THE EFFECTS OF LEGACY BUILDING ON THE GRIEF OF PARENTS AFTER THE DEATH OF A CHILD

by

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ABSTRACT

The present study focuses on how legacy building activities aid or inhibit grief processing in bereaved parents. 10 parents participated in semi-structured interviews to answer questions about the death of their child, personal grief, legacy building interventions, and suggestions for practitioners conducting legacy building. Interviews were transcribed, and themes from responses were coded and aggregated. These scores were analyzed to look for common variables across participants, experiences, and suggestions. As expected, findings showed more benefits of legacy building than risks. Additionally, legacy building items proved to provide emotional comfort among other positive benefits. Study implications are intended to provide practical suggestions for the improvement of practices.

I. INTRODUCTION

There are roughly 17 million parents caring for sick or hospitalized children in the United States (Akard et al., 2021). Additionally, an estimated 4 million children around the world are in or in need of a form of palliative care (Akard et el., 2021). Children facing life-threatening illness, injury, and impending death have shown higher levels of worry, anxiety, and depression, adding to family and parental stress during end-of-life care and post-death responsibilities (Zimmerman et al., 2018). Because the grief related to the death of a child is more complex and difficult to work through than the death of any other family member, as many as 63% of bereaved parents experience prolonged grief, which could significantly impact their level of personal functioning, even six months to a year after their loss (Andrews et al., 2020). The intervention of legacy building has been speculated to increase individual functioning and parental comfort levels (Akard et al., 2021; Andrews et al., 2020; Boles & Jones, 2021), but further research is needed to examine the effects of legacy building on grief processes. Thus, the present study examines the relationship among legacy building activities, severity of parental grief, and level of emotional comfort afforded by these activities.

Defining Legacy Building

While there is no universally accepted definition of legacy building, one study examining collaborative legacy building with cancer patients has defined it well; legacy building (also known as legacy making or legacy creating) is a continuous process of co-creating meaning in the form of a narrative produced within the context of a life (Cahalan et al., 2022). That is, legacy building is a process of preserving memories about a person that often leads to a tangible artifact (e.g., a handprint, pictures, writing, video recording, personal mementos). Importantly though, Boles (2014) has noted that the process of legacy building is more important and

impactful than the final product or legacy building activity done with the intention of strengthening relationships and creating emotional comfort. Items, which are the product of legacy building, are closely associated with the definition of legacy building used by pediatric hospitals- specific interventions used to alleviate stress in parents and patients and strengthen relationships (Boles & Jones, 2021). Boles and Jones (2021) also mention that this process can be intentionally planned as an intervention by palliative care team members such as child life specialists or nurses or can be spontaneously initiated by family members or terminally ill patients. However, no matter who initiates legacy building, behaviors and actions are always done with the intention to either be remembered or remember someone after death (Akard et al., 2021).

While most literature refers to legacy building as occurring near or after the time of death of a patient, some studies argue that legacy building can be done at any point across the lifespan (Boles & Jones, 2021). This lifelong process involves the shared meaning making created between two or more people in order to apply meaning to memories (Boles & Jones, 2021). However, by this definition of legacy building, there is no clear boundary between a legacy building activity and a normal arts and crafts project, and any activity done across the lifespan could be viewed as legacy building under the right conditions. Thus, the present study operationalizes legacy building as activities or behaviors collaboratively done by dying individuals, bereaved family members, health care team members, and community members to create a final tangible product with the intention of being remembered or remembering the deceased.

Legacy Building for Emotional Comfort

Studies have shown that when children are hospitalized, there are a number of losses that occur, the first being loss of normalcy (Boles, 2014). Because of more ambiguous and less recognizable losses like these alongside treatment, hospitalized children and their families are more prone to emotional suffering (Basak et al., 2019; Cahalan, et al., 2022). Consequently, higher stress levels and emotional distress during hospitalization can lead to longer hospitalizations and lower survival rates of patients (Cristal et al., 2018). Similarly, the emotional distress of a parent after losing a child has potential to be more severe and last longer than emotional distress related to the loss of other relationships (Andrews et al., 2020). Additionally, life threatening diseases can lead to anticipatory grief, or grief that arises before death once it is deemed inevitable by parents or caregivers (Coelho et al., 2018). Therefore, legacy building interventions might be crucial to the parents' emotional wellbeing after the death of their child.

While legacy building can be important in lessening the grief following the death of a child, parents often have different reasons as to why legacy building helps during bereavement. Love et al. (2022) identified many common themes across individuals' responses when asked to describe the reasons for legacy building, the use of the tangible object created in legacy building, and potential implication for practitioners. Reasons for legacy building included meaning making, continuation of relational bonds, proof that the life of the child held and still holds value. Uses of tangible objects were coded as for safe-keeping, display, having a dedicated time of use, and determining which items to keep after the death of the child. Timing, advice for the improvement of practices, and individualized care practices were coded under implications for practitioners.

Theoretical Framework

One way legacy building can help parents cope with the loss of a child is by providing the groundwork for meaning making (Clancy & Lord, 2018). Meaning making occurs when two or more individuals either consciously or unknowingly decide what an experience or object means together (Carter & Fuller, 2015). Creating meaning together is the foundation of legacy building, and the experience allows the patient, family, and health care team members to collectively come to an unspoken decision on the lasting impact of a dying child and what their life means (Clancy & Lord, 2018; Leigh, 2017). This can be extremely beneficial for parents, as the death of a child may challenge personal beliefs about God or spirituality, potentially dismantling religion as a meaning making system and further complicating grief (Leigh, 2017). Furthermore, because the death of a child can easily be viewed as meaningless and sometimes even preventable, the co-created meaning established in legacy building can lessen the burden of parents' grief, as parents who were not able to make sense of their child's death grieved more intensely and longer than parents who were able to create meaning and make sense of their child's death (Leigh, 2017).

To understand meaning making and legacy building in greater depth, it can be viewed through the lens of symbolic interactionism. This theory provides a micro-level framework that allows the family to be viewed in terms of repetitive patterns of interactions in which meaning is assigned (Carter & Fuller, 2015; Mead, 1934). The first basic assumption of symbolic interactionism is that individuals create meaning and symbols through communication, both spoken and through gestures (Mead, 1934). For example, a widespread meaning created by interactions within Western cultures is a head nod meaning "yes." The second basic assumption is that behavior is motivated by personal identity while the third is that society has a unique

relationship with each individual (Mead, 1935). Symbolic interactionism also says that meaning drives individuals, and an individual will act upon the meanings they create. This is especially important in end-of-life care, as the meaning loved ones associate with the deceased and the death of the deceased may impact how they are grieving.

In terms of legacy building, aspects of the tangible project can become a collection of co-created, meaningful symbols when favorite colors, hobbies, or religion is involved. Post-mortem, these co-created symbols become representative of the child and the product becomes a tool to connect the parent with the memory of the child. However, if symbols focused on during legacy building are not meaningful for the child or the parents, the legacy building intervention will not be as effective. Cahalan et al. (2022) briefly discuss that legacy building catered towards the need of the child and family shows increased levels of emotional comfort. Because of this, it is important that the child life specialist, nurse, or palliative care team member has an established relationship with the patient and family if possible so that the intervention can be catered to the needs of the family as best possible.

In addition to symbolic interactionism, Kubler-Ross (2014) introduced the five stages of grief of the dying person to the field. These stages are denial, anger, bargaining, depression, and finally acceptance. Kubler-Ross describes the stages as linear, and a person must overcome each stage before moving on to the next. However, while the theory covers common emotions that a grieving person might experience, this theory has been heavily critiqued because grief is often not linear and is unique from person to person (Kubler-Ross, 2014). Because of this, grieving individuals might not go through the stages in the order that Kubler-Ross proposed, come back to stages, or skip stages altogether. In addition, individuals may also feel and experience multiple stages at the same time (Kubler-Ross, 2014). Despite this, when looking at the theory non-

linearly, it can still provide a helpful theoretical framework for analyzing a grieving individual and family.

While Kubler-Ross's stages of grief were initially intended for the dying individual, David Kessler proposed that the stages can apply to grief of all individuals. Kessler also added onto Kubler-Ross's stages of grief by adding a sixth stage: finding meaning (Kessler, 2020). While the word "closure" is a common term associated with Kubler-Ross's final stage of acceptance when healing from a loss, Kessler argues that meaning-making is a more accurate term. While closure might imply moving on from the death of both a person and a relationship, meaning-making keeps the relationship between survivors and deceased alive and finds meaning in the death of the deceased (Kessler, 2020). The addition of this sixth stage not only makes Kubler-Ross's five stages of grief more relevant to the grieving narrative, but also provides a theoretical framework for legacy building. Because the stages of grief do not have to follow a linear pattern, individuals can begin the grieving process with meaning-making through legacy building. By beginning with making meaning, there is a chance that the grieving process may reduce distress in the following stages of the grieving process.

The Role of CCLS in Legacy Building

A certified child life specialist (CCLS) is a member of the pediatric health care team responsible for developmentally appropriate interventions. These interventions can often include procedural preparation and support, distraction, patient advocacy, appropriate medical education for both the patient and family, and play opportunities to encourage developmental growth and maintenance during hospitalization (McGee, 2003). Child life specialists often intervene at points of high stress or crisis within the family, one of which can be the death of a child. When this occurs or is expected to occur, child life specialists take on the task of legacy building with

the family. Common legacy building activities may include handprints on canvas, hand molds, or cutting and saving locks of hair. Older children and teenagers may choose to journal, write songs, create art, or record video diaries. More recently, technology such as digital stethoscopes have been able to be utilized by child life specialists so measures such as electrocardiographs can be included into legacy building activities (Andrews et al., 2020). These activities can be altered to fit the needs or personality of the patient or family and may strengthen relationships between patient and family, provide the patient with comfort in knowing that they will not be forgotten, and provide the family with a tangible object that may provide emotional comfort after the death of the child.

While child life specialists are most often the initiators of legacy building, members of the palliative care team or even family members may decide to initiate activities (Boles & Jones, 2021). However, other health care staff such as nurses, doctors, and chaplains may also be trained on how to perform legacy building so that they may be included in activities, especially if they built a strong connection with the patient and family.

Purpose

While some studies have focused on the effects of legacy building with adults or childhood cancer patients with a limited sample size, little research has focused on the response of parents to legacy building interventions (Akard et al., 2021; Boles & Jones, 2021; Cahalan et al., 2022; Jennings, 2002). Therefore, further research examining how legacy building with parents and child patients outside of the hematology-oncology unit are needed to fully understand the spectrum of legacy interventions and to make data more generalizable to the population of bereaved parents. Thus, the present study examines the relationship among legacy building activities, severity of parental grief after losing a child, and the level of emotional

comfort that was afforded to bereaved parents through legacy building activities or products. Two research questions will be addressed:

1. How does legacy building impact the grief of bereaved parents?
2. How could legacy building be improved upon based on the experiences of bereaved parents?

It was expected that legacy building will not only help build connection with the child but provide emotional comfort. Based on the findings of Love et al. (2022) and Cahalan et al. (2022), the study also expected that parents would suggest that practitioners allow more personalization in and time for legacy building activities when possible as well as recommend that practitioners use clear communication about the purpose of legacy building and use discretion for proper timing of interventions.

II. METHODOLOGY

Participants

Participants included 10 bereaved parents of a child who engaged in any form of legacy building with their child before, at, or soon after death. Additionally, at least six months must have passed between the interview and the death of the child, as previous studies have concluded that bereaved parents see this was the most appropriate timing for a sensitive interview (Butler et al., 2019; Hynson et al., 2006). While demographic information on age, gender, race, income, and age of child at death were collected, there were no eligibility limitations placed on these variables. Demographic information can be found in Figure 1. Participants were recruited from rural north Louisiana through an online announcement of the study and its purpose and through word of mouth after the online announcement.

Gender	**Age**	**Child Gender**	**Child Age**	**Number of Siblings**	**Years Since Death**	**How Child Died**
Female	55	Male	16	1	--	Car Accident
Male	58	Male	17	1	20	Car Accident
Female	--	Female	16	1	--	Cancer
Female	78	Female	18	1	--	Car Accident
Female	--	Female	18	2	--	Car Accident
Female	51	Male	4	1	18	Cancer

Female	45	Male	0	3	13	Anencephaly
Female	38	Unknown	0	2	12	Stillbirth
Female	70	Female	16	3	32	Car Accident
Female	65	Male	3	2	37	Cancer

Figure 2. Demographic Data of Participants.

Recruitment

To recruit participants, an infographic was created and was posted to social media platforms Facebook and Instagram as well as in online grief support groups. The infographic briefly described the purpose of the study and provided contact information for the principal investigator. Participants interested in the study contacted the principal investigator via email or phone, and the principal investigator ensured that the individual met the participation requirements for the study. After ensuring that the individual was within the participation guidelines, participants were given the option to complete their interview face-to-face or via Zoom, but all participants chose to meet in-person. Then, a meeting place and time was scheduled at the convenience of the participant in the location that the participant chose to allow for added comfort in interviews.

Design and Procedures

Semi-structured interview questions were developed from the measures of similar qualitative studies interviewing bereaved parents alongside literature discussing the implications and benefits of legacy building (Love et al., 2022). This format allowed for predetermined topics to be covered while still allowing natural conversation with participants and gave them space to include impactful experiences or suggestions that researchers may not have thought to ask about.

Interviews were conducted in person by the lead researcher. Individual interviews were scheduled to last approximately one hour, but participants were ensured that they did not have to completely fill up the time. The interviewer also accounted for extra time after the interviews as to allow the participant to share as long as they felt comfortable. Because of this, interviewed ranged in duration from 20 minutes to 2.5 hours. The interviewer also took into consideration a brief rapport building conversation before the beginning of the interview, which was allowed to happen naturally. This conversation was prompted by surface level conversation topics such as weather or how the participant's day was, but participants were allowed to steer this conversation in any direction they chose. Often, participants asked about the interviewer, and by obliging to answer personal questions, rapport was built more quickly.

Interview questions acted as guiding questions focused on the life and death of the child, family's health care and legacy building experiences, the meanings associated with legacy and legacy building activities, the parent's transition to bereaved, and the timing of interventions. Depending on the answers of the participant, the interviewer chose to ask additional questions or skip certain questions to allow participants to expand on a topic or avoid repeating parts of the conversation. Interview audio was recorded with the consent of the participant. Because most interviews were conducted with individuals who may have had trouble accessing the internet, participants were presented with physical informed consent forms and demographic surveys upon arrival at the interview site. The interviewer reviewed the informed consent form with the participant prior to beginning the interview, emphasizing that the interview can be stopped at any time if they feel uncomfortable. Participants were also given the option to be audio recorded during the interview. While most participants consented, three participants declined to being recorded.

To ensure the protection of participants and to allow for informed autonomy, consent forms mentioned the likelihood of psychological and emotional distress caused by grief as well as a brief outline of emotions associated with grief as described by Butler, Copnell, and Hall (2019). After interviews, audio was be transcribed, and transcriptions were coded and analyzed by the principal investigator and an undergraduate research team using SPSS. Data were then compared to look for emergent themes.

Risk Management

During interviews, it was imperative that the mental health and wellness of participants be prioritized over data collection. While participants were aware of the risk of psychological distress that may be brought on during interviews, as was stated in consent forms, grief may impact the participant's ability to comprehend or remember information on the consent forms (Alam et al., 2011). Therefore, the interviewer verbally reminded the participant about the purpose and risks of the study as well as their ability to stop the interview at any time prior to starting (Butler et al., 2019). Participants were encouraged to use their personal coping strategies during the interview, including crying to reduce emotional distress and discomfort if needed (Butler et al., 2019). Additionally, while most bereavement education encourages the use of the word "dead," Butler et al. (2019) found that it was helpful to let parents decide which terminology to use in order to prevent unnecessary emotional triggers and further build rapport with the participant. Because of this, the interviewer paid attention to the participants' language surrounding death and used similar language. If the participant appeared to be moving towards emotional distress, the interviewer gently moved from the topic causing distress to a related, less emotional topic or the interview was paused (Butler et al., 2019). While emotional distress was managed within the interview, a plan was in place to gently conclude the interview and contact

the licensed professional counselor on standby for immediate help if the participant threatened harm to themself or others or mentions any form of abuse (Butler et al., 2019). Additionally, the interviewer participated in QPR training (Question-Persuade-Refer Suicide Prevention Training) and was certified prior to conducting interviews to provide the highest quality help possible if participants shared about suicide ideation related to the loss of their child. However, while there is risk in the study, Butler et al. (2019) reported that even though most participants experienced strong emotions during interviews, all participants that did reported they did not view those strong emotions as harmful, but rather as a cathartic release. Similar research has found that individuals participating in bereavement interviews report being grateful to tell the story of their child even if the interview is emotionally challenging, as the topic of death can be uncomfortable for most people to talk about (Hynson et al., 2006).

Best Practices for Interviews

When conducting interviews, the present study will follow the suggestions for building rapport and maintaining professional boundaries from the study done by Butler et al. (2019). Researchers reported that interviewers needed to be skilled at quickly building an appropriate amount of rapport, as this will make the participants comfortable enough to share intimate details concerning the death of their child and the bereavement process. However, while rapport is crucial for the revealing of more intimate details, the interviewer should set personal boundaries as to not let the relationship become a friendship or therapist relationship (Hynson et al., 2006). The study by Butler et al. (2019) also discussed whether to include self-disclosure as a means of rapport building because participants may be interested in whether personal experience led to research on the topic. They concluded that the interviewer may disclose personal information regarding a death experience if asked, but to refrain if not asked. They also found that the

inclusion of self-disclosure did not alter the interview or information given by participants during the interview (Butler et al., 2019).

Measures

Demographics. Brief surveys that ask the participant to report on their own age, gender, ethnicity, education level, marital status, and estimates of yearly total household income were administered. Surveys also included questions on the demographics of the deceased child such as their age at death and number of siblings. All 10 participants were residents of rural north Louisiana communities, ranging in age from 38 to 78-years-old. Additionally, all participants were white, Protestant, middle class individuals. Participants also included 9 mothers and 1 father, and all participants were employed or retired. Children of participants ranged in age from fetus to 18-years-old when they died, and the death of all children occurred at least 12 years prior to the study. Causes of death ranged from sudden incidents like motor vehicle accidents to drawn out processes such as leukemia and anencephaly where parents may have experienced anticipatory grief.

Legacy Building Interviews. Interview questions were developed and piloted in a study conducted by Love et al. (2022). Prior to this study, prompts were reviewed by a director of bereavement services at a pediatric cancer center and a psychologist along with researchers who reviewed for validity of questions. The researchers developed a final interview guide of eight open ended questions along with probes to explore parents' experiences with legacy building as well as their suggested best practices concerning legacy building. These interview questions and probes can be found in supplemental Table A.

III. ANALYTIC PLAN

Emergent themes from the interview data were identified. These themes from across all narrative responses were organized into a structure for descriptive analyses. The frequency of each theme was reported, and an aggregate score was created for analytic purposes. To address research question one, aggregated scores from interview responses were compared to see which themes within responses occur most often. To address research question two, aggregated scores on suggestions for practitioners were compared to see what recommendations are common among bereaved parents.

IV. RESULTS

In total, 7 out of 10 participants agreed to be audio recorded during their interview. Therefore, while data from the 3 participants who declined to be recorded was used in the analysis of descriptive statistics, data taken from their interview was not included in the primary analysis or the Cohen's Kappa interrater reliability analysis. Among the 7 interviews coded for interrater reliability, raters identified 17 common themes found across interviews. The operational definitions of these themes can be seen in Figure 2. Interviews were coded in turns, a turn being a new start to a comment or explanation by the participant after the interviewer asked a question or made a comment. A single turn could display multiple themes, but no turn displayed a single theme more than once. Initially, interview transcriptions were coded by individual coders, with the interrater reliability score averaging 0.402. The principal investigator aimed to have a reliability score greater than 0.750 across all themes and interviewees, so coders reanalyzed interview transcription codes until a reliability score of 0.87 was reached. Codes of the principal investigator were used as the most reliable codes, acting as the golden standard to resolve disagreements between coders.

Community	Participation in a social group which can show support
Faith	Belief in God or religiosity that assists in processing grief
Wants to talk	Want to talk about child with family, friends, and community
Lack of closure	Lack of having finality of death of child
Finding good	Searching for something good/meaning that came out of child's death
Staying busy	Suppressing or ignoring grief through activity
Event held	Any event that is held in memory of child or support of family

Memorial site	Grave site, memorial marker on side of road, or stagnant marker
Financial donation	Scholarships or donations to organizations by family
Gift to family	Any physical item given to family to honor child
Ritual	Repeated activity done by family at a set interval or on a certain date
Keeping child's items	Maintaining of possession of child's items after death
Pictures	Keeping or looking at pictures
Wondering	Wonders what child would be doing if they were alive
Respect	Honoring of child's character and/or family without physical items
What would they want	Parent wonders what child would want them to do after their death
Hope	Positive attitude towards future or afterlife, religious or nonreligious

Figure 2. Operational definitions of emergent interview themes.

When looking at interview data, community was the only theme to be consistently present in all interviews, with a mean of 2.1 mentions per interview and a standard deviation of 1.101. However, faith (M=1.7, SD=1.567), wanting to talk about their child (M=1.4, SD=1.350), gifts presented to the family (M=1.5, SD= 1.080), and rituals (M=1.4, SD= 1.265) were mentioned in at least 8 out of 10 interviews. Additionally, respect for the child (M=0.2, SD= 0.422), lack of closure (M= 0.1, SD= 0.316), and staying busy (M= 0.1, SD= 0.316) were statistically insignificant as they were the most uncommon themes among interviews.

Additionally, significant quotes regarding emerging themes were taken into consideration when analyzing data. These include quotes such as follows:

> I didn't want a shrine for [my child], like in her room. I didn't want it just to be all her. So, what I did, and it took me about five years, and I gradually changed that room into a guest room but I took all the special things she loved. She loved cats

and collected cat figurines, so I have a case I put those in, and I have pictures spread throughout the house. But nothing… I don't have any more of her than I do other family members really. Just here and there, a smiley face or whatever. I knew from the beginning that… Different things work for different people. That might give them a lot of comfort to have a shrine, but I wanted to spread it out. Those items grow in value in your heart and soul through the years. That's all you have left of them. It increases in value. Your memories become more special as time goes on.

Well, the main thing I say is that if people don't have that faith basis, then I don't know how they handle it. Because that's your hope that they're in a better place. That's what gets you through. And they wouldn't come back here if they had the choice. And when we get there, we'll see why. And when this first happened, I always said the first thing I'm going to do when I die is ask God why this had to happen. But as the years went by, that's not as important anymore. And when I get there, that won't be important at all.

And do you remember those kits where you would sell things out of them? Her boyfriend's mother and daddy got three ceramic kittens. So, the year she died in 1992, her boyfriend's dad put that on her grave. And he leaves it every year since. He leaves it there around a week before Christmas and then he'll go back and pick it up after. And I'm just so amazed that they remember that because their son has gone on and married but they're still remembering her.

[The funeral home] was really sweet and they did the funeral. And I picked out a casket. And the casket I wanted didn't come in. But they didn't want to tell me

that, so they had someone on staff build one out of cedar. And they painted it. As a matter of fact, the day of his funeral, you could still smell the paint. They painted it black, and they had just me and my husband go in and we just had a graveside service. And he's buried next to my grandmother. The funeral home actually never charged us for the service. Me and my husband grew up with the guy who runs it and he was like I cannot charge you.

When I came home, some of the nurses from the hospital brought me a purple box. And she said I wouldn't encourage you to open it right now but when you get ready, it's just like a little memento for him and about a couple weeks, I decided to open it. And inside, they had actually taken pictures of him with his little baby hat they had sewn small enough to fit his head. They put him in a little blue gown and had taken pictures of him. And inside they had done a birth certificate with his hand and footprints. And they were like the size of my thumb. And inside was what would've been his armband, my armband, and all these sweet cards of prayer. Which to me meant so much because sometimes in a medical setting, people don't talk about prayer.

I do wish I had things for him or her. Those are the hardest things when you don't have something to hold on to. Like you need something just for yourself in a legacy way to acknowledge their existence. That's one of the hardest things about miscarriages is that there's no, there's nothing to say they were here. It's almost like they didn't matter because no one knew. So you carry that through your own family.

Yeah, we just cleaned his room up. He's still got his school clothes in his closet, uniforms and all that. Part of me wants to take it up there to the school and see if some other kid could use them but it's like part of him is still there.

What bothers me the worst is when somebody knows he's passed away and then they won't say something. I've lost several friends, and I think it's because they don't know what to say. Or they don't want to say his name thinking it's going to upset me. And I'd rather them just go ahead and say something rather than not say it.

V. DISCUSSION

While the initial focus of the study foresaw many physical items as being the most helpful for parent grief and bonding with the child, many intangible legacy building activities and coping mechanisms were common themes among participants. Because community was the most common and seemingly most impactful theme among the grief of participants, having a supportive community may be among the most helpful coping mechanisms for parents who have lost a child. Additionally, many parents said that it was more troubling when friends and family were reluctant or avoided talking about the deceased child, which may have been caused by individuals fearing it will bring up negative feelings. However, many parents discussed that while talking about their child may bring up negative feelings, it also brings up positive feelings to know that their child is remembered, and their grief is seen. One mother said "I know some people don't like talking about their kids that have passed, but it doesn't bother me. Actually, when somebody asks me, I'm not mad about it, I'm more flattered because that means he did something for them to remember him. He's not forgotten." Additionally, when asked about recommendations for service providers, another parent stated "I think talking about it helps. If people try to hold it all in and never talk about it, I could see where that would hurt you more. And people don't seem to want to do that because they don't want to upset you." Because of this, it is recommended that child life specialists and service providers that work with bereaved parents establish and provide a support group for these individuals.

While community was a common theme, participants often noted that community and faith were closely related due to participation in a local church. Many of the participants' local churches not only offered community through Sunday school classes, but also through religious grief groups. Additionally, religion offers a hopeful framework and foundation for views of the

afterlife, as many participants mentioned their belief that their child is in heaven and the solace that they find in that. Parents also discussed that religion can act as a foundation for finding meaning in the death of a child, with two parents in particular noting that they cannot fathom how individuals cope with losing a child without the meaning provided by religion.

In addition, interviews highlighted the ongoing relationship that parents can have with their children after death through the common theme of rituals. Especially common among parents of older deceased children, participants continued rituals they did with their child. Participants' rituals included hanging the child's stocking at Christmas, going to a special restaurant on the child's birthday, and watching the opening day of Texas Rangers baseball together. One participant in particular noted that even though the child is deceased, the relationship with the child continues and rituals help to strengthen it. It was also noted by the interviewer that many parents use present tense verbs when talking about characteristics of their child, only using past tense when referring to something their child did. Because of this, it is recommended that service providers validate or encourage a continuing relationship with their child after death and discuss the child in present tense.

While intangible items were more common themes in participants' interviews, the most common physical item used for grief were gifts presented to the family. In infants who died at birth and cancer patients, gifts were often given by nurses who helped deliver the baby or care for the patient and family. These included pictures, teddy bears, and notes from the nurses. In older children, especially those who died in motor vehicle accidents, plaques, garden stones, creations by classmates, and the child's sports uniform were common gifts to parents. One parent mentioned that it was not necessarily the gift itself that mattered the most, but the relationship the child had with the gift giver and the respect the gift giver had for the child that mattered more

in processing grief. She received a box of mementos put together by the nurses who helped deliver her child with anencephaly and supported her through his six-minute life. She said, "They're very special and touching. Matter of fact, [the nurse] was the one who delivered him and her and [another nurse] put the box together, and if you know them you know that's their heart. So of course, the box means a lot to me, but those ladies are the ones who thought to do that so they're very special to me." Because of this, it is recommended to service providers that the relationship with parents takes priority over a physical item when caring for bereaved parents and dying children.

Strengths

While there have been studies examining the relationship between parental grief and legacy building, these studies were primarily done with parents of hematology and oncology patients (Cahalan et at., 2022). This was the first study to examine how legacy building benefits bereaved parents of children outside of hematology and oncology units, providing insight on legacy building with parents of infants and children who died suddenly. This will also be among the first studies that focus on the grief of bereaved parents from a child life framework. The method of data collection also is expected to provide detailed insight into the grief of parents and provide practical suggestions to child life specialists and other practitioners providing end-of-life care.

As expected, based on past theories and research (Kessler, 2020), results highlight the role of legacy building in parents' finding meaning and building coping strategies. Themes that emerge from participants' narratives illustrate how the meaning-making keeps the relationship between themselves and their deceased loved one alive. This expectation is also supported by symbolic interactionism, as a core tenant of the theory states that meaning is created through the

interaction of two or more individuals (Mead, 1934). Because legacy building encourages the shared creation of a physical product, it is likely that meaning will be assigned to the legacy building product. The meaning assigned to the product is expected to bring parents emotional comfort during bereavement.

Limitations

While this study is among the first to examine legacy building with individuals who are not parents of primarily oncology-hematology patients, it is not without limitations. The sample in the present study was self-selected, leading to predominantly positive feedback on legacy building interventions and items. Additionally, the sample size of this study was small, consisting of only ten individuals of mostly older age. Most participants were female, with only one father participating, limiting insight on legacy interventions with males. Additionally, because all participants were white, middle-class, Protestant individuals from rural north Louisiana, this limits the scope of the study to make conclusions about legacy building interventions conducted with other races, ethnicities, cultures, and religions.

Implications

Findings include practical suggestions for child life specialists, end-of-life care providers, and individuals providing care for bereaved parents. Unlike the findings of Love et al. (2022), participants of the current study did not suggest that practitioners pay attention to the timing of interventions, offering them at both a convenient and meaningful time for the family and patient. However, a common theme among participants of the current study was ensuring that their child is remembered. Parents may also suggest allowing for more patient and family autonomy in legacy building activities. This could be done by letting the family and patient choose not only whether to perform legacy building activities, but also what kind. When possible, the patient and

family should also be given personalization choices such as choice of color or choice of song to add to a stuffed animal, as this can help to make the product more meaningful (Boles, 2014).

Additionally, findings from this study may also be considered with family members who are not parents, such as siblings and grandparents. Because the results and insight from parents from the current study shows that relationships are paramount when providing legacy building opportunities, activities and items may be altered to be more meaningful for individuals at different stages of development and grief.

Conclusion

Overall, the current study is expected to benefit the field of child life in several ways. While findings from this study can be utilized in improving the quality of end-of-life care and reducing parental grief, it is also expected to benefit participants by allowing parents to further process grief and build the legacy of their child through telling their story. This study is also a meaningful addition to the limited literature, not only on legacy building, but in the field of child life. Further research in this area should focus on obtaining a more generalizable sample size as well as developing a reliable and valid survey for data collection using common themes found through legacy building interviews of the present and recent studies (Love et al., 2022).

APPENDIX

Supplemental Table A

Interview Prompts and Probes

Warm Up Question: I didn't get the pleasure of meeting (child's name). Can you tell me about him/her?

1. How would you describe your child's legacy?
    a. How has your child impacted you, your family, your friends, your community, or others?
    b. Tell me more...tell me more...
2. What legacy items did you receive (e.g. finger print charm, handprint, hand mold, heartbeat song, other)?
    a. How and when were these items introduced to you?
3. How have you used the legacy item(s) that you received?
    a. How often do you think about or look at the legacy item(s)?
    b. How do they make you feel?
    c. How have they been helpful or not helpful to you and your family?
    d. Tell me more...tell me more...
4. Has the way that you've thought about or used the legacy item(s) changed over time?
    a. How so?
5. Do you feel differently about the legacy item now as compared to a few months (or a few years) ago?
    a. What feels different?
    b. Tell me more...tell me more...
6. What does your culture or community think of as legacy?
7. We are always trying to improve our current practice. How can we improve the process of providing legacy items in the future?
    a. Tell me more...tell me more...

Concluding Question: Is there anything else you would like to share?

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