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Bereaved Parents' and Siblings' Reports of Legacies Created by Children With Cancer

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Abstract

This qualitative study explored bereaved parents' and siblings' reports of legacies created by children with advanced cancer. Participants included 40 families of children who died from cancer, with 36 mothers, 27 fathers, and 40 siblings (ages 8–18 years). Individual interviews were completed at home approximately 10.68 months ($SD = 3.48$) after the child's death. Content analysis of interviews indicated that many children living with cancer did specific things to be remembered, such as making crafts for others, willing away belongings, writing letters to loved ones, and giving special gifts. Some children, particularly those who were very ill or died unexpectedly, did not intentionally do or say anything to be remembered. Legacies included bereaved individuals remembering children's qualities, concern for family, and beliefs about afterlife. Having advanced cancer appeared to motivate children to influence others' lives and prepare for their own deaths. Children's advice about how to live life inspired bereaved family members. Findings contribute to the current knowledge of legacy-making in children and offer implications for practice and future research.

Keywords

childhood cancer; pediatric death; legacy; bereaved parent; bereaved sibling

In the United States, more than 500 000 children have life-threatening illnesses, and more than 248 000 children are living with cancer (National Cancer Institute, 2005). The incidence of pediatric cancer is increasing, with approximately 10 400 new cases estimated annually among children aged 0 to 14 years (American Cancer Society, 2007). Although mortality rates have declined for many childhood cancers related to medical advances, cancer remains the leading cause of death by disease in children up to 15 years old. Thus, approximately 1500 children with cancer die each year.

For children whose deaths can be anticipated, efforts to create memories and confirm they are loved and will be remembered are important (Levetown, Liben, & Audet, 2004). Many children need and want to know they will not be forgotten. Gibbons (2001) suggested that their legacy is a spiritual concern of children. Children's legacies may include their accomplishments but also the differences that they have made in the lives of others. In the terminal phase of an illness, children of all ages may wish to attend to unfinished business, such as delegating who will receive certain belongings after their death, writing letters, drawing pictures, taking a special trip, or talking with significant people (Armstrong-Dailey & Zarbock, 2001).

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Legacy-making has received little empirical attention. One pilot study described a dignity therapy intervention as a “legacy-making exercise” (Chochinov et al., 2005). In this study, older adults with end-stage malignancies discussed issues that mattered most to them or that they most wanted remembered about themselves. The conversation was recorded and a transcript of their comments was provided to participants to give to a friend or family member. Results showed that after the legacy-making intervention, participants’ sense of dignity, purpose, meaning, and will to live increased, whereas suffering and depressive symptoms declined. In another study, adults living with advanced cancer reported being concerned about how they would be remembered, and the creation of a legacy was universal to all participants (Coyle, 2006). Creating a legacy appeared to be a significant component in the adjustment process for these adults. Because limited research has focused on understanding legacies of children with a terminal illness, the current study explored bereaved parent and sibling perspectives of how children living with cancer created legacies.

Methods

This study was part of a larger ongoing longitudinal study of families after the death of a child from cancer. Data collection for the larger study involved visits to bereaved siblings’ schools and homes in the first year after the death, followed by another home visit in the second year following death. This article reports qualitative interview data collected from a subset of families at the first home visit. Institutional Review Board approval was obtained at each of three participating children’s hospitals in the United States and Canada. Families were sent a letter of introduction from the child’s attending physician and recruited via phone 3 to 12 months after the child died.

Participants

At recruitment, eligible families (a) had a bereaved sibling 8 to 17 years old, (b) were fluent in English, and (c) lived within 100 miles of the hospital. Adopted, half-siblings, and stepsiblings were eligible if they lived in the home during the deceased child’s treatment, or if the parent reported that the sibling had regular ongoing contact with the child who later died. Of 60 eligible and located bereaved families, 41 (68%) participated in a home visit. Qualitative data were missing from one family because of a tape recording malfunction. Participants ($N = 99$) included 36 mothers, 24 fathers, and 39 siblings. The mean age of the mothers was 40.50 years ($SD = 7.35$), and 78% ($n = 28$) were Caucasian. Fathers averaged 43.88 years of age ($SD = 7.75$), and 83% ($n = 20$) were Caucasian. Parent educational level averaged 14.52 years ($SD = 2.24$). The revised Duncan, an index of occupational prestige or status (Nakao & Treas, 1992), evaluated family socioeconomic status; participating parents’ average score ($M = 44.20$, $SD = 25.10$) reflected clerical, sales, and service (eg, child care workers, law enforcement officers, dental assistants) occupations. Siblings were primarily female (64%, $n = 25$), Caucasian (72%, $n = 28$), and an average of 12.28 years of age ($SD = 2.64$). Deceased children averaged 12 years of age ($SD = 5.27$) at the time of death with approximately 2.73 years ($SD = 2.34$) from time of cancer diagnosis until death. Data were collected approximately 10.68 months ($SD = 3.48$) after the child’s death.

Procedures and Measures

Informed consent was obtained from participating parents at the beginning of the visit, and assent was obtained from participating children. As part of the larger study’s home assessment, research assistants administered a series of questionnaires and conducted semistructured interviews. For this study, individual interviews included an open-ended question with each participating family member. Participants’ responses were audiotaped for later transcription and coding. Data reported in this article were derived from answers to the following interview question developed by the research team:

Some parents/kids/teens have told us that their child/brother/sister did or said something before he/she died so that they would be remembered. Others haven't said much. What, if anything, did your child/brother/sister do or say so that he/she would be remembered? (Probe if needed: Did your child/brother/sister leave a special message or give you something special to keep?)

Analysis

Three researchers independently analyzed each transcript through content analysis, a qualitative approach for analyzing data from open-ended questions and reporting combined subject responses (Hickey & Kipping, 1996; LoBiondo-Wood & Haber, 2006). The purpose of this method is to provide knowledge, represent facts, offer new insights, and develop practical guides to action. Content analysis began with immersion, which involved repeatedly reading the transcripts to gain a sense of the data as a whole. Next, similar ideas were clustered together within excerpted quotes from 15 transcripts and preliminary categories emerged. The three researchers reviewed the suggested coding scheme and extracted quotes and regularly discussed the rationale for emerging categories. They reexamined data by recoding original transcripts and made mutually agreed on changes (eg, editing category names, exploring new categories, combining categories, dividing categories into subcategories). Fifteen new transcripts were added to the coding scheme and new codes were adopted when data did not fit into an existing category. The researchers kept memos containing questions, possible comparisons, and leads for follow up (Strauss & Corbin, 1990), while also tracking this decision trail. Responses that did not fit into an existing category were identified as *other* and reconsidered each time transcripts were recoded. The three researchers repeated this analysis process until they reached consensus and no new categories emerged. The researchers examined all data based on the final coding scheme and typed findings in narrative form, presenting each major category and exemplary quotes from participants. Member checking with 6 families occurred 12 months after the initial visit. A description emerged of family members' perceptions of how children living with cancer created legacies and the impact these legacies had on surviving parents and siblings.

Findings

Content analysis of interviews with bereaved parents and siblings identified four major themes: (a) many children living with cancer did and said things to be remembered, (b) some children living with cancer did not intentionally do or say anything to be remembered, (c) bereaved family members remembered deceased children, and (d) legacies provided inspiration for both bereaved family members and children living with advanced cancer.

Children Doing and Saying Things to Be Remembered

Many children living with advanced cancer did things to be remembered, including making crafts for others, willing away belongings, writing letters to loved ones, and giving special gifts. The majority of these children gave away things, such as personal belongings. A sibling said, "She [20-year-old] gave me lots of stuff. She gave me like a bunch of old t-shirts because she loved t-shirts. Those are special." One 3-year-old explicitly talked to her mom about giving away belongings so others could remember her:

One thing that me and her did before she passed ... we talked about her belongings. And each one of her nurses was to have a specific toy that she had. And she told me, she says, "Mommy, you have to give it to them after I am gone. And they have to know that I wanted them to have this to remember me."

Bereaved family members also described how children with cancer made special gifts for their loved ones. One female sibling reported,

Yeah, he [16-year-old] did [made] a cement stone, like a stepping stone. And he put sign language “I love you” and he put like “sis” on the bottom ... He did [one] for my mom, my dad, my grandma, and good friends of his.

Few ill children explicitly said their intent was to be remembered, yet their actions implied that this was their wish. One mother said,

We never had like the one moment to talk about that. But so, she [13-year-old] made these crafts ... flowers out of paper. We have that as a token of her. (Interviewer: So even though she didn’t do it purposely to be remembered by ...) No, no, no. But she just made it there [in the hospital] and she goes, “Okay, mommy, I thought you’d like one.” Or when her aunts would come or her cousins, she actually made some for them, too. (Interviewer: So she wasn’t aware that she was passing, but she made things for everybody?) Yeah. Yeah.

Similarly, one sibling did not perceive that her sister with cancer did or said anything to be remembered, yet the sibling reported that her 11-year-old sister said, “... All that I care for is that you remember me and don’t forget me.”

Children Not Doing or Saying Things to Be Remembered

Some bereaved family members reported that children did not intentionally do or say things to be remembered because of their illness, age, or unexpected death. A sibling said,

We didn’t know he [16-year-old] was going to pass away so quickly. When my mom was talking to him about making a will or whatever, he said he wasn’t ready for that. And she felt we could, that he could wait a little bit longer cause they thought he was gonna pass away at the end of the summer, but it ended up he sort of ended up passing away in the middle of the summer. And so because it’s so abrupt, he never actually told anybody, you know, about this and I want you to think of me when you look at this and that kind of stuff.

Some families perceived children with advanced cancer as not knowing they were dying, which may explain why they did not intentionally do or say anything to be remembered. A mother described her 7-year-old with cancer:

I don’t think he knew that he’d be going. I don’t think he realized. I don’t think he ever really realized he was really sick. I mean, it was just always a part of going to the hospital. He never really asked why his whole life. Yeah ... I don’t think he really realized that he was sick or anything.

One father did not want to discuss death with his 8-year-old son who was dying:

You know we never discussed these things with (deceased child) ... We never talked about death and dying to him. And I didn’t want to. It was, I didn’t think it was appropriate ... I didn’t want him to have those thoughts. I didn’t want him to be scared. As it turned out, it happened suddenly, and maybe that was for a reason. I don’t think he ever knew that this was gonna take his life ... I don’t know that he ever thought about dying. I really can’t say with confidence that he did.

A few bereaved families reported their child did not want to talk about death. A mother said,

He [12-year-old] didn’t really want to talk about his death at all. He didn’t want to talk about it; he didn’t want to think about it. He just wanted to get on with doing whatever he was going to do that day ... I would ask him if he wanted to talk about anything or if he had any questions or anything, and he would always say “nope” and change the subject. So I mean certainly he is known for a lot of things, and I don’t

think he'd done them with the intention of being remembered, but that's how it evolved.

Other family members perceived that their child with cancer did not need to do or say anything to be remembered. A father said, "I think she [14-year-old] was well aware of how deeply loved she was. So she didn't need to leave anything behind." A mother shared, "I asked her [17-year-old] actually if there was anything that she wanted me to relay to anybody, and she said, 'nope' cause everybody knew it from her that she loved them ... She never wanted to be famous or anything, but she wanted to be remembered."

One sibling shared how his 19-year-old brother living with advanced cancer realized that he had already left behind a legacy:

Before he died, he told me and his girlfriend and mom. He goes, "Before I die, I want to carry out a legacy or do something that nobody else has ever done." Then, 2 weeks later he goes, "You know, I have carried out a legacy. I've been like a dad to (sibling), and I've treated him like one more than the real dad did." And he goes, "I've already done what I needed to do."

Bereaved Family Members Remembering the Deceased Child

Qualities of deceased children—Some family members explicitly shared their memories of qualities of the deceased child. A father talked about qualities of his baby son who died at 9 weeks old and could not speak or communicate because of his age: "[He] touched a lot of lives in the hospital ... and has had a positive outreach to others ... reached people all around the world ... even with unspoken words." Others said their child was "really a great kid" or "such a funny kid," and many shared their child had a "positive outlook" and was "full of hope." One father remembered: "Unintentional was, to me, his [14-year-old] inner-strength. He faced it a lot better than I would have ... a load of courage."

Other bereaved parents and siblings shared snapshot stories which depicted qualities of the deceased child and captured pieces of who the child was. A father described his 16-year-old daughter:

There was a song ... It was the last thing she ever said and I remember ... "Let me see your grill" ... and it says "smile for me daddy." Cause I got my gold [teeth] ... So every time I hear that song I always think about her ... music ... that was her passion ... The last thing she said to me ... she smiled and said, "Let me see your grill daddy." That was the last thing she said to me before she stopped talking. She smiled to me and said that.

One mother remembered her 16-year-old son's requests:

Yes, he had special requests ... he wanted to be buried underneath the tree in the backyard. We didn't do that. He wanted to know if the hearse was gonna pick him up in a big car, and if it was, I suggested it was, he said, "Well, okay, well have them peel out for me cause I wanna peel out." So they peeled out of the drive. Yeah, crazy stuff.

Deceased children's concern for family—Bereaved individuals also remembered deceased children's concern for family. A mother recalled how her 8-year-old son with cancer told her, "Momma it's ok, it's ok." Another mother said, "He [16-year-old] did ask me if I was going to be ok. So that was pretty helpful."

Many survivors said their ill child told them, "I love you." One mother remembered her 15-year-old son telling her, "You know I love you. I really love you. Don't you ever forget that."

Similarly, a father said, “The night before he [7-year-old] passed away ... he just told me he loved me and goodnight ...” A sibling also shared, “She [4-year-old] said she loved me, and then I had to sing this crazy song for her.”

One bereaved mother said, “He [15-year-old] was just concerned about us.” Another mother noted,

He [12-year-old] prayed a lot ... asking for blessing from God. For everybody. But one thing is so weird that he never included himself in that. He says that I ask God to have mercy on you, and Mom and Dad and everybody in the family, in hospital, all the people who worked and everything, but he never asked anything for himself.

Deceased children’s belief about afterlife—A large number of participants recounted deceased children’s beliefs about an afterlife. Many talked about children believing they would go to Heaven or be with Jesus after they died. A mother remembered her 6-year-old daughter’s view: “Nine days before she died, she told me that she was going to go be with Jesus soon ... She said, ‘God’s put peace in my heart’.” Another mother shared,

She [3-year-old] told me not to worry about it, that she was going to make it all right with her friend. She went to Care-a-Lot Heaven. And knew she was going and told me that I would be there to meet her at the spot when it was my time to go. So she knew she was going. And I’ll never forget that. Being able to know that she would not forget me. Because she would be waiting for me at the spot. Knowing that, I knew she was going to be fine.

Other parents found comfort in remembering children saying they were going to Heaven. A father shared, “He [16-year-old] said, ‘I’m gonna go now, okay ... I’m gonna go to Heaven.’ ... he said he was gonna be okay.” Whereas some parents recalled their child’s belief about Heaven or Jesus, one mom was not worried because she knew her 4-year-old daughter was okay wherever she was,

I knew that she was really gone. She gave me a very big smile, so I know that wherever she is, she is okay and she was telling me that “Mom, its okay.” That’s why I’m not worried. I know she’s okay and I know she wanted to be okay with whatever or however.

Finally, a bereaved mother remembered a special message her 17-year-old son told his friends related to his certainty about life after death: “If I don’t come home, don’t feel sorry for me, be envious of me.”

Effects on Children With Cancer and Their Family Members

Inspiration for children with cancer—Their personal experience of living with cancer inspired the children to affect the lives of others. One mother recalled that her 16-year-old son “really made a strong impact on a lot of people, because of his strong faith and trust in God to be in control and do what He knows is best for everybody.” A bereaved father recounted what his 18-year-old daughter had written in a letter:

I’ve never seen anyone that had an effect on so many people so young without any effort ... I mean ... she said in her letter ... she said, “... I’d like to be well but I am not. And if my sickness in any way causes someone to come to Lord, to get close to Lord, then it’s worth it all ...”

Cancer also inspired children to prepare themselves for death mostly through confiding their wishes to loved ones. One mother shared the words of her 6-year-old child:

“Mom, I want you to buy this for me,” you know, her [deceased child], me, and (other friends) all their friends, “because they’re wings, it’s like angel wings for a Christmas present for them so we can all be angels.”

Most children with cancer were inspired to prepare others for their death. One mother quoted her 7-year-old son’s “intuitions” or “warning signs”:

He said, “I won’t be back” ... And he’s like, “But I won’t have a chance to get macaroni and cheese again” ... And he wanted me to sleep with him that night ... Maybe he knew.

A bereaved father perceived that his daughter prepared for death by giving away her “faith” before unexpectedly dying during surgery:

She was only 2 [years old], but she and my wife had these necklaces ... Right before she went into surgery—(Deceased child)’s [necklace] said “Faith” and (wife)’s [necklace] said “Strength.” And (deceased child) made them change ... she [deceased child] wanted to trade.

Inspiration for bereaved families—While cancer inspired children with cancer to live their lives differently, their advice, in turn, inspired bereaved parents and siblings to live life differently in the moment. A sibling shared, “He [17-year-old] was always telling me to work harder on things and do better.” A mom found guidance through her 19-year-old son’s message: “Somebody [my niece] was complaining. He looked at her and goes, ‘(Name of niece), I’m dying. Do you hear *me* complaining?’ And, when I even think about complaining, I’ll stop myself.”

References to God were evident in many messages about how to live life. One father described his 17-year-old son’s special message to a huge crowd from the pitcher’s mound of the school baseball field: “His statement was God ... He [ill child] said, ‘Jesus died on the cross for our sins, and I thank God for that.’ ... So that will always be a mark.” One mom carried on her son’s legacy. She said her 16-year-old ill son always had a special message: “His legacy he left was, ‘Do you know God?’ He did this to everybody that he ever met ... He would get the conversation around to God.” At the end of her interview, the mom was asked by the interviewer if there was anything else she would like to share. She asked, “Do you know God?”

Discussion

Although a few recent studies have examined the concept of legacy-making in adults with a terminal illness (Chochinov et al., 2005; Coyle, 2006), research exploring the concept of legacy-making in children has been lacking. Using qualitative data from a sample of bereaved parents and siblings within the first year of a child’s death, this study identified different types of legacies and their effects on both children with cancer and their bereaved families. Findings suggest that children living with cancer created legacies that were both intentional and serendipitous in nature. Findings related to intentional legacy-making seem similar to the concept of meaning making, which has been previously described as a dimension of ritual (Kobler, Limbo, & Kavanaugh, 2007). Kobler et al. proposed that rituals are intentional, purposeful actions used to provide opportunities for adding new meaning or reconstructing a prior meaning to profound life events. Although ritual was described to focus on bereaved families, Kobler et al. provided an example of a teenager living with cancer who realized his impending death. His “ritual of good-bye” included thoughtfully parting with his earthly belongings and writing letters to others. This suggests a possible relationship between legacy-making and meaning-making activities. However, serendipitous legacy-making seems to be a new phenomenon and more work is needed to better understand this dimension of legacy-making. In addition, legacy making seemed to span across all pediatric age groups and included

both males and females. Legacies inspired both the children with cancer and their family members. Findings support previous research regarding the significance that legacy-making may have on individuals living with cancer and their families (Chochinov et al., 2005; Coyle, 2006).

Our study also suggests that many children living with advanced cancer were aware of their impending death, as noted by most parents. Children exemplified awareness of death through their actions and implied words, indicating that some may communicate death awareness with actions before explicit communication can occur. Similarly, the American Academy of Pediatrics (2000) points out that children's hints to talk about death may be subtle. Kreicbergs, Valdimarsdottir, Onelov, Henter, and Steineck (2004) found that nearly half (47%) of parents in their study sensed their child was aware of his or her imminent death; only 13% of parents did not sense this awareness. Spinetta, Rigler, and Karon (1973) noted serious illness accelerates cognitive development:

To equate awareness of death with the ability to conceptualize it and express the concept in an adult manner denies the possibility of an awareness of death at a less cognitive level. If it is true that the perception of death can be engraved at some level that precedes a child's ability to talk about it, then a child might well understand that he is going to die long before he can say so. (p. 844)

Findings from this study should be considered in the context of several methodological limitations. Retrospective interviews with bereaved parents and siblings may not accurately reflect perceptions of children living with cancer; however, the unexplored phenomenon warranted a retrospective design before conducting prospective examination of a vulnerable or terminally ill pediatric population. Findings may not generalize across all terminal conditions as this study targeted only bereaved families' perceptions of children living with cancer. Because of fairly brief responses from participants in this study, only content analysis was performed. However, such description is valuable given the limited knowledge on legacy-making in children. Despite these limitations, this study addressed a gap in the literature by exploring legacies created by children with cancer through the perspectives of bereaved mothers, fathers, and siblings relatively early in their grief process. The inclusion of multiple data collection sites and good recruitment rates are strengths of this study. Findings indicated that legacy-making was significant for many children with cancer and their families.

Health care professionals can use findings from this study to open the door for families to discuss legacy-making and share what is currently known about how children want to be remembered. This study can also be used to help talk with other children who may not want or need to intentionally create a legacy but may need help to realize the serendipitous legacies they have already created. Pediatric oncology physicians and nurses are in an ideal position to assess patient needs and facilitate opportunities for children who may want to intentionally take part in legacy making. Furthermore, psychologists, social workers, chaplains, child life specialists, and other therapists can facilitate discussions about legacies between the dying child and family or help dying children and family members create memory books, photos, or artwork as a means of processing the impending death and discussing the child's wishes. They can also help children prepare spiritually for their own death by answering questions children or their families may have about legacy making or dying.

Certainly, more research is needed to further our understanding of legacy making in children living with cancer. Currently, there seems to be overlap with the concept of legacy making and other concepts such as dignity therapy (Chochinov et al., 2005) and meaning making (Kobler et al., 2007). Theoretical work is needed to clearly define legacy making and then develop and test a conceptual framework. Considering that this study retrospectively explored legacy making from bereaved family members' perspectives, prospective studies could add insight

on legacy making from the perspectives of dying children. Future work could include the integration of qualitative and quantitative methods to further examine legacy making. Studies might explore legacy-making activities, if any, currently being used in centers caring for dying children and the effects on the child and their family members. Overall, findings from this study contribute to the current knowledge of legacy making in children living with cancer and suggest directions for further research.

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