fine, 2015). However, research investigating spirituality as a source of support among parentally bereaved youth is sparse (Hay & Nye, 2006).

Drawing from work with bereaved adults, research shows that spirituality assists in meaning-making and coping with death (Wortmann & Park, 2009). Andrews and Marrota (2005) examined if similar processes were underway among bereaved youth. These authors indirectly evaluated spirituality through qualitative phenomenological inquiry designed to shed light on meaning-making and coping. In their study of six bereaved youth aged 4-to-9 (of any loss type), they did not directly ask participants about their spirituality but instead inquired via a semi-structured interview about how they have made meaning of their loss, how they have coped, and what has brought them comfort since their loss (Andrews & Marrota, 2005). In response, youth identified the comfort experienced within their spiritual relationship as a primary source of coping (Andrews & Marrota, 2005). The authors noted that five of the six participants remarked on having a spiritual connection to God or a higher power, and for these participants, their spirituality enhanced meaning-making processes to aid in coping with their grief (Andrews & Marrota, 2005). Although the child participants endorsed engaging in religious rituals such as

attending church, children identified their spiritual connection more readily and more frequently as a source of support (i.e., providing comfort), which aided in their grieving process (Andrews & Marrota, 2005). Children also identified God as serving a spiritual connection and reported benefit in the ability to have continuing bonds with the deceased through their spiritual connection and belief that the deceased was still with them (Andrews & Marrota, 2005). While this study sheds light on the support bereaved youth can derive from their spiritual connection in the face of loss, the authors did not directly assess or measure spirituality. Further, their sample size was small due to the difficulty of recruiting a bereaved youth population, which limited participant perspectives (Andrews & Marrota, 2005).

Additional qualitative research by Greeff & Joubert (2007) explored spirituality and resilience via qualitative semi-structured interviews with the caregivers of parentally bereaved youth (25 caregivers,  $M_{age}=48.3$ ,  $SD=7.7$  years). The themes that were developed from these caregiver interviews included spirituality offering youth comfort, notably increased spirituality in youth post-bereavement, shared faith between family members, youth trusting that God is in control, spirituality as a necessity and fundamental source of coping, youth seeking to understand God's will and purpose, and the belief that something positive will come from their loss. This work identified multiple mechanisms by which spirituality served as a source of support for these youth from their caregivers' perspective. These mechanisms included providing a source of comfort that youth would one day be reunited with their loved one in Heaven, bringing families closer together through shared spirituality and religious practices, and spirituality providing a source of strength to lean on for support (Greeff & Joubert, 2007). These findings, while informative, are derived from the adult's perspective rather than the youths' perspective. Accordingly, these could be projections of adult beliefs onto their child's experience, rather than

accurate reflections on the role of spirituality in the youths' lives. Research is lacking on how youth personally perceive their spiritual relationship in the aftermath of a death.

Indeed, no study could be identified that directly examined the role of spirituality as a source of support among parentally bereaved youth, highlighting the gap being addressed by the current study. Within the available literature, studies were identified that examined the role of spirituality among bereaved adults, bereaved parents, and emerging adults who were parentally bereaved during childhood (Becker et al., 2007; Lord & Gramling, 2014; Wortmann & Park, 2009). Research has also been published assessing the role of spirituality as a source of support and coping among youth in general (not bereaved youth; Dill, 2017). More specifically, an ethnographic study by Dill (2017) explored the role of spirituality among a predominantly urban Black identified ( $n = 20$ ) and Hispanic ( $n = 5$ ) sample of youth aged 12-to-20 years. Their results highlighted the important and active role of spirituality in the lives of these young adults, specifically through fostering spiritual coping strategies (Dill, 2017). Prayer was a commonly endorsed spiritual coping strategy, in addition to the belief that God is with them and will listen to their prayers and keep them safe (Dill, 2017). Youth also spoke to the comfort offered by always having God by their side (Dill, 2017). Finally, participants touched on the relief that came from giving their worry over to God. While this article did not specifically examine spirituality as a form of support, young adult participants spoke about the active, supportive, comforting, and protective role of their spiritual relationship (Dill, 2017). Specifically, the author noted that for these youths, spirituality serves as a reliable internal support when external supports fail (e.g., friends, family; Dill, 2017). In sum, existing research shows promise for the role of spirituality as a form of individual support for parentally bereaved youth; still, there is a need for more empirical work in this understudied area.

### ***Parent-Child Communication as Relational Support***

In line with the microsystem of Bronfenbrenner's model, we evaluated relational support through parent-child communication about the deceased. Existing research among bereaved youth highlights the potential for parent-child conversations regarding the deceased to serve as a form of relational support (Kaplow et al., 2012; Wardecker, et al., 2017). This is particularly true for communication characterized by positive reminiscing such as sharing favorite memories, looking at pictures or videos, and discussing positive traits of the deceased (Kaplow et al., 2012; Wardecker, et al., 2017). Further, positive reminiscing about the deceased with one's caregiver has been associated with promoting both meaning-making and optimism among bereaved youth while also bolstering the parent-child bond (Kaplow et al., 2012; Wardecker et al., 2017).

Our understanding of the role of parent-child communication among parentally bereaved youth is limited, even more so when accounting for youth's perspective on parent-child communication (Weber et al., 2019). Moreover, parent-child communication is often evaluated as a predictor variable or protective factor against negative mental health outcomes post-bereavement, rather than examined directly as a measure of relational support. For example, research by Wolchik and colleagues (2009;  $n = 50$ ) found that bereaved adolescents (ages 14-to-21) who indicated that their caregiver understood their feelings had lower rates of mental health problems than adolescents who did not feel understood by their caregivers. Furthermore, research by Howell and colleagues (2016) among bereaved youth ages 7-to-13 ( $n = 32$ ) also found that positive reinforcement and supportive communication from caregivers were associated with reduced posttraumatic stress symptoms. This work is an important and valuable addition to the literature; however, what is missing is a thorough examination of parent-child communication as a potential source of support from the perspective of bereaved youth.

Research suggests that positive parent-child relationships are characterized by open parent-child communication (Haine et al., 2008), yet minimal research has been conducted to extend this finding to parentally bereaved youth by examining communication between the surviving parent and child regarding the deceased caregiver. One study was found that indirectly approached this goal. Eppler (2008) used phenomenological and grounded theory methodology to identify contributors to resilience among bereaved youth. In this study, 12 parentally bereaved children, aged 9-to-12, were asked guided questions about their experience with loss and coping, after which they were instructed to write and narrate their story of personal loss. All participants experienced the death of a parent in the previous 36 months. Children from this sample identified that confiding in their surviving caregiver about the deceased and their grief was a critical and primary source of support (Eppler, 2008). Children's stories also captured extended support systems that were central to their coping (Eppler, 2008). These extended sources of support varied from siblings to grandparents and teachers, but not friends (Eppler, 2008). This work is a valuable addition to the literature that highlighted youth's perspectives and the importance of varied sources of support, but it also has notable limitations. Specifically, this study assessed children in only one developmental stage, featured a relatively small sample size, and was limited in the racial diversity of participants. Finally, this study did not directly examine parent-child communication as a source of relational support, and accordingly, these findings were secondary to the author's aim of examining resilience among bereaved youth. Therefore, our understanding of parent-child communication as a source of support is limited and further research directly examining this topic is needed.

In recognizing the need for this work, a recent study by Weber and colleagues (2019) utilized a qualitative approach with a descriptive and interpretive design to examine

communication between the surviving caregiver and parentally bereaved youth. This study featured eight interviews conducted with four families, including four parents and four children. Their results highlighted four overarching categories including the importance of open and honest parent-child communication, new challenges brought on by the loss of a spouse/parent that negatively affects communication, the importance of the caregiver communicating a need for help within their social network, and parent-child conversation about and remembering the deceased parent/spouse. This study focused primarily on the perspective and needs of the surviving caregiver and the struggles they face in navigating parent-child communication with their bereaved youth. This study is a valuable addition to the sparse bereavement literature, but it neglects to examine how reduced parent-child communication may impact the child in feeling supported by their caregiver. Further, the sample only reflects the perspective of four caregivers and four children who all experienced the expected (not sudden) loss of a parent to cancer. Finally, the age of the children and demographic characteristics of the families were not reported.

Despite knowledge of the critical importance of parent-child communication post-bereavement, children and parents alike experience challenges in facilitating open communication, which often stems from difficulty knowing how to talk to each other about the loss (Kaplow et al., 2012; Saldinger et al., 2004). Caregivers report experiencing difficulty engaging in open communication with their bereaved youth, despite knowledge of its positive impact on youth (Saldinger et al., 2004). Both quantitative and qualitative research suggests that children and parents also worry about overwhelming each other with grief by mentioning the deceased within a conversation, so instead, the thoughts and feelings remain unspoken (Barrera et al., 2013; Dowdney, 2005; Ellis et al., 2013). Further, differential parent-child grief reactions and in turn opposite communication styles (e.g., shutting down and refusing to communicate

versus regularly sharing emotions regarding the loss) can lead to strain in the parent-child relationship, followed by reduced communication (Barrera et al., 2013; Dowdney, 2005). Not surprisingly, qualitative studies have shown that a primary reason children and parents seek therapeutic services stems from a desire to receive assistance in improving communication within the family about the deceased (Akerman & Statham, 2014; Braiden et al., 2009).

Much of the existing research on parent-child communication has examined the impact of specific types of communication (e.g., open vs. closed) or the effectiveness of communication using quantitative measures. Knowledge is limited as to how open vs. closed or effective vs. ineffective communication impacts youth's perception of their parent-child relationship as a source of support beyond what was identified by Eppler (2008). No studies were identified that asked youth to describe how their caregiver communicates with them regarding parental loss or how parent-child communication affected their perception of the parent-child relationship as a source of support. Exploring patterns in caregiver-child communication in the aftermath of parental loss is important to understand optimal and sub-optimal communication. The current study will examine youth's perspective on how caregivers communicate with them about the loss of their other primary caregiver.

### ***Community Support via the Therapeutic Relationship***

Within Bronfenbrenner's Ecological Systems Theory, an additional source of support can be experienced through one's community as a part of their exosystem. One form of community support that may be accessed by bereaved youth is grief counseling. Many communities offer counseling services for bereaved children and families. What is unique about this form of support, as opposed to other common sources (e.g., family, peer, school/teacher, church), is having the ability to talk openly and freely about grief without fear of judgment or making others

uncomfortable. Grief can be an uncomfortable topic of conversation among adults, which is amplified among many youths who have not yet experienced the death of a close relative. This is supported by research highlighting that the peers of bereaved youth are uncomfortable when youth speak about their grief or deceased loved one (Dopp & Cain, 2012). Research also indicates that grief support offered by schools is often minimal and time-limited (Andriessen et al., 2019). Further, among parentally bereaved youth, the surviving caregiver is also often grieving, which has been shown to impact their ability to provide needed support (Weber et al., 2019). Therefore, grief counseling services may meet an unfulfilled need regarding confiding and processing feelings of grief. Bereaved youth also have the opportunity to feel supported by the therapeutic relationship formed with their counselor.

Despite the potential for grief counseling to serve as a source of community support for bereaved youth, our field is lacking research designed to evaluate grief counseling in this way. Instead, most research focuses on assessing the service needs of bereaved youth, help-seeking behavior among bereaved youth, and/or the effectiveness of specific grief interventions for this population. For example, a mixed-methods study was conducted by Dyregrov (2009) to determine the needs of bereaved adolescents and emerging adults. This study of Norwegian participants ages 13-to-27 ( $n = 32$ ) found that the majority (69%) of young people bereaved by suicide indicated a need for professional counseling (Dyregrov, 2009). Among those participants who engaged in counseling (52%), many adolescents reported positive relationships with their mental health providers, noting the support they experienced from their clinicians (Dyregrov, 2009). The key factors that contributed to adolescent satisfaction with their psychologist included provider flexibility in treatment implementation, the ability to speak openly and freely, providers actively encouraging clients by identifying their personal strengths, connecting their



clients to community resources, and offering empathy (Andriessen et al., 2017; Dyregrov, 2009). Still, some adolescents indicated dissatisfaction with their current or past experience in counseling. The factors contributing to this dissatisfaction included lack of empathy on behalf of the provider, viewing counseling as unhelpful by not having their issues addressed, and provider uncertainty, passivity, lack of empathy, and lack of compassion (Andriessen et al., 2017; Dyregrov, 2009). While the goal of this research was not to understand the value and significance of therapist support for bereaved youth, their results highlighted the potential benefits of emotional and/or instrumental support offered by mental health providers. However, as this research did not explicitly examine counseling as a form of support, more work is needed to understand how counseling may serve as an effective form of community support for bereaved youth. Further, as this sample included only adolescents, research among pre-adolescent youth is necessary.

The value of therapist support was also indirectly highlighted in research by Andriessen and colleagues (2019). This qualitative study aimed to understand help-seeking behavior among bereaved adolescents (ages 13-27, N=39). Their results indicated that adolescents sought help through informal support (e.g., support groups and church groups), formal support (e.g., individual counseling), and school-related support (e.g., school counselors). Adolescents who sought formal support through grief counseling readily identified the value of their relationship with their mental health provider. They reported that this relationship was fostered through building trust and provider normalization of their feelings (Andriessen et al., 2019). Adolescents also noted that having a space to talk openly and confidentially offered benefits above and beyond other forms of support (e.g., parental or peer support). Although this work advances the literature in understanding help-seeking behavior among adolescents, it is limited in that only

adolescents were assessed, so there remains a dearth of knowledge regarding younger children's response to counseling services.

Grief interventions among parentally bereaved youth have received minimal empirical attention, especially for pre-adolescent youth (ages 8-13). From meta-analyses, we see that individual grief therapy varies in its effectiveness ranging from small to moderate effect sizes (Currier et al., 2007; Rosner et al., 2010). However, there is evidence to suggest that youth who report a stronger therapeutic alliance experience more significant benefits from engaging in grief counseling (Andriessen et al., 2017; Andriessen et al., 2019; Dyregrov, 2009). Nevertheless, most research in this area examines the effectiveness of specific interventions in reducing psychopathology or grief symptoms, rather than the ability for interventions to serve as a form of community support. Much of the existing research in this area centers on specific intervention content (e.g., to treat depressive, grief, anxiety, and/or trauma symptoms; Bolen et al., 2021; Hill et al., 2019; Sandler et al., 2015), and neglects factors such as the therapeutic relationship or the support experienced through regular counseling sessions. This hinders our ability to understand what elements contribute to clients experiencing therapy as a form of support and in turn, how this affects treatment outcomes for parentally bereaved youth. Accordingly, it is critical to empirically examine the factors that bolster clients' feeling supported by their providers via grief counseling. Further, while research has documented that youth report a need for counseling, we do not understand why youth wish to attend or what they hope to gain from counseling (Dyregrov, 2009). By gathering the youth's perspective on these topics, the current study will be filling gaps in the literature regarding support parentally bereaved youth experience through counseling.

### **Gaps in the Literature**

Despite recommendations for qualitative research among bereaved youth by multiple stakeholders in the field, the literature is still relatively sparse (Sandler et al., 2008; Ungar et al., 2013). As such, we have yet to fully understand why, how, and in what context supports across youth's social ecology function post-bereavement; underscoring the critical need for empirical work in this area (Akerman & Statham, 2014; Brown et al., 2007, Hung and Rabin, 2009). Upon a comprehensive review of the literature, a trend noted in past research is the focus on bereavement among adults or emerging adults, with most studies missing the youth's perspective. Of the few studies that do include parentally bereaved youth, most are with adolescents. Thus, minimal empirical work has been done on youth during middle childhood (i.e., ages 8-12). Studies that represent the key developmental periods of childhood and adolescence are unaccounted for in the literature. In addition, the majority of studies with bereaved youth do not explicitly examine parental loss, but rather bereavement more generally (e.g., the death of peers, siblings, extended family members) and/or only assess specific types of bereavement, most commonly bereavement by suicide. Further, a large proportion of the current literature examines discrete quantitative variables, limiting the information we can gain from participants about their unique and personal experiences. Qualitative approaches, such as reflexive thematic analysis, allow for a more in-depth understanding of the participants' lived experiences. Qualitative analyses also offer insight into the expression and function of support variables, providing a nuanced understanding that is not always present in quantitative research.

Given that most research has been done with bereaved adults or caregivers, the youth's perspective on loss is widely missing from the literature. In fact, some studies of bereaved youth include the caregiver's perspective rather than the youth's perspective, leaving researchers and clinicians to speculate, rather than truly understand, bereaved youths' viewpoints. Finally, the

role of social support among bereaved youth, particularly multiple forms of social support, is underexamined. Therefore, research evaluating how different forms of support across ecological systems impact parentally bereaved youth is needed. Finally, the existing literature largely captures the perspective of White bereaved youth, neglecting the perspective of youth who hold other racial and ethnic identities.

### **Present Study**

The present study provides a detailed and rich understanding, via qualitative inquiry, of the impact of different sources of support across the social ecology among parentally bereaved youth. These social-ecological factors are examined at the individual level through the spiritual relationship and how that may change post-bereavement, at the relational level through caregiver-child communication regarding the deceased, and at the community level via therapist support experienced through grief counseling, to comprehensively assess their impact on parentally bereaved youth. The primary aim of the current study is to enhance understanding of patterns and variability in the ways that specific individual, relational, and community supports are operating to impact parentally bereaved youth. The current study aims to gather this information from the youths' perspective to garner a rich understanding of youth's experiences with social-ecological supports.

### **Methods**

This study was guided by the Journal Article Reporting Standards (JARS) for Qualitative Primary, Qualitative Meta-analytic, and Mixed Methods Research in Psychology (Levitt et al., 2018). Data for the present study were collected between the years of 2018 and 2021. Six participants were interviewed after the start of the COVID-19 pandemic. To our knowledge, COVID-19 was not the cause of death for the caregivers of any current study participants.

## Participants

Participants were 30 treatment-seeking youth ( $M_{age} = 12.53$  years,  $SD = 2.80$ ; Range = 8-17 years) who experienced the recent death of a parent ( $M = 8.53$  months since loss,  $SD = 8.15$ ). They were recruited from a hospital-affiliated grief therapy center located in the MidSouth, United States. Youth participants most frequently identified as girls (63.33%). Regarding race and ethnicity, most participants identified as non-Hispanic (90.00%), Black (40.00%), or White (43.33%). Most participants identified as religious (90.00%). All participants experienced parental loss, with the majority of youth experiencing the death of their father (70.00%). On average, youths were 11.7 years old ( $SD = 2.8$ , Range = 8-17 years) at the time of their parent's death. Parental bereavement was unexpected for the majority of participants (66.67%). The most frequently reported type of unexpected loss was sudden illness (26.67%), followed by suicide (20.00%), death due to an accident (e.g., drowning, 16.67%), and homicide (3.33%). Expected or anticipated parental loss was experienced by 33.33% of participants, with these losses being due to cancer or a long-term illness. Nearly all participants (93.33%) described their relationship with the deceased parent as very close or extremely close. At the time of their interview, participants had engaged in an average of five grief therapy sessions ( $SD = 2.50$ , Range = 1-10, Mode = 4). Participants varied in their therapeutic alliance with their provider. In response to the question, "I Like Spending Time with my Therapist," two participants indicated that this statement was not true for them, three participants indicated that this was a little true for them, 12 participants indicated that this was mostly true for them, and 13 participants indicated that this was very much true for them. Therapist ratings of therapeutic alliance with our participants varied, with one reported weak, two below average, eight average, nine above average, and ten strong therapeutic relationships. Additional demographic information is presented in Table 1.

Table 1. *Demographic Variables*

<i>Variable</i>	<i>n = 30 (%)</i>	<i>Variable</i>	<i>n = 30 (%)</i>
<b>Child Race</b>		<b>Surviving Caregiver Relationship</b>	
Asian American	1 (3.33)	Aunt	2 (6.67)
Biracial/Multi-racial	4 (13.33)	Father	5 (16.67)
Black	12 (40.00)	Grandmother	2 (6.67)
White	13 (43.33)	Mother	21 (70.00)
<b>Child Ethnicity</b>		<b>Surviving Caregiver Gender</b>	
Hispanic	3 (10.00)	Female	25 (83.33)
Non-Hispanic	27 (90.00)	Male	5 (16.67)
<b>Child-Reported Religious Orientation</b>		<b>Family Income</b>	
Atheist	1 (3.33)	10,000-20,000	2 (6.67)
Catholic	4 (13.33)	20,000-40,000	2 (6.67)
No Religion	2 (6.67)	40,000-60,000	4 (13.33)
Non-denominational Christian	14 (46.67)	60,000-80,000	7 (23.33)
Protestant	8 (26.67)	80,000-100,000	6 (20.00)
Wiccan	1 (3.33)	>100,000	9 (30.00)

The present study sample size ( $n = 30$ ) is consistent with other published studies utilizing reflexive thematic analysis, which are typically smaller to allow for more depth in examination and understanding of the data and intimate knowledge of participant experiences (Braun & Clarke, 2006; Joffe, 2012). Recommendations for sample size vary significantly in the literature, but a widely used and cited tool (Fugard & Potts, 2015) has been developed to calculate the recommended sample size based on the population theme prevalence, the desired number of instances of encountering a theme, and the desired study power. When applying this tool to our sample and rates of bereavement, we achieve a power of 80% to detect at least two instances of each theme with a sample size of 29 (Fugard & Potts, 2015). Therefore, the current sample size is both in keeping with typical thematic analyses found in the literature, as well as recommendations from a commonly used thematic analysis pragmatic tool (Andriessen et al., 2019; Eppler, 2008; Fugard & Potts, 2015).

## **Procedure**

Institutional review board approval was obtained from the hospital in which the grief center is located as well as the lead author's university. Data for the current study were collected as part of a larger longitudinal mixed methods study entitled the Resilience Uniting Bereaved Youth (RUBY) study. Eligibility criteria for the RUBY study were as follows: 1) Being between the ages of 8-to-17, 2) Experiencing the death of a parent within the past 5 years, 3) English language proficiency, 4) No history of past or current pregnancy, and 5) No significant sensory or cognitive impairment. The inclusion criteria were selected with developmental and comprehension abilities in mind, ensuring that youth could reliably reflect on spirituality, grief, and parent-child communication. Further, youth pregnancy or severe cognitive impairment would likely impact the factors being examined in this study (e.g., parent-child communication), so they were determined as exclusionary criteria.

Participants were recruited utilizing purposive sampling (e.g., treatment-seeking and parentally bereaved youth). Recruitment took place at the Kemmons Wilson Center for Good Grief through direct referral by center staff. Specifically, grief therapists referred their clients to the project by providing general information about the study and requesting that clients complete a consent form for RUBY staff to contact them regarding participation and screening. During the screening process, participants were assessed for eligibility and provided information about the study, including the nature of study involvement. Upon enrollment in the study, participants chose an interview date and convenient location (e.g., Center for Good Grief, participant home, University of Memphis REACH lab) for the interview to take place.

Before beginning the interview, youth participants and their caregivers were informed of the nature of the project, the extent of their involvement, the option to withdraw at any time without consequence, limits to confidentiality, and any foreseen risks and benefits. Youth

participants signed an assent form, and their caregivers signed a parent permission form allowing their child to participate. After caregiver permission and child assent were obtained, trained study personnel administered the in-depth qualitative semi-structured interview featuring open-ended questions. Interviews were recorded using an audio recorder and later transcribed verbatim by study staff. All transcriptions were checked for accuracy by a second staff member. Youth received a \$15 gift card to compensate them for completing the qualitative interview.

## **Measures**

### ***Sociodemographic Information***

Youth completed a sociodemographic questionnaire that included items about their age, sex, race, ethnicity, and religion.

### ***Circumstances of the Loss***

Youth answered a series of questions about the circumstances of their parent's death, including their relationship to the deceased, the year the death occurred, how old they were when the death occurred, how their parent died, whether the death was sudden/unexpected or anticipated/expected, and how close they were to the deceased.

### ***Selected Qualitative Questions***

Four questions were selected from a larger semi-structured qualitative interview (12 questions total, see appendix A) based on their relevance to the current study aims. These questions included: (1) What role does spirituality play in your life?; (2) In what ways has your relationship with God/spirituality changed since the loss?; (3) How has your caregiver communicated with you about the loss?; and (4) "If you had the choice to continue counseling or discontinue, what would you choose? Why?". Two separate questions assessed spirituality to understand both the role of spirituality in the participants' lives and any potential changes to



spirituality experienced post-bereavement. These questions tapped into individual support in the social ecology. For questions about spirituality, participants were asked if they identified with the term “God” or if they would prefer a different term. Question three offered insight into a youth’s relational support via the child’s perception of parent-child communication. Finally, question four was used to assess community support in the form of therapist support via grief counseling.

### **Data Analysis**

Given the minimal research conducted in this area and the exploratory nature of this study, an inductive data-driven approach utilizing reflexive thematic analysis as described by Braun and Clarke (2019) is the optimal qualitative methodology to approach this research question, allowing coders to capture the youths’ perspective, using their words within our coding process. This method was chosen due to the flexibility it provides in identifying and analyzing themes within qualitative data that fit across a range of theoretical and epistemological approaches (Braun & Clarke, 2006, 2019; Guest et al., 2012). We approached our data through the theoretical position of social constructionism to explore latent themes. Social constructionism falls within the camp of relativist epistemology and ontology, determining that reality is dependent on human interactions and consciousness (Burr, 2015; Harper, 2011; Schwandt, 2000). Social constructionism asserts that both how knowledge is created and how we come to know or understand the world are constructed in the process of social interactions between individuals in a society (Burr, 2015; Harper, 2011; Schwandt, 2000). Accordingly, a social constructionist approach to reflexive thematic analysis considers the researcher’s role in conjunction with the participants in the co-construction of the findings (Doncaster et al., 2019).

### ***Coding Team***

The coding team consisted of three clinical psychology doctoral students (LMS, TRN, and LEJ), all of whom identify as White, cisgender women. The coding team reflects diversity in their geographic background in that one coder grew up in the Southeast, one in the Midwest, and one in the Midsouth. Two coders have spiritual beliefs consistent with nondenominational Christianity and one coder has spiritual beliefs consistent with Dualist Pantheism. All members of the coding team are clinical psychologists in training with varying levels of experience, but all with at least one year of therapy experience. Two coders have experienced parental bereavement as older children/adolescents (one paternal bereavement and one maternal bereavement).

The coding team recognizes that their background informs what they choose to study, how they choose to approach the research question, and which findings they see as most relevant in the data (Braun & Clarke, 2019; Palaganas et al. 2017; Titlestad et al., 2020). Although the team can attempt to enhance project rigor by having multiple parties involved and engaging in inter-coder reliability processes, subjectivity is present and impactful. In adopting an inductive approach to the data, in which the data drives the research findings, it is imperative to acknowledge the team's backgrounds and the contributions they have on the construction of meaning in the results (Braun & Clarke, 2019; Palaganas et al. 2017; Titlestad et al., 2020).

### ***Coder Training***

Before beginning the process of reflexive thematic analysis, each member of the team was trained through exposure to seminal and recent work by Braun and Clarke (e.g., 2006, 2019). The two lead coders (LMS and TRN) then practiced coding sample data and defining themes to establish a common basis of understanding. A theme is defined as a recurrent aspect within the data that represents an eminent feature of the participants' lived experiences and is captured by a central idea (Braun & Clarke, 2019; Brennan & Creaven, 2015). After strong

reliability ( $\kappa > .8$ ) was achieved among LMS and TRN within this practice data, the formal coding process for the current study began.

### ***Reflexive Coding Process***

Guided by the principles of thematic analysis, the coding process progressed through six standard phases that included: (1) immersion and familiarization with the raw data, (2) generating initial codes based on features of the raw data, (3) generating initial themes based on existing codes, (4) reviewing initial themes in comparison to the data to ensure accurate representation and fit, (5) refining, defining and naming overarching themes, themes, and subthemes and identifying illustrative quotes to represent each, and (6) producing the thematic maps for each question and final report. In this process, each coding phase built upon the previous phase to further refine and enhance the final result, as well as to ensure that the final product accurately represented the data (Braun & Clarke, 2006; 2019; Titlestad et al., 2020).

LMS compiled the dataset by identifying all participants from the RUBY study who experienced the loss of a parental figure and completed the qualitative semi-structured interview. The data were organized within an excel spreadsheet and uploaded to Dedoose for qualitative analysis (Dedoose, 2018). LMS and TRN then independently familiarized themselves with the data by reading through the entire dataset three times on their own. Following data familiarization, LMS and TRN systematically engaged in coding the data independently. As they worked through the data, they met weekly to discuss their identified codes (e.g., labels to describe content), consolidate any discrepancies, and modify existing codes as necessary. Of note, when youths' responses were captured by multiple themes or subthemes, they were included in all relevant categories. Therefore, multiple codes were allowed per participant response. Sometimes youths' responses were captured sufficiently by the overarching themes,

whereas other participant responses offered more detail that allowed responses to also be identified by a theme and/or subtheme.

Once coding was completed by LMS and TRN, they collated existing codes and began generating initial themes to represent broader patterns of meaning within the data (Braun & Clarke, 2006; 2019; Titlestad et al., 2020). LMS and TRN took an inductive approach, allowing the data to completely inform and drive the initial theme development. The coders discussed the scope and focus of each theme and subtheme (Braun & Clarke, 2019; Titlestad et al., 2020). These initial themes were then reviewed in relation to the raw data to ensure representativeness and identify any potential overlap in order to consolidate and subgroup themes. This analytic work of developing and modifying themes occurred over four meetings to refine and further define themes and subthemes. Themes were finalized based on inter-coder agreement ( $\kappa = .97$ ) that each theme accurately captured the data and was sufficiently distinct to warrant inclusion as separate themes. Thematic maps were then developed to visually represent the findings.

For the current project, overarching themes represent the overall global domains identified in participant responses to each question. Themes were secondary to the overarching themes and represent distinct patterns recognized within the broader domain of the overarching theme. Finally, subthemes relate to their concurrent theme by providing more detailed information to elaborate on the theme itself, when necessary. It is important to note that given the nature of open-ended semi-structured interview questions, the information gathered from participants was offered rather than prompted. Accordingly, the absence of participant endorsement of a theme does not mean an absence of that theme in their experience but rather simply in their offered response.

### ***Auditing Process***

The coding process was finalized through LMS working with an external auditor to ensure inter-coder reliability and credibility of the final product. Recent recommendations and guidelines for the assessment of inter-coder reliability suggest that 10-25% of qualitative data should be randomly selected and assessed by an auditor to ensure the representativeness and trustworthiness of the data (O'Connor & Joffe, 2020). For the present study, LEJ served in this role, as she was not involved in the original coding. Fifty percent of the data (15 participants) were selected via a random number generator and audited by LEJ. To assess coding reliability, LMS started by reviewing the four thematic maps with LEJ (Scrafford et al., 2020). LMS and LEJ then separately coded the first five random number generated transcripts using the thematic maps. After this initial coding, LMS and LEJ met to discuss their coding choices, note any discrepancies, and clarify any questions about the thematic maps. After this meeting, LMS and LEJ separately coded the final ten randomly selected transcripts, coding by theme and subtheme using the thematic maps. These ten transcripts were used to calculate inter-coder agreement. Across these ten transcripts, our inter-coder agreement was high ( $\kappa = .92$ ).

## **Results**

Among the participant responses, we identified ten overarching themes, 22 themes, and seven subthemes across the three sources of support (i.e., individual, relational, community). Participant responses to each question varied in length from a few words to a full paragraph. In reviewing participant response length and content for age discrepancies due to the large developmental span of our participants, no discrepancies were found. Specifically, our shortest responses were not those by our youngest participants, on the contrary, some of our longest responses came from participants aged 8-to-9 years. The number of participants endorsing each theme is reported in Table 2.

Table 2

*Thematic Table of Overarching Themes, Themes, and Subthemes by Source of Support*

Overarching Theme (OT)	Themes (T) and Numbered Subthemes	Participant Endorsement <i>n</i> = 30
<b><i>Individual Support</i></b> Positive and Active Role of Spirituality	-Through spirituality facilitating coping with the loss 1. Reduces worry ( <i>n</i> = 7) 2. Offers comfort knowing that God is always with me ( <i>n</i> = 5) 3. Provides moments of joy and hope for a better future ( <i>n</i> = 4) -Through spiritual engagement with their family -Through attending religious activities like church or youth groups	OT: <i>n</i> = 26 T: <i>n</i> = 19  T: <i>n</i> = 5 T: <i>n</i> = 3
Little to No Role of Spirituality	-Family forced and unwanted religiosity with no individual spirituality	OT: <i>n</i> = 4 T: <i>n</i> = 2
Stronger Spiritual Relationship	-Through an enhanced connection with God -Through increased prayer and conversation with God -By appreciating God's constant available presence and support in their lives -By developing a greater love for God through their experience of loss	OT: <i>n</i> = 20 T: <i>n</i> = 9 T: <i>n</i> = 9 T: <i>n</i> = 6 T: <i>n</i> = 3
No Change in Spirituality	-	OT: <i>n</i> = 5
Questioned Faith and Abandoned Religion	-By identifying the unfairness and betrayal of the loss, leading to abandoning prior belief systems	OT: <i>n</i> = 5 T: <i>n</i> = 3
<b><i>Relational Support</i></b> Open Communication about Deceased	-Through explicit acceptability of expressing grief-related thoughts and feelings -Through the caregiver and youth sharing a mutual understanding of their grief and offering reciprocal emotional support to each other -Through caregiver and youth expressing their shared longing for the deceased -Experiencing enhanced closeness with their surviving caregiver through open communication	OT: <i>n</i> = 11 T: <i>n</i> = 9 T: <i>n</i> = 7  T: <i>n</i> = 5 T: <i>n</i> = 3
Avoid Talking about Deceased	-Through the caregiver specifically avoiding talking about the deceased with their youth -Through both child and caregiver jointly avoiding mentioning or speaking about the deceased	OT: <i>n</i> = 10 T: <i>n</i> = 5 T: <i>n</i> = 5

Table 2 Continued

Overarching Theme (OT)	Themes (T) and Numbered Subthemes	Participant Endorsement <i>n</i> = 30
<b><u>Relational Support</u></b> Caregiver Directed Positively Valenced Communication	-By recommending the youth to engage in coping strategies such as journaling and positive thoughts	OT: <i>n</i> = 9 T: <i>n</i> = 6
	-By comforting the youth and reassuring them that everything will be okay	T: <i>n</i> = 5
	-Through encouraging the youth to maintain a connection with the deceased	T: <i>n</i> = 3
<b><u>Community Support</u></b> Remain in Counseling	-Because counseling is beneficial to their lives through:	OT: <i>n</i> = 26 T: <i>n</i> = 23
	1. Gained emotion regulation and coping skills ( <i>n</i> = 9)	
	2. Through decreased grief symptoms ( <i>n</i> = 7)	
	3. Experiencing relief from expressing their feelings ( <i>n</i> = 6)	
	4. By offering accountability and the opportunity for self-improvement ( <i>n</i> = 6)	
	-Because counseling is enjoyable	T: <i>n</i> = 7
	-Due to the strong therapeutic alliance with their therapist	T: <i>n</i> = 6
Choice to Discontinue Counseling	-Because counseling was unnecessary for them as they had already independently coped with their grief	OT: <i>n</i> = 4 T: <i>n</i> = 4

*Note.* Overarching Themes > Themes > Subthemes. The first column references each overarching theme (OT). Themes are listed in the middle column. If a theme had a subtheme, it is numbered below the theme with the number of participants endorsing that subtheme in parentheses. In the third column, OT references the number of participants endorsing the overarching theme listed in the first column, while T references the number of participants endorsing the theme stated in the middle column. Of note, when youths' responses were captured by multiple themes or subthemes, they were included in all relevant categories. Sometimes youths' responses were captured sufficiently by the overarching themes, whereas other participant responses offered more detail that allowed responses to also be identified by a theme and/or subtheme. Therefore, the numbers reflected in the themes and subthemes do not always add up to the total participant number of 30, as they do for the overarching themes.

## Individual Support Garnered from One’s Spirituality

At the individual level of the social ecology, the spirituality questions inquired, “What role does spirituality play in your life?” and “In what ways has your relationship with God/spirituality changed since the loss?” In response to these questions, the thematic analysis yielded two overarching themes regarding the role of spirituality: (1) Positive and Active Role of Spirituality, and (2) Little to No Role of Spirituality (See Figure 1). Most participants ( $n = 26$ , 86.67%) reported that spirituality played an active and positive role in their lives, whereas four participants (13.33%) did not describe spirituality as having a central role in their lives. Among youth endorsing an active role of spirituality, three themes and three subthemes were identified to describe patterns in participant responses. Among youth endorsing little to no role of spirituality, their responses were captured by the overarching theme and one additional theme.

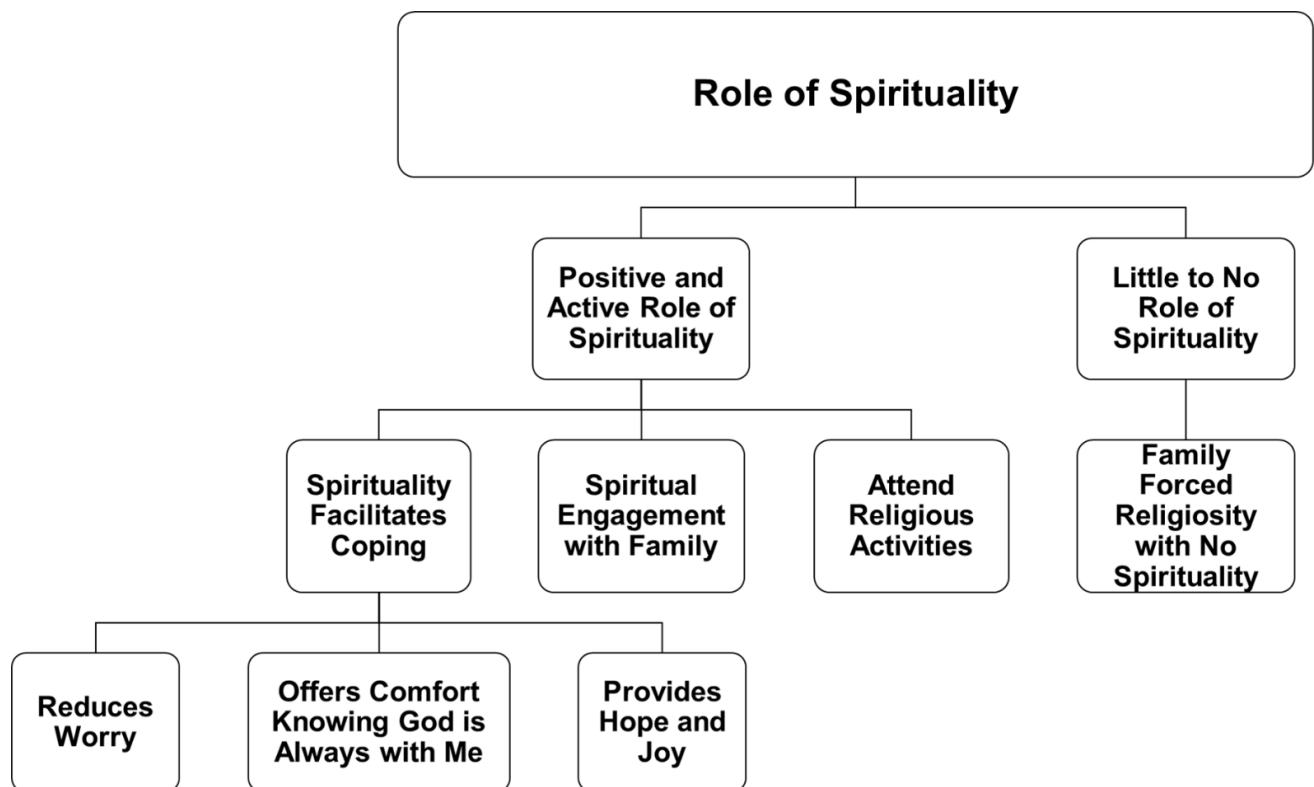


Figure 1. Thematic map for the inquiry: What role does spirituality play in your life?



### ***Overarching Theme: Positive and Active Role of Spirituality***

**Spirituality Facilitates Coping.** The most widely endorsed positive role of spirituality was its role in facilitating coping with grief ( $n = 19, 63.33\%$ ). Three subthemes were developed to reflect the various ways spirituality fostered coping among these youth. While the subthemes helped to expand upon the sources of coping, several participant responses were sufficiently captured by the theme, spirituality facilitates coping. These participants remarked that “*God helps me get through*” (10-year-old Biracial Hispanic boy, maternal loss) and “*It gives me purpose and helps me tune into the bigger parts of myself*” (16-year-old White girl, maternal loss).

**Subtheme: Reduces Worry.** For seven youth (23.33%), spirituality aided in coping by reducing their worries. One youth noted, “*Like my faith is that you trust God, and you put your worries to the side. You don’t need to think about the negative things. You need to think about the good things you have with the people you love*” (9-year-old White boy, maternal loss). Another participant reported, “*If I’m in a bad situation, if I talk to God, it makes me feel less stressed and it makes me feel less upset than I am, and it makes me calmer*” (10-year-old Black girl, paternal loss). Across participants endorsing this theme, they reported that their trust in God allowed their worries to be decreased and/or that they spent less time engaging in worry.

**Subtheme: Offers Comfort Knowing that God is Always with Me.** Five participants (16.67%) noted the comfort that they feel from knowing that God is “always with me.” One participant indicated, “*It impacts my life by just telling me that I won’t be alone and there’s actually somebody there, even though there’s somebody with me, there’s actually somebody sitting next to me and sitting in front of me and I know that God, he is the one and only person who actually sent his son to die for us*” (10-year-old Black girl, paternal loss). Another child

noted *“That he’s always there when you need him and when you’re in troubled times you can always pray and the Lord will come down and help. It makes me feel happy”* (9-year-old White boy, paternal loss). Unlike other inconsistencies in life, youth reported that God represents a constant presence to turn to for support that is readily available whenever they need support.

***Subtheme: Provides Hope and Joy.*** Another way in which spirituality facilitates coping for some youth ( $n = 4$ , 13.33%) was the outlet of hope and joy offered by their faith as a momentary escape from periods of grief. One adolescent remarked, *“I mean it gives me hope. Gives me hope that things will get better. That things can get better”* (17-year-old Black boy, paternal loss). Another child commented, *“It plays happiness in my life. It gives me joy”* (9-year-old White girl, paternal loss). Participants' responses highlighted the hope they have that their life will improve, something they believe due to their faith, in addition to the joy they experience during moments of spiritual connection.

***Spiritual Engagement with Family.*** When speaking to the active role of spirituality in their lives, a few youths ( $n = 5$ ; 16.67%) noted how spiritual practices are a large part of their family. For example, one adolescent noted *“A big role. I’ve always just had to make it stronger because I knew this happened, everything happens for a reason and I kind of just had to let it go and be okay and just know that it’s gonna be okay. It definitely has a big role and it’s just a family thing that I’ve done. It keeps me from like just blaming it on someone, just like it helps me in all in general because I can always have my spirit like help me go through everyone. It’s definitely helped, it’s always been a big thing in my family”* (14-year-old Black girl, paternal loss). Another child reported, *“God helps me get through stuff. Like if I’ve done something bad me and my dad would like do a prayer and tell him to forgive our sins, and I think that he’s helping me. Like at school, I’m not really crying that much anymore and overall I think that he*

*plays a good role in my life*” (10-year-old Biracial Hispanic boy, maternal loss). Participants spoke to the tradition of spirituality in their family and engaging in religious practices, such as prayer or attending church together. They also spoke to family encouragement of spiritual connection (e.g., “keep God first”). Among this group of participants, family engagement with spirituality was reported to be beneficial and not unwanted.

**Attending Religious Activities.** A small number of participants ( $n = 3$ , 10.00%) described the positive role of spirituality in their lives through their enjoyment of attending religious activities such as church and youth groups. One adolescent reported, *“It’s a huge role, like I go to youth groups every Sunday night and every Tuesday I go eat breakfast with the high school kids and my youth group leader. Then I also go to Wednesday night church”* (16-year-old White girl, paternal loss). Another participant noted, *“I’m Catholic. It helps me. I go to youth group and it’s fun and I go to church”* (14-year-old White girl, paternal loss). These youth derived benefits from engaging in religious activities such as mentorship from older youths, social support from peers, and enjoyment of these activities as fostering a positive role of spirituality in their lives.

### ***Overarching Theme: Little to No Role of Spirituality***

In this sample, four participants (13.33%) identified little to no role of spirituality in their lives. Two of these participants felt that church and religion were forced on them by their families and while they attend religious activities with their families, they do not identify as having a personal spiritual relationship. Another participant identified ambivalence about their spiritual relationship, remarking *“It’s complicated. I mean I’m still questioning but at the same time I guess it happened for a reason. Like trying to understand like why did it happen in the first place and like why did he choose us specifically?”* (14-year-old Black girl, paternal loss).

Another adolescent participant succinctly remarked, “*Very little*” (15-year-old White boy, maternal loss), referencing the minimal role of spirituality in his life.

**Family Forced Religiosity with No Individual Spirituality.** Two participants (6.67%) commented about the forced role of religion in their lives by their families and the absence of a personal spiritual connection. One adolescent remarked, “*A significant amount, because I go to Catholic school, but if it were up to me, it would be none at all, because it’s so forced on me that it’s making me not like it anymore. I just don’t like any of it*” (15-year-old White girl, paternal loss). Another participant noted, “*It doesn’t really play a great role. Well, my mom raised us to where we had the idea of being just good people, so it was more like a moral base, but right now because I live with my aunt and uncle, Catholicism is like really huge. But as an individual it doesn’t really play that great of a role. I tend to not connect with most of religion*” (17-year-old Asian American girl, maternal loss). These participants essentially spoke to going through the motions with their caregivers, but resenting or not connecting with religion themselves.

### ***Inquiry Regarding Spiritual Change***

For the question assessing “In what ways has your relationship with God/spirituality changed since the loss,” three overarching themes were identified: (1) A Stronger Spiritual Relationship After Loss, (2) No Change in Spirituality, and (3) A Period of Questioned Faith and Ultimately Abandoned Religion (See Figure 2). The majority of participants reported developing a stronger spiritual relationship in the aftermath of caregiver loss ( $n = 20$ , 66.67%). Still, five participants (16.67%) reported no change in their spiritual relationship post-bereavement; and the remaining five (16.67%) reported that parental loss led to a period of questioning their previous religious beliefs and ultimately abandoning their religion due to faith and life “not adding up.” Among youth describing a strengthening of their spiritual connection, four themes were

identified to describe their patterns of responses. For those detailing no change to their spiritual relationship, the overarching theme adequately captured their responses, requiring no additional themes or subthemes. For the overarching theme of questioned faith and abandoned religion, an additional theme was included to portray participant shared experiences.

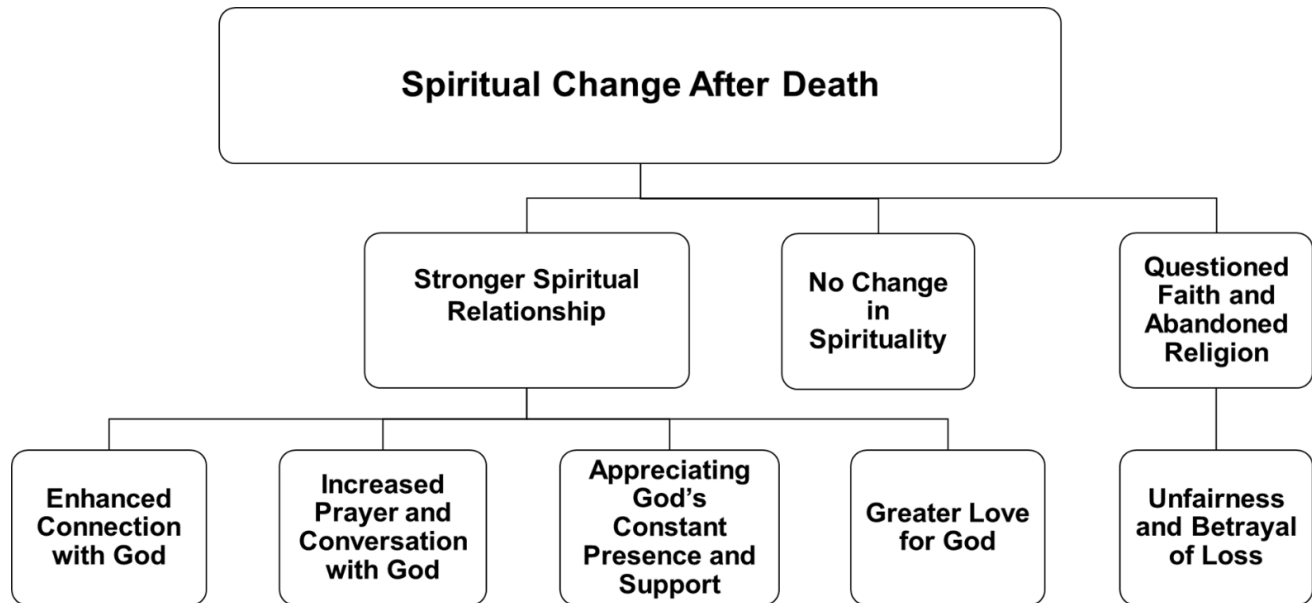


Figure 2. Thematic map for the inquiry: In what ways has your relationship with God/spirituality changed since the loss?

***Overarching Theme: Stronger Spiritual Relationship***

**Enhanced Connection with God.** Multiple participants ( $n = 9$ , 30.00%) reported a more connected or enhanced spiritual relationship now, as compared to before their parental loss. One participant responded, “I’ve gotten closer to God. God has helped me like be more calm and less stressed about the situation” (16-year-old White girl, paternal loss). A second participant remarked, “Well at first I wasn’t really into the whole like God thing. I knew I was connected to God, but I didn’t. I wasn’t as connected as I am right now” (10-year-old Biracial Hispanic boy, maternal loss). Many participants used the phrasing “closer to God” and “growing stronger” to

describe the evolution of their spirituality post-bereavement. Many of these participants turned to their faith to understand and cope with their loss, which contributed to the growth in their faith.

**Increased Prayer and Conversation with God.** Several participants ( $n = 9$ , 30.00%) reported an increase in time spent praying and conversing with God since the loss of their parent. One adolescent indicated, *“I am able to go to him more. I am able to go to God more about situations of my own that I hope he can help me with. And it helps”* (17-year-old Black boy, paternal loss). Finally, another child commented, *“It’s changed a lot. I used to think about him a lot, and now I think about him way more than a lot. And, I pray a lot more”* (9-year-old White boy, maternal loss). After the loss of their parent, these participants indicated being more likely to go to God with problems and engaging in prayer more regularly and more often.

**Appreciating God’s Constant Presence and Support.** A handful of participants ( $n = 6$ , 20.00%) spoke to appreciating the dependability of God. One adolescent remarked, *“It’s gotten stronger. I can depend on and I can talk to God whenever I like need it and I know that he’s always listening, he’s always there for me, so I just know he’s with me at all times, because sometimes you just need that and I’m glad that I have that”* (14-year-old Black girl, paternal loss). Another youth spoke to the transition in believing in God after feeling his help through this loss, reporting that *“Before I was mostly doubting God, I was thinking before my dad died I mostly asked God are you really real or not, but when my dad died I knew that God was there because he always helped us through, so I figured out now that he’s there”* (10-year-old Black girl, paternal loss). These participants acknowledged experiencing God’s ceaseless presence in their lives and its role in strengthening their spiritual relationship.

**Greater Love for God.** Three participants (10%) described developing more love for God after experiencing the loss of their parent. Specifically, one participant noted, *“It’s changed*

*by just like having a greater love for him, having a greater connection with him. It's just been like he's like sending helpful people to me, and brand new people that I don't even know that can help me still. And they could become my friends to send me like the people that can be good. And he sends away the people that can be bad for me"* (11-year-old Black boy, paternal loss).

Another participant commented, *"It just made me love him even more knowing that he's helping me through this transition* (12-year-old Black girl, paternal loss)." For these participants, their greater love for God developed out of gratitude for the aid they experienced as coming from God in helping them cope with this difficult loss.

#### ***Overarching Theme: No Change in Spirituality***

Five participants (16.67%) reported that they had not experienced a change in their spirituality after the loss of their caregiver. Most participants were succinct in their responses to this question, offering responses such as, *"It hasn't really changed that much"* (14-year-old White girl, paternal loss). Though one participant elaborated on their experience, identifying that their already strong spiritual relationship had stayed strong and had not changed, stating, *"He's always been there for me. When I felt really sad, he's there for me. It's like He just came from Heaven down to me and talked to me"* (9-year-old White girl, maternal loss). No additional themes were necessary due to participant responses being fully captured by the theme below.

#### ***Overarching Theme: Questioned Faith and Abandoned Religion***

For a small number of participants ( $n = 5$ , 16.67%), the loss of their parent spurred questions about if there was truly a higher power, and ultimately led to the loss of their previous faith system. One participant noted, *"It's made me kind of question if there really is something. I don't really believe in anything"* (15-year-old White boy, maternal loss). For others, this loss of faith was more emotionally charged in feeling deeply betrayed by God.

**Unfairness and Betrayal of Loss.** Three participants (10.00%) who stopped ascribing to religion described the injustice and betrayal felt by the death of their parent. One participant indicated, *“Yeah, because after he died I was like, what is this? I was actually looking into things and being like, that doesn’t make any sense. Why would I believe that? My mom, because my dad was a super faithful person, so she’s always like, “Because he was so faithful, doesn’t that make you want to be more faithful?” I was like, no, not really, because like, he was so faithful to God, but God took him away technically. So, it doesn’t add up for me”* (15-year-old White girl, paternal loss). Another youth reported, *“Um, I kinda felt like, cause I had before been like thinking that Christianity and that kind of thing that was something I wanted to follow like greatly and then I kinda realized that life is so random and complex and like a lot of people after mom died tried to explain it, and they couldn’t and they would just their only answer would be like “well, it’s there for a reason” and like that kinda really kinda made me be like well, dissociate from religion being the core of my life at all because I don’t know it, it didn’t really seem to hold mom there so I was just kinda done with it at that point”* (17-year-old Asian American girl, maternal loss). Some participants spoke to a set of fundamental shifts in their belief system after the loss due to the betrayal they felt from God. Other participants also noted the unfairness of the loss and their difficulty grappling with why their parent was taken away.

### **Parent-Child Communication as Relational Support**

For the question assessing relational support we asked, “How has your caregiver communicated with you about the loss?” The thematic analysis yielded three overarching themes concerning parent-child communication about the deceased: (1) Open Communication about Deceased, (2) Avoid Talking about Deceased, and (3) Caregiver Directed Positively Valenced Communication (See Figure 3). There was substantial variability in participant responses to this



question and several themes emerged. A little over one-third of participants ( $n = 11, 36.67\%$ ) reported having open communication with their caregiver about the deceased. This open communication provided space for youth to report whatever they were feeling and permitted the surviving parent to do the same through reciprocal support. One-third of participants ( $n = 10, 33.33\%$ ) reported avoidance of communication with their caregiver about their deceased parent. This was split into two themes whereby either the participant's caregiver explicitly avoided engaging in communication about the deceased with their child or both the child and caregiver jointly avoided talking about the deceased parent with each other. The final nine participants ( $30.00\%$ ) described patterns of communication in which the caregiver displayed overt positive undertones. This communication seemed to be steered by caregivers in a way that promoted adaptive coping and reduced youths' experience of, and rumination about, grief. The three overarching themes and nine themes are outlined below.

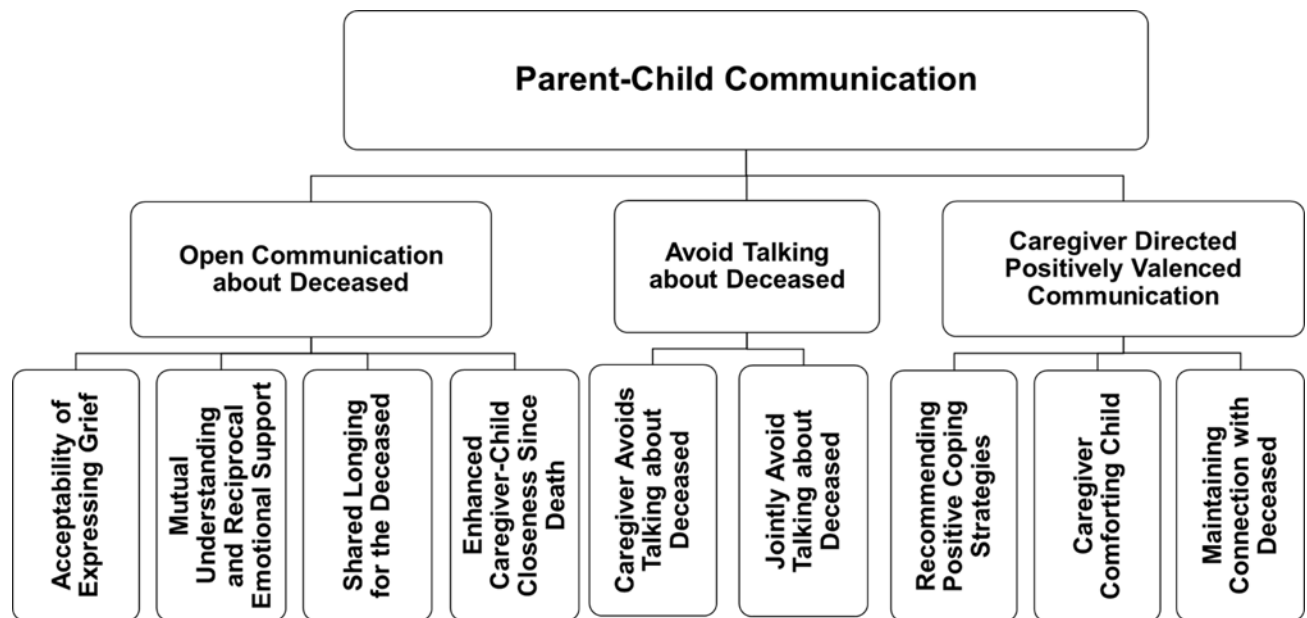


Figure 3. Thematic map for the inquiry: How has your caregiver communicated with you about the loss?

### ***Overarching Theme: Open Communication about Deceased***

**Acceptability of Expressing Grief.** A number of participants ( $n = 9$ , 30.00%) underscored that expressing their grief was allowed or encouraged within their family. For example, one participant noted, *“We’re really vocal about all of our feelings, idk we’re a close family and we talk a lot”* (15-year-old White girl, maternal loss). Another participant remarked on the increase in family communication of feelings since their parent’s death, noting *“We talk a lot more, way more. Sometimes a little too much.”* (13-year-old Black girl, paternal loss). Youths’ responses highlighted feeling comfortable sharing their feelings with their caregiver, that it was okay to do so, and often validated and/or reciprocated.

**Mutual Understanding and Reciprocal Emotional Support.** Several youths ( $n = 7$ , 23.33%) endorsed a shared understanding of grief between themselves and their caregiver in which they offered reciprocal emotional support to each other. For example, one participant stated, *“When I usually cry, she (grandmother) cries with me, cause it’s like really...like she’s like with me. Like, I can tell her my emotions and she’ll cry with me, and when I cry, she’s just she feels exactly how I feel”* (9-year-old White boy, maternal loss). Another youth noted, *“We communicate about it very well. Because those are things we can both bond on because we were both affected by them. Both of them, my dad and my sister, in negative ways. So, we’re both able to talk freely”* (15-year-old White boy, maternal loss). These youth noted that because themselves and their caregiver were both grieving, they understood each other’s pain and were able to offer the needed support to each other by drawing on their shared experience of grief.

**Shared Longing for the Deceased.** For a subset of participants ( $n = 5$ , 16.67%), open communication was expressed as a shared longing for the deceased parent expressed by the youth and their surviving caregiver. One participant noted, *“Ya know, we’ll say about how much*

*we miss him, we'll talk about good times we had with him. If something happened and it kinda reminded us of him, we'll talk about it"* (17-year-old Black boy, paternal loss). A second participant remarked, *"We talk at least every day about it. Just you know, what we miss about him and if something reminds us of him, we like watch a video or something"* (14-year-old Black girl, paternal loss). Communication between these youth and their parents involves sharing that they each miss their deceased loved one, what they miss about them, and/or reminiscing on their memories together.

**Enhanced Caregiver-Child Closeness Since Death.** Three youth (10.00%) reported an increased closeness in the relationship with their surviving caregiver post-bereavement. For instance, one participant highlighted, *"We've talked about it and we've gotten closer and we've gotten to just tell each other that its' okay and sometimes if we just kind of both break down we're there for each other and we can help each other out. We've definitely come closer in that aspect of it and I just, knowing I can talk to my mom about it if I need to and she would talk to me about it if she needs to is a real good thing"* (14-year-old Black girl, paternal loss). A second participant noted, *"It was very nice when me and my mom would cry or we would talk together or just communicate together about it. And our relationship was already closer than most, I think. So we talked about it, and it got more closer"* (10-year-old Black girl, paternal loss). These youth spoke to a heightened bond formed with their surviving caregiver in the aftermath of their parent's passing that was fostered by open communication.

### ***Overarching Theme: Avoid Talking about Deceased***

**Caregiver Avoids Talking about Deceased.** Five participants (16.67%) endorsed that their caregiver intentionally avoids communication regarding the deceased. One participant reported that instead of speaking directly to them, their caregiver instead sent them to see a

counselor to talk about their feelings, *“Sending me to counseling. That’s it. Because she doesn’t talk to me about it. Yeah, it’s just, she sends me to other people to talk about it”* (15-year-old White girl, paternal loss). A second participant indicated that their mother avoids talking about their deceased parent because they know it saddens the youth, saying, *“She knows that it kind of makes me sad and stuff so she really kind of stays away from it, but when it all happened, she talked to me about it and stuff”* (12-year-old Biracial Hispanic boy, paternal loss). For some participants, this lack of communication was resented by the youth and viewed as shirking of their caregiver responsibility. Whereas other participants did not directly indicate satisfaction or dissatisfaction with their caregiver’s lack of communication with them.

**Jointly Avoid Talking about Deceased.** Five participants (16.67%) indicated that both themselves and their surviving parent try to avoid any mention of the deceased. One adolescent remarked, *“No, I don’t. So my sister and I came into the house at an older age, 17, so obviously we kinda disrupted things a little bit and I think family dynamics was something that they [new caregivers] wanted to maintain. And so they wanted that relationship of the parent, mother, and father, and we did not, so we did not really connect well because I had just lost my mom and then suddenly these two people there were kinda like wanting to be the parents, and so my mom was something we never really talked about. And then also like they’re polar opposites in ideologies and like ways of life and so it wasn’t something we vibed on so we just didn’t talk about it”* (17-year-old Asian American girl, maternal loss). Another participant reported, *“Well, I know she tries to have like serious conversations and stuff. It’s just like I guess whenever we talk, we’re always on different sides, and we’re always on different points of views. So, like we’re never really like successfully communicate with each other”* (16-year-old Multi-racial girl, paternal loss). Youth reporting content in this theme seem to have different ways of coping with their

grief than by communicating with their caregivers. In addition, some of these youth also indicated less of a solid and stable parent-child relationship, which may contribute to the mutual discomfort and avoidance of communication regarding the deceased.

***Overarching Theme: Caregiver Directed Positively Valenced Communication***

**Recommending Positive Coping Strategies.** A subset of participants ( $n = 6, 20.00\%$ ) reported that their caregiver encourages adaptive coping strategies that could help ease their grief, such as journaling and focusing on positive thoughts or memories. One child remarked, *“Well she tells me to think more about the good things than the bad things. Because like, I don’t know why but like, but I just always think about that one time we were at the funeral home, but I didn’t get to see him. And she said don’t think about that, think about all the good memories that you had, all the stuff he bought you, and everything you made for him. She says that I need to get a journal and write down or draw all the things that I think about that’s about him. All the memories I have and everything, and to write them down and keep them”* (11-year-old Black boy, paternal loss). Another participant reported, *“We just talk about all of the good memories and stuff* (16-year-old White girl, paternal loss).” These parents encourage their children to focus on their good memories to assist them in coping with their grief. It is unclear whether expression of grief is wholly discouraged, though it is clear that these youth are encouraged by their caregivers to access positive memories as a way to contend with their loss.

**Caregiver Comforting Child.** Five youth (16.67%) endorsed parent communication consistent with comforting and encouraging the youth that everything will be okay. For example, one youth remarked that *“We talked about it’s not your fault, it’s just God’s way, He just called him home and that He doesn’t put nothing hard that we can’t handle, so God knows that we can handle this”* (10-year-old Black girl, paternal loss). Another youth reported, *“She talks to me just*

*by telling me that everything's gonna be okay"* (12-year-old Black girl, paternal loss). These youths describe an experience whereby their caregivers recognize the negative emotions they are experiencing and reassure them either by highlighting their inner or God-given strength to handle this pain, or indicating that it will get better with time.

**Maintaining Connection with Deceased.** A few youths ( $n = 3$ , 10.00%) reported that their caregiver encouraged them to continue to maintain a connection with their deceased parent, reminding them that their caregiver will "always be with them." One youth highlighted, "*She usually just if she sees a flock of birds flying, she'll say it's daddy. She loves talking to him. She tells me that he's watching over us and that he's caring for us*" (12-year-old Black girl, paternal loss). A second child remarked that "*He talks to me like, "You should always remember the good things about her, and know that she will always love you and she'll always be there for you"*" (9-year-old White girl, maternal loss). These participants indicated that part of their communication with their caregivers centers around reminding them that the caregiver is still watching over them and/or waiting for them in heaven.

### **Community Support via the Therapeutic Relationship**

Finally, our inquiry regarding community support asked, "If you had the choice to continue counseling or discontinue, what would you choose? Why?". The thematic analysis yielded two overarching themes: (1) Remain in Counseling, and (2) Discontinue Counseling (See Figure 4). The vast majority of youth ( $n = 26$ , 86.67%) reported that they would choose to continue with their current grief counseling rather than discontinue counseling ( $n = 4$ , 13.33%). The participants' reasons for choosing to continue counseling were identified within three themes and four subthemes detailed below. Whereas participant reasoning for choosing to discontinue counseling was succinctly captured within a single theme.

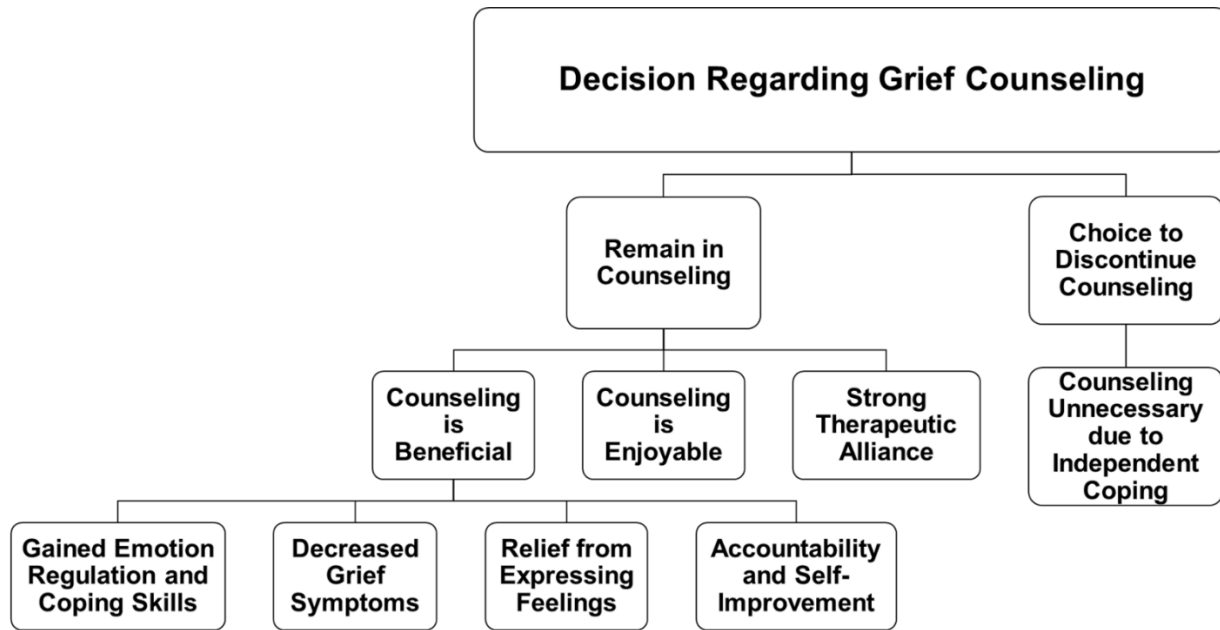


Figure 4. Thematic map for the inquiry: If you had the choice to continue counseling or discontinue, what would you choose? Why?

**Overarching Theme: Remain in Counseling**

**Counseling is Beneficial.** The vast majority of youth used language to indicate that counseling was beneficial to their lives. Twenty-three participants (76.67%) reported that they wish to continue counseling due to the benefits they experienced from grief counseling. The types of benefits are defined by four different subthemes.

**Subtheme: Gained Emotion Regulation and Coping Skills.** Nearly one-third of participants ( $n = 9$ , 30.00%) endorsed that counseling was beneficial to them, specifically by helping them gain tools to regulate their emotions and coping skills to contend with the strong feelings brought on by parental loss. In this vein, one participant reported, “Continue (counseling) because it’s helpful. I’m trying to learn about calming yourself down. (Before counseling) certain times I would just be mad. Now, I calm myself down. I learned to not be mad at people for no reason” (12-year-old Black boy, paternal loss). Another participant indicated,

*“Continue cause counseling just really helps me a lot. And it makes me feel like happy and it really helps me with my emotions and stuff”* (9-year-old White boy, maternal loss). Youth reported that counseling has helped them to gain these tools, and that attending regular counseling helps them remember to use these tools and/or gain new coping skills.

***Subtheme: Decreased Grief Symptoms.*** Multiple youths ( $n = 7, 23.33\%$ ) stated that their grief symptoms had decreased over the course of their treatment. One participant noted this through reporting, *“I’d definitely continue it but we were talking about spreading them (appointments) out a little more because I’m kinda getting better and I don’t have as much to talk about, but I think it’s (counseling) definitely good. It just helps me cope and it’s nice to have an unbiased party to talk to”* (15-year-old White boy, maternal loss). A second participant reported, *“I would choose to continue counseling because it helps me. It helped me overcome sadness”* (10-year-old biracial Hispanic boy, maternal loss). Despite improvements in grief symptoms, these youth did not report a decision to stop counseling due to their improvement; rather, they still desired continued support. In particular, multiple youths noted that grief ebbs and flows over time, and having regular counseling is important to process each stage of grief.

***Subtheme: Relief from Expressing Feelings.*** A handful of participants ( $n = 6, 20.00\%$ ) reported experiencing relief from sharing their feelings openly with their counselor. Notably, several youths reported feeling more comfortable talking with their therapist over their family members. One participant reported, *“I would choose to keep doing it because it helps. Because when I feel like I can’t get it off my chest with my mom, I can get it off my chest with my counselor”* (17-year-old Black boy, paternal loss). Another participant indicated, *“I would choose to continue because it’s like I said before it’s easier to like not store in the feeling it’s easier to express the feeling”* (10-year-old White girl, paternal loss). For several youths, therapy



provided the only outlet where they felt comfortable speaking openly about their grief. For these youth, sharing their feelings offered a sense of relief from the weight of holding these feelings inside in other contexts (e.g., home, school, with peers).

**Subtheme: Accountability and Self-Improvement.** Six participants (20.00%) identified appreciating the accountability offered by counseling to continue the processing of their grief, as well as the opportunity for self-improvement. For one adolescent participant, this looked like, *“Continue, because I think that therapy in a way, like obviously I could cope if I stopped tomorrow, but I think that it just betters you as a person because grief is a process and so you experience different things over time, so having it over time rather than when just right after its happened and then that being it, I think that it’s better”* (17-year-old Asian American girl, maternal loss). Another youth noted, *“I would choose to continue counseling because it helps you push for more and you know that every week I have to tell her something that I grew upon or didn’t grow in that I want to fix or try to change and that I wanna grow in. Counseling helps me push harder”* (13-year-old Black girl, paternal loss). Some participants noted that if counseling were to end, they might return to minimal discussion of their feelings of grief. Participants also reported that having the regularly scheduled appointments motivated them to make progress on the goals they developed with their counselors and continue their self-improvement. These quotes highlight the multifaceted personal growth and support that youth may derive from attending grief counseling.

**Counseling is Enjoyable.** Approximately one-quarter of participants ( $n = 7$ , 23.33%) stated that they would choose to remain in counseling because they enjoyed engaging in counseling. These youth indicated that therapy is “fun” and something that they look forward to each visit. Specifically, youth noted enjoying the grief-related activities they engaged in during

their visits (e.g., making ceramic tiles to memorialize their deceased parent). One participant noted, *“I would choose to continue because I enjoy actually talking to someone about how I feel and having to do those little art projects and stuff. Like not too long ago, I made a ceramic tile, it represented my mom, and I took that idea and added some more, and my dad adds more to our house, and my sister and I are going to put those tiles in our bathroom”* (14-year-old Black girl, maternal loss). Further, multiple youths also noted the “really nice” personality of their therapist in the same breath as identifying counseling as “fun,” highlighting that a positive relationship with their therapist may further promote counseling as a beneficial experience. There were multiple similar responses to the following excerpt, *“I would choose to continue it because it’s fun, I like my therapist and I like learning about talking about my feelings”* (12-year-old Black girl, paternal loss). These positive and enjoyable experiences in grief counseling contribute to motivating participants to continue attending sessions.

**Strong Therapeutic Alliance.** One-fifth of participants ( $n = 6$ , 20.00%) continued counseling because of the strong therapeutic alliance they had with their grief counselor. For instance, one participant stated, *“Keep going (to counseling) because I love them dearly and they’ve been helping me. They’ve been putting a lot of effort into helping children with needs”* (9-year-old White girl, maternal loss). Another individual remarked, *“I would choose to keep on working with my counselor because she’s helpful, she’s kind, she’s very nice and generous. I think all the kids should be thankful for what they have been doing for them”* (8-year-old Biracial Hispanic girl, maternal loss). These participants spoke to the kindness demonstrated by their counselors, appreciation of the effort put forth by their counselors to help them, the generosity of their providers, and the care dedicated to listening and understanding the youth’s perspective. Having a strong alliance and connection to the therapist was a clear motivator for some youth to

continue therapy.

### ***Overarching Theme: Choice to Discontinue Counseling***

**Counseling is Unnecessary due to Independent Coping.** Four youth (13.33%) indicated that they would choose to discontinue counseling because they found it unnecessary and/or unhelpful. These youths reported that they did not believe counseling was providing an added benefit for them. For example, one respondent indicated, “*Discontinue, just because I didn’t feel like it helped me that much, because I felt like I had dealt with my situation before I got there*” (15-year-old White girl, paternal loss). Similarly, another youth reported, “*I would discontinue, I mean I don’t get much out of it. I get over things pretty-well myself*” (14-year-old White boy, paternal loss). These youths did not report negative experiences with therapy, but rather a lack of need for the additional support offered by grief counseling. Interestingly, three of these four youth also avoided communication with their caregiver regarding the deceased, which may represent that they cope with the loss through methods other than communicating with others.

## **Discussion**

Available research underscores the monumental impact of parental loss on youth functioning. This qualitative study was designed to identify the unique impact of social supports within different ecological systems in the lives of parentally bereaved youth. Rather than narrowly focusing on one system of social support (e.g., friends or family), the current study took a holistic approach to examine the impact of support from multiple systems in youths’ social ecology. Findings shed light on the variability within these social support domains among bereaved youth. In turn, these results highlight that there is no one-size-fits-all approach to supporting parentally bereaved youth. However, there is consistent evidence that additional

supports beyond the surviving caregiver, such as spirituality and therapist support via grief counseling, generally serve a beneficial role in fostering coping among parentally bereaved youth.

### **Individual Support Garnered from Youth's Spirituality**

The vast majority of participants identified spirituality as serving an active and positive role in their lives. Among those participants that identified as spiritual, all but one belonged to a denomination of the Christian faith. Striking similarities were found in the language used by participants in the current study and responses in the existing literature to describe the role of spirituality in their lives. One example is the ubiquitous use of the word 'comfort' by bereaved youth, which was used by current study participants and noted in all of the reviewed articles (Andrews & Marotta, 2005; Dill, 2017; Greeff & Joubert, 2007; Rooney et al., 2020). Similar to youth in other published studies, the source of spiritual comfort was multi-faceted for the current study participants, with some describing the comfort experienced in knowing that they will one day be reunited with their loved one, whereas others noted the comfort of having God's presence continually with them. The death of a loved one as a child can bring on feelings of anxiety and insecurity that spirituality seems to ease for some youth, giving them a sense that they are not alone and have someone watching over them or standing with them. This feeling of comfort may help explain why spirituality often serves as a protective factor against psychopathology among youth (Bryant-Davis, 2012; Dill, 2007; Hay & Nye, 2006; James & Fine, 2015).

Other similarities between past studies of spirituality and the current research include spirituality as a facilitator of coping, prayer as a form of spiritual coping that increased post-bereavement, spirituality serving to reduce worry for youth, spiritual engagement together with family members, and an enhanced spiritual relationship post-bereavement (Andrews & Marotta,

2005; Dill, 2017; Greeff & Joubert, 2007; Rooney et al., 2020). The majority of participants both in the current study and in the previously cited literature identified as belonging to a denomination of the Christian faith. The similarities between findings in the current study and past literature likely relate to the overlap in culture and doctrine within the Christian faith. For example, our findings are interchangeable with Christian youth from East Oakland, California (Dill, 2017), which highlights the commonality in faith responses across regions. If current study participants held different beliefs or faith systems other than Christianity, our results may not be as aligned with past research.

One major difference between our findings and previously published research is offering the perspective of youth whose faith changed as a result of their parent's death. For some youth, their faith grew, with those who previously felt uncertain about their spirituality becoming more connected and leaning on their faith as a source of support. Other youth who previously had strong spiritual beliefs began to seriously question those beliefs after the loss of their caregiver. While this loss of faith reflects a small subset of study participants, it is a perspective that has not been previously identified in the literature. The additional grief through feelings of betrayal from God is an important area for continued research, as these already vulnerable bereaved youth also lost a second source of support through the abandonment of their spirituality. Still, two-thirds of participants in the current study experienced a growth in their faith from pre- to post-loss. Most of the existing literature examines the presence or absence of spirituality, with only one known study evaluating a change in faith (Greeff & Joubert, 2007). It is important to consider whether changes in faith, either becoming stronger or weaker, are related to the youth's age. Spiritual exploration is more common in adolescents than young children (Good & Willoughby, 2008) and among the five participants in the current study who questioned and/or abandoned their faith,

all were adolescents ranging in age from 14-17 years. Our findings highlight that a change in faith, whether that be growth, reduction, or loss, is a common response to caregiver death and should be attended to by future researchers and clinicians working with bereaved youth.

While spirituality was generally described as being an individual source of support, which aligns with how it is conceptualized in the literature (Hill & Pargament, 2003), some youth also described aspects of their spirituality that fit within Bronfenbrenner's microsystem. For example, youth discussed attending religious activities like church services or youth groups and engaging in spiritual practices with their family members. Thus, our findings indicate that some youth who endorse spirituality as a source of individual support also experience relational support through their spiritual activities and practices. Our findings also highlight the importance of assessing spirituality when examining youth's support network, given that it is clearly important for many youths even though it is often overlooked by service providers. In sum, our findings generally align with Ecological Systems Theory in viewing spirituality as an individual source of support, as well as the buffering hypothesis which highlights that social support serves a buffering role by promoting adaptive coping. For a majority of the participants, spirituality was associated with spiritual coping. While we did not examine mental health outcomes directly, it is possible that some of these adaptive spiritual coping strategies (e.g., prayer, connection with family) may facilitate adaptive outcomes among bereaved youth.

### **Parent-Child Communication as Relational Support**

Findings showed large variability in how youth felt supported by the parent-child relationship and opportunities to communicate about the deceased. Responses ranged from youth feeling closer to their surviving caregiver because of the loss and speaking openly with them about the deceased, to youth and caregivers who did not have a close relationship and avoided

talking about their shared experience of loss. Further, some youth expressed that their caregivers stepped into a protective role to help them cope with the loss and reminisce about their loved one. Across the three main themes or patterns that emerged from the data, a picture of the parent-child relationship materializes. Some youth and caregivers showed open communication about the deceased and seemed to have an evenly balanced relationship in which both parties were on the same level. These children and caregivers may have had the experience of going through this loss together and offering support to each other. Another set of youth and caregivers appeared to avoid communication about the deceased. These dyads dealt with the fallout of the loss individually and did not rely on each other for support. A third set of youth and caregivers showed a positively valenced communication style in which the caregiver takes on the caretaking supportive role and the child takes on the role of being supported. It is important to note that these are simply patterns, and data does not suggest that one pattern is superior to another.

These patterns have not all been empirically documented, but parts of the existing literature on parent-child communication relate to each theme and help contextualize the findings. The first theme is consistent with research examining “open parent-child communication.” Consistent with previous research findings we see that among current study youth who reported open communication with their caregiver regarding the deceased, they often spoke about this communication from a place of gratitude and sometimes described the development of an enhanced caregiver-child closeness (Eppler, 2008; Kaplow et al., 2012; Wardecker, et al., 2017). A subgroup of study participants who endorsed open and regular communication described talking with their caregiver about their shared longing for the deceased and engaging in reminiscing about their lost loved one together, which fits with existing research showing the positive impact such conversation can have on the parent-child bond (Kaplow et al.,

2012; Wardecker et al., 2017).

Two themes expressed by youth who reported an open and regular dialogue with their caregiver were not identified in the previous literature, including the acceptability of expressing grief and mutual understanding/reciprocal emotional support. When asked about communication with their caregiver, many youths spoke about it being acceptable to go to their caregiver with their grief, that their emotions were not dismissed and/or their caregivers did not try to cheer them up, but rather just allowed the grief to be present. Other youth described an unspoken understanding that both themselves and their caregiver were enduring similar pain from the loss, and accordingly, there was a shared view of their experience and in turn reciprocal emotional support. When centered in the existing literature, one article touched on similar processes. Research by Shapiro and colleagues (2014) found that warm, sensitive, and engaged communication between surviving mothers and their bereaved youth was associated with improved outcomes and decreased levels of maladaptive grief and depression (Shapiro et al., 2014). Themes identified in the current study are complementary to warm, sensitive, and engaged communication. Responses from youth in this open communication category allude to feeling understood and emotionally supported by their caregiver. It is possible that open and regular caregiver-child communication about the deceased helps youth feel supported by their caregiver, which is consistent with past research highlighting that family relationships are generally closer when parent and child engage in open communication (Weber et al., 2019). Furthermore, open expression of thoughts and grief between parent and child are associated with better outcomes among bereaved youth (Howell et al., 2016; Weber et al., 2019).

Findings from the theme “avoid talking about the deceased” are also supported by available literature which highlights numerous factors that may lead to reduced communication



or support between the surviving caregiver and bereaved youth. The surviving caregiver is often grieving, which may impact their ability to provide support to their child (Andriessen et al., 2019; Dopp & Cain, 2012; Dyregrov, 2009). This is amplified by the fact that caregivers may struggle to engage in open communication with their bereaved youth, reporting that they do not know how to do so effectively (Saldinger et al., 2004). Further, parents worry about overwhelming their children with grief by mentioning the deceased, so instead the thoughts and feelings remain unspoken (Barrera et al., 2013; Dowdney, 2005; Ellis et al., 2013). It appears that some youth and their caregivers prefer to say nothing about the death and completely avoid the topic of their deceased family member. What our study does not address is the effect of this avoidance. Questions that remain include: Can youths still perceive their caregiver as supportive without having open communication about their grief? Could youth experience a lack of communication as caregivers being supportive of their wants and needs? Still, some of the participants reported that the lack of communication contributed to challenges in the relationship with their caregivers, so some youth in this category did not experience relational support.

The third and final category, caregiver directed positively valenced communication, can be seen as a hybrid of the previous two categories, in which there is some encouraged avoidance of grief and sad memories, but also regular communication regarding positive coping strategies, positive memories, and caregiver sensitivity through comforting youth. In reviewing the research literature, this style of communication has not previously been described, rather overarching categories like open or closed communication are referenced (Kaplow et al., 2012; Saldinger et al., 2004). In evaluating sensitive communication, as well as effective parent-child communication, it is important to consider the child's needs, and these needs vary by a number of factors including developmental stage and personality (Weber et al., 2021). For some youth,

this form of parent-child communication was beneficial in which caregivers encouraged reflecting on positive memories each time they mentioned a negative feeling, comforted and consoled them, and helped them maintain a connection to their deceased caregiver. However, other youth may have experienced this form of parent-child communication as discouraging emotional expression or invalidating their experiences. This form of parent-child communication highlights the importance of parent-child fit, as the match between what a child needs/wants from their caregiver and the caregiver's parenting style may not always foster effective relational support. For instance, youth may want to openly speak about their grief as a way to process emotions and their parent may instead encourage them to focus on positive memories and not to think about their grief, or vice versa. As we did not examine youth satisfaction with their caregiver's communication style, we cannot assess the effectiveness of this form of parent-child communication. It is clearly a pattern that needs further empirical exploration, as both positive and negative effects on the caregiver-child relationship could stem from this form of communication, depending on the child's age, needs, and desires (Weber et al., 2021).

### **Community Support via the Therapeutic Relationship**

Many youths readily spoke about their positive experiences with grief counseling. The majority of participants indicated that if given the choice, they would continue engaging in grief counseling. When contextualizing our findings in the small body of research in this area, the reasons that our participants identified wanting to continue therapy were similar to factors that contributed to adolescent satisfaction with psychologists in previous studies (Andriessen et al., 2017; Dyregrov, 2009). Factors noted by existing research included provider flexibility in treatment implementation, the ability to speak openly and freely, providers actively encouraging clients by identifying their personal strengths, connecting their clients to community resources,

and offering empathy (Andriessen et al., 2017; Dyregrov, 2009). These map onto our participant responses including relief from expressing feelings, offering accountability and self-improvement, counseling being beneficial, and experiencing a strong therapeutic alliance with their provider. Current study findings are also consistent with research highlighting that youth who report a stronger therapeutic alliance experience more benefits from engaging in grief counseling (Andriessen et al., 2017; Andriessen et al., 2019; Dyregrov, 2009). Existing research provided more information on reasons for dissatisfaction with counseling than did our few participants who would choose to discontinue grief therapy; however, both participants in previous research and participants in this study acknowledged feeling that therapy is unhelpful as a reason for discontinuing or general dissatisfaction with counseling (Andriessen et al., 2017; Dyregrov, 2009).

Given that current knowledge regarding grief therapy focuses almost solely on specific interventions and their effectiveness, rather than factors that lead clients to feel supported in therapy, there is little literature in which to contextualize our findings. By neglecting this important factor, many current grief interventions overlook research that highlights the importance of the therapeutic alliance in the effectiveness of treatment (Norcross, 2002). In fact, an article examining the effectiveness of grief counseling among adults underscored the absence of research on the therapeutic relationship in grief counseling, and strongly encouraged the field to move towards examining this crucial aspect of treatment (Jordan & Neimeyer, 2003). The current study makes progress towards this call to action by identifying what factors led youth to continue in grief therapy, with the therapeutic alliance being a central element.

Participants identified several reasons why they would choose to continue counseling. Youth spoke of the many benefits experienced in counseling including developing an increased

ability to manage their emotions and cope with their feelings, seeing a decrease in their grief symptoms, experiencing relief from having an outlet to speak about their grief, and having the continued accountability to face their feelings through regular therapy. Youth also described the support experienced through their strong therapeutic alliance with their counselor and how much they enjoyed counseling due to their “nice” provider. Still, this was not a universal sentiment given that four youth did not derive benefits from therapy and would choose to discontinue attending counseling sessions if given the opportunity. There is much to learn about what factors make grief counseling effective and enjoyable for bereaved youth. The current study adds to the literature by highlighting the many ways in which having grief therapy served as a support for bereaved youth that aided in their ability to cope with the loss. This support was external to their microsystem and provided a safe space for them to process emotions and feelings that they may not be comfortable expressing with family or friends.

In sum, youths indicated numerous ways that individual and community supports facilitated their coping with grief and made their grief more manageable. However, when speaking about communication with their surviving caregiver, the facilitation of coping was not as commonly endorsed, and youths did not feel uniformly supported. When we center these findings in the literature and the social support models that grounded this research, the results underscore the benefit of having sources of support from multiple levels of one’s social ecology. These findings further highlight the importance of having supports across multiple systems that provide different types of support to meet the complex needs of bereaved youth.

Perhaps the benefits derived from these varied supports come through addressing different needs or aspects of well-being (e.g., psychological, spiritual, and emotional). One published thematic analysis of the psycho-social needs of parentally bereaved adolescents and

young adults (aged 12-23) found seven distinct needs that included the (1) need for support and understanding, (2) need for guidance and assistance coping with feelings, (3) need for opportunities to talk to other parentally bereaved youth, (4) need for information, (5) need for respite from grieving to have fun, (6) need for time and space for grieving, and (7) need for help with everyday household tasks (Patterson & Ranganathan, 2010). It would be impossible for one source of support to meet all of these needs. Accordingly, our findings highlight how support from one's spiritual relationship, one's parent-child relationship, and one's therapeutic relationship with their grief counselor can contribute in unique ways to these distinct needs and work together in supporting the youth.

### **Clinical Implications**

Results of the present study provide important clinical implications for parentally bereaved youth, as well as provisional guidance for mental health professionals and intervention programs serving this population. When bereaved youth present to counseling, findings suggest that it would be beneficial to thoroughly evaluate the youth's current sources of support and any recent changes to these supports (e.g., decreased parent-child communication, loss of faith). With this information clinicians can determine where therapeutic attention may be needed, such as bolstering existing supports, repairing struggling supports, and/or introducing additional forms of support. For instance, among youth who rarely communicate with their caregiver about their loss, family therapy and/or parent training may be indicated. By understanding what supports the youth already has, and the benefit or lack thereof, service providers can develop strategies to strengthen supports that are limited, as well as help the youth identify and access additional supports (e.g., family counseling, extended family, church members).

Results also highlight the importance of clinicians reviewing positive parenting and open

communication strategies with parents of bereaved youth, such as validating youth's feelings and grief. In addition, clinicians should address barriers to parent-child open communication, such as caregivers feeling overwhelmed or depressed by the death. Youths' clinicians may also assist caregivers in connecting to therapists of their own. Research underscores that caregivers of bereaved youth are often struggling emotionally, which can impact parent-child relations, so caregiver referral and intervention may positively impact child outcomes (Weber et al., 2019; 2021). For parents who need assistance navigating discussions about sadness or grief with their child, therapists can model these conversations (Weber et al., 2019). Given the variability in parent-child communication, clinicians should assess what current parent-child communication styles are evident, and how these styles are viewed by the child in terms of helpfulness and satisfaction. Such information could help determine if additional intervention is necessary.

Findings suggest that assisting the youth in developing an array of complementary coping strategies that fit with their values and can be used across their social ecologies may be beneficial, including prayer, identifying and expressing emotions, journaling, gratitude practices, and support seeking. Our findings and existing research also indicate that incorporating caregivers into some of these coping strategies (e.g., family prayer, reminiscing about the deceased, expressing and validating emotions) could lead to greater development within the caregiver-child relationship and better outcomes for youth (Kaplow et al., 2012; Wardecker, et al., 2017; Weber et al., 2021). Our results also highlight the importance of directly assessing youth's spiritual beliefs and how they change over time. Given that many participants experienced a change in their faith, this direct assessment could shed light on areas for intervention (e.g., anger and grief from the loss of faith) or protective factors (e.g., spiritual coping strategies) to incorporate into treatment.

In order to be more responsive to the needs of parentally bereaved youth, future grief interventions should consider a social-ecological framework that amplifies and strengthens multiple sources of support to create an enriched community network. Many existing grief interventions have a narrow focus, often addressing processes within the individual and their family through parenting support (e.g., Family Bereavement Program; Sandler et al., 2013). While these interventions have shown positive effects, their short and long-term benefits could be bolstered by assisting youth in accessing additional supports within their community that are tailored to the youth's values and needs (e.g., mentorship programs, peer support groups for bereaved youth, youth group programs via churches, individual counseling). By modifying already effective interventions to evaluate and expand sources of support for youth and their families, the benefits of these services could be bolstered.

### **Limitations**

The current findings should be evaluated with certain limitations in mind, many of which can inform future research efforts. The sample represented only parentally bereaved youth who were currently or had previously sought grief counseling. Many youths do not seek therapy following a death, and undoubtedly the majority of those who do likely have support from an adult in accessing this resource; accordingly, findings may differ among non-help-seeking bereaved youth. Further, most of the sample is comprised of female caregivers and girls who experienced the death of their father. The perspectives of youth with surviving fathers as their primary caregivers were largely absent in the data. In addition, considering the degree to which spirituality and religiosity are emphasized in the South and Mid-south regions of the US, study results may be divergent from a similar study conducted in geographical areas with more variability in religious orientation (e.g., Islam, Judaism). Due to the majority of participants

ascribing to a denomination of the Christian faith, our study represents the spiritual perspective of youth with a Christian-based view of spirituality, which limits understanding of other forms of spirituality and their ability to serve as a source of support. Additionally, this study was cross-sectional, limiting our understanding of change in supports over time. Finally, while the sample size is in keeping with other thematic analyses, the current study only represents the perspectives and experiences of 30 parentally bereaved youth.

### **Future Directions**

The current findings offer insight into directions for future research. Future research should examine additional sources of support such as extended family (e.g., grandparents, aunt/uncle, siblings), mentors, peers, and school personnel across multiple regions of the country. It would also be helpful for future research to evaluate additional systems within Bronfenbrenner's ecological model. Specifically, the current study did not evaluate the mesosystem that includes the interactions, or lack thereof, within the individual, microsystem, and exosystem (e.g., school personnel working with parents to promote functioning). It would also be helpful to examine how the macrosystem may be influencing youth, including what supports may be culturally driven and how they vary across different cultures and regions. For example, it would be valuable to assess if some of the consistent language utilized by youth in discussing spiritual support is driven by cultural messages shared by individuals within the same religion and how that differs in other cultures.

It would be valuable for future research to assess youths' perspectives on the effectiveness of supports in promoting their well-being. Longitudinal and mixed-methods research incorporating both qualitative and quantitative data to examine social-ecological supports of parentally bereaved youth will also allow us to see how supports change over time.



This research should capture youth soon after their loss and follow them over multiple years. Ideally, this research would include measures of each form of support being examined (e.g., spirituality, peer support, school support, parent support, extended family support, coach or mentor support), as well as youth satisfaction with each source of support (both quantitatively and qualitatively) and multiple outcome measures (e.g., prolonged grief, resilience, well-being). While the current study addresses gaps in our knowledge by including a sample spanning middle-childhood to adolescence (e.g., ages 8-17), it would be helpful for future research to specifically target the most understudied developmental period of middle childhood (e.g., 8-11 years), which is largely absent from the literature. Given that youth's understanding of death is heavily influenced by their development, future studies should examine distinct differences within the middle-childhood, pre-adolescent, and adolescent developmental periods in response to parental bereavement.

## **Conclusions**

The current study has numerous strengths that contribute to the nascent youth bereavement literature. It expands on past research by assessing a variety of social supports from the youths' perspective, which differs from the existing literature that often centers on one form of social support and/or captures the perspective of the caregiver rather than the youth. By interviewing youth directly within a relatively short period (i.e., on average, nine months) since the death of their caregiver, we gained a unique perspective on youth supports in the aftermath of significant trauma. Further, by inquiring about these supports in a semi-structured interview format we were able to explore themes and patterns among participants through their unconstrained responses. In addition to applying sound methodology through reflexive thematic analysis and an inductive data-driven approach, the authors engaged in auditing the coding using

inter-rater reliability to increase the rigor and trustworthiness of the results. The current study also extends the literature by featuring a larger sample than most existing qualitative studies as well as greater participant diversity.

Overall, findings indicate that individual support through spirituality and community support through grief counseling were viewed as beneficial sources of support by most youth. These supports offered a space to vocalize emotions and grief and provided a sense of comfort in helping youth feel that they were not alone in their loss. Findings also highlight the variable impact of parent-child communication in that for some youth it served a similar role to the other supports by providing a safe space to process emotions and promote coping, but for other youth, it was less beneficial or entirely unavailable. This study underscores the importance of cultivating a variety of supports across multiple systems in the bereaved youth's social ecology.

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## Appendix A Screening Questionnaire

### Resilience Uniting Bereaved Youth (RUBY) Study Screener

**TODAY'S DATE:** \_\_\_\_\_

**DIRECTIONS: We would like to ask you a few questions to see if you and your child are eligible to take part in our study.**

IF PARTICIPANT IS NOT ELIGIBLE BASED ON THEIR RESPONSE TO ANY OF THE QUESTIONS, STOP AT THAT POINT, THANK THEM FOR THEIR TIME, AND ASK THEM IF THEY HAVE ANY QUESTIONS.

1. Is English your primary language?	NO	0	Not Eligible
	YES	1	
2. Are you 18 years of age or older?	NO	0	Not Eligible
	YES	1	
3. Do you have a child who is between 8-17 years old?*	NO	0	Not Eligible
	YES	1	
*Note: if parent has more than one eligible child, state that ALL children in the 8-17 age range are invited to participate.			
4. Are you the primary caretaker (legal guardian) who is responsible for the day-to-day care of the 8-17 year old child/children?	NO	0	Not Eligible
	YES	1	
*Note: if participant is not legal guardian but is the primary caretaker for the child they are still eligible.			
5. Is English your child's/children's primary language?	NO	0	Not Eligible
	YES	1	
6. Did your child/children experience the death of a loved one in the past 5 years?	NO	0	Not Eligible
	YES	1	
7. Is your child/children currently pregnant or have they ever been pregnant?	NO	0	
	YES	1	Not Eligible
8. Does your child/children have any severe sensory or cognitive impairments?	NO	0	
	YES, describe:	1	Not Eligible

IF PARTICIPANT IS ELIGIBLE, SAY:

**We would like to invite you and your child/children to participate in our study about how loss and other adverse experiences, along with risk and protective factors, may affect you and your child/children.**

Eligible, Agree to participate.

Eligible, Refuse to participate. Reason: \_\_\_\_\_

Not Eligible (see reason above).

**CONTACT INFORMATION:**

**Name:** \_\_\_\_\_

**Home Phone:** \_\_\_\_\_ **Cell Phone:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_ **Mailing Address:** \_\_\_\_\_

**Are there other ways to contact you?** \_\_\_\_\_

**Appendix B  
Demographics Questionnaire**

1. **How old are you?** \_\_\_\_\_

2. **When is your birthday?**

Month	Day	Year

3. **Are you male or female?**

Male	Female	Other
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. **What is your current grade in school?**

<input type="checkbox"/>	Third
<input type="checkbox"/>	Fourth
<input type="checkbox"/>	Fifth
<input type="checkbox"/>	Sixth
<input type="checkbox"/>	Seventh
<input type="checkbox"/>	Eighth
<input type="checkbox"/>	Ninth
<input type="checkbox"/>	Tenth
<input type="checkbox"/>	Eleventh
<input type="checkbox"/>	Twelfth

5. **Have you changed schools in the past year?**

<input type="checkbox"/>	No, I went to this school last year and this year
<input type="checkbox"/>	Yes, this is my first year at this school

6. **How would you describe your religion?**

<input type="checkbox"/>	NONE
<input type="checkbox"/>	ANGLICAN
<input type="checkbox"/>	ATHIEST
<input type="checkbox"/>	BAPTIST
<input type="checkbox"/>	CATHOLIC
<input type="checkbox"/>	JEWISH
<input type="checkbox"/>	METHODIST (INCLUDING AFRICAN METHODIST EPISCOPAL [AME])
<input type="checkbox"/>	MUSLIM
<input type="checkbox"/>	NONDENOMINATIONAL CHRISTIAN
<input type="checkbox"/>	PENTECOSTAL - CHURCH OF GOD IN CHRIST (COGIC)
<input type="checkbox"/>	PRESBYTERIAN
<input type="checkbox"/>	7TH DAY ADVENTIST
<input type="checkbox"/>	OTHER: _____
<input type="checkbox"/>	DON'T KNOW



**Appendix C**  
**Circumstances of the Loss Questionnaire**

**Next, we will ask you some questions about loved ones that you have lost.**

**1. How many close friends or family members do you know who have died? \_\_\_\_\_**

**2. Whose death has been the most difficult for you in the past month? \_\_\_\_\_**

**3. How difficult has this death been for you in the past month?**

Not at all difficult	A little difficult	Difficult	Very difficult	Extremely difficult
1	2	3	4	5

**4. How did you know this person?**

- |  |   |
|--|---|
| <input type="checkbox"/> BIOLOGICAL FATHER | <input type="checkbox"/> SISTER/STEPSISTER            |
| <input type="checkbox"/> STEP FATHER       | <input type="checkbox"/> BROTHER/STEPBROTHER          |
| <input type="checkbox"/> ADOPTIVE FATHER   | <input type="checkbox"/> UNCLE                        |
| <input type="checkbox"/> BIOLOGICAL MOTHER | <input type="checkbox"/> AUNT                         |
| <input type="checkbox"/> STEP MOTHER       | <input type="checkbox"/> COUSIN                       |
| <input type="checkbox"/> ADOPTIVE MOTHER   | <input type="checkbox"/> BOYFRIEND/GIRLFRIEND         |
| <input type="checkbox"/> GRANDFATHER       | <input type="checkbox"/> CLOSE FRIEND                 |
| <input type="checkbox"/> GRANDMOTHER       | <input type="checkbox"/> OTHER, PLEASE SPECIFY: _____ |

**5. How long did you know this person (in years)? \_\_\_\_\_**

**6. How close were you with this person?**

Not at all close	A little close	Somewhat close	Very close	Extremely close
1	2	3	4	5

**7. When did this death occur? \_\_\_\_\_**

**8. How old was this person when they died? \_\_\_\_\_**

**9. How old were you when this person died? \_\_\_\_\_**

**10. Did you witness the death?**

- YES  
 NO

**11. Did you attend the funeral?**

- YES  
 NO

**12. How did this person die?**

- ILLNESS, PLEASE SPECIFY: \_\_\_\_\_  
 ACCIDENT  
 MURDER/HOMICIDE  
 SUICIDE  
 OVERDOSE OF DRUGS/ALCOHOL  
 OLD AGE  
 OTHER, PLEASE SPECIFY: \_\_\_\_\_

**13. Was their death expected?**

- YES  
 NO

## Appendix D Qualitative Interview Guide

**The next part is where I would ask you open-ended questions. Some families may feel that answering multiple choice questions does not get at their true experiences with therapy and the grieving process; therefore, we would like to give you the opportunity to share some of your experiences. If you choose to participate you will receive an extra \$15 gift card in addition to the gift card you will receive for the previously answered questions. Would you like to participate in this optional opportunity?**

Yes, **Continue Below**

No

1. What has been the most helpful part of counseling?
2. What has been the least helpful part of counseling?
3. What are some things you've learned about yourself through counseling?
4. If you had the choice to continue counseling or discontinue, what would you choose? Why?
5. What role does spirituality play in your life?
6. In what ways has your relationship with God/spirituality changed since after [MOST DISTRESSING EVENT]?
7. How has your [CAREGIVER] communicated with you about [MOST DISTRESSING EVENT]?
8. A little while ago, we talked about different ways that you dealt with [MOST DISTRESSING EVENT]. How similar was the way that you responded to [MOST DISTRESSING EVENT] to how you've dealt with difficult situations in the past?

[1]-Very different	[2]-Somewhat different	[3]-Neither similar nor different	[4]-Somewhat similar	[5]-Very similar
--------------------	------------------------	-----------------------------------	----------------------	------------------

Why did you respond in this way to [MOST DISTRESSING EVENT]?

9. What has been the most challenging part about dealing with [MOST DISTRESSING EVENT]?
10. Have any good things happened because of [MOST DISTRESSING EVENT]?
11. What advice would you give to kids and families who are going through a similar situation?
12. What else do you think we should know?

## **Appendix E IRB Approval**

Institutional Review Board  
Division of Research and Innovation  
Office of Research Compliance  
University of Memphis  
315 Admin Bldg  
Memphis, TN 38152-3370

PI: Kathryn Howell  
Department: Psychology  
Study Title: (FACILITATED BAPTIST) Resilience Uniting Bereaved Youth (RUBY)  
IRB ID: 4257  
Submission Type: Renewal  
Level of Review: Expedited

IRB Meeting Date:  
Decision: Approved  
Approval Date: April 20, 2021  
Expiration Date: April 19, 2022

### Findings:

The IRB has reviewed the renewal request. The University of Memphis Institutional Review Board, FWA00006815, has reviewed your submission in accordance with all applicable statuses and regulations as well as ethical principles.

Approval of this project is given with the following obligations:

1. If this IRB approval has an expiration date, an approved renewal must be in effect to continue the project prior to that date. If approval is not obtained, the human subjects consent form(s) and recruiting material(s) are no longer valid and any research activities involving human subjects must stop.
2. When the project is finished a completion form must be completed and sent to the board.
3. No change may be made in the approved protocol without prior board approval, whether the approved protocol was reviewed at the Exempt, Expedited or Full Board level.
4. Exempt approval are considered to have no expiration date and no further review is necessary unless the protocol needs modification.
5. Human subjects training is required every 2 years and is to be kept current at [citiprogram.org](http://citiprogram.org).

Thank you,  
James P. Whelan, Ph.D.  
Institutional Review Board Chair  
The University of Memphis.

Note: Review outcomes will be communicated to the email address on file. This email should be considered an official communication from the UM IRB.

## Appendix F Parent Permission Form

### INFORMED CONSENT FOR PARTICIPATION IN A RESEARCH STUDY: Parent Permission for Youth Participation

**Title of Study:** Resilience Uniting Bereaved Youth (RUBY)

**Protocol No.:** 16-18

**Investigator:** Angela Hamblen Kelly, LCSW, Director of Kemmons Wilson Family Center for Good Grief

**Participating Investigator:** Kathryn Howell, PhD from the University of Memphis

**Telephone:** 901-678-1541

This form has information about this research. Where it says, “See Below”, there is more complete information later in this form. You and the research personnel will discuss this information, so you can decide whether or not to take part in this research. Make sure you discuss your concerns and have all your questions answered before deciding to take part in this research.

<b>Informed Consent</b>	It is important that you understand this research so that you can decide whether or not your child to take part. This process is called informed consent. To make your decision, you must consider all the information below. You should especially consider: <ul style="list-style-type: none"> <li>• The purpose of this research.</li> <li>• How this research differs from standard medical care.</li> <li>• The procedures and the drug(s)/device(s) involved in this research.</li> <li>• The risks.</li> <li>• The alternatives to taking part in this research.</li> </ul>
<b>Voluntary Participation</b>	Your child does not have to take part in this research. It is your choice whether or not you want he/she/they to take part. If you choose not to have your child take part or choose to end their participation at time, there will be no penalty to you or to your child or loss of benefits to which you are otherwise entitled.
<b>Purpose</b>	The purpose of this research is investigate how experiencing the death of a loved one affects caregiver, youth, and family functioning. This study will help us understand risk and protective factors within individuals and among family units that may contribute to psychological difficulties or well-being over time.
<b>Number of Participants</b>	About 150 people will take part in this research.
<b>Duration</b>	Your child will be in this research study for about 6 months.
<b>Procedures &amp; Experimental Parts of the Study (See add'l info Below)</b>	While your child(ren) are in the study, he/she/they will complete a survey at two time points, and each of those visits will take approximately 2 hours to complete. Participation involves minimal risk.
<b>Risks</b>	Taking part in this study involves certain risks. Some participants may experience embarrassment, distress, or upsetting emotions when discussing potentially sensitive topics of adverse life experiences. In addition to the risks described below, there may also be risks that are not known at this time possible risk could be the negative consequences of having sensitive information your child shared in this study revealed but get caution is exercised to prevent information from being shared If your child has any medical issues during this study, contact an investigator ( <i>see Contacts below</i> ).
<b>Costs</b>	There are no known costs for participation in the study.

<b>Payment</b>	Your child will receive a \$15.00 gift card for the first quantitative survey you complete, a \$15-dollar gift card for answering qualitative portion of the interview.
<b>Ending Study Early</b>	There are a number of reasons you and your child may decide or be asked to stop the study early (example: medical issues). Your child may also have to stop the study early even if you do not want to. You and the research personnel will discuss the reasons if this becomes necessary. If you do leave the study early, you may be asked to have some of the evaluations/procedures described in this form.
<b>Contacts</b>	<p><b>For questions about the study or research related medical issues:</b></p> <ul style="list-style-type: none"> <li>• Main Investigator- Angela Hamblen-Kelly at (901) 861-5656</li> <li>• Sub-Investigator- Dr. Kathryn Howell at (901) 678-1541</li> <li>• Research Coordinator- Taylor Napier at (901)-678-3036</li> </ul> <p><b>If you need to contact someone other than the study personnel about a concern or your rights as a research subject:</b></p> <ul style="list-style-type: none"> <li>• Baptist Institutional Review Board at 901-226-1677 or 901-226-1678</li> </ul> <p><b>If you would like to speak to a person who is not affiliated with this research study to discuss problems, concerns or question, or to obtain information or offer input:</b>  Rev. Anthony Burdick, Director of Pastoral Care, Baptist Memorial Health Care Corporation at 901-226-5025</p>

## INTRODUCTION

Your child is one of 150 children, ages 8-17 years old, who is being asked to participate in a research study. Before agreeing to allow your child to participate, it is important that you read and understand the following explanation of the proposed procedures. This document describes the purpose, procedures, benefits, risks, discomforts and precautions of the study. It also describes the alternative procedures that are available to you, and your child's right to withdraw from the study at any time. No guarantees or assurances can be made as to the results of the study. The process of consenting for your child to take part in this study involves a study staff member reviewing this document with you in its entirety and answering any questions that you may have about your child's participation in this study. Once your questions have been answered, you will indicate with your signature on the last page if you give permission for your child to participate. You will be given a copy of this parent permission form to retain for your records. In addition, a study staff member will review the study with your child and let your child make his or her own decision as to whether or not to participate in the study. Your child will only participate in this study if you give your permission and if your child chooses to participate.

## PURPOSE

The purpose of this study is to investigate how experiencing the death of a loved one affects caregiver, youth, and family functioning. This study will help us understand risk and protective factors within individuals and among family units that may contribute to psychological difficulties or well-being over time. Specifically, we will examine how history of exposure to adversity (i.e., death of a loved one, maltreatment, abuse, exposure to violence) coping styles, mobilization of available resources, mental health, family structure, and mental health counseling influence bereaved youth and their caregivers.

## VOLUNTARY PARTICIPATION

Your child's participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which your child would be otherwise entitled, and you may discontinue their participation at any time

without penalty or loss of benefits to which you are otherwise entitled. Choosing not to participate in this study will not influence the services and level of care that your child receives from the Center for Good Grief.

## **PROCEDURES**

- The research will be conducted at the Kemmons Wilson Center for Good Grief Collierville and Midtown locations (Baptist Collierville campus at 1520 West Poplar Avenue Collierville, TN 38017 and at the Midtown satellite center, Kemmons Wilson Center for Good Grief Milla's House campus located at 28 South Evergreen Street Memphis, TN 38104), or at another location of your choosing.
- Your child will complete our survey at two time points, and each of those visits will take approximately 2 hours.
- The total amount of time your child will be asked to volunteer for this study is 4 hours over the next 6 months.
- If you agree to allow your child to be part of the research study, he/she will be interviewed by a study staff member who will be asking questions about the impact of adverse experiences, grief, mental health functioning, parenting, coping, and grief counseling on resilience.
- The study staff member will enter your child's answers into an iPad®, and your child will be offered a copy of the questions so that he/she can follow along during the interview.
- The first section of the interview will be survey questions, and the second section will be a set of open-ended questions.
- We will audio record your child's responses to the open-ended questions to make sure that we accurately capture everything he/she says. The content of these tapes will be transcribed and then the original tapes will be erased after the transcriptions have been checked for accuracy. All tapes will be kept in a locked filing cabinet in a locked research lab prior to destruction.
- The same survey will be administered at both time points to examine change in functioning during the elapsed six months.
- Your child will complete the survey with one staff member while you complete the caregiver survey with another staff member at the same time. Your child will complete the survey in a private room.
- Your child's counselor at Center for Good Grief will also be given a survey to complete questions regarding your child's therapy (number of sessions attended, engagement in care, and the therapeutic relationship).

## **POSSIBLE RISKS**

- To the best of our knowledge, participation in this study will cause no more than minimal risk and discomfort.
- Some youth may experience: embarrassment, distress, or upsetting emotions when discussing potentially sensitive topics of adverse life experiences (i.e., sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)), grief, psychological functioning, and family dynamics.
- An additional possible risk could be the negative consequences of having sensitive information shared in this study revealed.
- If your child becomes upset or concerned by the questions, or if your child wishes to get more information about any of these topics, please contact the study investigators, Angela Hamblen Kelly at 901-861-5656 or Dr. Kathryn Howell at 901-678-1541.
- Steps have been taken to protect your child's privacy and confidentiality by not linking your child's responses to his/her name.
- If, during the interview, your child experiences distress or discomfort, our study staff will connect you with clinicians at the Center for Good Grief.
- Your child also has the choice to end the study at any time or skip questions that feel uncomfortable.
- In general, researchers have taken steps to minimize the risks of this study, but there may be unknown risks.

## **RISKS TO PREGNANT WOMEN AND UNBORN OR NURSING CHILDREN**

Children who are pregnant are not eligible to participate in this study.

## **ALTERNATIVE TREATMENTS & CHOICES**

Your child may choose not to participate in this research.

## **POSSIBLE BENEFITS**

There is no direct benefit to your child for taking part in this research. However, some people find that answering questions like the ones included in the current study offer them insight into their own experiences and personal strengths. Your child's willingness to take part in this study may help other children who experience a loss by helping researchers and clinicians understand how adversity affects youth and their families. Once all participants have been interviewed, researchers will examine the data for patterns in risk and protective factors that may influence psychological well-being among youth and family members affected by a recent death. This information will help the Center for Good Grief enhance their services. It will also inform the development of new programs to improve well-being and inhibit negative consequences among bereaved youth and their families.

## **COSTS FOR PARTICIPATION**

Neither you nor your child are financially responsible for any aspect of this study. You will not be billed for your child's participation in this study, and there are no costs associated with participation.

## **COMPENSATION FOR INJURY**

In the event of psychological injury to your child from participation in this research study, Baptist Memorial Hospital Collierville, Kemmons Wilson Family Center for Good Grief (both Collierville and Midtown locations), and the University of Memphis do not have funds for patient compensation either for lost wages or for treatment; however you do not waive any legal rights by signing the consent. Therefore, Baptist Memorial Hospital Collierville, Kemmons Wilson Family Center for Good Grief (both Collierville and Midtown locations), and the University of Memphis do not provide reimbursement for such injuries.

## **COMPENSATION FOR PARTICIPATION**

Your child will receive a \$15 Target gift card as compensation for his/her time at each of the two interview time points. An additional \$15 Target gift card will be given to the child if he/she chooses to participate in the audio-recorded interview at the end of his/her questionnaire. He/she will be given the initial gift cards upon completion of the first interview. If your child begins the survey, but then chooses to end the interview early due to discomfort or distress, he/she will still receive the gift card for his/her time. Your child will be given the second gift card upon completion of the second interview, occurring 6 months after the first interview. If you and your child schedule a second interview with our research study and meet our study staff for the second interview but choose to end the interview early due to discomfort or distress, your child will still receive the gift card for his/her time.

## **CONFIDENTIALITY (HIPAA)**

### **What is the HIPAA Privacy Rule?**

The "Privacy Rule" is a Federal regulation under the Health Insurance Portability and Accountability Act (HIPAA) of 1996 that protects certain health information. It was issued by the government to make sure that your medical and health information is protected and not shared with others without your permission. Participants in research studies may be protected by this regulation. Most participants in research studies will need to sign an informed consent form which includes an Authorization for the use and release of certain health information.

**What is “Protected Health Information” (PHI)**

Protected health information (PHI) is information about you and your health. PHI collected in this study may include information about your mental health, as well as basic demographic information.

**Will this information be used and/or given to others?**

Information is collected for this study: To do the research; to study the results of the research, and to see if the research was done right.

Under federal privacy regulations, you have the right to determine who has access to your personal health information. By signing this consent form, you are authorizing the researchers’ access to your PHI collected in this study and to receive your PHI from the Kemmons Wilson Family Center for Good Grief where you have received health care.

There is the potential risk of loss of confidentiality. Every effort will be made to keep your information confidential; however, this cannot be guaranteed.

There are some situations when we will have to give your child’s information to others. For example, the law requires us to tell authorities if your child reports information about being abused, about another child being abused, or about an elderly person being abused. Additionally, if your child is a danger to themselves or someone else we will have to report this to authorities. If, during your child’s participation in the project, we have reason to believe that any child or elder person is a victim of abuse or neglect, we are required to report this information to the authorities. Abuse is defined as situations in which a person is suffering from, has sustained, or may be in immediate danger of suffering from or sustaining a wound, injury, disability, or physical or mental condition caused by brutality, neglect, or other actions or inactions of a parent, relative, guardian, or caretaker. Neglect occurs when a parent or caretaker allows a child to experience avoidable suffering or fails to provide basic essentials for physical, social, and educational development. Neglect, physical abuse, sexual abuse, and mental abuse are all reportable offenses. If we (i.e., the principal investigators, project coordinator, and study interviewers) become aware of child or elder abuse and/or neglect, we are required by law to report this to the applicable Department of Children’s Services or the Bureau of Investigation’s Crimes Against the Elderly in your state. If, during your child’s participation in the project, we learn that your child is in serious danger of hurting themselves or someone else, we are required to report this to local authorities, such as by calling 911.

**Research records**

All electronic research records will be stored on an encrypted computer where your child’s information is replaced with a code and password only known to the research personnel, except as required by law (such as reports of child abuse, harm to self or others, etc.).

When internet is not available, paper surveys will be given to participants rather than electronic surveys. These paper survey responses will be stored in locked file cabinets in locked rooms at the University of Memphis and will be accessible only to research personnel and the specified entities listed in this section, except as required by law (such as reports of child abuse, harm to self or others, etc.).

**Presentations/Publications**

Participant responses will be reported on as a whole. Individual responses will not be discussed in a way that would allow your child to be individually identified as a participant. Participants’ identifying details will not be provided in research reports or publications, and all final data will be anonymous and in aggregate form when published.

**Authorization to Use and Disclose Information for Research Purposes**

Most studies require authorization to use your child’s private health information, signing this consent form provides that authorization for this study. This section of the consent form is intended to inform you about how your child’s health information will be used or disclosed in the research study. Your child’s information will only be used in accordance with this informed consent form and as required or allowed by law. Please read carefully before signing.



Your child's PHI will not be used or disclosed to any other person or entity, except as required by law, or for authorized oversight of this research study by other regulatory agencies, or for other research for which the use and disclosure of your child's PHI has been approved by the IRB. Your child's PHI will be used only for the research purposes described in the Introduction of this consent form. Your child's PHI will be used until the study is completed.

### **Entities with Potential Access to your PHI**

The following parties are authorized to use and/or disclose your child's health information in connection with this research study:

- The principal investigator
- The research team
- Baptist Compliance Office
- Baptist Institutional Review Board - The Baptist IRB is a committee established to review and approve research involving human subjects. The purpose of the IRB is to ensure that all human subject research be conducted in accordance with all federal, institutional, and ethical guidelines. The mission of the IRB is to protect the rights and welfare of human research participants. The Baptist IRB may review your PHI as part of its responsibility to protect the rights and welfare of research subjects.

The parties listed in the preceding paragraph may disclose your child's health information to the following persons and organizations for their use in connection with this research study:

- The Office for Human Research Protection
- Federal and other regulatory agencies as required
- Researchers at the University of Memphis affiliated with this study
- Research Compliance and Audit personnel from the University of Memphis

Because of the need to release information to these parties, absolute confidentiality cannot be guaranteed. Your child's information may be re-disclosed by the recipients described above, if they are not required by law to protect the privacy of the information.

The results of this research study may be presented at scientific or medical meetings or published in scientific journals. Your child's identity will not be disclosed except as authorized by you or as required by law. However, there is always some risk that even de-identified information might be re-identified.

### **Confidentiality**

1. A random family number will be assigned to each family to link data from youth and their parents at multiple assessment time points. Your child's responses to the study surveys are not linked to your child's identifying information. The only tracking file connecting your family ID with your child's name is password protected and stored on a HIPAA compliant encrypted, password protected computer that is not connected to the internet for optimal security. This tracking file is stored separately from all study data.

2. All electronic records will be stored on an encrypted, password protected computer. All paper records will be stored in a locked filing cabinet in a locked room at the University of Memphis, to which only study staff have access. At the end of the study period all links between subject numbers and identifying information will be deleted and printed materials will be destroyed within one year following data collection and final analyses.

### **Cancellation of Authorization**

Your authorization for the use and/or disclosure of your child's health information will end on December 31, 2025 or when the research project ends, whichever is earlier.

If you terminate this authorization, continued use of your child's PHI already obtained before the termination is permitted and its use is necessary in completing the research. However, PHI collected after your termination of this authorization may not be used in this study. If you refuse to sign this authorization, your child will not be able to participate in this research study. If you terminate this authorization, then

your child will be withdrawn from the study. You may terminate this authorization in writing at any time by contacting the principal investigator listed on the first page of the consent form or study staff by sending a letter to this address: Kemmons Wilson Center for Good Grief (CGG) 1520 West Poplar Avenue Collierville, TN 38017

I understand that this authorization is voluntary and that I may refuse to sign this authorization. I understand that my refusal to sign does not affect payment for services, my ability to obtain treatment, or my eligibility for benefits or enrollment.

### **CONTACT FOR QUESTIONS**

Before you consent for your child to take part in this study, please ask us any questions that come to mind now. If you have questions, suggestions, concerns, or complaints about the study after you complete this interview, you can contact the study investigators: Angela Hamblen Kelly at 901-861-5656 or Dr. Kathryn Howell at 901-678-1541. We will give you a copy of this consent form to take with you.

If you would like to speak to a person who is not affiliated with this research study to discuss problems, concerns or questions, or to obtain information or offer input please call Rev. Anthony Burdick, Director of Pastoral Care, Baptist Memorial Health Care Corporation at 901-226-5025.

### **STUDY WITHDRAWAL**

If your child decides to take part in the study, your child still has the right to decide at any time that he/she no longer wants to continue. Your child will not be treated differently if he/she decides to stop taking part in the study.

Once your child withdraws and/or once you withdraw your permission, your child will not be able to continue in the study. No new data will be added to the database once you withdraw, but all data collected prior to withdrawal may still be used as part of the study.

Study involvement may be terminated after initiating the survey if you or your child chooses to terminate, or if the interviewer determines that your child has become overly distressed, is unable to follow directions, if the survey is more risk than benefit, or if the study has to end early for a variety of other scientific reasons. Additionally, your child's participation may be stopped without your consent if he/she fails to follow the guidelines outlined in this permission form. If the parent wishes to withdraw the child from the study at any other time, they may do so by contacting the study investigators: Angela Hamblen Kelly at 901-861-5656 or Dr. Kathryn Howell at 901-678-1541.

### **NEW FINDINGS:**

If the researcher learns of new information in regard to this study, and it might change your willingness for your child to stay in this study, the information will be provided to you. You may be asked to sign a new permission form if the information is provided to you after your child has joined the study.

CONSENT SIGNATURE PAGE TO FOLLOW  
**CONSENT FOR YOUR CHILD TO PARTICIPATE IN THE STUDY**

The research study, procedures, risks and benefits have been explained to me. I have read and understand all of the above, been given the opportunity to ask questions, and my questions have been answered to my satisfaction. I voluntarily agree to allow my child to participate in this research study. I will be given a copy of this signed and dated consent form for my own records. I do not give up any of my child's legal rights by signing this consent form.

\_\_\_\_\_  
Printed name of child

\_\_\_\_\_  
Signature of parent or individual legally authorized to consent to the child's general medical care

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of parent or individual legally authorized to consent to the child's general medical care

\_\_\_\_\_  
Signature of second parent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed name of second parent

If signature of second parent not obtained, indicate why: (select one)

- |  |   |
|--|---|
| <input type="checkbox"/> The IRB determined that the permission of one parent is sufficient. | <input type="checkbox"/> Second parent is incompetent   |
| <input type="checkbox"/> Second parent is deceased   | <input type="checkbox"/> Second parent is not reasonably available                                      |
| <input type="checkbox"/> Second parent is unknown  | <input type="checkbox"/> Only one parent has legal responsibility for the care and custody of the child |

\_\_\_\_\_  
Signature of person obtaining consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of person obtaining consent

- Assent
- |  |
|--|
| <input type="checkbox"/> Obtained  |
| <input type="checkbox"/> Not obtained because the capability of the child is so limited that the child cannot reasonably be consulted. |

## Appendix G Youth Assent Form

### YOUTH ASSENT FOR PARTICIPATION IN A RESEARCH STUDY

**Title of Study:** Resilience Uniting Bereaved Youth (RUBY)

**Funding Source:** None

**Investigator:** Angela Hamblen Kelly, LCSW, Director of Kemmons Wilson Family Center for Good Grief

**Participating Investigator:** Kathryn Howell, PhD from the University of Memphis

**Telephone:** (901) 678-1541

Ms. Angela Hamblen Kelly from the Center for Good Grief and Dr. Kathryn Howell from the University of Memphis would like to ask you and your parent (or the main person taking care of you) to be in a research study that they are doing with children like you who have had someone that they are close to die.

While your parent or caregiver is answering some questions, I will have questions for you, too. I'll ask you about yourself, your family, your feelings, things that are hard for you, and what you do when these hard times happen. We will also talk about the death of your loved one. The questions should take us about 1.5-2 hours. We'll answer these questions in a quiet, private room. We will also be asking your counselor some questions about how you two get along and how you have been doing in counseling. We will not be asking any personal questions about what you and your counselor talk about in therapy.

You will be asked to answer these questions twice: once now and again in 6 months. After you finish answering the questions each time, you will get a \$15 gift card to Target to thank you for your time. You will also have an opportunity to receive another \$15 if you choose to complete a recorded interview about your experience. You can skip any questions that you don't want to answer and stop any time you like. If you get upset and do not want to finish, we can stop the interview.

We will not use your name with any of your answers. The only time that I have to tell someone else your name, or any of your answers, is if I am required to by law. This includes if you are being hurt by an adult, or if you plan to hurt yourself or someone else. Does that sound okay to you?

Youth gives assent (agrees) to participate.

Youth would rather not participate.

Youth's Name and Age: \_\_\_\_\_

Youth's Signature: \_\_\_\_\_

Interviewer's Name: \_\_\_\_\_

Interviewer's Signature: \_\_\_\_\_

Date: \_\_\_\_\_