Healing the hearts of bereaved parents: Impact of legacy artwork on grief in parents whose children died of cancer

by

Megan Renee Schaefer

A dissertation submitted to the Graduate Faculty of
Auburn University
in partial fulfillment of the
requirements for the Degree of
Doctor of Philosophy

Auburn, Alabama
December 12, 2020

Keywords: legacy-making, bereavement, grief,
pediatrics, meaning-making

Approved by

Elizabeth Brestan-Knight, Co-chair, Full Professor of Psychology
Wendy N. Gray, Co-chair, Pediatric Psychologist at Children’s Hospital of Orange County
Steven K. Shapiro, Associate Professor of Psychology
Jesse S. Michel, Associate Professor of Psychology

Abstract

Approximately 12% of youth with cancer do not survive, representing a devastating loss for parents. Strategies to improve parent coping have been understudied, and no studies have examined the impact of legacy-making interventions on bereaved parents' grief. Though legacy-making activities are frequently offered as standard care to children with terminal illness and their families, these interventions have received little empirical attention in the literature. Furthermore, only one study exists on the impact of legacy-making interventions in pediatric populations. Thus, this study qualitatively explores the grief experiences of bereaved parents who have participated in legacy artwork with their child prior to his or her death from cancer. Twelve bereaved parents and 12 healthcare providers participated in individual semi-structured interviews guided by the Dual Process Model of Grief and Continuing Bonds theory. Parents also completed the Prolonged Grief Disorder-13 (PG-13), Beck Depression Inventory-II (BDI-II), and the Life Attitude Profile-Revised (LAP-R). Quantitative data were analyzed via descriptive and test statistics, and qualitative data was analyzed via conventional content analysis. Five themes emerged from the interviews. Legacy artwork 1) allows for family bonding and opens lines of communication between family members regarding the child's impending death, 2) provides opportunities for parents to engage in life-review and meaning-making of the child's death, 3) is often displayed in parents' homes and helps them continue their bond with their deceased child, 4) can ameliorate parents' grief and psychosocial functioning following the death of their child, and 5) may reduce compassion fatigue and burnout among healthcare providers as well as provide an outlet for coping with the death of their patients. There were no significant differences in grief, depression, and attitude towards life between parents who participated in legacy artwork versus the comparison samples. These findings suggest that participating in legacy artwork interventions may result in self-reported positive outcomes for bereaved parents prior to and following their child’s death including family bonding, enhanced communication, meaning-making, and improvements in grief. As a result of these benefits, pediatric palliative care programs may consider offering legacy artwork as an intervention for children with terminal illness and their families.

Acknowledgments

With boundless appreciation, I would like to extend my heartfelt gratitude and appreciation to the people who helped bring this dissertation into reality. I'm deeply indebted to my adviser, Dr. Wendy Gray, whose expertise was invaluable in the formulating of the research topic and methodology in particular. Her profound belief in my work and ability to complete this project was greatly appreciated. Additionally, I would like to acknowledge my colleagues, Scott Wagoner and Margaret Young, who were instrumental in assisting me with the qualitative analyses and who also demonstrated unparalleled support throughout the entire process. I would also like to thank Dr. Avi Madan-Swain, Dr. Michael Barnett, and Amy Brown from Children's of Alabama Hospital for their extensive knowledge and guidance regarding pediatric oncology, parental bereavement, and legacy-making. I am extremely grateful for the opportunities I was given to conduct my research and further my dissertation at Children's of Alabama. Furthermore, I cannot begin to express my thanks to the Society of Pediatric Psychology and the Auburn University Department of Psychology for their financial support of this project. I also had the great pleasure of presenting my proposal of this project at the St. Jude's Pediatric Palliative Care Symposium's Young Investigator Award Banquet, which was hugely beneficial in the development of this dissertation. I was honored to receive feedback from bereaved parents and renowned individuals in the field. Lastly, I want to express my sincere appreciation to all of the healthcare providers who generously donated their time to participate in this study as well as to all of the bereaved parents who courageously showed vulnerability in sharing their children's stories with me. May their children's beautiful legacies continue to live on through this work.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

PG-13	Prolonged Grief Disorder-13
BDI-II	Beck Depression Inventory-II
LAP-R	Life Attitude Profile-Revised

Healing the hearts of bereaved parents: Impact of legacy artwork on grief in parents whose children died of cancer

According to the National Cancer Institute (2014), approximately 15,780 children and adolescents are diagnosed with cancer per year. Although pediatric cancer research has significantly advanced in the last few decades, roughly 12 percent of youth diagnosed with cancer will not survive (Siegel, Ma, Zou, & Jemal, 2014). In fact, cancer still remains the leading cause of death by disease among youth post-infancy, leaving thousands of parents mourning their children's deaths yearly (Siegel et al., 2014). The death of a child is extremely difficult for parents to process as it goes against the natural order of life where children should outlive their caregivers (Wheeler, 2001). Losing a child often shatters parents' identities by disrupting their prized roles of provider and protector to the deceased child (Bowlby, 1980; Edelstein, 1984). When compared to other types of bereavement, parental bereavement has been described as a more intense and prolonged grieving process (Rando, 1986).

Currently, the literature evaluating parental perspectives on end-of-life care focuses on areas such as pain management, level of medical information provided by doctors, and assistance with end-of-life decision making (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Meyer, Burns, Griffith, & Truog, 2002). However, the research is scarce regarding the impact of complementary, supportive interventions on psychosocial functioning of children and their families in pediatric palliative care programs. Palliative care is defined as a specialized type of care offered to patients with terminal illness and their families that seeks to alleviate pain and suffering in the patient while improving overall quality of life for all involved (Pastrana, Jünger, Ostgathe, Elsner, & Radbruch, 2008). Quality of palliative care (e.g., perception of support from healthcare providers) leading up to the child's death appears to predict bereaved parents' long-term adjustment, thus highlighting the importance of providing optimal palliative care to both children and their families (McCarthy et al., 2010; Rando, 1986). In a study examining the circumstances surrounding the deaths of hospitalized children, researchers found less than one-third of families received interdisciplinary support (e.g., child life, pastoral care, psychology/behavioral health) during their time in palliative care (Carter et al., 2004). This appears to be a major gap in the pediatric palliative care literature, which is alarming given this subspecialty's mission to focus on achieving the best possible quality of life for children with terminal illnesses and their families (Liben, Papadatou, & Wolfe, 2008). Although health status is a large part of quality of life, the terminal illness experience also affects other areas of functioning, such as emotional and social, that need to be addressed just as importantly (Eiser & Morse, 2001). Research demonstrates that chronic illness not only impacts the child's quality of life but also directly affects their families' quality of life (e.g., parents, siblings), particularly when the illness has progressed to a terminal stage and death is imminent (Eiser, Eiser, & Stride, 2005).

Individual and Family Outcomes of Terminal Illness and Resulting Grief

Throughout a child's cancer journey, quality of life for the child and parents quickly declines due to the negative side effects from treatment (e.g., pain, nausea, lack of energy), long stays in the hospital, reduced work hours, and fears about the future (Eiser et al., 2005). In cases where the child dies of cancer, numerous negative consequences associated with parental grief have been identified, such as declines in psychological well-being (e.g., depression, anxiety), increased risk for psychiatric hospitalizations, somatic symptoms (e.g., loss of appetite, sleep disturbances, fatigue), immense anger and hostility, long-term mortality due to illnesses (e.g., cancer, cardiovascular problems), poor health behaviors (e.g., smoking, alcohol consumption), marital disruption (e.g., divorce), and a lower sense of purpose in life (Alam, Barrera, D'Agostino, Nicholas, & Schneiderman, 2012; Kreicbergs, Lannen, Onelov, & Wolfe, 2007; Li, Laursen, Precht, Olsen, & Mortensen, 2005; Li, Precht, Mortensen, & Olsen, 2003; McCarthy et al., 2010; Rando, 1986; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008; Wing, Burge-Callaway, Rose Clance, & Armistead, 2001). When combined, these negative outcomes result in dramatic reductions of quality of life in bereaved parents (Song, Floyd, Seltzer, Greenberg, & Hong, 2010). Additionally, many bereaved parents report feelings of incompetence for not being able to save their child, which leads to intense guilt (Barrera et al., 2007). Compared to other types of caregivers, mothers appear to express the most intense grief reactions to the death of a child (Alam et al., 2012).

Theoretical Frameworks of Grief

The Dual-Process Model of Grief (DPM) seeks to explain how individuals cope with the loss of a loved one (Schut, 1999). This model provides insight on individual differences in the ways that people cope with grief, thus allowing one to make predictions of good versus poor adaptation to bereavement (Stroebe & Schut, 2001). In this model, two categories of coping associated with bereavement are described: loss-orientation and restoration-orientation coping (Schut, 1999). Loss-orientation coping emphasizes grief work and processing the loss experience (e.g., concentrating on the loss, crying, talking with others about the deceased child), while restoration-orientation coping focuses on addressing secondary stressors associated with consequences of bereavement (Schut, 1999). This includes responding to stressors that result in reorienting one's self in the world without the deceased person (e.g., adjusting to life after child's death, focusing on parenting surviving children). The DPM presents a dynamic and flexible process in which the bereaved individual oscillates between loss-orientation and restoration-orientation coping (Schut, 1999). According to this model, confronting and avoiding aspects of both loss and restoration appear critical to healthy coping with bereavement. Therefore, individuals who focus on their loved one's loss in a controlled manner while also restoring their daily functioning will be classified as engaging in good adaptation to their bereavement experience (Barrera et al., 2007). On the other hand, individuals who focus too heavily on loss-orientation coping (i.e., overwhelming grief) or restoration-orientation coping (i.e., minimal grief) will most likely display poor adaptation to bereavement. Thus, a perfect balance between loss-orientation and restoration-orientation coping is necessary (Barrera et al., 2007). Prior literature shows that mothers tend to engage in more loss-orientation coping whereas fathers in more restoration-orientation coping (Meij et al., 2008; Schut, 1999).

Similar to the DPM, the Continuing Bonds theory is another popular grief theory (Klass, Silverman, & Nickman, 1996). This theory states that in order for bereaved individuals to come to a resolution with their grief over a loved one, they must develop a continuing bond with the deceased that is maintained over time (Klass et al., 1996). In parental grief, these continuing bonds may occur through the child's prized possessions, religious devotions, photographs, journal writing, or sharing memories of the child (Davies, 2004). Newer research has provided support for the critical role of continuing bonds in grief resolution, particularly in bereaved parents (Foster et al., 2011). Though the bond is no longer based on physical existence of the child, reconstructing a new internal relationship/connection with the deceased child and integrating his or her memory into a different shared reality appears essential in parental bereavement (Field, 2006; Rubin, 1981; Saiki-Craighill, 2002). Furthermore, bereaved parents reported that remembering and maintaining a bond with their deceased child provided a great source of healing and comfort, eased the transition from past to future times, and facilitated their coping during this traumatic time (Klass, 2001; Talbot, 2002). By continuing the bond, the deceased child remains present in the lives of their loved ones (Decinque et al., 2006; Price, Jordan, Prior, & Parkes, 2011).

Grief Interventions and Bereavement Support in Pediatric Palliative Care

Fortunately, preliminary evidence regarding the impact of complementary, supportive interventions on parents' psychosocial functioning throughout their child's illness journey appears promising. Positive feedback has been elicited by parents who have participated in music and art therapies with their child with a terminal illness (Knapp et al., 2008; Lindenfelser, Grocke, & McFerran, 2008). For example, bereaved parents reported that engaging in music therapy with their child was a healing process for both entities during this time of adversity, and this experience was a significant component of remembrance after the child's death (Lindenfelser et al., 2008).

Overall, long-term grief outcomes were better in parents who believed that healthcare providers were taking the initiative to provide extra support (e.g., safe space to discuss concerns, counseling, alternative activities) during and after their child's final months of life (Kreicbergs et al., 2007). Relatedly, research demonstrates that it is critical for pediatric palliative care providers to continue contact with the family after the child's death. Attending the child's funeral, holding remembrance ceremonies, planting memorial trees, releasing balloons, and sending follow-up sympathy cards are all supportive strategies that have been positively received by bereaved families when implemented by pediatric palliative care providers (Knapp et al., 2008). Evidence also exists for a nurse-led telephone support program in which nurses on the pediatric oncology unit periodically called bereaved families over a course of 13 months, providing psychoeducation and support especially during difficult anniversaries (Darbyshire et al., 2013).

By monitoring parents' psychosocial functioning throughout the child's illness, pediatric palliative care providers can better identify those parents who will be in critical need of mental health support following the child's death. Providing these parents with community supports such as mental health resources and local support groups has also shown to be effective in improving parental bereavement (Knapp et al., 2008). Bereaved parents desire to establish relationships with other parents who similarly understand their experience, thus highlighting the importance of facilitating support groups among parents whose children have died (Decinque et al., 2006). In summary, continuing to identify supportive interventions during this difficult time for children with terminal illness and their families is essential in improving the overall quality of pediatric palliative care both prior to and following the child's death.

Legacy-Making

Legacy-making is a fairly novel intervention that was designed specifically for individuals with terminal illness, whose deaths are anticipated, and their families (Foster et al., 2009). Allen and colleagues (2008) described legacy-making activities as "projects that may 1) assist individuals and families in initiating the process of life review, and 2) resulting in a product that can be enjoyed by family and friends prior to and after the individual's death" (Allen, Hilgeman, Ege, Shuster Jr, & Burgio, 2008, p. 1030-1031). Creating a legacy piece such as a painting, scrapbook, or music album, allows patients with terminal illness the opportunity to leave a physical object representative of their identity behind (Foster et al., 2009). Though legacy-making is being implemented in palliative care settings across the country, the effectiveness of this activity has received little empirical attention in the literature.

Connection of Legacy-Making to Meaning-Making

Finding meaning in response to the loss of a loved one is a core element in coming to terms with one’s grief (Neimeyer, 2000). Initially after a death, the bereaved may focus on finding an answer to the question of why their loved one died. This questioning may progress into identifying the positives that potentially resulted from the loss (Neimeyer, 2000). By creating or reconstructing meaning, bereaved individuals are able to integrate their painful loss into a redefined identity with new meanings, goals, and purposes (Barrera et al., 2009). Previous research demonstrates that legacy-building promotes meaning-making (Kobler, Limbo, & Kavanaugh, 2007). When individuals with terminal illness request their loved ones to join them in co-creating a legacy piece, they are initiating the first step in encouraging their family to find and reconstruct meaning from this adverse experience (Kobler, Limbo, & Kavanaugh, 2007).

Most legacy pieces become a dialogue of meaning that individuals with terminal illness want shared with the world after their death. For example, a child may create a legacy artwork piece centered around his favorite superheroes saving the day. When his bereaved mother views this piece, she may engage in meaning-making by drawing on the memories of this child’s legacy and his courageous spirit that inspired and continues to inspire those who knew him. She may begin to reformulate the child’s purpose in life (e.g., inspiring others) and thus strive to carry on his legacy by fundraising money for pediatric cancer research or volunteering at a local children’s hospital. In conclusion, the relationship between legacy-building and meaning-making appears to ameliorate the negative symptoms associated with grief and lead to greater appreciation of new aspects of life following the child’s death.

Legacy-Making Interventions in Adults with Terminal Illness

In adults approaching the end of life, legacy-making interventions have been favorably received by both patients and their caregivers in four studies. Firstly, Chochinov and colleagues (2005) implemented dignity therapy, a form of legacy-making, with terminally ill patients, which invited patients to openly discuss their personal legacies or what they would hope their loved ones to remember most about them. The sessions were transcribed and edited, and the patients were given the opportunity to gift their loved ones with the final version. After participating in the intervention, patients reported that dignity therapy helped bolster a sense of meaning and purpose to their lives, reduce suffering, and increase their will to live (Chochinov et al., 2005). Not only did dignity therapy benefit the patients, but they also claimed that this intervention positively impacted their family members and would continue to help them following the patient's death (Chochinov et al., 2005).

Following this novel study, new researchers conducted a qualitative study examining the experiences of adult patients with terminal cancer (Coyle, 2006). Participating in legacy-making was deemed as important, urgent, and time-sensitive by all participants. Many described their legacy pieces as "bridges between existence and non-existence," thus indicating that their legacies would live on following their death (Coyle, 2006). Another study examined the efficacy of a family-based legacy-making intervention in older adults with life-limiting illnesses by comparing differences between the intervention and control group (Allen et al., 2008). The legacy interventions varied from writing stories, creating scrapbooks, and videotaping special moments. Familial outcomes of legacy interventions were the target of this study. Upon the completion of legacy-making, caregivers in the intervention group demonstrated more positive outcomes than the control group such as reduced caregiving stress, decreased breathing difficulties, increased religious meaning, and improved social interactions with the ill family member (Allen et al., 2008).

Most recently, a group of researchers qualitatively examined legacy-making in young female adults with cancer (Keim-Malpass, Adelstein, & Kavalieratos, 2015). Each young woman created an illness blog that tracked her journey with cancer, documenting her thoughts, feelings, and special memories. Results demonstrated positive benefits for the young women as creating illness blogs allowed them to engage in life-review and leave behind a public display of words, pictures, and life experiences for their loved ones to remember after their death. Additionally, these illness blogs provided a unique opportunity for families to commemorate the legacy of their loved one by keeping the blog updated (Keim-Malpass et al., 2015). Based on these four studies in adult populations with terminal illness, legacy interventions appear to hold promise for both patients and their families.

Legacy-Making Interventions in Youth with Terminal Illness

Compared to adult populations, literature on legacy-making interventions in pediatric populations with terminal illness is scarce. Youth with terminal illness often report a desire to be remembered by their loved ones after their passing (Foster et al., 2009). Legacy-making assures youth that they will always be loved and never forgotten, regardless of their physical presence in the world (Levetown, Liben, & Audet, 2004). Additionally, legacy activities offer a heartwarming opportunity for children to express themselves and create lasting memories with their families (Levetown et al., 2004). For children whose deaths can be anticipated, legacy-making activities provide them with a modality to influence, inspire, and comfort their loved ones while also preparing them for their impending death (Foster et al., 2009). Children can create legacies intentionally or serendipitously by making crafts for others, willing away their belongings, writing letters to loved ones, giving special gifts, or setting examples of living courageously (Foster, Dietrich, Friedman, Gordon, & Gilmer, 2012; Foster et al., 2009). From a familial perspective, creating physical legacy pieces gives the family members a tangible way to remember the child (Foster et al., 2012).

Currently, only one study exists on the impact of legacy-making interventions in pediatric populations. Foster-Akard and colleagues (2015) conducted a study that was primarily focused on examining the feasibility of digital storytelling in children with cancer. In addition to feasibility, preliminary effects of the legacy-making intervention on outcomes related to quality of life were also reported by comparing differences between the intervention and control group (Akard et al., 2015). Similar to Chochinov et al's (2005) study with adults, the researchers video-recorded interviews with children in which they described legacy topics such as their personal characteristics (e.g., appearance, personal traits), the things they like to do (e.g., hobbies, interests), and their connectedness with others (e.g., telling family members how much they are loved). These video recordings were provided to the families after completion (Akard et al., 2015). From the parents' perspectives, creating digital stories helped their children express their feelings, cope with their illness, and feel better in all quality of life realms (e.g., emotionally, socially, physically, spiritually). Additionally, parents reported that the digital stories provided emotional comfort, improved their coping, and facilitated communication between themselves and their children (Akard et al., 2015). Overall, feasibility was strong for the implementation of digital storytelling, indicating that legacy-making has the potential to improve quality of life in children with terminal illness and their families while the child is alive (Akard et al., 2015). However, no study has examined the impact of legacy-making activities on parents' bereavement following the death of their child.

Rationale and Goals for the Current Study

In a national survey of children's hospitals on legacy-making activities, 97% of hospitals included in the survey (N= 77) reported offering some type of legacy-making as standard care to children with terminal illness and their families (Foster et al., 2012). Though this activity is commonly offered to families, 90% of the respondent healthcare professionals who implemented these interventions believed that more research is needed on legacy-making to better understand its impact and to determine whether it's a worthwhile and valuable intervention for youth and their families. Specifically, additional research examining more individualized legacy-making activities and their impact on psychosocial outcomes as well as investigating legacy-making's role in parents' bereavement is needed (Foster et al., 2012).

In order to optimize pediatric palliative care, we need to identify proactive and supportive interventions that will positively impact the family following the traumatic event of their child's death. Research on joint grief interventions tailored toward both children with terminal illness and their families is lacking. Although one study exists detailing preliminary parent and child outcomes from legacy-making (Foster et al., 2009), no studies have examined the impact of a legacy-making activity on parental grief following the death of their child from cancer. Relatedly, the previously mentioned study only focused on digital story-telling. Therefore, it is critical for researchers to follow the adult literature by examining additional specific legacy-making activities (i.e., art, music) in order to understand whether differences exist between modalities. Overall, the research on legacy-making in children with terminal illnesses and their families is scarce with little empirical evidence to support its implementation. This is problematic given the high percentage of its utilization in pediatric hospitals (Foster et al., 2012).

The current study explores the grief experiences of bereaved parents who participated in a specific legacy-making intervention (e.g., legacy artwork) facilitated by an art therapist with their child with terminal cancer. Legacy artwork was chosen as the specific activity because art-based approaches provide substantial opportunities for self-expression (Romanoff & Thompson, 2006). In addition, healthcare provider perspectives on legacy artwork were also examined due to their direct involvement with these children and their families in creating the artwork and providing bedside palliative care. Healthcare providers are considered the gatekeepers to this activity as they are the ones who refer their patients to the art therapist for legacy-making. After the death of the child, these healthcare professionals often provide periodic follow-up calls to the bereaved families, which gives them insight into the families' psychosocial functioning and grief journeys. Thus, healthcare providers are in an excellent position to comment on the impact of legacy-making activities on bereaved parents.

Given the emerging nature of this field, a mixed-methods approach is utilized with a heavy emphasis on qualitative exploration. Theories on legacy-making are currently in progress due to the novelty of this activity; thus, no quantitative measures have been created to specifically examine the legacy artwork experience. However, within this study, quantitative measures were administered to assess parent outcomes (i.e., grief, psychosocial functioning, attitude towards life) following their child's death. Additionally, because engaging in legacy artwork with a terminally ill child is a very unique and individualized experience for each family, a purely quantitative approach would not capture the complexity and distinctiveness of each family's story. Information obtained through this mixed-methods approach will guide future quantitative research as well as provide valuable information on the usefulness of incorporating legacy artwork into pediatric palliative care programs.

Method

Participants

Approval from the hospital and university's Institutional Review Board (IRB) were obtained before any recruitment procedures began. Participants were bereaved parents/caregivers of children who were hospitalized for cancer and had received treatment in a children's hospital located in the Southeastern United States. As is recommended in qualitative research, recruitment continued until data saturation was reached (Guest, Bunce, & Johnson, 2006). Data were considered saturated when no additional information was learned from subsequent interviews (Guest et al., 2006). The bereaved parents/caregivers were drawn from a sample of approximately 40 families who had participated in creating legacy artwork with their children.

Inclusion criteria for parents/caregivers were defined as the following: 1) experienced the death of a child from cancer, 2) at least 6-months had passed since death of the child, 3) their child participated in a legacy artwork activity (e.g., paintings, clay sculptures) with the art therapist, 4) parent/caregiver was age 19 years or older, and 5) parent/caregiver was English speaking. The time-frame of 6-months post-death was chosen based on study results reporting that grieving families agreed to study participation at around six months post-death, on average (Akard et al., 2014). Additionally, those families who requested no further contact from healthcare providers after the child's death were excluded from the study (*n*= 5). All bereaved parents/caregivers were compensated $75 for their time and efforts and also received a personalized thank-you note for their participation in the study.

In addition to bereaved parents/caregivers, a sample of healthcare providers drawn from a 50-person in-patient medical team were interviewed. Providers were currently members of the integrated pediatric oncology team at the hospital or had previously held a position within the last 10 years. Financial compensation was not offered to the healthcare providers upon completing the study, but they received a personalized note thanking them for their contributions.

Procedure

Because this study was intended to recruit a diverse sample, different recruitment strategies were used depending on the target population.

Bereaved Parents/Caregivers

Eligibility for parent/caregiver participants was proactively determined by accessing the pediatric oncology department's database of deceased patients which included information such as the child's diagnosis, date of death, mailing address, and phone numbers. Following this initial screening, a two-step recruitment procedure was implemented. First, potential participants were mailed a recruitment letter specifically detailing the purpose of the study, the rationale for selecting them as possible participants, and a brief review of the procedure along with two copies of the informed consent form and a demographic questionnaire. In the recruitment letter, potential participants were provided with a brief introduction from the principal investigator, describing her background and experience in working with this population. They also received the investigator's contact information (e.g., phone number and email address) in order to express interest in participating in the study as well as a note stating that she would follow up with them via phone in two weeks. The recruitment letter was signed by the principal investigator, the pediatric psychologist working with the oncology population, and the oncology/pediatric intensive care unit teams at the hospital to promote familiarity with the healthcare providers that supported them throughout their child's illness experience. Second, the principal investigator conducted follow-up phone calls using an IRB-approved script approximately two weeks after the recruitment letters were mailed. The purposes for the follow-up call were to confirm whether families had received the mailed information, to provide a more detailed explanation of the study, to answer the families' questions, and to gauge interest in study participation. Throughout the call, the principal investigator focused on personalization by referring to the parents/caregivers and the deceased child by their names. To lessen emotional distress during the recruitment process, researchers avoided mailing letters and calling families around the child's birthday, his or her death anniversary, and other holidays. Passive refusal was determined after three call attempts (Akard et al., 2014), and no further recruitment contacts were attempted. Thirty-eight recruitment letters were mailed to families. Of the 38 letters sent, five were returned to sender due to a change of address since the child's death. After sending the recruitment letters, the principal investigator successfully initiated contact with 75% of the remaining 33 families via phone. The phone numbers of the other 25% of potential participants were disconnected.

After expressing interest in the study, participants were presented with two options regarding the completion of consent forms and the demographic questionnaire: 1) to choose to send them in the mail or, 2) to choose to scan the document and email it to the investigator. Once consent and the demographic form were obtained, the principal investigator scheduled an in-depth, semi-structured interview with the bereaved parents/caregivers focused on their experiences engaging in a legacy artwork project with their child, the activity's impact on their grieving process, and feedback to improve the service for future families. Quantitative measures examining outcomes for parents/caregivers following their child's death were administered after the interview.

Healthcare Providers

A selected sample of healthcare providers with direct involvement in oncology, palliative care, and/or the legacy artwork experience were recruited through an email describing the study, sent by the psychosocial director of the pediatric oncology department. After sending the email, the psychosocial director followed-up individually with each of the selected healthcare providers to determine their interest in study participation. Those who were interested received two copies of the consent form explaining the background, procedure, and aims of the study. The primary investigator reviewed the consent form with providers before participation. Healthcare providers took part in a similar semi-structured interview but one that was tailored to their individual perceptions of legacy artwork's impact on bereaved parents/caregivers' grief following the death of their child. They were asked to provide feedback on how to improve the legacy artwork experience for families. Interviews were scheduled at a time of convenience for healthcare providers; thus, their busy work schedules were accounted for when trying to find an ideal time to conduct the interview. After participating in the interview, they also completed a demographic form.

Measures

Qualitative Interview

Development of measure and theoretical underpinnings. A 30 question semi-structured interview was created by the principal investigator, based on her current experiences working with families of youth who died of cancer (See Appendix 1). To protect the vulnerability of the participants, the principal investigator carefully selected the questions and focused on wording them in a sensitive manner. Questions were influenced by previous studies that have specifically examined the grief experiences of bereaved parents (Currie et al., 2016).

Most importantly, the development of the interview was guided by two prominent grief theories, the Dual-Process Model of Grief and Continuing Bonds (Klass et al., 1996; Schut, 1999).

Following the initial development of the interview, the principal investigator sent the interview to a panel of experts (e.g., pediatric psychologists, pediatric palliative care physician, bereavement coordinators) in psychosocial concerns, grief, palliative care, pediatric oncology, and qualitative methodology to contribute face and content validity for the interview questions and structure. Based on their expertise, they provided feedback on the questions included in the interview, specifically identifying words or phrases that may be perceived as insensitive or confusing/difficult to interpret. The questionnaire was revised according to their inputs and edits in order to complete the final version of the interview, which was focused primarily on understanding bereaved parents/caregivers' legacy artwork experience coupled with its impact on their grief after their child's death. Other questions regarding the influence of legacy artwork on their child's quality of life, their perceptions of their child's perspectives for the activity, and feedback to improve the legacy artwork program were also included. Each interview started with open-ended questions and progressed to more specific and targeted questions. The healthcare provider version of the interview similarly matched the parent/caregiver's version but was more tailored to their professional perspectives of legacy artwork's impact on bereaved parents/caregivers' psychosocial outcomes.

Database of Deceased Patients and Medical Records

For those who consented to participate, specific medical history information was extracted from the database of deceased patients maintained by the institution's pediatric oncology department. Examples included type of cancer, specific reason for death, number of relapses, date of death, amount of time the child endured cancer, and additional complications that ensued following the cancer diagnosis. The principal investigator also had access to the child’s medical records if the parents/caregivers agreed to sign the authorization for use/disclosure of protected health information which was attached to the informed consent document.

Demographic Questionnaire

A demographic questionnaire tailored to bereaved parents/caregivers was created specifically for this study (See Appendix 2). Information such as age, gender, marital status, and relationship to child (e.g., parent, grandparent) were solicited. The demographic questionnaire for healthcare providers was shorter, and the included questions asked for basic demographics (e.g., age, gender) and professional history (e.g., type of profession, years of experience, level of training).

Prolonged Grief Disorder (PG-13)

Parents/caregivers’ prolonged grief symptoms were measured using the Prolonged Grief Disorder (PG-13) questionnaire (Prigerson, Vanderwerker, & Maciejewski, 2008). This is a 13-item self-report measure that has been reliably (Cronbach’s alpha= .82) used as a diagnostic tool (Prigerson, Horowitz, & Jacobs, 2009). Items within the measure assess the frequency and intensity of prolonged grief symptoms on a five-point Likert scale. Scores range from 11 to 55. Prior research provides evidence for a cutoff of 34 in the bereaved, which distinguishes those individuals who have significant mental health problems related to their grief from those who tend to display less impairment in psychosocial functioning (Prigerson, Vanderwerker, & Maciejewski, 2008). Clinical levels of prolonged grief were determined by the diagnostic algorithm offered in the scoring manual of the PG-13 (Prigerson, Vanderwerker, & Maciejewski, 2008).

Beck Depression Inventory- Second Edition (BDI-II)

Psychosocial functioning of the bereaved parents/caregivers was measured via the Beck Depression Inventory- II (Beck, Steer, & Brown, 1996). This is a 21-item self-report measure that asks participants to rate the extent to which they have experienced depressive symptoms during the past two weeks on a four-point Likert scale. Total scores range from zero-63, with higher scores indicating higher levels of depression. Specific cutoff scores have been established to determine the level of depressive symptoms a participant is experiencing (i.e., zero-13: minimal; 14-19: mild; 20-28: moderate; 29-63: severe). Thus, total scores of 20 or higher indicate levels of depressive symptoms associated with clinical depression (Kendall, Hollon, Beck, Hammen, & Ingram, 1987). The BDI-II is considered a highly reliable (Cronbach's alpha= .91) and valid instrument in distinguishing those respondents whose depressive symptoms meet criteria for clinical depression compared to those who are experiencing less severe symptoms and has been supported in bereaved populations (Beck et al., 1996; Znoj & Keller, 2002).

Life Attitude Profile Revised (LAP-R)

Participants' purpose and meaning of life were assessed with the Life Attitude Profile-Revised questionnaire (Reker, 1992). This is a 48-item reliable (Cronbach's alpha= .86) and valid instrument which includes the following six dimensions: Purpose (i.e., having life goals, having a mission/sense of direction in one's life), Coherence (i.e., having a consistent understanding of self, others, and life), Choice/Responsibility (i.e., perception of having personal agency in directing one's life), Death Acceptance (i.e., whether a person has achieved death transcendence), Existential Vacuum (i.e., having a lack of meaning, goals, and direction in life), and Goal Seeking (i.e., searching for new and different experiences and an eagerness to get more out of life) (Reker, 1992). Domain scores such as the Personal Meaning Index and Existential

Transcendence can be derived. This measure has been shown to be predictive of many outcome variables including psychological well-being and life satisfaction (Reker, 1992).

Administration of Measures

Interview. Each one-on-one interview was conducted by the principal investigator, who had three years of clinical interviewing and therapy experience along with a Master's degree in Clinical Psychology. The researcher displayed flexibility by allowing the time, location, and modality of the interview to be dependent on participants' preferences, convenience, and comfort levels. Possible options included a phone interview or an in-person interview at either the participant's home or the children's hospital. Presenting various locations and modalities of the interview are methods grounded in prior literature examining bereaved individuals and emphasizes the importance of granting bereaved participants some sense of control over the research process (Kavanaugh, Moro, Savage, & Mehendale, 2006). Prior research examining bereaved parents' experiences with grief found that some families preferred an additional location besides the hospital, due to the potentially traumatic memories associated with this particular setting (Currie et al., 2016). Additionally, parents may desire to process this emotionally intensive topic in the comfort of their own home (Currie et al., 2016).

In addition, the healthcare providers in this study were offered interviews via the phone or in-person at the hospital. Though the interviews were expected to last one to two hours, participants guided the duration of the interview based on the amount of information they were willing to share regarding their experience with legacy artwork and with grief following their child's death. All interviews were audio-recorded for data transcription and analysis purposes. These extra measures were necessary to avoid the potential loss of data.

Prior to the start of the interview, the principal investigator planned for additional time with the bereaved parents/caregivers to reinforce rapport-building and enhance the comfort level between the interviewer and the participant. This additional rapport-building time included looking at the child's mementos, the legacy artwork project, and/or photographs of the child.

Once the interview began, all participants were reminded of the purpose of the study. The interviewer explained that there were no right or wrong answers to questions asked in the interview, thus emphasizing the importance of providing honest answers. Participants were assured that it was acceptable to skip any questions that may elicit feelings of discomfort or psychological distress and that they have the right to withdraw from the study at any time. All participants were encouraged to request clarification on questions with confusing or unclear phrasing.

The interviewer facilitated the semi-structured interviews with participants by following a scripted format. Other than querying the participants for more information, the interviewer did not deviate from the questions presented in the script. Participants were encouraged to request breaks as needed throughout the interview. Because this interview had the potential to evoke negative emotions in participants, the principal investigator secured access to licensed psychologists if the need to seek supervision during an interview arose. When suicidal ideation was mentioned in the interview or endorsed on the BDI-II, the principal investigator consulted with a licensed psychologist and followed a standard protocol that would be used in a therapy session if this circumstance occurred (i.e., risk assessment, creating a coping card with the parent/caregiver). The licensed psychologists were also available on an as-needed basis to debrief the interviews with the principal investigator. These debriefings primarily included conversations related to processing the content of the interview and were initiated by the principal investigator when she needed additional support due to the emotionally intensive nature of topics discussed.

After all of the questions in the parent/caregiver interview were asked, the interviewer inquired what it was like to participate in the interview (Currie et al., 2016). This closing question alerted the investigator to any problems the interview may have caused the parents/caregivers and allowed the investigator a chance to respond to suggestions for future participants (Kavanaugh et al., 2006). Throughout the interview, the principal investigator recorded those questions that elicited behaviors associated with crying to determine which questions were most difficult to answer. Following the completion of the interview, the principal investigator provided a list of additional grief resources such as local mental health providers and support groups to the bereaved parents/caregivers. Lastly, both bereaved parents/caregivers and healthcare providers were asked whether they were interested in participating in member checking via telephone or email. Member checking involves participants receiving the initial analysis of the deidentified results in order to provide them with an opportunity to verify the findings and clear up any misconceptions. This validation strategy of soliciting participants' feedback is commonly utilized in qualitative research to establish support claims for the credibility of the findings (Creswell & Poth, 2017).

Quantitative measures. Following the interview, bereaved parents/caregivers were asked to complete the PG-13, BDI-II, and LAP-R. Like the interview, participants were given several options to complete these measures. These included filling out the measure in-person, completing it online via Qualtrics, or scanning a copy of the completed version and emailing it to the principal investigator.

Data Management

Participant signed consent forms were stored in a locked file drawer in a secure laboratory located in Cary Hall Room 128. Audio files were downloaded on a secure network drive immediately after completion of the interview and were only accessible to the principal investigator and her research team members. After the data were downloaded onto the shared drive, copies on recording devices were deleted. Data from the demographic questionnaire and other quantitative measures were retained in a hardcopy form and were entered into an SPSS database that was also saved onto a secure network drive. All participants were assigned a subject identifier to protect their confidentiality. Because the interviews were audio-taped, identifying data was linked with the participant's data. However, upon transcription of the interviews, all identifying information was removed from the data. Throughout data analysis, pseudonyms were used to replace identifying information of deceased children, parents/caregivers, and healthcare providers.

Thematic Analyses

Regarding the qualitative data, all interviews were first transcribed verbatim by trained undergraduate research assistants. In addition to participants' verbal responses, specific behaviors such as laughing and crying (i.e., witnessing crying during in-person interview, hearing a sniffle, hearing a break in the participant's voice) were recorded throughout the transcription process. Each interview transcription was checked a second time for accuracy by one of a group of other research assistants who did not create the original transcription.

Researchers analyzed the qualitative data using conventional content analysis, which is a qualitative approach commonly used to analyze data from open-ended questions (Hsieh & Shannon, 2005). Though prior research exists on the Dual Process Model of Grief and Continuing Bonds theory, an inductive approach was chosen for data analysis to allow the researchers to discover emerging codes within the data, given its specificity to the legacy artwork experience (Klass et al., 1996; Schut, 1999). Therefore, the first step of content analysis involved immersion within the transcripts by three independent researchers, all of which were graduate students holding a Master's degree in Clinical Psychology. Each researcher engaged in open coding, which included repeatedly reading the transcripts to gain a sense of the data as a whole and then identifying similar concepts that reoccur often. After a group discussion, the three researchers created the codebook by classifying the reoccurring concepts in the interviews as preliminary codes, or succinct basic analytic units.

Following the creation of preliminary codes, each transcript was coded by the same three independent researchers. Each researcher received specific training on qualitative coding and the initial codebook from the principal investigator before beginning the official process. The training also involved detailed discussions regarding the definitions of each code as well as potential examples of data that would match each code. After the initial training on the codebook, the other two researchers engaged in coding exercises with practice transcripts developed by the principal investigator. The threshold to establish reliable coding before beginning official data analysis was 80% agreement among researchers. All researchers met periodically to discuss whether additional codes needed to be added to the codebook as new topics emerged in the data. After the first phase of coding was complete, all three researchers met to discuss their results. When discrepancies arose, the researchers conducted a vote for consensus. Interrater reliability among researchers was high (κ= .84) in the first phase of coding.

In the next phase of coding, the three researchers grouped similar codes into broader conceptual categories by examining the continuous interactions between codes in the individual transcripts. Once conceptual categories were identified, the process of thematic analysis was initiated. Themes are defined as the highest level of qualitative analysis and are generally overarching summaries of the identified conceptual categories. Interpretive themes from the study were thus determined by summarizing and looking for interrelationships among the most prevalent conceptual categories. Those conceptual categories that occurred most frequently were deemed major themes, and those that occurred less frequently but still offered valuable information were reported as minor themes. Because themes were identified through multiple group discussions, the interrater reliability for thematic analysis was 100%.

Following the creation of themes, the investigator sent the current results to those participants who agreed to participate in member checking, a validation technique in which participants are invited to check the qualitative results for accuracy and resonance with their experiences. After receiving their feedback regarding the accuracy of the results, the investigator incorporated their suggestions in the final reporting of the manuscript.

Statistical Analyses

Quantitative data from the demographic questionnaire was analyzed via descriptive statistics. To help place the brief quantitative findings in the context of broader literature, the principal investigator compared the participant-reported results on the psychosocial measures (i.e., grief, depression, attitude towards life) to that of other published studies examining the same outcomes in bereaved parents of children who died of cancer (Lichtenthal et al., 2015; McCarthy et al., 2010). These comparisons were made via independent samples t-tests using the published means and standard deviations of each comparison population. These values were then compared to those of the reference group of participants in this study.

Given the potential for extreme responses to significantly skew the data due to small sample size, quantitative data were examined for outliers. An outlier was defined as a data value that is unusually large or small compared to values of the same construct (Aguinis, Gottfredson, & Joo, 2013). Outliers were identified via a standard deviation analysis and a box plot. More specifically, data points with a distance of two standard deviations above or below the mean and those that fell beyond the boxplot's whiskers were excluded prior to running descriptive and test statistics (Aguinis, Gottfredson, & Joo, 2013). With regard to prolonged grief, one participant's data were excluded. Investigators chose to exclude this particular case due to the abovementioned quantitative criteria for an outlier. In addition to the quantitative criteria, this participant's demographics (e.g., recency of child's death, length of child's cancer treatment) rationalized the decision to exclude the data as this participant's experience appeared markedly different than those reported by other participants.

Throughout the research process, the principal investigator engaged in reflexivity by keeping a journal that included self-reflections, personal biases, and subjectivity. This journal was also a means for keeping a detailed audit trail with theoretical, methodological, and coding memos (Creswell & Poth, 2017). More specifically, this audit trail documented the investigator's thinking process ranging from changes in methodological design, to tracking the evolution of codes, and theme development per data analysis session.

Ethical Considerations

Though bereaved individuals are considered vulnerable populations in research due to the nature of their experiences, it is important to clarify that in prior studies, these participants described their research involvement as therapeutic and empowering (Currie et al., 2016; Dyregrov, 2004). Many bereaved individuals reported a positive experience due to the opportunity to share their story, to express their pain and feelings, to process their bereavement experience, and to help others who are grieving (Dyregrov, 2004). Similarly, others stated that talking about their bereavement experience with a researcher helped them heal and find meaning in their loss (Dyregrov, 2004). When deciding on whether conducting a research study examining vulnerable populations is worthwhile, the risk/benefit ratio always needs to be considered. Though eliciting emotional distress is certainly a risk in this study, it seems that the benefits outweigh the risks. Data on palliative care interventions are limited, given that experiencing the death of a child is rare for parents (Akard et al., 2013). By participating in this study, bereaved parents/caregivers can provide valuable insights on developing interventions for future families who will similarly experience the death of a child.

Results

Participants

Bereaved parents. Out of 38 eligible families, 12 bereaved parents participated in the study. Common reasons for study refusal included a lack of interest (24%) and busy schedules (8%), with 32% never returning the investigator’s follow-up phone call. Recruitment ended after the 12th parent due to confirmation that data saturation had been reached. Eleven of the parents completed both portions of the study whereas one parent elected to only participate in the interview. Mothers comprised 83% (10 participants) of the sample while only two fathers participated. All participants were Caucasian. The average age of parent participants was 41.17 years old, and most identified as Christians (92%). The mean length of time elapsed since child death was 3.17 years (SD= 40.8 months, range= seven months-10 years). Participant parent demographics are presented in Table 1.

In regard to the demographics of their children, 50% were male. The average age of the child at time of cancer diagnosis was 6.05 ± 5.54 years old (range: 3 months-19 years old). Most children were diagnosed with a subtype of leukemia (50%). Sarcomas (25%) and brain tumors

(25%) comprised the remainder of diagnoses in this sample. The age of the child at his or her time of death ranged from eight months to 21 years old with a mean age of 8.64 ± 5.73 years old. Refer to Table 2 for additional demographics of the children.

Healthcare providers. Twelve healthcare providers participated in the study. The healthcare providers represented a variety of medical professions including three art therapists, two child-life specialists, two pediatric hematologists/oncologists, two registered nurses, a nurse practitioner, a palliative care physician, and a chaplain. These healthcare providers averaged approximately 7.75 years of experience working with the pediatric oncology population. Additional healthcare provider demographics are reported in Table 3.

Legacy Artwork Experience

The length of interviews ranged from 45 minutes to four and a half hours, with one hour and 15 minutes being the average. Fifty-eight percent of parents chose to participate in the interview via a phone call while the remainder (42%) preferred an in-home interview. Fifty-eight percent of interviews with healthcare providers also occurred over the phone. For both parents and healthcare providers, data saturation was believed to be reached by the 10th interview. However, two additional interviews were conducted with each informant group to confirm this.

The type and content of legacy artwork projects varied among participants. Paintings (83%) were the most common project endorsed by families and providers, but other modalities of art reported by families included graffiti (8%), bronze molds (8%), and collages (8%). Some families (33%) noted that they created more than one type of legacy artwork project with their child. Healthcare providers also mentioned clay molds, plaster sculptures, and wall murals. Many projects included the child’s handprints and/or footprints. Eighty-three percent of parents reported that the art therapist introduced the project to them, whereas the remaining 17% stated the child-life specialist was the first provider to mention legacy-making to them. Most projects (95%) were described as family art projects, meaning the patient, siblings, and parents were all involved in the creation under the facilitation of the art therapist. Two bereaved parents noted that their children had limited mobility and significant cognitive impairments at the time of creation but were still able to participate in the project with the guidance of family members. Although healthcare providers reported that most families chose to participate in legacy artwork when offered, reasons for refusal of participation included denial of the child's condition, child or parent's disinterest in art, difficulties in scheduling the activity, child's exhaustion, and feelings of overwhelm from child and/or parent with the child's current treatment plan.

Five major themes emerged regarding the legacy artwork experiences of bereaved parents whose children died of cancer. Each theme is discussed below with representative quotes included within the text as well as in Table 5.

Reported by both informant groups

Theme 1. Creating legacy artwork projects facilitates family bonding and memory-making and opens lines of communication between family members regarding the child's impending death (n= 12 parents, 12 healthcare providers).

Participants emphasized that the process of creating the legacy artwork was equally as important as the finished product. Many parents reported that creating legacy artwork as a family allowed them opportunities to spend quality time with one another and build lasting memories. One participant noted, "*I think it was helpful for the family. We now have a, we created a memory with him, and those things are the most important things now. He's gone so memories with him are very special to us*." Another mother elaborated on the family bonding that took place during the creation of the project, "*It was a stress-free experience. I said, 'We are here. We* *are now. We are together as a family in this room.' We asked everybody else to leave, so it gave us as a family probably an hour of bonding time with nobody else in the room. And we just spent time with him, so it was really good for us*." Many parents appeared to treasure this family bonding because for some, they were the last moments of being together. As one participant stated, "*It was the last thing we did as a final four. Creating that family tree will forever be something we all shared together*."

Several participants commented that engaging in legacy artwork allowed families to become more vulnerable with one another and begin discussing the emotionally-intense topic of the child's impending death. When asked about the benefits of legacy artwork, one healthcare provider reported, "*It leads to more open communication. I think the child's death is the big elephant in the room that nobody wants to talk about. So, when you give them an indirect way to kind of open up and start talking, different thoughts and questions come up, and it feels as if it is safer to ask in some of those legacy-making moments than just sitting and having a conversation*."

Most families expressed their desire to have these crucial conversations with their children but noted that it was oftentimes difficult to know how to start them, especially depending on the age of the child and his or her siblings. Art was reportedly a safe outlet to express these challenging thoughts and emotions, which resulted in deeper and more meaningful conversations. For example, a healthcare provider shared her experience with a family who benefited from using legacy art as a way to facilitate communication with one another, "*There was a teen who was really depressed, and there were a lot of cultural things surrounding death that made it difficult for him to engage openly and honestly about his concerns about dying to his family. Creating a legacy artwork project (e.g., mural of a knight wearing a coat of armor and* *holding a shield) as a family allowed an opportunity for his parents to begin opening up and having conversations with him about what it means to protect others from difficult news and how to allow others to enter your space and become a little more vulnerable.*" Many described the experience of creating legacy artwork as a "door-opening" to these tough conversations.

Theme 2. Legacy artwork provides opportunities for parents to engage in life-review and meaning-making of the child's death (n= 11 parents, 10 healthcare providers).

Participants repeatedly discussed the value of the meaning behind the legacy artwork projects. Many described a vast array of different meanings represented in the artwork including the child's personality, memories with the child, the things the child loved, and the thoughts and emotions of the child at the time of creation. When asked to describe what legacy artwork entails, one provider elaborated, "*Art is a representation of who we are in that moment, and who we are is our identity. And so, art is a reflection of the child, their identity -- whether they are creating their legacy or creating a picture of their favorite animal or using their favorite colors. With words, we can fake. We can kind of tell our alternate story of who we want to be and we can wear masks sometimes, but with art, it very quickly strips away the masks, and the legacy becomes, you know, a child giving a story, an image, creating a sculpture, that's completely reflective of who they are, and it's demonstrated through the process of how it was created. Demonstrated through the colors they choose, through whether they work quickly or slowly or tediously. Art is a reflection of the joy. A reflection of life, and because it is a creation, it is the antithesis to death and dying. And so for families, along with that joy, there is meaning that is created and that meaning moves through grief whether it is anticipatory or post-loss of their child.*"

Engaging in meaning-making through the legacy artwork projects was reported to positively influence parents' grief as well as help the child process his or her impending death. In most of the legacy artwork projects, the art therapist focused on implementing a metaphor to assist families in making meaning of the child's illness journey. Finding meaning through this traumatic experience of a child dying of cancer was reported as healing by several parents. One father specifically spoke of a poem written about his child's legacy artwork that was read at her memorial service. Under her guidance and direction, he painted a canvas of the yellow brick road featured in the Wizard of Oz along with its characters to describe her journey with cancer.

The poem states: *"We finished the original Wizard of Oz book tonight at bedtime. It said, 'I realize that for my entire life, I had missed the point of the story, and it really hits home.' As my voice broke, I read about how badly Dorothy wanted to get home. She never asked to be thrown into a new world in such a violent way. It was just a whirlwind that threw her around. It dropped her into a scary place that she knew nothing about. For us, that whirlwind is cancer. What she didn't realize until the very end is that it mattered. Without Dorothy's journey, the scarecrow would have never gotten off that pole in the cornfield. The tinman never would've realized his potential for love. And the lion would've never embraced his power and strength. No matter where you are, if you're looking around and wondering, 'Why me?' and you're scared to death, it matters who knows how many lives have been changed because of your journey. Just keep pushing on. Everyone gets home in the end.'"* He followed the reading of this poem with a statement expressing his comfort in knowing where his daughter is after her death, *"The point of the Wizard of Oz was – it's the yellow brick road, that's heaven. That's the foundation of my belief in where she's going. God sent an angel to take my kid. That's what that tells me. It's okay."*

Theme 3. Following the child's death, parents display the legacy artwork in their home and take comfort in using these projects to continue their bond with their deceased child (10 parents, 8 healthcare providers).

Ten of the 12 bereaved parents reported displaying the legacy artwork project in their home. Most explained that they wanted the piece in a popular area of their home such as the living room so that visitors could enjoy the project. One mother reported on the location of her daughter's legacy artwork, *"We definitely have it somewhere special and obvious, you know, out where everyone can see it that comes into our house. We want people to admire it."* Other locations for the legacy art projects included hallways, offices, bedrooms, and a classroom. One provider shared a story of a bereaved parent whom she is still connected with, *"The legacy was that after her daughter died, the mom took the entire wall mural home and put it in her bedroom. Now the art piece continues to have an existence somewhere else, and it has a name and it has a story."*

Several parents reported interacting with the projects as a way of continuing their bond with their child beyond his or her physical existence. Interacting with the projects most commonly involved staring at the piece and reminiscing on memories as well as placing their hands on top of the child's handprints. Despite the physical absence of their child, parents explained that the legacy artwork facilitated a comforting connection with their deceased child. One mother described her interaction with her son's art project, *"And then in the end, um, he signed it, with a paint pen, and um, there's actually a texture to it cause he went into the paint with it. And so, I remember him painting it. I remember him signing it, you know. I always touch it. And I always kind of run my fingers across where he signed it, where he tagged it. And that just…ahh, there's something about like a tag tile, you know. I don't know why, you know, but I* *know that he wrote it, I know that he did it, and it takes me back to him. Sorry, I'm choking up."* Another mother added, *"I'll put my hands on the glass sometimes on top of his small handprints, and I'll feel like I'm holding him again. His sisters do the same thing. Even though one is only two, she knows that those are brother's handprints, and she loves to go touch them. It's comforting for the whole family."* Lastly, one mother commented on how the artwork reminds her that her son is still with her in spirit, *"He would always give me crap about being a Georgia fan. And he would do his Daddy the same about being an Alabama fan. I could be having a really bad day and I can walk through and see his Auburn-themed canvas, and I'm like 'look, he's still picking at me even afterwards.' It just warms my heart knowing he is still with me."*

Healthcare providers stated that during funerals or memorial services, families often referenced the new location of the legacy artwork to them, which was frequently a special place in their home. From their perspectives, it was clear that the families greatly valued the pieces and wanted to continue speaking of the legacy-making that occurred at the hospital when their child was alive. Moreover, several healthcare providers emphasized the significance of these pieces immediately after the child's death. While the creation of the projects was always valued by families, the death of the child initiated a new connection and meaning to the legacy artwork for parents. Specifically, one healthcare provider elaborated on her experiences watching families immediately after the death of their child in the hospital, *"These legacy artwork pieces help families have something to hold in their hand when they walk out the door. You know, something that they can feel like they are taking a piece of their children with them and where they can feel a sense of closeness to the patient. One of the hardest things I've seen families do is just not really knowing how to walk out of the hospital without their patient, but these legacy artwork projects allow them to take a piece of their child home with them."*

Though the majority decided to openly display their child's legacy projects, two of the parents commented that the project was a reminder of traumatic times. For example, one parent expressed why her child's artwork is still hidden in the closet, *"I haven't been able to actually put it out yet. The pain is still too deep. When I'm ready to, I'll bring it out. It's all up to me."*

Reported by individual informant groups

Theme 4 (Parent-only theme). The experience of participating in legacy artwork ameliorated parents' grief and psychosocial functioning following the death of their child to cancer (10 parents).

Parents indicated a relationship between the legacy artwork experience and their grief following the death of their child. Reflecting on the experience and interacting with the tangible item created were reported as beneficial in helping parents cope with their intense grief. These legacy artwork projects were commonly called *"treasured items"* and *"prized possessions,"* in light of their importance along the parents' grief journeys. One participant explained, *"We attach positivity to it when we use it as a part of our child's memorial service or in an ongoing way, and we continue to attach meaning to it. With meaning, there is hope. There is um this knowledge that life is never going to be the same. Um, but the grief is profound, and it's real and it's hard and it's deep. Um, but it offers us a little bit of hope in reminding us that it was a life well lived-- that they were here, that they did make this, and that it wasn't something that was just made up. And there is hope in that. You know, there is hope in the masses."*

Other parents spoke of the peace and acceptance that the artwork brings to them during their most difficult days of bereavement. As one parent noted, *"The family circle artwork brings me a peace. When I look at it all these years later, I just feel kind of a sense of peace about her* *death. So, I definitely think, especially when we are having a hard time, I think it means a whole lot to all of us."*

Lastly, some parents commented that looking at the legacy artwork after their child's death facilitates a healthy expression of pent-up emotions related to their grief. When asked to describe his reaction to looking at the piece after his child's death, one father stated, *"I'm a mechanical engineer. I've been doing it for 30 years. So, I am very pragmatic, and it's almost as if to get through this loss, you have to shed so many tears [crying], and every time I do that, it feels better. It helps me cope with the loss of my son. So, when I see his artwork, I cry, and that helps me get through."*

Theme 5 (Healthcare provider-only theme). Legacy artwork has the potential to reduce compassion fatigue and burnout among healthcare providers as well as provide an outlet for coping with the death of their patients (7 healthcare providers).

Although not a major focus of the study, it is important to note that legacy artwork has the potential to positively impact healthcare providers as well as bereaved parents. Several healthcare providers reported experiencing compassion fatigue and burnout after repeated exposure to pediatric deaths. Furthermore, many stated that they developed special relationships with their patients when providing direct medical or psychosocial care, which resulted in personal grief following the death of the child. The facilitation of legacy artwork for healthcare providers was discussed in two different ways. In regard to offering specific sessions for healthcare providers, one provider explained, *"Care providers do experience their own grief and loss. So, we would conduct a 'Refresh and Restore' session every now and then where we would invite the care team to come together. I remember once we painted trees, and we worked with the metaphor of trees because, you know, trees you could deeply root, but then they also go through* *the seasons of change. It was very restorative with the care team to have their own experience to create and to remember the lives that they have cared for."*

Another provider furthered the importance of offering these opportunities for medical staff, *"When care teams start to get to a point where you know, the next death is just another death—when you start to see that there is some post-trauma that begins to accumulate, and it's worsened with the loss, then art can be a wonderful and powerful intervention to have them be a part of."*

Other providers mentioned their role in assisting with the legacy artwork projects of patients and their families. For example, one teenager wanted a mural wall that resembled a butterfly sanctuary. With the help of the art-therapist, they cut out butterflies and asked healthcare providers to color a butterfly and write a message of love and support. Each butterfly was attached to a wall in her hospital room until she was surrounded by butterflies filled with inspirational words and memories. In response to her participation in this project, one provider stated, *"It was an important way for us to honor her while she was still here and to show our support and also a little bit of personal expression of our grief for her. Through this project, she developed really meaningful relationships with her care team, and when we think back to that, we can remind ourselves of the special and important moments we shared, even though the outcome was not what anybody wanted."*

Feedback to Improve the Legacy Artwork Intervention

Feedback to improve the legacy artwork intervention was solicited from both healthcare providers and bereaved parents. Both groups of informants agreed on two key points for program development: 1) Legacy artwork should be offered as early and frequently as possible, and 2) Legacy artwork should be offered to all children with cancer to mark their illness journey rather than exclusively posing it as an end-of-life project. In support of these changes, one healthcare provider stated, *"I mean I personally think the earlier the better. We don't have to make it seem like this doom and gloom sort of thing that you know, 'Oh, well you better do this now because you're never going to get an opportunity again to remember your child.' If we wait too long, then it suddenly becomes the death project. Whereas you know, giving it, framing it as something that is going to give you guys the opportunity or a chance to do something together to make these wonderful memories and regardless of the outcomes, you're going to have this beautiful thing to mark this moment of your life, of your journey."* Parents corroborated with this feedback, and one specifically expressed how offering the project earlier may improve the introduction of the piece, *"I would not want a person to come in and tell me, 'oh well, you don't know how long you may have her so we are going to do legacy work.' I would have been angry because I still had hope. I think saying 'This is just a part of her story and this is just going to be a way for you to mark this time of her story' would be more helpful and comforting*."

Many healthcare providers also emphasized the stress that comes along with only offering the project when a child is terminally ill. One participant commented on how delayed timing of legacy projects has the potential to elicit negative memories for families, *"I love the legacy work we can do when the child is awake and alert and interactive opposed to the legacy projects when the child can no longer participate. I worry that if we wait too long, we solidify a memory for families of when the child has died or is dying. And I think there's a tendency to idolize, for point of a better word, the dying child instead of the child in these moments."* This distress not only affected the families but also impacted healthcare providers, such that they felt pressured to ensure an art piece was created before the child died. This appeared to be overwhelming and emotionally challenging for many.

As one provider explained, *"There is this kind of rush that is a pressure to create something and oftentimes, that comes with a lot of trauma and crisis for staff and families. There was just such a craving, such a desire to have something because families were anticipating that their child was dying."* Another provider shared her story of completing a legacy project with the mother after the child's condition unexpectedly regressed, *"We had started a ninja turtle painting with him on a canvas that he and his mom worked on together. Between one session and the next, he took a turn for the worse. I went up to the intensive care unit and he's on life support, unconscious. But his mom still wanted to finish this painting, so I held the little boy's hand in mine and we painted. It was the hardest thing I've ever done."* Some healthcare providers noted that the worst outcome of legacy projects is when they are unfinished due to an unexpected change in the child's condition as this occasionally leaves families with a lack of closure.

Additionally, several healthcare providers alluded to the importance of communicating the positive benefits of legacy-making to members of the medical team who are less familiar with complementary supports. As one provider commented, *"If we all agree that this is hugely important for the child's processing as well as the parents' grief and bereavement, then it should be just as important as all those other things. Right? It's not just this afterthought. It's not just a nice thing that we do for these kids that are sick, but it's an integral part of their care plan."*

Another provider added, *"I think there is a lot of value in having buy-in from the team. If an oncologist states 'part of your care is going to be using art as a tool for exploration,' there is a lot of weight that comes from him/her validating this activity. Then families may go, 'Oh, this might be as important as some of the other modalities of care that are being offered.'"* Many providers believed addressing this knowledge barrier would result in more referrals for legacy-making and thus a higher participation rate from families.

Though not major themes, parents reported a variety of recommendations to improve their experience with legacy artwork including hiring a full-time art therapist as opposed to a contracted position in order to increase the art therapist's availability for families. For example, one parent commented, *"It would be cool if they had a full-time art therapist, you know, somebody who was very much involved in the day-to-day, knows what we have been through that week. I think the experience would be so much richer if there was a full-time person doing legacy work and other types of art therapy."* Another parent expressed her opinion based on stories she heard from other families on the oncology floor, *"The art therapist was there when we were going through it, but I know that she was not there every day of the week. Some families needed her the most on those days she was absent. This service needs to be available every day of the week for all families."* Others discussed a desire for the art therapist to have her own personal space in the hospital so that families can escape their hospital rooms when creating. When providing this feedback, one parent relayed her daughter's wishes, *"My daughter used to always say, 'Wouldn't it be cool if [art therapist] had her own office with a giant window on the cancer floor? Sometimes, I just need to get out of this room.' We all needed a change of scenery at times. Having a separate place to create would have been magical."*

Finally, parents shared their visions about the hospital holding an art show or auction to commemorate the lives of the young patients who had died in the past year by displaying their legacy projects and selling other pieces of artwork created by the children in the hospital. One parent described his vision, *"I think it would be really cool for the hospital to hold an art show, you know, show the things the kids have done. It would be neat to write a quick paragraph under* *each one, 'this is so-and-so and this is what he went through and this is what he and his family drew.'"* Holding an art show or auction would provide parents with opportunities to share their children's stories and talents with others after the child's death. As one mother stated, *"In terms of legacy, his artwork enables me to be proud and to talk about him and to brag about him. Because like what I've shown you, look how proud I am! To have our children's legacy artwork formally recognized in an art show or an auction, I think that would make all of the difference in the world for us as parents."*

Quantitative Measures

Prolonged Grief-13 (PG-13). The total PG-13 scores ranged from 18 to 46 among participants in the sample. Seventeen percent of parents (two participants) in the sample met criteria for a clinical diagnosis of prolonged grief disorder compared to the 12% (14 of 120 bereaved parents) in Lichtenthal et al's (2015) study. One of these two participants who met criteria for prolonged grief disorder was also one of the participants who reported not displaying the legacy artwork in her home. Additionally, one participant's total score (i.e., 46) met criteria for an outlier and thus was excluded from the following analysis. No significant difference emerged in mean total prolonged grief scores between the legacy artwork intervention group (M= 24.7, SD= 6.60) and the comparison sample (M= 28.7, SD= 9.40) (Lichtenthal et al., 2011); $t(130)$= 1.44, p= .15 (Figure 1).

Beck Depression Inventory-II (BDI-II). Based upon BDI-II scores, seven parents (64%) were experiencing no or minimal depressive symptoms, one (9%) mild depressive symptoms, and three (27%) moderate depressive symptoms. Scores ranged from three to 26 in this sample. Using a cut-off total BDI score of 20, three (27%) parents in the sample from this study were experiencing clinically significant levels of depressive symptoms compared to the 13 parents (22.4%, 13 of 58 participants) in the comparison study sample (McCarthy et al., 2010). The mean total BDI-II score of the legacy artwork intervention group (*M*= 12.72, *SD*= 7.60) was not significantly different than that of the comparison sample (*M*= 13.82, *SD*= 9.17) (McCarthy et al., 2010); *t*(105)= .40, *p*= .69 (Figure 2).

Life Attitude Profile Revised (LAP-R). No significant differences in purpose, coherence, choice/responsibleness, death acceptance, existential vacuum, goal-seeking, and existential transcendence emerged between the legacy artwork intervention group and the comparison sample (Lichtenthal et al., 2011). The means, standard deviations, ranges, and test statistics are provided for each dimension and domain in Table 4.

Bereaved Parents' Experiences of Study Participation

All parents reported a positive experience participating in the interview despite the sensitive nature of the study topic. Many explained that there are few occasions in which they are given the opportunity to share their child's story. As one parent stated, *"We want to tell you the stories. We want to tell you the fun and the times that we did this and did that because it's almost like a secret society that nobody wants to ask about, you know?"*

Other parents reported that participating in this interview was therapeutic as it provided them an opportunity to give back to future families who will similarly experience the death of their child. One participant elaborated on her experience, *"Even though some of it is painful, I enjoy talking about her. I feel like it would be helpful information, and you know you can use it however it will benefit somebody else who will be in the same position of losing their child."* Additionally, some parents stated that they were pleasantly surprised by their experience as they were anticipating it to be difficult. When asked about her experience participating in the study, one parent noted, *"It was a lot easier than I expected. I didn't completely come apart. This* *conversation made me realize that his legacy lives on as we speak. I just want to say thank you. This has filled my heart up, this talking, you know, reminiscing through the stories. I'm smiling really big right now."*

Reflexivity

Due to the emphasis on qualitative methodology in this investigation, it is important to report on the researcher's experiences, position, perspectives, and values related to this study and how these factors may have influenced the research process (Berger, 2015). This clarity of the researcher's background provides readers with a richer, more developed understanding of complex phenomena such as the legacy artwork experience.

The principal investigator was a masters-level graduate clinician with two years of clinical experience working with the pediatric oncology population, including both patients and their families. When conducting interviews with the bereaved parents, the principal investigator occasionally struggled to strike a balance between her role as a researcher and as a clinician with psychotherapy experience. Though her primary role was to gather information about bereaved parents' grief and experiences with legacy artwork, she often felt compelled to offer supportive and encouraging prompts throughout the interview. However, she remained conscientious about her primary role as a researcher and thus recognized moments when she needed to maintain an empathic distance in order to avoid her instinctive desire to provide therapeutic services to parents in distress.

Secondly, the principal investigator noted occasional instances of feeling guilt when, as a result of the interview, parents experienced distress. To address these uncomfortable feelings, the principal investigator focused on building rapport early on with the participants by demonstrating a strong interest in learning about the child's identity and allowing families to share unrelated stories throughout the interview as a form of healing. Her feelings of guilt were mostly ameliorated at the conclusion of the interview when participants expressed the value of participating in the study and how grateful they were to share their child's story with someone who was interested in helping future bereaved parents. Thirdly, given the emotional nature of this interview, the investigator focused on engaging in self-care throughout the data collection process. Meditating before each interview helped the researcher establish mental clarity so that she could be fully present during the interviews. Relatedly, journaling after each interview offered the researcher an opportunity for healing by personally expressing the challenging emotions and thoughts that arose from hearing participants' stories.

Discussion

Through semi-structured interviews with parents and healthcare providers, we were able to gain a deeper understanding of the potential benefits legacy artwork interventions offer to bereaved parents following the death of their child. Similar to prior work in this field, our findings demonstrated that participating in legacy-making assisted children and parents in coping with anticipatory grief over the child's impending death (Akard et al., 2015). However, these results are unique in that they suggest that these benefits may continue to persist beyond the child's life and carry over into parents' bereavement.

Several key themes emerged from our interviews. Specifically, we found that legacy artwork 1) facilitates family bonding and memory-making and opens lines of communication between family members, 2) provides opportunities for parents to engage in life-review and meaning-making of the child's death, 3) is often displayed in parents' homes and helps them continue their bond with their deceased child, 4) can ameliorate parents' grief and psychosocial functioning following the death of their child, and 5) may reduce compassion fatigue and burnout among healthcare providers as well as help them cope with the death of their patients.

Family Bonding and Communication

Consistent with previous studies, our findings suggest that parents greatly value time with their child in the hospital without interference from the medical team during end-of-life care (Weidner et al., 2011). Recognizing that their time is limited with their child, families desire to have bonding moments together without the chaos of healthcare providers coming in and out of their child's hospital room (Weidner et al., 2011). Because legacy-making activities are specifically designed for the child and his or her family, they provide stress-free opportunities for the families to engage and spend quality time with one another. Parents in our study reported creating treasurable memories as a family while engaging in the legacy artwork intervention. Through family togetherness, the patient is reminded that he or she is not alone, which is a common fear of children who are dying (Stillion & Papadatou, 2002). As the family creates a legacy artwork project, they are solidifying memories of being together and providing support for one another as they process the child's imminent death through art expression and conversation.

Open and honest conversations about a child's impending death are vital between a child and his or her parents (Beale, Baile, & Aaron, 2005). Despite the numerous benefits of engaging in open and honest communication with their child, many parents still express hesitation, particularly because it can be very difficult to know the best way to initiate a conversation about death with a child. Jalmsell, Kontion, Stein, Henter, and Kriecbergs (2015) conducted a study examining how bereaved parents chose to communicate about death with their child dying of cancer. Parents in this study reported four primary communication strategies. These included communicating about death by using narratives (e.g., fairy tales, movies), talking about friends and family that had died, talking about life after death, and preparing for death through practical preparations (Jalmsell, Kontio, Stein, Henter, & Kreicbergs, 2015). However, it is important to note that all of the communication strategies identified by Jalmsell and colleagues (2015) were initiated by the child, not the parent.

Waiting for the child to initiate this conversation may be problematic for a variety of reasons. Firstly, children with advanced cancer usually know and suspect their imminent death long before their parents and healthcare providers are ready to disclose the information (Hilden, Watterson, & Chrastek, 2000; Spinetta, 1974). Relatedly, these children can frequently sense that something is wrong based on cues such as their families' and healthcare providers' behaviors and emotions (Aldridge, Shimmon, Miller, Fraser, & Wright, 2017). Secondly, children who anticipate their impending death often experience confusion, frustration, distress, isolation, and anger when they perceive that their parents and healthcare providers are avoiding these crucial conversations (Abadía-Barrero & LaRusso, 2006; Fredman, 1997; Hilden et al., 2000; Last & Van Veldhuizen, 1996; Valdimarsdóttir et al., 2007). They may also lose trust in their family and healthcare providers if information is withheld, which has been shown to negatively impact the quality of their relationships in the final months of their lives (Last & Van Veldhuizen, 1996). Thirdly, avoiding this topic with children is associated with poorer dying outcomes (e.g., more painful or unhappy death) (Fredman, 1997). Though these conversations are challenging for parents to initiate, research demonstrates that parents who report talking about death with their child do not regret this decision (Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004). In fact, those parents who decided against having these conversations with their child prior to his or her death often experience immense regret after the child's death (Kreicbergs et al., 2004). Therefore, identifying interventions to facilitate these daunting conversations would be valuable for pediatric patients, families, and their healthcare providers.

Previous studies in pediatric legacy-making (e.g., digital storytelling) suggested that legacy-making activities created a valuable opportunity for children and families to talk about death (Akard et al., 2015; Foster et al., 2012). Our findings demonstrated continued promise for the role of legacy-making interventions in allowing difficult conversations about death to naturally occur between a child and his or her family. Similar to Jalmsell and colleagues' (2015) study, some of our families commented that they could indirectly talk about the difficult subject of death without specifically referring to the child's imminent death when creating these projects. By relying on the metaphors implemented throughout the art projects, families could have conversations with their children that would have otherwise been deemed as too difficult. The metaphors served as a bridge to talk about an emotionally-charged topic in a safe and sensitive manner. Through legacy-making activities, parents and children are provided with subtle triggers that naturally lead into tough conversation topics. This reduces the pressure on patients, parents, and the healthcare providers to initiate the conversation without support and allows them the space to discuss the future such as dividing prized possessions to family members and friends, making a bucket list, and choosing the things that are most important to the children when they die.

Meaning-Making

Finding meaning is a fundamentally important component of grieving (Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Lichtenthal, Neimeyer, Currier, Roberts, & Jordan, 2013). Previous research on meaning-making models notes that families construct their realities and the ways they understand the world based on a shared set of global meanings (Gillies & Neimeyer, 2006; Reiss, 1981). These global meanings represent the family's existence as a unit through their assumptions, beliefs, traditions, and values (Reiss, 1981). When a family experiences the death of a child, their core beliefs are shattered as this event goes against the natural order of life (Gillies & Neimeyer, 2006). Due to the confusing nature of this traumatic event, families seek opportunities to make sense of their loss by developing a new set of assumptions, beliefs, and rituals (Reiss, 1981). Those families who are able to make meaning out of their loss tend to report less anxiety and depression, decreased post-bereavement stress, reduced rates of prolonged grief disorder, and an enhanced ability to heal (Holland, Currier, & Neimeyer, 2006; Nadeau, 2001; Neimeyer, Baldwin, & Gillies, 2006; Wu et al., 2008). As parents in this study worked with their children to create a legacy artwork project, they were initiating the process of meaning-making together as a family. Processing their feelings and emotions through art allowed families in our study to establish new global meanings and to retell their story in the wake of their child's imminent death. Thus, the theoretical foundation of meaning-making informs the use of legacy artwork as a promising intervention for bereaved parents who will experience the death of a child (Gillies & Neimeyer, 2006).

The experience of creating a legacy artwork project provided ample opportunities for bereaved parents to create new meaning or reconstruct prior meanings about the life of their child and his or her impending death (Kobler et al., 2007). Engaging in meaning-making relative to the child's life is congruent with findings in the pediatric legacy-making study examining digital storytelling (Akard et al., 2015). In the study's intervention, parents were able to engage in a review of the child's life when watching the videos as the child shared his or her personal characteristics, the things they liked to do, and their connection with others (Akard et al., 2015). Although some of the aspects of legacy artwork resulted in life review, like the digital storytelling intervention (Akard et al., 2015), parents in our study also discussed meaning-making specifically focused on the child’s approaching death. Most parents found meaning behind the artwork whether that was through a metaphor or the child’s personal telling of their story when creating the piece. This meaning-making ultimately facilitated their journey through grief as it resulted in processing anticipatory grief prior to the child’s death which led to a deeper understanding once the child died. Another study complemented these findings by demonstrating that legacy-making activities inspired bereaved parents to find a new sense of meaning and to live their lives differently following the death of their child (Foster et al., 2009). In summary, our findings highlight the importance of bereaved parents’ search for meaning prior to and following the death of their child and indicate the therapeutic potential of legacy artwork to help parents discover this desired meaning.

Continuing Bonds

Our results suggest that the concept of legacy-making may be associated with the Continuing Bonds Theory (Klass et al., 1996). As this theory proposes, our bereaved parent participants reported that they maintained connections with their deceased child through the legacy artwork piece (Klass et al., 1996). The legacy artwork became a tangible memento that the parents could view, reminisce on, and interact with in order to feel a sense of closeness to their child following the child’s death. While prior studies have demonstrated a connection between tangible mementos and remembrance of the child (Foster et al., 2011; Normand, Silverman, & Nickman, 1996; Root & Exline, 2014), this study is the first to explore the possible association between legacy-making and continuing bonds post-death. Based on parents’ responses, it appears that continuing bonds with the child through his or her legacy artwork served as the mechanism to helping parents cope with the death of their child. Knowing that the artwork included the child’s handprints, preferences, and signature, parents reported finding comfort that a piece of their child still remained with them even in the absence of the child’s physical presence.

Prior literature discusses two types of continuing bonds (Field, Gal-Oz, & Bonanno, 2003). One bond is through physical means, and the other is through spiritual connections (Field et al., 2003). According to bereaved parents in our study, continuing bonds occurred through both keeping the legacy artwork project in a special place (i.e., physical means) as well as reminiscing on positive memories of the experience while looking at the artwork (i.e., spiritual connections). The act of continuing bonds with a deceased loved one has repeatedly been deemed as adaptive, positive, and helpful in the healing process of the bereaved (Klass, 2001; Klass et al., 1996; Park & Benore, 2004). Therefore, continuing bonds via the legacy artwork project most likely contributed to the amelioration of grief and psychosocial functioning mentioned by parents.

Parents’ Grief and Psychosocial Functioning

Our findings suggest that bereaved parents experienced long-term improvements in grief and psychosocial functioning as a result of participating in legacy artwork with their child prior to his or her death. These findings are consistent with previous literature. For example, in the pediatric digital storytelling intervention study, 17% of the parents reported that participating in the intervention served as a coping strategy for them while 46% noted that the digital stories provided comfort (Akard et al., 2015). However, it is important to note that only 20% of their parent participants had experienced the death of their child at the time of survey completion meaning that the majority of the results were focused on parents’ anticipatory grief over their child’s impending death. Therefore, our results from bereaved parents are novel, given the inclusion criterion of at least six months following the death of the child.

Eighty-nine percent of hospitals who participated in a nationwide survey by Foster and colleagues (2012) reported that one primary goal of offering legacy-making interventions was to benefit bereaved families in the hopes that the legacy-making activity would serve as a coping strategy following the child’s death. By interviewing bereaved parents, our results are the first to illustrate that this goal of legacy-making intended by children’s hospitals is potentially being met. Our bereaved parent participants reported that the legacy artwork product as well as the experience of creating it were positively influential in their grief journey after the death of their child. As such, legacy artwork appears to hold promise in positively impacting both anticipatory grief and grief post-death of the child.

By reminiscing on the memories associated with the legacy artwork piece, bereaved parents were engaging in loss-oriented coping, which is supported by the Dual Process Model of Grief (Schut, 1999). Many parents explained how the legacy artwork facilitated working through their grief, whether that was through crying, longing for the child, processing the death, or feeling peace that the child is no longer suffering. Although this was not a primary aim of our study, many bereaved parents also reported methods of restoration-orientation coping. This suggests that the majority of our participants were experiencing healthy grieving such that they oscillated between loss-orientation and restoration-orientation coping (Schut, 1999).

Impact of Legacy-Making on Healthcare Providers

Although the primary focus of our study aimed to explore the legacy artwork experience of bereaved parents, our results also demonstrated that healthcare providers may benefit from legacy-making too. As many of our participants mentioned, healthcare professionals working in oncology are at high risk for experiencing burnout, emotional exhaustion, depersonalization, secondary trauma, and compassion fatigue (Trufelli et al., 2008). This is particularly problematic as these symptoms that result from working in an emotionally-intensive career can cause serious repercussions for the providers’ well-being and may also compromise their work with patients and families (Trufelli et al., 2008). In one study exploring coping of healthcare professionals working in oncology, debriefing with colleagues, receiving professional psychological therapy, practicing yoga, receiving massages, and focusing on ‘happier times’ were the primary self-care strategies identified (Trufelli et al., 2008). Unfortunately, there is a lack of official support mechanisms in place for healthcare professionals in oncology and palliative care.

The phenomenon of staff participating in legacy-making interventions as a form of coping has been relatively unexplored in the literature. However, one study utilizing mixed methodology briefly mentioned one healthcare provider’s perspective who believed that participating in legacy-making activities may result in benefits for the staff as well (Foster et al., 2012). Our study expanded on this finding, suggesting that healthcare providers can also experience personal benefits (e.g., processing grief from multiple deaths, honoring their patients in a safe space, reducing compassion fatigue and burnout) from either participating in their own legacy-making or assisting with the legacy projects of their patients. If healthcare providers are able to recognize personal benefits of legacy-making, they will be more likely to refer patients and their families to this activity. Therefore, in order to optimize the well-being of healthcare providers taking care of children with terminal illness and their families, hospitals may consider incorporating formal and structured time for providers to engage in legacy-making.

Integration of Qualitative and Quantitative Findings

Our bereaved parent participants who engaged in a legacy artwork intervention did not significantly differ from the comparison samples of bereaved parents in the areas of grief, depression, or attitudes toward life (Lichtenthal et al., 2011; McCarthy et al., 2010). Our study sample demonstrates that parents do not have to meet certain risk factors, such as prolonged grief or clinical depression, in order to reap the benefits of participating in a legacy artwork intervention with their child. Therefore, these findings provide further evidence that legacy artwork should be offered to all families, even those who do not present with a specific risk factor for poor coping (e.g., depression).

It is also important to note that the quantitative data resulted in one outlier. Specifically, one participant's prolonged grief score was 46, which was 2.5 standard deviations above the mean. Recency of child death may have been a factor. This parent experienced the death of her child eight months after data collection, resulting in one of the shortest time spans between death and time of interview. In contrast, among our other participants, the average time since the death of the child was three years. This participant's qualitative experiences also differed slightly from that of the larger group. For example, this parent was one of the two who reported that she was unable to hang up her child's legacy artwork due to the emotional pain it caused her when looking at it. Additionally, based on the research protocol, the investigator followed up with a licensed psychologist after interviewing this particular parent, due to concerns about her responses.

Grief is a multi-faceted experience and one that changes over time depending on a variety of factors (Stroebe, Hansson, Stroebe, & Schut, 2001). Therefore, it is difficult to determine the specifics behind this participant's differing clinical presentation compared to the other bereaved parents. However, this warrants a great need for longitudinal research to track bereavement trajectories over time. Longitudinal studies would expand our understanding of how grief evolves through the years but would also provide helpful information about interventions. For example, at what point are bereavement interventions deemed helpful for those who are grieving? How often should healthcare providers follow-up with families who are grieving? Specific to our legacy artwork intervention, do families' opinions about the benefits of creating this project evolve through different stages of grief? These questions should be explored in future research.

Ethics of Parental Bereavement Research

Despite numerous studies suggesting the benefits of research participation for bereaved parents (Akard et al., 2014; Dyregrov, 2004; Hynson, Aroni, Bauld, & Sawyer, 2006), obtaining approval for these sensitive research studies still presents challenges. Specifically, research committees in the past have expressed hesitation in approving these protocols due to preconceptions that bereaved parents are considered vulnerable and may experience more harm than benefits during study participation (Buckle, Dwyer, & Jackson, 2010; Dyregrov, 2004; Hynson et al., 2006). In fact, research proposals exploring grief and death are more likely to be rejected than other studies exploring personal human experiences (Dyregrov, 2004). By rejecting these protocols, research committees have reinforced the idea that bereaved populations need protection from the research process such that they may not be in a position to provide informed consent (Buckle et al., 2010; Hadjistavropoulos & Smythe, 2001). Moreover, qualitative research is frequently flagged as the most concerning methodology for the bereaved, given its emphasis on collecting in-depth and personal data (Hadjistavropoulos & Smythe, 2001). Additionally, some investigators interested in this line of work may be reluctant to conduct studies in fear of inducing emotional and psychological distress in bereaved parents (Duncan & Cacciatore, 2015).

Contrary to the abovementioned concerns of research committees, 100% of our bereaved parent participants reported a positive and beneficial experience following their study participation. Many participants expressed appreciation for the therapeutic nature of the qualitative interview which allowed them to share their story with an interested and engaged listener. Furthermore, bereaved parents explained the isolation and emotional pain they feel when people stop asking about their child who has died. Opportunities to share their children's stories were reported as few and far between, suggesting that restricting bereaved parents from participating in research studies may deprive them of potential benefits.

Our findings indicate that investigators should continue designing and conducting research studies with bereaved parents. As endorsed in our interview, bereaved parents experience the benefits of meaning-making through the continued telling of their story as well as the empowerment to help other families who will similarly experience the death of their child. By advancing the research base in palliative care and grief through their participation, our participants stated that they were enabling their child's legacy to continue past his or her death. These research findings also translate into areas of future program development for bereaved parents. Not only do bereaved parents appear to appreciate research participation opportunities, but they are also privileged to serve on family advisory councils following their child's death.

St. Jude's Children's Research Hospital is leading the way by establishing the first Quality of Life Steering Council which consists of bereaved parents, chaplains, social workers, child life specialists, and palliative care clinicians (Snaman et al., 2017). This group has been tasked with developing and expanding the bereavement program at St. Jude's Children's Research Hospital. Bereaved parents have been instrumental in improving palliative care and bereavement services at St. Jude's by creating and disseminating bereavement resources, serving as mentors for newly bereaved parents, planning remembrance ceremonies, providing feedback on interventions, and educating (e.g., role playing) palliative healthcare professionals on communication strategies for delivering difficult news. Similar to the benefits of research participation, many of these parents commented that participating as a member of this council has empowered them to continue building their child's legacy (Snaman et al., 2017).

Study Strengths and Limitations

Our findings should be considered in light of the study's strengths and limitations. This study was the first to qualitatively explore the experience of participating in legacy artwork from both bereaved parents' and healthcare providers' perspectives. Therefore, major strengths of this paper include a novel contribution to the research literature in addition to a triangulation of data sources. Use of theory and expert opinion to guide the development of our semi-structured interview and the analysis of our data also enhances the strength of our findings. Lastly, several validation strategies were used throughout data analysis to ensure the rigor of the data. Consensus was reached among three researchers for both the initial coding and theme derivation phases, thereby increasing the reliability of our analyses. Participants were also invited to engage in member checking once the initial themes were decided in order to provide their final feedback on the findings (Cho & Trent, 2006).

As with many studies incorporating qualitative methodology, selection bias is always a possibility. Recruitment occurred until data saturation was reached in both the bereaved parent and healthcare provider samples. However, it is possible that the bereaved parents who agreed to participate in our study may be better psychologically-adjusted compared to those parents who expressed disinterest or did not return the investigator's recruitment calls. Due to these potential differences, the legacy artwork experiences reported by our participants may be qualitatively different than the experiences of those parents who refused participation. Likewise, the majority of our parent participants were mothers, so the parent perspectives presented in this study may not generalize to fathers. The ethnicity and religious background of our participants were also homogenous. Relatedly, some of the demographics of our participants, specifically the marital and socioeconomic statuses, were not representative of the state's census data, suggesting that our results may be more skewed to intact families with higher socioeconomic statuses. These potential biases limit the ability to determine whether this legacy-making intervention would be beneficial for those from other backgrounds.

Our healthcare provider sample may also be biased. Specifically, it is possible that the healthcare providers who volunteered to discuss their perspectives of legacy artwork may be more inclined to refer families to this activity due to favorable impressions compared to those healthcare providers who may be less enthusiastic about complementary supports. The majority of the 38 eligible healthcare providers (71%) who did not participate were due to a lack of response to the investigator's recruitment emails and phone calls. Reasons for not returning the investigator's contact are unknown. The remaining 29% of healthcare providers who declined participation was a result of busy schedules. Moreover, our healthcare provider sample only averaged 7.75 years of experience working with the oncology population, which may also impact the generalizability of our findings. It is possible that healthcare providers with more experience working with this particular population may have different perspectives on legacy-making.

In addition to selection bias, our study was only conducted at one children's hospital in the country, which may limit the generalizability of the findings. Relatedly, findings may not generalize across all pediatric terminal illness populations as our study specifically targeted bereaved parents of children who died of cancer. The time span between the legacy artwork experiences and data collection also presents concern of possible memory inaccuracies. However, this limitation is the nature of bereavement research, given the ethics of recruiting bereaved parents. Because research recommends waiting six months after the child's death before recruiting, researchers' timeframes to conduct studies are limited. Additionally, recruiting bereaved parents immediately after the child's death would limit our ability to examine prolonged bereavement and the long-term impact of engaging in legacy artwork. Furthermore, the changing nature of grief and the wide range in years since the child's death among participants introduces potential confounds. Specifically, different stages of grief may impact the way parents reflect on their experience of participating in a legacy-making intervention, such that parents whose child died several years ago may report a different experience than parents whose child died within the past six months.

Furthermore, the qualitative data in this study was solely analyzed by human researchers. Thus, the qualitative analysis was subject to human error. Validation strategies such as relying on consensus among three researchers for theme development as well as implementing member checking with participants were employed to address the potential of human bias in the analyses. Several software packages designed for qualitative analysis such as ATLAS.ti and NVivo are becoming more common to help researchers with complex organization of data (Pope, Ziebland, & Mays, 2000). The evolution of these software programs appears promising in improving the rigor of qualitative analysis. However, it is important to note that despite the benefits of qualitative software, researchers' analytical skills are still needed alongside these programs to further the analysis beyond the counting of basic descriptive codes (Pope, Ziebland, & Mays, 2000).

Lastly, our study design did not allow us to make quantitative comparisons within the sample to determine if grief, depression, and attitude towards life significantly improved as a result of legacy-making. Our study only included a post-assessment of these measures as we specifically recruited bereaved parents/caregivers; thus, we did not have information on parents' grief, depression, and attitude towards life prior to engagement in the legacy intervention. In order to make comparisons within the sample to determine if legacy artwork improved these outcomes, parents will need to be recruited prior to participating in legacy artwork so that researchers can gather pre-assessment data.

To address our inability to make within sample comparisons, we chose to compare bereaved parents in our sample to other samples of bereaved parents in which similar outcomes were measured. These comparison samples were drawn from non-intervention studies. The purpose of these studies was to describe and understand the clinical presentation of bereaved parents by administering measures of grief and psychosocial functioning. However, comparing the presentation of our participants to other samples of bereaved parents also poses a couple limitations. First, our sample size is significantly smaller than the comparison samples, which reduces the power and our ability to detect meaningful differences between the groups. Secondly, because the studies with the comparison samples were not focused on legacy-making, we are unable to determine whether participants engaged in legacy-making. Similarly, we do not have information on other interventions (e.g., therapy) or supportive strategies that these comparison samples relied on, thus decreasing our confidence in making comparisons between the two groups. Due to these limitations in our quantitative design, our results regarding grief and psychosocial functioning are limited to the qualitative data which suggests that bereaved parents found legacy artwork to be helpful in coping with their distress.

Future Directions

Further studies in pediatric legacy-making activities would enhance the reliability and generalizability of our findings. Because this study primarily adopted qualitative methodology, it will be important to conduct quantitative studies evaluating differences in grief, meaning-making, and psychosocial functioning between parents/caregivers who chose to participate in a legacy-making intervention and those who declined participation. This will allow researchers to understand differences in bereaved families' experiences depending on whether they decided to participate in legacy-making activities during their child's illness journey. More research is also needed to determine the ideal time in the child's illness trajectory to offer legacy-making activities to patients and their families. A careful balance must be struck between being sensitive to family's emotional needs while also providing the highest quality of psychosocial care to all pediatric patients. By only offering the project when a child's prognosis is deemed terminal, it is possible that we are excluding other children with cancer and their families who may greatly benefit from a legacy-making intervention. As reported in this study, both bereaved parents and healthcare providers expressed a preference for not waiting until the prognosis is terminal to engage in legacy-making activities, as this results in distress, missed opportunities, and the potential to solidify legacy-making as a "death activity."

Although this study provided information on the benefits of legacy artwork for bereaved parents, it is essential that other specific legacy-making activities, such as music videos or illness blogs, are explored in pediatric populations. In a study by Foster and colleagues (2012), 61% of hospitals endorsed incorporating legacy art into interventions for children with cancer and their families. Handprints/hand molds (97%), locks of hair (88%), memory books (84%), and photography (75%) were the most common forms of legacy-making activities incorporated into hospitals. Advancing literature on other legacy-making activities implemented in hospitals, such as writing, music, and video (Akard et al., 2015) will allow children's hospitals to offer an array of evidence-based and individualized legacy-making interventions that will appeal to children and families with varied interests. This will allow pediatric patients and their families the opportunity to choose a form of self-expression (e.g., art, video, music) that best fits the needs of the family.

Additionally, research exploring the benefits of legacy-making from both the dying child's and siblings' perspectives is greatly needed. By gathering multiple informants' perspectives, researchers will be able to incorporate components into the legacy-making intervention that will best serve the needs of each group. Also, in order to expand the implementation of legacy-making activities, studies should be conducted with other pediatric terminal illness populations (e.g., sickle cell disease, cardiology, transplant) to determine if the positive effects of this intervention persist beyond patients with cancer and their families. Eighty-four percent of children's hospitals surveyed about legacy-making reported that patients with any life-threatening illness were offered legacy-making activities (Foster et al., 2012). Unfortunately, research about legacy-making in pediatrics only exists within the oncology population.

Finally, the National Institute of Nursing Research (2011) has emphasized a need for pediatric palliative care research to move in the direction of intervention rather than exclusively focusing on improving the training of palliative care providers. This study is unique in providing a foundation for the further exploration of a palliative intervention that has the potential to decrease the suffering of children with cancer and their families. When evaluating intervention research, extramural funding agencies, such as the National Institutes of Health, are primarily interested in whether behavioral health interventions are deemed relevant, acceptable, and beneficial by the target populations (Meissner, 2011). The findings in this study clearly demonstrate that both bereaved parents and healthcare providers found legacy artwork to be a relevant, acceptable, and beneficial intervention for anticipatory grief and bereavement. Unfortunately, research funding for complementary supports and palliative care is minimal, thus limiting investigators' abilities to conduct rigorous studies and advance the scientific knowledge in these areas (Chen et al., 2014; Ernst, 1999). Without research to support the benefits of complementary supports and grief interventions, hospitals will be less likely to allocate clinical funds to these services, thus resulting in a loss of interventions that may be particularly beneficial for bereaved parents/caregivers and their families. Therefore, studies evaluating the efficacy of complementary psychosocial interventions in palliative care should be prioritized in order to improve the clinical services offered to pediatric patients and their families.

Clinical Implications

Our interviews with bereaved parents and healthcare providers about their experiences with legacy artwork indicate that there are numerous benefits to participating in legacy-making. These reported benefits suggest that children's hospitals may consider implementing legacy-making activities into their pediatric palliative care programs. In order to ease the implementation of legacy-making, it is important to provide guidance based on bereaved parents' and healthcare providers' feedback for improving the intervention as well as discuss the potential barriers that may interfere with families' access to these activities. These guidelines are summarized in Table 6.

Although healthcare providers recognize many benefits of legacy-making activities, our study in combination with previous literature (Foster, 2012) demonstrates that personal factors, lack of knowledge and familiarity with the intervention, and fears of eliciting negative emotional responses may contribute to healthcare providers’ hesitation to offer legacy-making to patients and their families. Specifically, healthcare providers who identified as medically-oriented (e.g., oncologists, nurses) expressed more concern about introducing legacy-making to patients and families compared to psychosocial providers. This difference is most likely a result of several factors including background, training, and experience in helping patients and families cope with illness and impending death as well as comorbid psychosocial conditions. Families’ access to legacy-making is dependent on healthcare providers as they are the primary gate-keepers to this activity; thus, it is critical to address these barriers and increase providers’ comfort to introducing legacy-making.

Knowing the “perfect” time to introduce legacy-making was a commonly endorsed barrier to providing families access to legacy-making. As many participants mentioned, offering legacy-making earlier was preferred rather than delaying the process until the child’s condition was deemed terminal. Many positive outcomes result for patients, parents, and healthcare providers when legacy-making is offered earlier. First, the family is granted multiple opportunities to engage in meaning-making throughout the child’s illness journey instead of attempting to create meaning in one window of time shortly before the child’s death, which tends to be the most stressful time period for families. Secondly, offering legacy-making earlier increases the likelihood that the patient will be able to fully participate in the activity (i.e., awake rather than in a comatose state, less physical and cognitive limitations resulting from the cancer). Many participants stated that the legacy artwork in which the child was able to fully participate often held more meaning for families. Thirdly, extending the timeline of legacy-making allows patients and families the opportunity to develop rapport with the art therapist. By building rapport early on, families may be more open to being vulnerable with the art therapist during sessions, leading to increased meaning-making. Engaging in legacy-making earlier also eliminates the possibility of bereaved families exclusively taking home an unfinished piece after the child's death due to an unexpected change in health because they will have had several opportunities to create legacy projects together prior.

In addition to benefitting the patients and families, offering legacy-making earlier serves healthcare providers too. Instead of feeling pressure to ensure a legacy piece is created within the child's final days, healthcare providers are given sufficient time to facilitate legacy-making with the family, resulting in a less stressful experience for everyone involved. This mitigates feelings of guilt for healthcare providers if a project is not completed before the child's death and also decreases the likelihood that the art therapist would have to create a piece with a deceased child (e.g., creating a piece with his or handprints/footprints so that the family has something to take home). Although participants in our study recommended offering legacy-making earlier in the child's illness journey, this timing is not representative of what is currently happening at children's hospitals. Of the seventy-seven children's hospitals who participated in Foster and colleagues' study (2012), only 12% reported offering the legacy-making activities to the patient shortly after his or diagnosis. Thus, it may be helpful for pediatric palliative care programs to reevaluate the timing in which they offer legacy-making to patients and their families.

Relatedly, navigating the content of the introduction of legacy-making to families was also reported as a barrier to offering the artwork to families. Many healthcare providers feared using the wrong terminology when introducing the project, which may lead to emotional pain, questioning (e.g., "Does this mean my child is dying?"), and worry for the families. Rather than using jargon such as "legacy artwork," participants agreed that families are most receptive to the project when it is introduced as "artwork that will mark the child's illness journey." By introducing the artwork as a way to remember different parts of the child’s illness journey, there is less emphasis placed on the child’s death when creating the pieces. This reduces the stigma of legacy-making being viewed as “death projects” or the “last piece the patient created before dying.” Instead, there is more opportunity for meaning-making along the way which allows families to be more present during the legacy-making experiences rather than focused on what the offering of this project may mean for the child’s health status. Training healthcare staff how to deliver a uniform and compassionate introduction for legacy artwork would significantly improve the implementation of this activity.

Other barriers to legacy-making included a lack of knowledge and poor communication among healthcare providers. Despite recognizing benefits of legacy-making, medically-oriented healthcare providers are generally less familiar with psychosocial interventions compared to psychosocial providers. One step to reduce this gap in knowledge is for psychosocial staff to disseminate literature and experiential information to healthcare providers regarding legacy-making for patients and their families. By educating medically-trained staff on legacy-making, they will become more familiar and comfortable discussing the intervention with their patients and families. This will also most likely increase the referrals for this activity if legacy-making becomes a commonplace subject of discussion between medical and psychosocial providers. Additionally, providing opportunities for healthcare providers to engage in legacy-making interventions as a form of healing for their personal grief of patients may further their understanding on the positive outcomes that can ensue.

In regard to communication, it would be beneficial for art therapists and child-life specialists to join interdisciplinary oncology team meetings in which they could provide updates on the legacy projects (e.g., families who have participated, barriers when creating the projects, benefits of creating the project) to medical staff. Tracking the families who have participated would ensure that all families are granted sufficient opportunities to engage in legacy-making and that no families are forgotten due to a miscommunication among providers. During these meetings, art therapists would also be privy to medical updates of each patient from the oncologists and nurses. This information would help them assess the emotional needs of each patient and family and to prioritize their time accordingly.

Many bereaved parents also emphasized logistical barriers that hindered legacy artwork. First and foremost, several reported the need for the art therapist to be hired full-time rather than contracted. Hiring a full-time art therapist would improve the accessibility of legacy artwork such that families would no longer be limited to a couple nights a week. This would also allow art therapists to be present at the time of each child's diagnosis. If art therapists met families at the time of diagnosis and legacy-making was presented as an integral part of the treatment plan upfront, just as chemotherapy, families would most likely place greater emphasis on participating in the intervention. Secondly, providing the art therapist with his or her own office on the oncology floor would also illustrate the significance of his or her role as a member of the interdisciplinary treatment team. However, if financial barriers prevented hospitals from hiring an art therapist full-time, offering a space with art supplies for families to create during all times of the day would be useful. Although the art therapist may not be present for every moment of creation, the family would no longer be limited by the therapist's hours and could continue to build on the meaning-making initiated by the art therapist in the introductory session.

Finally, healthcare providers should keep in mind additional opportunities to connect with bereaved parents after the death of their child. As many bereaved parents highlighted in their interviews, there is a sudden loss of support and a great sense of isolation following the death of their child. Additionally, few opportunities exist for bereaved parents to share their children’s stories. Hosting art fairs and remembrance ceremonies where families could share their child’s legacy artwork with other bereaved families would be a healing experience. By expressing their pride and love for their children at these memorial events, bereaved parents would be reminded that their child’s legacy lives on despite their physical absence. Through these remembrance events, bereaved parents would have the chance to connect with others who have experienced the death of a child, thus forming supportive friendships with one another. Beyond legacy artwork, developing ways for bereaved parents to give back to the hospital (e.g., serving on family advisory councils, developing or modifying bereavement interventions) or to newly grieving families (e.g., mentoring bereaved parents) provides a unique and special opportunity for bereaved parents to keep their child’s legacy alive.

Conclusion

In conclusion, our preliminary findings suggest that incorporating legacy artwork into pediatric palliative care programs may result in benefits for bereaved parents, particularly following the death of their child. Additionally, they highlight the significance of having interdisciplinary teams with complementary supports on pediatric units to comprehensively address the needs of patients and their families. By further developing legacy-making interventions, it our hope that the lives of deceased children will be honored and that through these activities, bereaved parents may experience an alleviation of emotional suffering following the traumatic experience of their child dying.

References

Abadía-Barrero, C. E., & LaRusso, M. D. (2006). The disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS in Sao Paulo, Brazil. *AIDS Patient Care & STDs*, *20*(1), 36–43.

Aguinis, H., Gottfredson, R. K., & Joo, H. (2013). Best-practice recommendations for defining, identifying, and handling outliers. *Organizational Research Methods*, *16*(2), 270-301.

Akard, T. F., Dietrich, M. S., Friedman, D. L., Hinds, P. S., Given, B., Wray, S., & Gilmer, M. J. (2015). Digital storytelling: An innovative legacy-making intervention for children with cancer. *Pediatric Blood & Cancer*, *62*(4), 658–665.

Akard, T. F., Gilmer, M. J., Friedman, D. L., Given, B., Hendricks-Ferguson, V. L., & Hinds, P. S. (2013). From qualitative work to intervention development in pediatric oncology palliative care research. *Journal of Pediatric Oncology Nursing*, *30*(3), 153–160.

Akard, T. F., Gilmer, M. J., Miller, K., Steele, A. C., Hancock, K., Barrera, M., . . . Gerhardt, C. (2014). Factors affecting recruitment and participation of bereaved parents and siblings in grief research. *Progress in Palliative Care*, *22*(2), 75–79.

Alam, R., Barrera, M., D'Agostino, N., Nicholas, D. B., & Schneiderman, G. (2012). Bereavement experiences of mothers and fathers over time after the death of a child due to cancer. *Death Studies*, *36*(1), 1–22.

Aldridge, J., Shimmon, K., Miller, M., Fraser, L. K., & Wright, B. (2017). "I can"t tell my child they are dying'. Helping parents have conversations with their child. *Archives of Disease in Childhood-Education and Practice, 102*(4), 182–187.

Allen, R. S., Hilgeman, M. M., Ege, M. A., Shuster Jr, J. L., & Burgio, L. D. (2008). Legacy activities as interventions approaching the end of life. *Journal of Palliative Medicine, 11*(7), 1029–1038.

Barrera, M., D'Agostino, N. M., Schneiderman, G., Tallett, S., Spencer, L., & Jovcevska, V., . . . Schneiderman, G. (2007). Patterns of parental bereavement following the loss of a child and related factors. *OMEGA-Journal of Death and Dying*, *55*(2), 145–167.

Barrera, M., O'Connor, K., D'Agostino, N. M., Spencer, L., Nicholas, D., Jovcevska, V., . . . (2009). Early parental adjustment and bereavement after childhood cancer death. *Death Studies*, *33*(6), 497–520.

Beale, E. A., Baile, W. F., & Aaron, J. (2005). Silence is not golden: Communicating with children dying from cancer. *Journal of Clinical Oncology*, *23*(15), 3629–3631.

Beck, A. T., Steer, R. A., & Brown, G. K. (1996). Beck Depression Inventory-II. *San Antonio*, *78*(2), 490-498.

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234.

Bowlby, J. (1980). *Attachment and loss: Loss, sadness and depression (Vol. 3)*. New York, New York: Basic Books.

Buckle, J. L., Dwyer, S. C., & Jackson, M. (2010). Qualitative bereavement research: Incongruity between the perspectives of participants and research ethics boards. *International Journal of Social Research Methodology*, *13*(2), 111–125.

Carter, B. S., Howenstein, M., Gilmer, M. J., Throop, P., France, D., & Whitlock, J. A. (2004). Circumstances surrounding the deaths of hospitalized children: Opportunities for pediatric palliative care. *Pediatrics*, *114*(3), e361–e366.

Chen, E. K., Riffin, C., Reid, M. C., Adelman, R., Warmington, M., Mehta, S. S., & Pillemer, K. (2014). Why is high-quality research on palliative care so hard to do? Barriers to improved research from a survey of palliative care researchers. *Journal of Palliative Medicine*, *17*(7), 782–787.

Cho, J., & Trent, A. (2006). Validity in qualitative research revisited. *Qualitative Research*, *6*(3), 319–340.

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology*, *23*(24), 5520–5525.

Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics & Adolescent Medicine*, *156*(1), 14–19.

Coyle, N. (2006). The hard work of living in the face of death. *Journal of Pain and Symptom Management*, *32*(3), 266–274.

Creswell, J. W., & Poth, C. N. (2017). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, California: Sage Publications.

Currie, E. R., Christian, B. J., Hinds, P. S., Perna, S. J., Robinson, C., Day, S., & Meneses, K. (2016). Parent perspectives of neonatal intensive care at the end-of-life. *Journal of Pediatric Nursing*, *31*(5), 478–489.

Currie, E. R., Roche, C., Christian, B. J., Bakitas, M., & Meneses, K. (2016). Recruiting bereaved parents for research after infant death in the neonatal intensive care unit. *Applied Nursing Research*, *32*, 281–285.

Darbyshire, P., Cleghorn, A., Downes, M., Elford, J., Gannoni, A., McCullagh, C., & Shute, R. (2013). Supporting bereaved parents: A phenomenological study of a telephone intervention programme in a paediatric oncology unit. *Journal of Clinical Nursing*, *22*(3–4), 540–549.

Davies, R. (2004). New understandings of parental grief: Literature review. *Journal of Advanced Nursing*, *46*(5), 506–513.

Decinque, N., Monterosso, L., Dadd, G., Sidhu, R., Macpherson, R., & Aoun, S. (2006). Bereavement support for families following the death of a child from cancer: Experience of bereaved parents. *Journal of Psychosocial Oncology*, *24*(2), 65–83.

Duncan, C., & Cacciatore, J. (2015). A systematic review of the peer-reviewed literature on self-blame, guilt, and shame. *OMEGA-Journal of Death and Dying*, *71*(4), 312–342.

Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science & Medicine*, *58*(2), 391–400.

Edelstein, L. (1984). *Maternal bereavement: Coping with the unexpected death of a child*. New York: Praeger Publishers.

Eiser, C., Eiser, J. R., & Stride, C. B. (2005). Quality of life in children newly diagnosed with cancer and their mothers. *Health and Quality of Life Outcomes*, *3*(1), 29-34.

Eiser, C., & Morse, R. (2001). Quality-of-life measures in chronic diseases of childhood. *Health Technology Assessment*, 5(4), 1-157.

Ernst, E. (1999). Funding research into complementary medicine: The situation in Britain. *Complementary Therapies in Medicine*, *7*(4), 250–253.

Field, N. P. (2006). Unresolved grief and continuing bonds: An attachment perspective. *Death Studies*, *30*(8), 739–756.

Field, N. P., Gal-Oz, E., & Bonanno, G. A. (2003). Continuing bonds and adjustment at 5 years after the death of a spouse. *Journal of Consulting and Clinical Psychology*, *71*(1), 110-117.

Foster, T. L., Dietrich, M. S., Friedman, D. L., Gordon, J. E., & Gilmer, M. J. (2012). National survey of children's hospitals on legacy-making activities. *Journal of Palliative Medicine*, *15*(5), 573–578.

Foster, T. L., Gilmer, M. J., Davies, B., Barrera, M., Fairclough, D., Vannatta, K., & Gerhardt, C. A. (2009). Bereaved parents' and siblings' reports of legacies created by children with cancer. *Journal of Pediatric Oncology Nursing*, *26*(6), 369–376.

Foster, T. L., Gilmer, M. J., Davies, B., Dietrich, M. S., Barrera, M., Fairclough, D. L., . . . Gerhardt, C. (2011). Comparison of continuing bonds reported by parents and siblings after a child's death from cancer. *Death Studies*, *35*(5), 420–440.

Fredman, G. (1997). *Death talk: Conversations with children and families*. London: Karnac Books.

Gillies, J., & Neimeyer, R. A. (2006). Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology*, *19*(1), 31–65.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, *18*(1), 59–82.

Hadjistavropoulos, T., & Smythe, W. E. (2001). Elements of risk in qualitative research. *Ethics & Behavior*, *11*(2), 163–174.

Hilden, J. M., Watterson, J., & Chrastek, J. (2000). Tell the children. *Journal of Clinical Oncology*, *18*(17), 3193–3195.

Holland, J. M., Currier, J. M., & Neimeyer, R. A. (2006). Meaning reconstruction in the first two years of bereavement: The role of sense-making and benefit-finding. *Omega-Journal of Death and Dying*, *53*(3), 175–191.

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288.

Hynson, J. L., Aroni, R., Bauld, C., & Sawyer, S. M. (2006). Research with bereaved parents: A question of how not why. *Palliative Medicine*, *20*(8), 805–811.

Jalmsell, L., Kontio, T., Stein, M., Henter, J.-I., & Kreicbergs, U. (2015). On the child's own initiative: Parents communicate with their dying child about death. *Death Studies*, *39*(2), 111–117.

Kavanaugh, K., Moro, T. T., Savage, T., & Mehendale, R. (2006). Enacting a theory of caring to recruit and retain vulnerable participants for sensitive research. *Research in Nursing & Health*, *29*(3), 244–252.

Keim-Malpass, J., Adelstein, K., & Kavalieratos, D. (2015). Legacy making through illness blogs: Online spaces for young adults approaching the end-of-life. *Journal of Adolescent and Young Adult Oncology*, *4*(4), 209–212.

Kendall, P. C., Hollon, S. D., Beck, A. T., Hammen, C. L., & Ingram, R. E. (1987). Issues and recommendations regarding use of the Beck Depression Inventory. *Cognitive Therapy and Research*, *11*(3), 289-299.

Klass, D. (2001). Continuing bonds in the resolution of grief in Japan and North America. *American Behavioral Scientist*, *44*(5), 742–763.

Klass, D., Silverman, P. R., & Nickman, S. L. (1996). Continuing bonds. Washington DC: Taylor & Francis.

Knapp, C. A., Madden, V. L., Curtis, C. M., Sloyer, P. J., Huang, I.-C., Thompson, L. A., & Shenkman, E. A. (2008). Partners in care: Together for kids: Florida's model of pediatric palliative care. *Journal of Palliative Medicine*, *11*(9), 1212–1220.

Kobler, K., Limbo, R., & Kavanaugh, K. (2007). Meaningful moments: The use of ritual in perinatal and pediatric death. *MCN: The American Journal of Maternal/Child Nursing, 32*(5), 288–295.

Kreicbergs, U. C., Lannen, P., Onelov, E., & Wolfe, J. (2007). Parental grief after losing a child to cancer: Impact of professional and social support on long-term outcomes. *Journal of Clinical Oncology*, *25*(22), 3307–3312.

Kreicbergs, U., Valdimarsdóttir, U., Onelöv, E., Henter, J. I., & Steineck, G. (2004). Talking about death with children who have severe malignant disease. *New England Journal of Medicine*, *351*(12), 1175–1186.

Last, B. F., & Van Veldhuizen, A. M. H. (1996). Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8–16 years. *European Journal of Cancer, 32*(2), 290–294.

Levetown, M., Liben, S., & Audet, M. (2004). Palliative care in the pediatric intensive care unit. In B. Carter & M. Levetown (Eds.), *Palliative care for infants, children, and adolescents: A practical handbook*, (pp. 273–291). Baltimore, Maryland: The Johns Hopkins University Press.

Li, J., Laursen, T. M., Precht, D. H., Olsen, J., & Mortensen, P. B. (2005). Hospitalization for mental illness among parents after the death of a child. *New England Journal of Medicine*, *352*(12), 1190–1196.

Li, J., Precht, D. H., Mortensen, P. B., & Olsen, J. (2003). Mortality in parents after death of a child in Denmark: A nationwide follow-up study. *The Lancet*, *361*(9355), 363–367.

Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: Challenges and emerging ideas. *The Lancet*, *371*(9615), 852–864.

Lichtenthal, W. G., Currier, J. M., Neimeyer, R. A., & Keesee, N. J. (2010). Sense and significance: A mixed methods examination of meaning making after the loss of one's child. *Journal of Clinical Psychology*, *66*(7), 791–812.

Lichtenthal, W. G., Neimeyer, R. A., Currier, J. M., Roberts, K., & Jordan, N. (2013). Cause of death and the quest for meaning after the loss of a child. *Death Studies*, *37*(4), 311–342.

Lichtenthal, W. G., Nilsson, M., Kissane, D. W., Breitbart, W., Kacel, E., Jones, E. C., & Prigerson, H. G. (2011). Underutilization of mental health services among bereaved caregivers with Prolonged Grief Disorder. *Psychiatric Services*, *62*(10), 1225–1229.

Lindenfelser, K. J., Grocke, D., & McFerran, K. (2008). Bereaved parents' experiences of music therapy with their terminally ill child. *Journal of Music Therapy, 45*(3), 330–348.

McCarthy, M. C., Clarke, N. E., Ting, C. L., Conroy, R., Anderson, V. A., & Heath, J. A. (2010). Prevalence and predictors of parental grief and depression after the death of a child from cancer. *Journal of Palliative Medicine*, *13*(11), 1321–1326.

Meij, L. W., Stroebe, M., Schut, H., Stroebe, W., Bout, J., Heijden, P. G., & Dijkstra, I. (2008). Parents grieving the loss of their child: Interdependence in coping. *British Journal of Clinical Psychology*, *47*(1), 31–42.

Meissner, H. I. (2011). Use of qualitative methods to ensure acceptability of interventions. *Journal of Public Health Dentistry*, *71*, S83.

Meyer, E. C., Burns, J. P., Griffith, J. L., & Truog, R. D. (2002). Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*, *30*(1), 226–231.

Nadeau, J. W. (2001). Family construction of meaning. In R. A. Neimeyer (Ed.), *Meaning construction & the experience of loss* (pp. 95-111). Washington DC: American Psychological Association.

National Institute of Nursing Research. (2011). *The science of compassion: Future directions in end-of-life and palliative care*. Retrieved from http://www.ninr.nih.gov/researchandfunding/scienceofcompassion.

Neimeyer, R. A. (2000). Searching for the meaning of meaning: Grief therapy and the process of reconstruction. *Death Studies, 24*(6), 541–558.

Neimeyer, R. A., Baldwin, S. A., & Gillies, J. (2006). Continuing bonds and reconstructing meaning: Mitigating complications in bereavement. *Death Studies*, *30*(8), 715–738.

Normand, C. L., Silverman, P. R., & Nickman, S. L. (1996). Bereaved children's changing relationships with the deceased. In D. Klass, P. R. Silverman, & S. L. Nickman (Eds.) *Series in death education, aging, and healthcare. Continuing bonds: New understandings of grief*, (pp. 87–111). Philadelphia, PA: Taylor & Francis.

Park, C. L., & Benore, E. R. (2004). You're still there: Beliefs in continued relationships with the deceased as unique religious beliefs that may influence coping adjustment. *The International Journal for the Psychology of Religion*, *14*(1), 37–46.

Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F., & Radbruch, L. (2008). A matter of definition–key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*, *22*(3), 222–232.

Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: Analysing qualitative data. *BMJ: British Medical Journal*, *320*(7227), 114-116.

Price, J., Jordan, J., Prior, L., & Parkes, J. (2011). Living through the death of a child: A qualitative study of bereaved parents' experiences. *International Journal of Nursing Studies*, *48*(11), 1384–1392.

Prigerson, H. G., Horowitz, M. J., Jacobs, S. C., Parkes, C. M., Aslan, M., Goodkin, K., ... & Bonanno, G. (2009). Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS medicine*, *6*(8), 1-12.

Prigerson, H. G., Vanderwerker, L. C., & Maciejewski, P. K. (2008). A case for inclusion of prolonged grief disorder in DSM-V. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 165-186). Washington, DC, US: American Psychological Association.

Rando, T. A. (1986). *Parental loss of a child*. Champaign, Illinois: Research Press.

Reiss, D. (1981). *The family's construction of reality*. Cambridge, Massachusetts: Harvard University Press.

Reker, G. T. (1992). *The Life Attitude Profile- Revised (LAP-R)*. Peterborough, ON: Student Psychologists Press.

Rogers, C. H., Floyd, F. J., Seltzer, M. M., Greenberg, J., & Hong, J. (2008). Long-term effects of the death of a child on parents' adjustment in midlife. *Journal of Family Psychology*, *22*(2), 203-211.

Romanoff, B. D., & Thompson, B. E. (2006). Meaning construction in palliative care: The use of narrative, ritual, and the expressive arts. *American Journal of Hospice and Palliative Medicine®*, *23*(4), 309–316.

Root, B. L., & Exline, J. J. (2014). The role of continuing bonds in coping with grief: Overview and future directions. *Death Studies*, *38*(1), 1–8.

Rubin, S. (1981). A two-track model of bereavement: Theory and application in research. *American Journal of Orthopsychiatry*, *51*(1), 101-109.

Saiki-Craighill, S. (2002). The personal development of mothers of terminal cancer patients: How Japanese women change through the experience of caring for and losing their children to cancer. *Qualitative Health Research*, *12*(6), 769–779.

Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, *23*(3), 197–224.

Siegel, R., Ma, J., Zou, Z., & Jemal, A. (2014). Cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, *64*(1), 9–29.

Snaman, J. M., Kaye, E. C., Levine, D. R., Cochran, B., Wilcox, R., Sparrow, C. K., . . . Baker, J. (2017). Empowering bereaved parents through the development of a comprehensive bereavement program. *Journal of Pain and Symptom Management*, *53*(4), 767–775.

Song, J., Floyd, F. J., Seltzer, M. M., Greenberg, J. S., & Hong, J. (2010). Long-term effects of child death on parents' health-related quality of life: A dyadic analysis. *Family Relations*, *59*(3), 269–282.

Spinetta, J. J. (1974). The dying child's awareness of death: A review. *Psychological Bulletin*, *81*(4), 256-260.

Stillion, J. M., & Papadatou, D. (2002). Suffer the children: An examination of psychosocial issues in children and adolescents with terminal illness. *American Behavioral Scientist*, *46*(2), 299–315.

Stroebe, M. S., Hansson, R. O., Stroebe, W. E., & Schut, H. E. (2001). *Handbook of bereavement research: Consequences, coping, and care.* Washington, DC: American Psychological Association.

Stroebe, M. S., & Schut, H. (2001). Meaning making in the dual process model of coping with bereavement. *Meaning Reconstruction and the Experience of Loss*, 55–73.

Talbot, K. (2002). *What forever means after the death of a child: Transcending the trauma, living with the loss*. New York, New York: Taylor & Francis.

Trufelli, D. C., Bensi, C. G., Garcia, J. B., Narahara, J. L., Abrão, M. N., Diniz, R. W., . . . Del Giglio, A. (2008). Burnout in cancer professionals: A systematic review and meta-analysis. *European Journal of Cancer Care*, *17*(6), 524–531.

Valdimarsdóttir, U., Kreicbergs, U., Hauksdóttir, A., Hunt, H., Onelöv, E., Henter, J.-I., & Steineck, G. (2007). Parents' intellectual and emotional awareness of their child's impending death to cancer: A population-based long-term follow-up study. *The Lancet Oncology*, *8*(8), 706–714.

Weidner, N. J., Cameron, M., Lee, R. C., McBride, J., Mathias, E. J., & Byczkowski, T. L. (2011). End-of-life care for the dying child: What matters most to parents. *Journal of Palliative Care*, *27*(4), 279–286.

Wheeler, I. (2001). Parental bereavement: The crisis of meaning. *Death Studies*, *25*(1), 51–66.

Wing, D. G., Burge-Callaway, K., Rose Clance, P., & Armistead, L. (2001). Understanding gender differences in bereavement following the death of an infant: Implications of or treatment. *Psychotherapy: Theory, Research, Practice, Training*, *38*(1), 60-73.

Wu, L., Bonanno, G., DuHamel, K., Redd, W. H., Rini, C., Austin, J., . . . Martini, R. (2008). Pre-bereavement meaning and post-bereavement distress in mothers of children who underwent haematopoietic stem cell transplantation. *British Journal of Health Psychology*, *13*(3), 419–433.

Znoj, H. J., & Keller, D. (2002). Mourning parents: Considering safeguards and their relation to health. *Death Studies*, *26*(7), 545-565.

Table 1.

Bereaved Parents' Demographics

	Mean ± SD or %
Relationship to child	
Mother	83% (10/12)
Father	17% (2/12)
Marital Status	
Married	67% (8/12)
Divorced	25% (3/12)
Single	8% (1/12)
Ethnicity	
Caucasian	100%
Religion	
Christian	92% (11/12)
Non-religious	8% (1/12)
Age	41.17 ± 8.20 years old
Education	
Graduate degree	33% (4/12)
Bachelor's degree	25% (3/12)
Some college	25% (3/12)
High school diploma	17% (2/12)
Work Status	
Full-Time	58% (7/12)

Unemployed	33% (4/12)
Part-Time	8% (1/12)
Income	
$100,001-125,000	55% (6/11)
$25,001-50,000	27% (3/11)
$125,001-150,000	9% (1/11)
$0-25,000	9% (1/11)

Table 2.

Children's Demographics

	Mean ± SD or %
Gender	
Male	50% (6/12)
Female	50% (6/12)
Ethnicity	
Caucasian	100%
Age at time of cancer diagnosis	6.05 ± 5.54 years old
Diagnosis	
Subtype of leukemia	50% (6/12)
Sarcoma	25% (3/12)
Brain tumor	25% (3/12)
Number of relapses	1.55 ± .82
Treatment regimen	
Chemotherapy	100% (12/12)
Radiation	42% (5/12)
Surgeries	25% (3/12)
Bone marrow transplants	8% (1/12)
Experimental trial	67% (8/12)
Age at time of death	8.64 ± 5.73 years old
Location of death	
Hospital	92% (11/12)

Home	8% (1/12)
Number of siblings at time of death	
Zero	17% (2/12)
One	50% (6/12)
Two	8% (1/12)
Three	8% (1/12)
Four	17% (2/12)
Age of siblings at time of death	9.45 ± 6.42 years old

Table 3.

Healthcare Providers' Demographics

	Mean ± SD or %
Sex	
Female	83% (10/12)
Male	17% (2/12)
Ethnicity	
Caucasian	84% (10/12)
Bi-racial	28% (1/12)
Middle Eastern	8% (1/12)
Age	37.33 ± 6.33 years old
Profession	
Art therapist	25% (3/12)
Child-life specialist	17% (2/12)
Pediatric hematologist/oncologist	17% (2/12)
Registered nurse	17% (2/12)
Nurse practitioner	8% (1/12)
Palliative care physician	8% (1/12)
Chaplain	8% (1/12)
Years of experience with the pediatric oncology population	7.75 ± 4.25 years

Table 4.

Life Attitude Profile Revised (LAP-R) scores

	Mean ± SD (range)			
	Legacy artwork intervention group (Schaefer et al., 2019)	Comparison sample (Lichtenthal et al., 2015).	*t*	*p*
Dimension Scores				
Purpose	38.28 ± 9.77 (20-50)	36.26 ± 9.53 (10-56)	.70	.49
Coherence	42.91 ± 8.13 (27-52)	37.85 ± 9.11 (10-55)	1.85	.07
Choice/responsibleness	41 ± 8.14 (28-52)	41.18 ± 7.66 (19-56)	.08	.94
Death-acceptance	38.73 ± 4.05 (34-45)	36.71 ± 8.73 (12-56)	.79	.43
Existential vacuum	28.82 ± 7.07 (15-37)	26.77 ± 9.03 (11-49)	.76	.45
Goal-seeking	38.91 ± 7.50 (23-49)	36.26 ± 8.11 (19-56)	1.09	.28
Domain Scores				
Personal Meaning Index	81.18 ± 17.42 (47-102)	74.12 ± 17.63 (25-109)	1.32	.19
Existential Transcendence	93.18 ± 30.51 (36-139)	88.97 ± 32.66 (-12-167)	.43	.67

Table 5.

Themes surrounding the legacy artwork experience

Themes	Quotes
Theme 1. Creating legacy artwork projects facilitates family bonding and memory-making and opens lines of communication between family members regarding the child's impending death (n= 12 parents, 12 healthcare providers).	*"The daddy/mommy/me handprint legacy artwork was very meaningful because it was all of us working on that art as a family. We were creating memories as a family. So that helps to fill a small void in my heart, knowing we have those memories as a family with him."* -Parent
	"It's only meaningful if you do it all together. Some people don't realize until it's too late that it was the experience that really mattered, not the products." -Parent
	"The legacy artwork project is not just a tangible thing they are taking home. There is so much more to it. Through the art process, they have created so many family memories which are just as important." -Healthcare provider

“The little girl did not have the words to express what was a deeper, spiritual, inexpressible type thing. But through her artwork, she could share with her parents that she was ready to let go. It opened the doors to a crucial conversation for the family and one that allowed the daughter to be free.” -Healthcare provider

“Just like children who express themselves through play, art has the potential to open families up to deeper conversations. If you’re spending time working on a piece of art together, it may open the door to some important conversations. Oftentimes, families and patients want to have those conversations, but they don’t know how to start them. They may be difficult conversations, but they are conversations that need to happen.” -Healthcare provider

“We felt like creating the legacy artwork allowed us to talk about tough things without feeling pressured. It helped us put our feelings out there and to express ourselves. Sometimes, you just can’t put your pain into words. So instead of burying them, we used the art to share them with each other.” -Parent

Theme 2. Legacy artwork provides opportunities for parents to engage in life-review and meaning-making of the child’s death (n= 11 parents, 10 healthcare providers).	*“Legacy artwork tells not just the story of the child’s illness. It is the story of the who the child is currently and who they were and what that means. It is about their experiences and their whole journey.”* -Healthcare provider *“During the creation of legacy artwork, parents of the patient begin to reminisce and somehow come up with a metaphor for that child’s life and what meaning they attach to the child within their family system. For example, one time, a family made a circle of handprints and the metaphor was ‘we are always together,’ and ‘regardless of how our family system changes after her death, we are still one.’”* -Healthcare provider *“When asking if there is anything she would like me to change on the painting, my little girl said, ‘Can you make the yellow brick road bigger so momma can go with me?’ That’s when I knew she was seeing heaven.”* -Parent

"The legacy artwork showed that our family is an everlasting circle. Her handprints in the middle of ours represented us surrounding her with love, but at the same time, the butterfly she made with her handprints meant that we were giving her the freedom to fly, take her wings, and go to heaven to be with God. This painting expresses what our family was like in our last moment as one but also tells me that we will all be together again someday." -Parent

"We chose gold for her handprint on the family tree. It was for childhood cancer, but it was also for who she was as a child. It was shiny, and that's how she was. She was meant to shine. That's who she was and who she will always be no matter if she is with us or not. We knew her light would just keep on shining."
-Parent

"When you look at it, all you see is his legacy. It speaks volumes. You see love. You see sunshine. You see the kind of kid he was. You can tell that the only thing on his mind that day was not that he was sick. It wasn't that he was in the

	hospital. It was just that he was sitting in his room with his mommy and it mattered what was going on. He felt safe, happy, and warm. But the painting also shows that I'm leaving you. It shows that maybe he knew something about himself that I didn't know and that maybe God had talked to him." -Parent
Theme 3. Following the child's death, parents display the legacy artwork in their home and take comfort in using these projects to continue their bond with their deceased child (n= 10 parents, 8 healthcare providers).	*"This family stayed in contact with me for a few years, and the mother said, 'That piece of artwork, we had it framed, and it hangs above our fireplace in our living room. It is a constant reminder of the goodness of her time here with us.' This artwork helped them feel connected and attached to her despite her being gone."* -Healthcare provider *"At the funeral, the grandfather told me he hung the piece up above his mantle as soon as he got home from the hospital."* -Healthcare provider *"I have it hanging up on the wall. I took pictures while we all painted it together and so around his legacy piece, I have the pictures of us painting it."* -Parent

"The legacy piece, the last piece, that piece is in the living room. I love to change the decorations around it, and so every now and then, I'll spice it up with something new. Makes me feel close to her." -Parent

"After the patient passes away, the families are clinging to anything that reminds them of their child or anything that can give them the feeling of closeness to their child. Having these legacy artwork pieces can help them immensely because it is things they can look back on, it is memories, and they can hold that piece and touch it and feel a little bit closer to the child." -Healthcare provider

"The art legacy is that it is tangible, that it is something the families can hold onto. These pieces the families chose to take with them, chose to keep, chose to frame, and chose to hang up in their spaces are a continual reminder of the connection and the relationship between them and their child. And so legacy

	artwork offers an opportunity for parents to feel like their child is still teaching them, still giving them something, and still with them." -Healthcare provider
	"There are so many reminders and symbols of her in that piece. I love this piece because it is something that I can always hold onto and that it is something that is part of her. Her fingerprints are mixed in the paint that was used to create this piece, and that is so special to me." -Parent
	"When your child is gone, you can't see him, touch him, feel him, talk to him. But this painting is something that he created, something he touched, something he put himself into. And so in a way, it substitutes for him—if you can even imagine that being possible." -Parent
Theme 4. The experience of participating in legacy artwork ameliorated parents' grief and	*"Well at first when he passed, it was hard for me to look at his artwork, but then I realized this shouldn't make me sad. It brings back happy memories, and I will*

psychosocial functioning following the death of their child to cancer (n= 10 parents).	*just take his art piece off the wall, and I'll sit there and hold it and look at it and think of the good memories. It has helped me move through my grief journey."* -Parent *"The artwork is comforting to us. It helps move us from like being in a bad mood to a better mood especially on those really hard days."* -Parent *"It brings back…fun…you know, just good memories. It brings back a memory of being with him. You know, so, again, what it does, it takes you back to that—that happy moment. You know, because really in the end you have memories. You know and how do you keep those memories alive, and those positive ones. And um, and in a way, they're very comforting, you know, especially on grief burst days when you're struggling to make it through."* -Parent *"I definitely look at a picture of her and then look at the artwork and reflect on her. I'll look at her little handprint and see the size of her hand. I also love seeing*

	her name on there. When I reflect on it, it takes me back to when we made it together with her, and I smile. That brings me peace and helps alleviate a little bit of the pain and loss." -Parent *"That piece reminds me that there's more out there. It reminds me of those special moments in life, so it definitely influences the way I process my grief and the way I see life. It makes each day just a little bit easier."* -Parent *"When I look at that piece, I think of sadness, but I also think of how much he meant to me and how special he was and how blessed I was to have him and to be his mom. Even though I only had him for 8.5 years, he was still mine, and he was still him, and he was still my kid. I would never change that. So I feel very grateful and that helps me with my grief."* -Parent
Theme 5. Legacy artwork has the potential to reduce compassion fatigue and burnout among	*"I have also done a legacy art session for staff. It was a set aside time to kind of push back from providing care and process loss. I mean just time to think about*

healthcare providers as well as provide an outlet for coping with the death of their patients (n= 7 healthcare providers).	*patients they've lost and process that in a non-threatening environment. So I think it's beneficial for families for sure but the way the staff gravitated to it was pretty cool to witness also."* -Healthcare provider *"These art sessions for staff are so important because there is so much compassion fatigue and burnout, you know, with nurses and oncologists, especially with the direct care staff. I even remember the cleaning staff helping with some of the legacy projects and participating in the staff art sessions."* -Healthcare provider *"I can remember a time when the art therapist was in the conference room with art materials. It was just for the staff and Dr. Xxx allowed the staff to take a break and go create art at anytime throughout the day. We were to create as a form of self-care and as a way to process recent losses of children . This was during a tough season, a lot of deaths in a row. It was very emotional but also a neat experience."* -Healthcare provider

Table 6.

Suggestions for hospital staff to improve the implementation of legacy artwork and other bereavement interventions for bereaved parents

---

Suggestions for medical providers and art therapists at time of child’s diagnosis

1. Emphasize the importance of legacy-making to patients and families at time of diagnosis. Present legacy-making as an integral part of the treatment plan similar to chemotherapy and medical tests.
2. Have the art therapist meet the patient and family at time of diagnosis. He/she should be presented as an important member of the interdisciplinary team.

Suggestions for all healthcare providers regarding the introduction of legacy artwork

1. Offer legacy artwork projects early (i.e., close to child’s diagnosis) and frequently throughout the child’s illness journey regardless of the outcome.
2. Introduce the legacy artwork as an “art project that will mark different stages of the child’s illness journey.” Do not use the words “legacy artwork.”

Suggestions for all healthcare providers to improve communication with one another

1. Art therapists and child-life specialists should regularly attend interdisciplinary oncology meetings and provide updates on families’ legacy artwork participation to medical providers. During these meetings, art therapists should also take note of medical updates for each patient in order to assess the emotional needs of each family.
2. Art therapists or child-life specialists should track families’ participation in legacy artwork in order to ensure that all families are provided an opportunity to participate.
3. Art therapists and child-life specialists are encouraged to share research and experiential information of legacy-making with medical providers in order to increase

their familiarity with the intervention and to improve their knowledge about the benefits of participation.

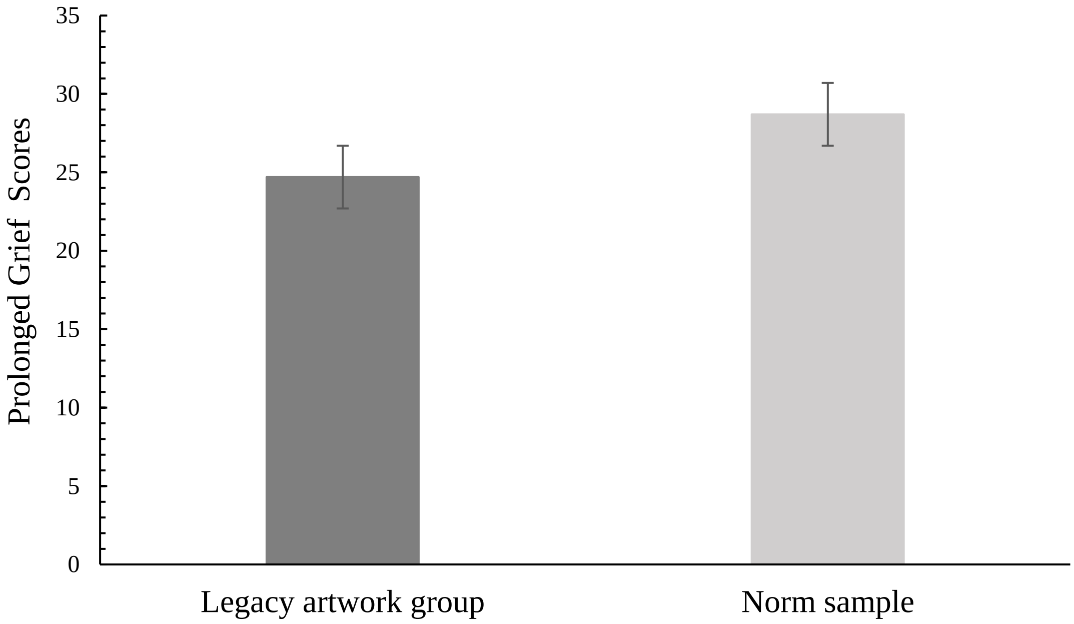
Suggestion for art therapists related to self-care of the entire medical team

1. Legacy-making interventions should also be offered for healthcare providers as a way for them to process their personal grief of patients and to model healthy coping.

Suggestions for healthcare administration and hospitals' logistics/planning committees

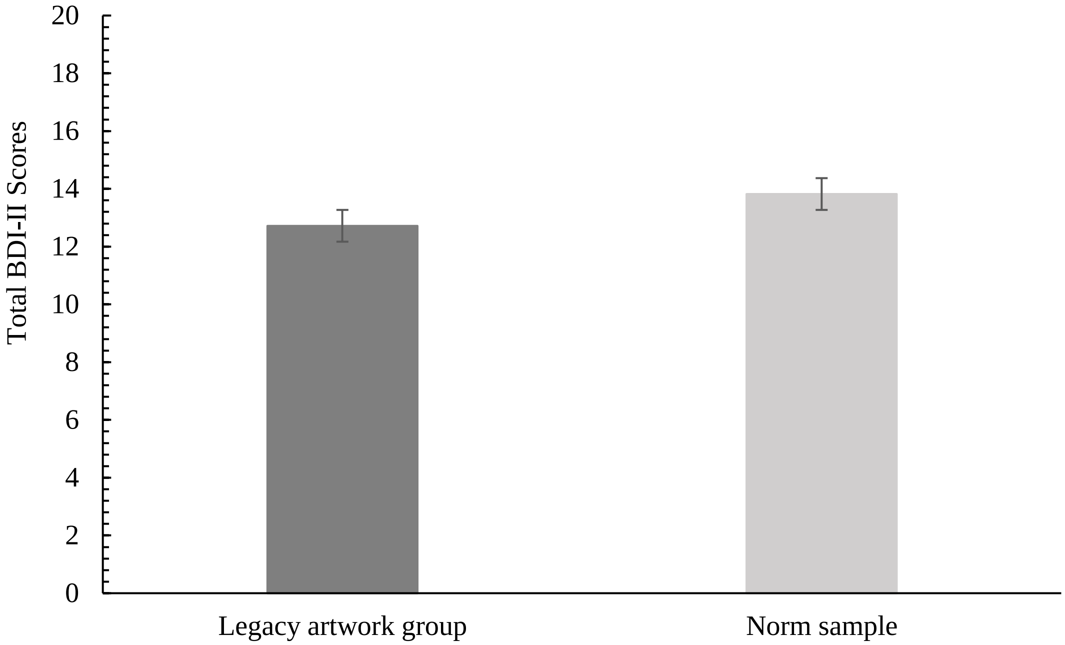
1. Hire a full-time art therapist to improve the accessibility of art therapy services for patients and their families.
2. Provide the art therapist with his/her own personal office space on the oncology floor to emphasize her importance on the interdisciplinary team.
3. Hold art shows/fairs and remembrance ceremonies so that bereaved parents have opportunities to share their child's legacy artwork pieces and to connect with other bereaved parents.
4. Create opportunities for bereaved parents to carry their child's legacy such as forming family advisory councils, mentoring bereaved parents, and developing bereavement interventions.

Figure 1. Differences in prolonged grief between parents in the legacy artwork group and those in the comparison sample



*= significant at *p*<.05 level

Figure 2. Differences in total BDI-II scores between parents in the legacy artwork group and those in the comparison sample



*= significant at *p*<.05 level

Appendix 1

Interview Script for Caregivers/Parents

Format:

1. **Introduction**
    a. ***Welcome:*** "Thank you for joining me in today's interview. You have been invited to participate because your point of view is very important to us. We greatly appreciate your contribution to this project. This interview is not a test. There are no right or wrong answers. We are simply interested in what you think and feel about the questions we will ask you."
    b. ***Statement:*** "The purpose of this interview is to learn more about your experience participating in a legacy artwork project with your child and the art therapist, Amy Brown, and how this experience has influenced your grieving process."

2. **Warm up**
    a. Set the tone and set participants at ease
        i. "Prior to participating in legacy artwork at our hospital, had you ever heard of legacy-making activities before? If so, when? What did you already know about them?"
            - Clarify definition of legacy-making activities afterwards: "These are projects created by your child or as a family to provide a lasting memory of your child."

3. **Establish easy and nonthreatening questions**
    a. "Who introduced the legacy artwork to your family? How was the legacy artwork introduced to you and your child? When was this activity introduced to your family?"
    b. "What artwork project did you create with your child?"
        i. "How did your child/family choose this specific project?"
    c. "Who helped in the creation of this project? Who was present (i.e., siblings, parents, healthcare providers) or who all participated in this project?"
        i. "Why did these individuals choose to participate in the legacy artwork activity?"

4. **Establish more difficult questions**
    a. Experience of legacy artwork
        i. "Walk me through your experience with the artwork project. Tell me everything you remember."
            - "What conversations occurred during the creation of the legacy artwork?"
            - Evaluate religiosity on demographic questionnaire. If a religion is indicated, ask the following: "Did religious or spiritual beliefs

influence your child's legacy artwork project? If so, tell me more about that."

b. ***Thoughts on legacy artwork project and its value***

1. i. "What thoughts and feelings did you have the first time you looked at your child's artwork?
2. ii. "Sometimes, caregivers say their child's legacy is represented by his/her art project. Tell me your thoughts about this related to your child's art project?" If they endorse a yes, follow-up with, "How is your child's legacy represented by his/her art project? How does your child's legacy live on through this piece and throughout your current life?"
3. iii. "Sometimes, caregivers find it helpful to create a legacy artwork project with their child. What was it like for you?"
4. iv. "Sometimes, caregivers find it meaningful to create a legacy artwork project with their child. What are your thoughts on this?" If they endorse meaning from the experience, follow-up with, "How meaningful of an experience was participating in legacy artwork for you and your child? How so?"
5. v. "Were there any negative aspects of the legacy artwork experience?"
6. vi. "Sometimes caregivers say their child's legacy artwork promotes meaning-making related to their grief (i.e., ability to understand and/or make sense of child's death. What are your thoughts on this?"

c. ***Location and reference of legacy artwork after creation***

- i. "Did your child ever refer to the legacy artwork after its creation? If yes, when and how so? In the days leading up to your child's death, was the legacy artwork referenced by the child or you all as caregivers? If yes, when and how so?"
- ii. "After the creation of the project, where did you all keep the artwork?"
- iii. "How has your child's artwork been used since your child died? Where do you keep the artwork? Is it displayed openly at your home or do you know where it is right now?"
- iv. "What thoughts and feelings come to mind for you when looking at your child's legacy artwork project now? How are these thoughts and feelings different from the first time you looked at the child's project?"

d. Grief Experience

- i. "Tell me your child's story."
    - Type of cancer, age child was diagnosed, relapses, treatment, experimental trials, age at death, age of siblings at death, location of death
- ii. "Tell me about your experience with grieving the loss of your child. What has this been like for you and your family?"
    - Negative consequences resulting from grief
    - Growth or benefits?

      iii. "There are two types of coping primarily seen in bereaved individuals. One is focused specifically on the loss of the child (i.e., concentrating on loss, crying) whereas the other one focuses on adjusting to a new way of living after the loss (i.e., adjusting to life after child's death, parenting surviving children, volunteering in memory of child). How would you describe your coping strategy? Do you do more of the first or the second or an equal amount of both? What coping strategies do you currently rely on?"
      iv. If religion is indicated, "Some people say their spirituality influenced their grieving? What are your thoughts about that?"
      v. "In what ways, if any, do you continue your bond with your deceased child?"
      vi. "Sometimes, caregivers say their child's legacy artwork project influences their grieving. Tell me your thoughts on this related to your own experience."
      vii. "Some bereaved families say it is very important to have the experience of creating a legacy artwork project with their child with cancer? What are your thoughts on this?"
      viii. "Some families believe it is important to have a physical item that represents their child's legacy after his or passing. What is your opinion on this?"
   e. ***Thoughts/feedback on current supportive interventions offered in palliative care***
      i. "What would you like to change about how the legacy artwork project was introduced to you (i.e., presentation, who introduced it, time of presentation, frequency of presentation)?"
      ii. "How could this service be improved for future families?"
      iii. "What other services/supportive strategies did healthcare providers provide prior to and after your child's death (i.e., attending child's funeral, remembrance ceremony, continued contact [how much?], follow-up sympathy cards)?"
      iv. "What other supportive activities do you wish staff offered during this difficult time?"
      v. "How supported did you feel by the medical team prior to and after your child's death on a scale from 0 (not supported at all) to 10 (fully supported. Tell me the reasoning behind the number you chose."

5. **Wrap-up**
   a. ***Identify and organize the major themes from the participant's response***
      i. "Let me attempt to summarize the key ideas I have heard about your experience with legacy artwork and grief."
      ii. "Is there anything else you would like to add that we have not had the opportunity to talk about today?"
   b. ***Checking in on experience of interview***

        i. "What was it like to participate in this interview with me today?"

6. **Member check**
    a. "After the completion of all the interviews with participants, would you be interested in discussing and providing your feedback on the preliminary findings? This is completely optional and can be done via phone or email. The results will be deidentified."

7. **Closing statements**
    a. ***Answer any remaining questions***
        i. "As we come to a close, I would like to remind you that the audio of this session will be transcribed. You and your child's names will be removed from the transcript so that you will remain anonymous. All information will be deidentified. Are there any questions that I can answer for you?"
    b. ***Express thanks***
        i. "Thank you again for your contribution to this project. This was a very informative interview and your open and honest responses will be an enormous asset to our work. Again, we very much appreciate your involvement

Interview Script for Healthcare Providers

Format:

1. **Introduction**
    a. ***Welcome:*** "Thank you for joining me in today's interview. You have been invited to participate because your point of view is very important to us. We greatly appreciate your contribution to this project. This interview is not a test. There are no right or wrong answers. We are simply interested in what you think and feel about the questions we will ask you."
    b. ***Statement:*** "The purpose of this interview is to learn more about your perspective on caregivers' experiences participating in a legacy artwork project with their child with cancer and art therapist, Amy Brown. Specifically, we are interested in your view on how this experience may influence their grieving process following the loss of their child."

2. **Warm up**
    a. Set the tone and set participants at ease
        i. "How are you as a professional involved with the legacy artwork experience offered to families here at Children's of Alabama? To what level of involvement (i.e., direct/indirect) do you have with this project?"

(Depending on degree of involvement, not all questions will apply to each healthcare provider. Route appropriately based on previous question.)

3. **Establish easy and nonthreatening questions**
    a. "What types of legacy artwork projects have you witnessed or heard about families creating with their child?"
        i. "How did these children/families choose their specific projects?"
    b. "Who helped in the creation of these projects? Who was all present (i.e., siblings, parents, healthcare providers)? Why did these particular members choose to participate?"

4. **Establish more difficult questions**
    a. Thoughts on legacy artwork project and its value
        i. "Tell me the things you remember about the legacy artwork experiences you have witnessed. What were some of the most memorable moments with families?"
            - "What conversations occurred during the creation of legacy artwork?"
        ii. "What reactions/thoughts/feelings were elicited by families and the children participating in legacy artwork?"
        iii. "What personal thoughts or feelings were elicited when you witnessed/participated the legacy artwork experience?"
            - "What is your favorite thing about legacy artwork projects?"

        - "What is most difficult for you when watching/participating in this activity?"
    iv. "Some families say their child's legacy is represented through his or her artwork. What are your thoughts on this?" If they believe this to be true, follow-up with, "How are children's legacies represented through their artwork?"
    v. "Some families believe legacy artwork is a meaningful experience for the child with cancer and his/her family. What is your opinion on this?"
        - "What benefits may families experience throughout this process? What may be negative aspects of this project?"
    vi. "Some families say a child's legacy artwork promotes meaning-making for them (i.e., ability to understand and make sense of their child's death? Tell me what you think about this."

b. ***Location and reference of legacy artwork after creation***
    i. "Did you ever hear a child or caregiver refer to the legacy artwork project after its creation? If so, when and what did they say?"
    ii. "How may families use their child's artwork after the child's death?"

c. Grief Experience
    i. "Tell me about the grief experience among caregivers who have lost a child to cancer. What grief responses do you typically see as a healthcare professional? What coping strategies seem to help these families?"
        - Negative consequences resulting from grief?
        - Growth or benefits?
    ii. "Some caregivers say a child's legacy artwork project impacts their personal bereavement and grief experience. What do you think of this?"
    iii. "Some families say it is important to have the experience of creating legacy artwork with their child. Tell me your thoughts on this."
    iv. "Some families also say it is important for them to have physical representative of their child's legacy after his or her death. What is your opinion on this?"

d. Thoughts/feedback on current supportive interventions offered in palliative care
    i. "What would you like to change about the introduction of legacy artwork to families (time of presentation, who should introduce it)?
    ii. What changes would you want to make about the facilitation of this project? How could this service be improved for future families?"
    iii. "What supportive strategies do you currently offer as a healthcare professional to families of children who have passed away from cancer?"
    iv. "What other services/supportive strategies do you think would be helpful to offer to families prior to and after their child's death (i.e., attending child's funeral, remembrance ceremony, continued contact [how much?], follow-up sympathy cards)?"
    v. "What barriers do you perceive in implementing legacy artwork as a healthcare professional? What are barriers associated with other

supportive interventions offered to families prior to and after child's death?"

5. **Wrap-up**
    a. ***Identify and organize the major themes from the participant's response***
        i. "Let me attempt to summarize the key ideas I have heard about your perspective of legacy artwork"
        ii. "Is there anything else you would like to add that we have not had the opportunity to talk about?"
6. **Member check**
    a. "After the completion of all the interviews with participants, would you be interested in discussing and providing your feedback on the preliminary findings via phone or email? This is completely optional. The data will be deidentified."

7. **Closing statements**
    a. ***Answer any remaining questions***
        i. "As we come to a close, I would like to remind you that the audio of this session will be transcribed. You will be assigned false names for the purpose of transcript and data analysis so that you will remain anonymous. Are there any questions that I can answer for you?"
    b. ***Express thanks***
        i. "Thank you again for your contribution to this project. This was a very informative interview and your open and honest responses will be an enormous asset to our work. Again, we very much appreciate your involvement."

Appendix 2

DEMOGRAPHIC INFORMATION
CAREGIVERS

Please answer these questions about you and your family. Some items are to be checked while others are fill-in-the-blank.

1. Your ethnic background
   _______ Black/ African American _______ White/Caucasian ______ Bi-racial
   _______ Hispanic/Latino _______ Asian/Pacific Islander
   _______ Middle Eastern _______ American Indian/ Alaskan Native
   _______ other (please fill in the blank) _______________

2. Please select your identified sex:
   _______ Male
   _______ Female
   _______ Other (please fill in blank)

3. What is your age in years? ____________

4. What is your relationship to the child?
   ______ Mother ________ Step-mother _________ Grandfather
   ______ Father ________ Step-father _________ Grandmother
   ______ Aunt ________ Uncle _________ Legal guardian
   ______ Other (please fill in the blank)

5. What is your highest level of education?
   ______ Some High school ________ High school diploma _______ Some college
   ______ Associate's degree _________ Bachelor's degree
   ______ Post graduate training _________ Graduate degree

6. What is your occupation? __________________

7. What is your work status?
   _______ Not employed ________ Part-time ________ Full-time

8. Yearly household income before taxes (please check one):
   ____ $0 – $25,000 ____ $25,001 - $50,000 ____ $50,001 – $75,000
   ____ $75,001 – $100,000 ____ $100,001 – $125,000 ____ $125,001 – $150,000
   ____ $150,001 – $175,000 ____ $175,001 – $200,000 ____ Over $200,000

9. Marital status
   _______ Single _______ Divorced _______ Partnered
   _______ Married _______ Remarried _______ Separated
   _______ Widowed _______ Other (please fill in the blank)

10. Was there another adult caregiver living in the home during your child’s life (e.g., child’s father, mother, step-mother, step-father, etc.)?
______ Yes
______No

If yes, who?________________________

11. Religion and/or spiritual belief system
_______ Atheist
_______ Hindu
_______ Non-religious
________ Buddhist
________ Jewish
_________ other (please fill in the blank) ___________
_______ Christian
_______ Muslim

12. Do you have other children?
_______ Yes
________ No

    a. If yes, how many? Daughters/sons?_______________________________

    b. How old are your children now? ___________________________________

DEMOGRAPHIC INFORMATION
HEALTHCARE PROVIDERS

Please answer these questions about yourself and your profession. Some items are to be checked while others are fill-in-the-blank.

1. Your ethnic background
   _______ Black/ African American _______ White/Caucasian ______ Bi-racial
   _______ Hispanic/Latino _______ Asian/Pacific Islander ______ Middle Eastern
   _______ American Indian/ Alaskan Native ___________ other (please fill in the blank)

2. Please select your identified sex:
   _______ Male
   _______ Female
   _______ Other (please fill in blank)

3. What is your age in years? ____________

4. What division are you associated with at Children's of Alabama? _______________

5. What is your current profession? ____________________________

6. How many years have you worked with the pediatric oncology population? _________

7. How many years have you worked in palliative care (if relevant)?
   ____

8. How many years have you been associated with the legacy artwork project?
   ____