National Survey of Children's Hospitals on Legacy-Making Activities

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Abstract

Objective: Many hospitals offer legacy-building activities for children with serious illnesses or their family members, yet legacy-making has received little empirical attention. This descriptive cross-sectional study examined healthcare provider perceptions of legacy-making activities (e.g., memory books) currently offered by hospitals to pediatric patients and their families.

Methods: Healthcare providers in seventy-seven (100%) teaching children's hospitals across the United States completed an electronic survey.

Results: Nearly all providers surveyed reported offering legacy-making activities to ill children and their families, with patients and families usually completing the activity together. Most activities were offered before a patient died and when cure is no longer being sought. Perceived outcomes included benefit to bereaved families and a tangible memento of their deceased child.

Conclusion: Legacy-making may enhance life and decrease suffering for dying children and their families. Healthcare professionals can facilitate opportunities for children and their families to build legacies. Additional research is needed to examine activities across different age groups and conditions, the best time to offer such activities, and associations with positive and negative outcomes for ill children, their family members, and the bereaved.

Introduction

FOR CHILDREN AND ADOLESCENTS living with life-threatening illnesses, efforts to build memories and confirm they are loved and will be remembered are important.¹ Many children need and want to know that they will not be forgotten. 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, or talking with significant people.² Legacy-making can be defined as doing or saying something that is remembered, including both intentional and serendipitous legacies.³ Examples of legacy-making activities include memory books, hand molds, songwriting, artwork, photographs, and videos. While some children's hospitals offer such activities to pediatric patients, legacy-making has received little empirical attention.

Previous work has suggested that legacy-making may be important and helpful for individuals with life-limiting conditions and their families.³⁻⁸ Legacy-making activities in-

cluding life review, dignity therapy, board games, or creative arts have been shown to benefit adult patients living with advanced cancer and their family members,⁴⁻⁸ but have rarely been tested in pediatric populations. A qualitative study explored bereaved parents' and siblings' reports of legacies by children who had died of cancer.³ Content analysis of interviews with 36 mothers, 27 fathers, and 40 siblings indicated that some children living with cancer did specific things to be remembered, such as making crafts for others, willing away belongings, and writing letters to loved ones. Legacy-making appeared to help ill children influence others' lives and prepare for their own deaths, while inspiring and comforting family members.

Findings from Foster and colleagues contribute to the current knowledge of legacy-making in children.³ However, retrospective interviews with bereaved parents and siblings may not accurately reflect perceptions of children living with cancer. Many hospitals offer legacy-building activities for children with serious illnesses and/or their family members that have typically been presented in the literature via

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TABLE 1. COUNTS AND PERCENTAGES DESCRIBING LEGACY-MAKING ACTIVITIES (N=77)

What legacy-making activities does your facility offer? (Select all that apply.)	
Hand molds/handprints	75 (97.4%)
Lock of hair	68 (88.3%)
Memory book or journal	65 (84.4%)
Photography	58 (75.3%)
Art	47 (61.0%)
Writing (e.g., letters, poetry, etc.)	44 (57.1%)
Songwriting/music	35 (45.5%)
Video	15 (19.5%)
Other	15 (19.5%)
What department or program offers these activities?	
Child life	73 (94.8%)
Nursing	36 (46.8%)
Palliative care	22 (28.6%)
Other	17 (22.1%)
Hospice	5 (6.5%)
Who participates in completing the activity?	
Patient and his/her family together	59 (76.6%)
Staff (e.g., staff does the activity and gives the result to the family)	52 (67.5%)
Family alone	26 (33.8%)
Patient alone	25 (32.5%)
Other	20 (26.0%)
What pediatric patients are offered legacy-making activities?	
Patients with any life-threatening illness	65 (84.4%)
Patients with cancer	33 (42.9%)
Other	24 (31.2%)
Patients with neurodegenerative diseases	23 (29.9%)
Approximately how many patients at your facility participate in legacy-making activities each year?	
0-10	25 (33.8%)
11-20	7 (9.5%)
21-30	17 (23.0%)
31-40	12 (16.2%)
41-50	6 (8.1%)
>50	7 (9.5%)
What point in the illness trajectory are patients and/or families offered these activities?	
Before the patient dies: When cure is no longer being sought	31 (42.5%)
Other	23 (31.5%)
After a child dies	10 (13.7%)
Before the patient dies: Soon after patient's diagnosis	9 (12.3%)
Legacy-making activities are offered:	
As a part of standard of care	70 (97.2%)
Only if requested by the patient and/or their family	2 (2.8%)
What is the goal of these activities provided at your facility? (Select all that apply.)	
To benefit bereaved families	69 (89.6%)
To benefit child/patient	59 (76.6%)
To benefit the family while the child is ill	53 (68.8%)
Other	8 (10.4%)
How do these activities help your patients and families? (Select all that apply.)	
Gives family members tangible ways to remember the deceased child	74 (96.1%)
Coping strategy for family members who have experienced the death of a child	66 (85.7%)
Coping strategy for child patients	58 (75.3%)
Coping strategy for family members who have an ill child	57 (74.0%)
Creates an opportunity for children and families to talk about death	57 (74.0%)
Creates an opportunity for child patients to express themselves	54 (70.1%)
Gives children opportunities to do or say something to be remembered	52 (67.5%)
Other	7 (9.1%)
What do you perceive is difficult for patients or families participating in legacy-making activities? (Select all that apply.)	
It is emotionally hard for families to participate (e.g., it takes hope away from families)	59 (76.6%)
It is physically hard for patients to participate (e.g., they are too sick, too tired)	35 (45.5%)
It is emotionally hard for children to participate (e.g., these activities make children sad)	21 (27.3%)
It is developmentally difficult for children (e.g., these children do not understand what these activities mean)	16 (20.8%)
Other	9 (11.7%)

Note: Totals for each item in the survey may be greater than 100% as they are not mutually exclusive.

anecdotal stories or newsletters.^{9,10} The purpose of this study was to explore staff perceptions of legacy-making activities currently offered by children's hospitals to pediatric patients living with serious illnesses.

Methods

Perceptions of legacy-making activities were assessed through use of a REDCap survey developed specifically for this purpose. REDCap is a secure, web-based application for building and managing online surveys and databases. Three content experts in pediatric palliative care each identified questions they perceived to be important. After discussion regarding clarity and appropriate brevity, consensus regarding the wording of the instructions and survey questions was reached. Survey questions are embedded in Table 1.

After institutional review board approval, primary teaching children's hospitals ($N=77$) that were members of the National Association of Children's Hospitals and Related Institutions (NACHRI)¹¹ were identified via the publicly available NACHRI hospital directory website.¹¹ Research assistants from the Vanderbilt Institute for Clinical and Translational Research, who were trained by the principal investigator and were experienced in working on studies focused on palliative care, called each hospital using a script to locate the single, best qualified person at the facility to answer survey questions regarding legacy-making activities offered to pediatric patients. Staff members asked to speak with the facility's (1) pediatric palliative care director, (2) child life director, or (3) nursing director, respectively, to explain the study purpose and identify the person best qualified to participate in the study. After the potential participant was identified, study details were shared via phone, or via email if requested by the participant during the initial phone call.

For interested participants who verbally agreed to receive the electronic REDCap survey link, the staff members documented the appropriate email address to which the survey link was immediately emailed. The electronic link included an introduction describing the goal of the project. A definition of legacy-making was provided, including examples of legacy-making activities. Details included that the survey would take about 5 to 10 minutes to complete, responses would be anonymous, results would only be reported in aggregate to maintain confidentiality of each hospital, and consent would be shown by completion of the survey. The introduction requested that the survey be completed within two weeks and explained that all participants would receive a \$20 Starbucks gift card. The last question of the REDCap survey documented the participant's name and institution so that we could link participants with the previously documented mailing address. The gift card incentive was mailed within one week to the appropriate participant when REDCap notified the principal investigator that a survey was completed.

After the first 10 hospitals were called, the research team evaluated participant responses for evidence of understanding the survey questions. Research assistants were also queried for any challenges experienced in the phone call recruitment. Based on the evidence, no changes to the survey or methodology were made. Follow-up calls were made to 18 (24%) participants who were initially unable to be reached or for whom we needed corrections to previously documented email addresses. Follow-up emails and phone calls were made to one

FIG. 1. Participant characteristics: Facility region.

participant who did not complete the survey within the two weeks. Approximately 96.25 hours were dedicated to participant recruitment (1.25 hours per hospital, $N=77$). Data collection occurred over six months (September 2010 to March 2011).

After downloading data from the REDCap environment, descriptive counts and frequencies were generated using SPSS 18.0 (SPSS Inc., Chicago, IL). Chi-square tests were used to examine differences in distributions in the offering of legacy-making activities among hospital geographic locations and number of beds. An alpha value of 0.05 was used for assessing statistical significance. Many respondents typed open-ended comments expanding on their responses to survey items. Two researchers independently reviewed responses to the open-ended survey question regarding suggestions for legacy-making activities, and qualitative content analysis identified recurrent themes.

Participants

Of 77 teaching children's hospitals identified on the NACHRI website, 100% participated in the survey ($N=77$). Participants included 76 (99%) child life specialists and 1 (1%) recreation therapist. Sixty-four percent ($n=49$) of participants represented hospitals with a palliative care team. See Figures 1 and 2 for additional participant characteristics.

FIG. 2. Bed size of facilities in study.

Results

Ninety-seven percent ($n=75$) of facilities offered legacy-making activities to children or their families, including parents and siblings. Differences between the distribution of offerings of legacy-making activities among hospital geographic locations and number of beds were not statistically significant. Ninety percent ($n=69$) of participants suggested that more research is needed on legacy-making activities. See Table 1 for all counts and percentages describing legacy-making activities.

Forty-five participants provided open-ended feedback for suggestions regarding legacy-making activities for children. Four major recommendations emerged: (1) need more research and knowledge dissemination (2) offer activities sooner in illness trajectory, (3) increase staff education, and (4) individualize legacy-making activities.

Fourteen (18%) participants suggested the need for further research and dissemination of knowledge on legacy-making activities. A child life director suggested long-term follow-up studies on families and siblings. Another participant recommended that researchers find out what parents say about how the legacy-making activity helped them through their ordeal. Some participants desired more information and ideas about legacy-making activities, while others would like to know what others are doing. Another suggested more surveys of those who offer this service and conferences on this topic.

Eleven (14%) suggestions related to the offering of activities sooner in the illness trajectory. One participant said, "A lot of people tend to wait until the child is near death. It is important that this is done as a standard of care from the beginning of diagnosis." One respondent recommended legacy activities for "earlier in the process so they can fully participate." Another said, "It would be interesting to see if it makes a bigger impact on the child and family if you offered legacy-making activities earlier versus later. For example, when the child is first diagnosed versus when they are (receiving) palliative care." One participant added, "It isn't always end of life, but sometimes saying goodbye to some of themselves, literally. In one case, a teen patient had to have a leg amputation. So our staff helped this boy to cast a mold of his leg." Another participant recommended "not always looking at them (legacy-making activities) from the 'after death' perspective. These activities can be fantastic for a patient who survives to look back on as tangible evidence of their psychosocial and physical journey."

Nine (12%) participants suggested an increase in staff education in regards to legacy-making: "Offer education for professionals so that they can better understand how to approach sensitive situations such as these." Another participant shared, "Legacy-making can be important throughout a serious illness...but the medical team...is not always ready for some of these activities." Another reflected, "I wish that all staff were better at encouraging and helping families participate in legacy-making, rather than just doing it themselves." One participant suggested potential benefit to staff: "[It's] something useful for staff who worked with the patient and family who has died or (is) dying. Especially those that die after being hospitalized for a long time with the regular staff on a day-to-day basis. It's hard on them."

In addition, eight (10%) participants suggested the need to individualize legacy-making activities for each child and his or her family. One participant shared, "It is important to offer

families the option of participation – being present when legacy-making activities are being created, or having legacy materials created not in their presence. Sharing with families that their choice will be respected." Another participant commented on the balance between standardizing and individualizing these services: "We are working...to standardize how/when we offer to each patient or family, while being able to individualize." Others suggested, "Be flexible, offer a variety of activities" and "find out as much as you can about the child and family, what is important to them." One participant suggested, "Just taking the cues from the children as to how much they want to do or if they want to do it."

Discussion

This novel study described staff perceptions of legacy-making activities currently offered by children's hospitals across the United States to pediatric patients and their families. Nearly all hospitals reportedly offered legacy-making activities to children near end-of-life and their families. Participants perceived both positive and negative effects of legacy-making activities. Reports of frequency, nature, timing, and outcomes of activities varied.

Our findings suggest that legacy-making may have positive effects for ill children and their family members, such as giving ill children opportunities to do or say something to be remembered, creating opportunities for ill children to express themselves or communicate about death, providing a coping strategy for patients and family members (before and after the death), and offering tangible memories for families. The positive nature of legacy-making is consistent with previous studies, which have shown patient benefits including decreased breathing difficulties, distraction from pain and negative thoughts, increased religious meaning, greater social interaction, leaving a legacy, preparation for end of life, greater appreciation for self, as well as improved family communication and decreased caregiver stress.⁴⁻⁸ However, previous studies have focused on adult and elderly adult patients⁴⁻⁷ and have rarely explored legacy-making specific to pediatric populations.³ Interestingly, our study uniquely suggests potential benefits for staff members, particularly nurses, who may contribute to legacy-making activities with or for ill children and their families, a phenomenon unexplored in current literature. More work is needed to differentiate helpful aspects of legacy-making activities (e.g., the creation process or the tangible product/memento) and potential benefits for pediatric patients, family members, and health care staff.

Specifically, participants most often reported that legacy-making helped bereaved families by providing a tangible way to remember the deceased child. This suggests that the concept of legacy-making may be associated with the Continuing Bonds Theory.¹² Klass and colleagues¹² proposed that bereaved individuals maintain connections with deceased loved ones. Previous work has shown that bereaved parents and siblings often maintain tangible mementos (e.g., photographs, scrapbooks, the deceased child's personal belongings) to remember their deceased loved one.¹³ However, studies have rarely examined possible associations between legacy-making (especially prior to death) and continuing bonds post-death.

Although participants mostly focused on the positive nature of legacy-making activities, many participants also

perceived potential negative aspects. Interestingly, more participants perceived emotional difficulties for the family members versus the ill children themselves. This could be explained in part by developmental differences between children and adults. Children begin to understand that death is permanent and universal during Piaget's concrete operational stage of development, which generally occurs between 5–10 years of age, and then begin to think more abstractly between ages 10 to 13 years.¹⁴ Children's developmental perceptions of death may allow them to focus more on the concrete nature of legacy-making (e.g., creating a craft) rather than parent caregivers who could possibly interpret that legacy-making may imply death is imminent. In turn, parent caregivers may find it difficult to participate or allow their child's participation.

A new idea emerged to expand legacy-making opportunities across the illness trajectory, not just at end of life or during bereavement. Most children's hospitals offered legacy-making activities to dying children and their families. Similarly, previous studies have examined legacy-making as a concept associated with end of life.^{3–8} However, some of our participants suggested that legacy-making may have greater impact if initiated much sooner in the illness trajectory (e.g., at diagnosis of a life-threatening illness). Some reports noted potential benefits of legacy-making for children whose illness results in cure and survival. The potential positive effects of legacy-making in the lives of children throughout the illness trajectory, including survivorship, is a new and significant area of inquiry.

Another unique feature of our study was the 100% participation rate. Electronic surveys may be a successful data collection strategy for future studies recruiting samples of health care staff. An important aspect of recruitment included personal phone calls to each hospital to identify the best qualified individual to answer the survey questions. Follow-up calls were also made to participants who agreed but did not complete the survey within two weeks. Trained staff members who made recruitment phone calls were flexible in offering study information verbally during the first phone call attempt, or via email if requested by potential participants. Immediately emailing the survey to participants who agreed also likely contributed to our high response rate, as well as the short time required to complete the survey. Furthermore, the \$20 Starbucks gift card incentive likely assisted in participation.

Several limitations to this assessment must be noted. This assessment was exploratory and descriptive and limited to hospitals that were members of NACHRI; therefore, results may not generalize to other children's hospitals in the United States or across the world. Our results were limited to staff reports, which do not necessarily reflect perceptions of other health care professionals not represented in our sample (e.g., physicians, nurses) or patients or their family members. However, our study had a 100% participation rate and offers strong evidence to begin further discussions on pediatric legacy-making activities.

Results of this study suggest that legacy-making is a significant area of inquiry that may enhance life and decrease suffering for children with life-threatening conditions and their families. Health care professionals can facilitate opportunities for children and their families to build legacies in a developmentally and culturally appropriate way, individual

to each child and family. Staff should receive training so that they feel comfortable with such sensitive topics and are well equipped to present and deliver legacy-making services to children and their families. Nurses are in an ideal position to identify good candidates for legacy-making and to open the door to discuss these ideas with children and family members. Child life specialists can contribute to developing individualized and developmentally appropriate legacy-making opportunities for patients and their families. Physicians and advanced practice nurses can help facilitate researchers' access to potential research participants (child patients and their family members) so that we can together advance pediatric palliative care and improve services to these vulnerable patients and families.

As the first study of its kind to describe the current state of legacy-making services offered to pediatric patients and their families, our findings provide a foundation to further build evidence on legacy-making in pediatric palliative care. More work is needed to further define the concept of legacy-making and to differentiate among similar terms such as legacy-building and meaning-making. We also need research to determine appropriate terminology for legacy-making discussions with children; some perceive that the term "legacy" should not be used with ill children as it could imply that death is imminent; however, evidence is lacking to determine how ill children define "legacy." Additional research is needed to examine activities across different age groups and conditions; the best point in the illness trajectory to offer legacy-making activities; and associations with positive and negative outcomes for ill children, family members, and hospital staff. Further, we need to identify existing instruments or develop new instruments that could measure legacy-making. An assessment tool could assist professionals in screening and identifying patients that could benefit from legacy-making opportunities. Further research is also needed to develop educational tools for staff and identify multidisciplinary roles (physician, nurse, child life specialist, social worker, psychologist, etc.) in regards to legacy-making activities. Overall, findings from this study advance the state of pediatric palliative care and offer suggestions for future research.

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