Black, K., Romer, K., Myers, A., Minor, A., Kelly, D. M., Spence, D. D., Warner, W. C., Peacock, E., Tulley, C., & Rhodes, L. N. (2025). Outpatient Legacy Building: A Survey of Children's Hospitals. *The Journal of Child Life: Psychosocial Theory and Practice*, *6*(1). https://doi.org/10.55591/001c.141760

Original Articles

Outpatient Legacy Building: A Survey of Children's Hospitals

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Keywords: legacy, outpatient setting, memory making, legacy building, child life, child life specialist, bereavement

https://doi.org/10.55591/001c.141760

The Journal of Child Life: Psychosocial Theory and Practice

Vol. 6, Issue 1, 2025

Although the definition of legacy remains elusive, the literature describes legacy building as activities that promote lasting meaning during healthcare experiences. Legacy building is often offered to inpatient pediatric patients with life-threatening diagnoses. Recent studies have aimed to explain the importance of and perception of inpatient legacy building interventions. This study evaluated legacy building offered to outpatient pediatric patients.

Researchers electronically surveyed National Association of Children's Hospitals and Related Institutions (NACRI), now Children's Hospital Association (CHA), member hospitals regarding their legacy building interventions. Child life and nursing professionals from 48 hospitals completed the survey; 43 have outpatient settings at their institution.

Fourteen percent (n = 6) of respondents reported not offering any legacy building opportunities to their outpatient population, whereas 7% (n = 3) of respondents reported not offering legacy building at their facility at all. Respondents attributed this decrease to time constraints, lack of support from multidisciplinary staff, and limited resources. Most interventions were initiated when no further treatment was being pursued rather than earlier in an illness trajectory.

Implications for practice include dedicated child life coverage in clinical settings, partnering with nonprofit organizations to offer legacy building opportunities, and ongoing education to increase multidisciplinary buy-in. Further studies should evaluate service expansion opportunities earlier in an illness trajectory. Additionally, costs and benefits of outpatient clinic legacy building should be investigated.

Legacy building is conceptualized as a connection between past, present, and future (Keller et al., 2024) and as "intergenerational" or exploring one's impact on others (Boles et al., 2020). Additionally, legacy-building activities are a means for patients to express their journey with illness and injury to ensure that, regardless of outcome, patients' stories survive (Sisk et al., 2012). Pediatric legacy-building activities have been defined as those that promote lasting memories of children during adverse healthcare experiences (Horrillo, 2019).

Both patients and family members experience benefits when participating in legacy-building interventions (Keller et al., 2024). Legacy-building interventions have the potential to improve patient and parent coping, reduce distress, provide families with opportunities to create memories and communicate openly with one another, and promote continuation of family bonds (Akard et al., 2021). Additionally, involving patients and families in these activities can help normalize the healthcare environment (Gouge, 2021). Providers and healthcare teams may use these interventions to aid children and families in managing distress to improve outcomes (Keller et al., 2024) and to create memories that will last throughout the child's lifetime (Gouge, 2021). Research shows that child life specialists are most often the healthcare professionals facilitating these interventions to improve both patient and family coping (Akard et al., 2021).

A recent study found caregivers feel powerless when they are unable to create these memories and connections with their child while in healthcare settings (Koch et al., 2021). To incorporate intergenerational approaches and provide opportunities to be created and facilitated over a lifespan, interventions aimed at creating legacy should be process-driven rather than outcome-driven, as the process of creat-

ing a memory or personalized item is typically what creates meaning and memories for families (Akard et al., 2021). For example, caregivers report that moments and interactions as simple as holding their child or changing a diaper help create memories and meaning which in turn build legacy.

However, Foster et al. (2012) hypothesized that legacy-building activities are often only used in the inpatient setting during end-of-life admission. According to the Centers for Disease Control and Prevention National Center for Health Statistics (2024), 95% of children under the age of 18 in the United States were seen in an outpatient setting in 2023. In addition, as many as 13.8 million children in the United States live with one or more lifelong medical conditions, and visits for children with chronic conditions grow each year as advances in medicine are made (Child and Adolescent Health Measurement Initiative, 2020). Due to these advances, more pediatric patients receive long-term care for chronic conditions in outpatient settings, specifically in outpatient clinic settings (Abrams et al., 2018). This shift to providing more advanced outpatient services allows for unique opportunities, including the facilitation of legacy-buildinginterventions in outpatient clinic settings. Yet, no research has examined the use of legacy-building interventions specifically in the pediatric outpatient setting.

Purpose

As care for children with long-term illnesses has shifted to outpatient settings, there is a need to better understand the role of legacy-building interventions in the outpatient setting. The purpose of this study was to explore the availability of legacy-building activities in the pediatric outpatient clinic setting. The following research questions were explored:

1. What is the frequency of legacy-building interventions in the outpatient clinics?
2. What types of legacy-building interventions take place in the outpatient setting?
3. What are the barriers to implementation of legacy-building interventions in the outpatient setting?
4. If offered, who facilitates legacy interventions in the outpatient setting?

Method

Recruitment and Eligibility

After approval by the Institutional Review Board of XXXXX, the research team contacted hospitals within the Children's Hospital Association (CHA) network to recruit participants. The research team contacted CHA member hospitals via telephone utilizing contact information from the Association of Child Life Professionals (ACLP) directory. Therefore, eligible participants were affiliated with children's hospitals with CHA membership and child life programs. Those individuals who were not part of CHA, did not work in an outpatient clinic, or were from a hospital without a child life program were excluded. Individuals at their institution best suited to answer the survey questions were identified as potential participants. This included child life specialists and nursing staff when child life staff were not available. The potential participants' phone numbers and email addresses were documented for follow-up. Researchers contacted the potential participants by phone to gather interest and request involvement in the study. If the individuals could not be reached by phone, an email was sent to the participant to provide a summary of the study and to request a return phone call to the study team. All hospitals were attempted to be contacted at least three times by phone, email, or a combination of both.

Procedure

Interested individuals received a general study description and were presented with a consent disclosure statement via phone. Individuals provided consent by agreeing to complete the survey. Subsequently, researchers sent participants a link to the survey through the Research Electronic Data Capture (REDCap; Harris et al., 2009) tool hosted at The University of Tennessee Health Science Center, which was specifically developed for this study to collect data on the availability of legacy-building interventions in their outpatient setting. If requested, participants could complete the survey by phone with a research team member. Participants typically took 5 to 10 minutes to complete the survey. Researchers sent an auto-generated email reminder to participants who did not complete the survey within one week. Data collection occurred from August 2021 to December 2021.

Materials

Through the survey link in REDCap, participants completed 12 questions regarding the types of legacy-building opportunities offered, locations and timing of legacy-building interventions within their healthcare setting, who is typically involved in these opportunities, intended goal(s), and barriers to offering these opportunities. Survey questions were developed by the researchers and included multiple choice options with the opportunity to write in answers for "other." The survey questions were not tested for validity or reliability before the study; therefore, the accuracy and comprehensiveness of the questions may be limited.

Data Analysis

Descriptive statistics were reported to characterize legacy-building interventions in the healthcare setting. Frequency counts and percentages were calculated and provided for the legacy building survey questions and their corresponding responses. When "other" was marked, the authors looked carefully at the written responses and added those to the question categories when they matched or created new categories.

Results

Participants

A total of 117 healthcare institutions were contacted at least once via telephone; 35 (30%) institutions passively refused to participate by not responding to voicemails. Thirty-four (29%) representatives verbally agreed to participate during an initial phone call but did not complete an emailed survey. Forty-eight (41%) representatives completed a survey; however, five of these respondents identified themselves as working in an inpatient setting. The remaining 43 (37%) representatives completed the survey for this study. When asked what type of healthcare institution the respondents represent, 32 (74.4%) worked in an outpatient center with multiple clinics, nine (20.9%) worked in a stand-alone outpatient clinic, and two (4.7%) worked in an emergency room and an outpatient unit (emergency department). Demographic data on the respondents and hospitals were not collected to protect the privacy and confidentiality of the respondents.

Location(s) Where Legacy Building is Offered

Fourteen percent (n = 6) of respondents reported not offering any legacy-building opportunities to their outpatient population, whereas 7% (n = 3) of respondents reported not offering legacy building at their facility at all. Institutions that reported not providing legacy building-opportunities to outpatients indicated time constraints, limited staffing, and a lack of resources as the greatest barriers. Additional written responses stated that legacy-building opportunities were strictly offered to inpatients and their families (see Table 1).

Department/Staff who Offer Activities in an Outpatient Setting

Child life staff members most often (n = 32, 86.5%) offered and engaged in legacy-building interventions with patients and families in outpatient settings. Respondents also identified nursing (n = 1, 2.7%) and palliative care (n = 2, 5.4%) staff members as responsible for offering legacy building to outpatients and their families. Additional "other" responses (n = 2, 5.4%) included collaborations between child life, palliative care, and music therapy professionals.

Types of Activities Offered

Participants most often reported offering hand/foot molds (n = 35, 81.4%), memory books (n = 23, 53.5%), music opportunities (n = 3, 53.5%), locks of hair (n = 21, 48.8%), photography (n = 20, 46.5%), and writing opportunities (n = 14, 32.6%). Additional "other" responses included fingerprint charms, prayer shawls, worry stones, memory boxes, and bead programming (see Table 1). One hospital described a framework for how individualized interventions are offered, saying "We do our best to consider the individual child and provide resources to create a project that is special to the family."

Who Participates in Activities

Over half (n = 18, 51.4%) of all respondents explained that legacy-building interventions in outpatient settings are typically completed by a patient and family together, with 17.1% (n = 6) reporting that staff completes legacy-building interventions alone and then provides items to a patient and/or family. Only one respondent reported that patients (2.9%) or families (0%) complete legacy-building activities independently. Additional responses (n = 10, 28.6%) included legacy building being completed in various combinations of patient, family, and medical staff due to patient and family wishes and a patient's cognition level at that point in the illness trajectory.

Almost three-quarters of respondents (n = 32, 74.4%) reported legacy-building opportunities are incorporated as an individual activity to be completed with a staff member with an explicit intent of promoting legacy building. Because more than one answer could be selected, almost half of the respondents (n = 21, 48.8%) reported legacy-building opportunities are incorporated into a patient's outpatient visit as a part of another intervention with a staff member, where the legacy building is a byproduct. Remaining responses (n = 11, 25.6%) reported it as an activity to be taken home for completion.

Timing of Activities

The majority of participants initiate legacy-building activities in an outpatient setting around a patient's death, offering opportunities only when further treatment is no longer being pursued (n = 31, 72.1%) or after a patient's death (n = 15, 34.9%). Around 30% (n = 13) reported that legacy-building activities commence soon after a new patient diagnosis. Only 10 (23.3%) respondents reported incorporating legacy building as a standard of care for all outpatients.

Barriers

Over half (n = 21, 55.3%) of participants indicated an emotional burden on a patient and/or family as the most difficult part of engaging in legacy building in an outpatient setting, with 7.9% (n = 3) citing physical limitations of sick patients and 5.3% (n = 2) identifying developmental limitations of patients and their ability to understand intended meaning of legacy-building activities. Several respondents (n = 12, 31.6%) also listed "other" barriers, including lack of resources, limited staffing, fast pace/scheduling of outpatient clinic appointments, trajectory of a patient's illness or rapid changes in status, and medical staff not supporting activities being completed earlier.

Discussion

This study aimed to identify types of legacy-building interventions taking place in an outpatient setting, when they are taking place, and to identify barriers preventing

Table 1. Counts and Percentages for Legacy Building Activities (N = 43)

Survey Questions	Survey Results
Locations Where Legacy Building is Offered What type of outpatient setting do you represent?	
Outpatient center with multiple clinics	32 (74.4%)
Stand-alone outpatient clinic	9 (20.9%)
Emergency department	2 (4.7%)
Type of Activities Offered as a Whole What legacy building activities does your facility offer as a whole to patients? Please select all that apply.	
Hand/foot molds or ink/paint prints	40 (93.0%)
Photography	30 (69.8%)
Memory book or journal	30 (69.8%)
Lock of hair	35 (81.4%)
Writing opportunities (letter, writing, poetry, etc.)	19 (44.2%)
Music opportunities (song writing, heartbeat recordings, etc.)	31 (72.1%)
Video	11 (25.6%)
*Other Art Remembrance keepsake	19 (44.2%) 3 (7.0%) 16 (37.2%)
None	3 (7.0%)
Why does your facility not offer legacy building as a whole to patients?	
Time constraints	1 (33.3%)
Lack of resources	0 (0%)
Limited staffing	1 (33.3%)
No needs assessed	0 (0%)
Other (Offered across the street in inpatient hospital)	1 (33.3%)
Type of Activities Offered to Outpatients What legacy building activities does your facility offer to outpatients specifically? Please select all that apply.	
Hand/foot molds or ink/paint prints	35 (81.4%)
Photography	20 (46.5%)
Memory book or journal	23 (53.5%)
Lock of hair	21 (48.8%)
Writing opportunities (letter, writing, poetry, etc.)	14 (32.6%)
Music opportunities (song writing, heartbeat recordings, etc.)	23 (53.5%)
Video	8 (18.6%)
*Other Art Remembrance keepsake Counseling	16 (37.2%) 1 (2.3%) 14 (32.6%) 1 (2.3%)
None	6 (14.0%)
Why does your facility not offer legacy building to outpatients?	
Time constraints	2 (33.3%)
Lack of resources	0 (0%)
Limited staffing	2 (33.3%)
No needs assessed	1 (16.7%)
Department/staff Who Offer Activities in the Outpatient Setting Which department or program primarily offers legacy building activities in your outpatient setting?	

Child life	32 (86.5%)
Nursing	1 (2.7%)
Palliative care	2 (5.4%)
*Other Child life & palliative care Child life and music therapy	2(5.4%) 1 (2.7%) 1 (2.7%)
If Child Life primarily offers legacy building opportunities in the outpatient setting, how many Child Life Specialists are in your department?	
0-5	10 (31.3%)
5-10	5 (15.6%)
10-15	5 (15.6%)
5-20	3 (9.4%)
>20	9 (28.1%)
Who Participates in Activities Who typically participates in completing legacy building activities in your outpatient setting?	
Patients and their families together	18 (51.4%)
Staff (completes activity and provides to patient and/or family)	6 (17.1%)
Patient alone	1 (2.9%)
Family alone	0 (0%)
*Other Family with Staff Siblings	10 (28.6%) 9 (25.7%) 1 (2.9%)
How are legacy building opportunities being incorporated into the patient's outpatient visit? Please select all that apply.	
As an activity to be taken home for completion	11 (25.6%)
As an individual activity to be completed with a staff member with the explicit intent of promoting legacy building	32 (74.4%)
As a part of another intervention with a staff member where legacy building is a byproduct	21 (48.8%)
Other	0 (0%)
**Which pediatric patients are offered opportunities for legacy building in your outpatient setting? Please select all that apply.	
Patients at end of life	3 (7.0%)
Patients with any life-threatening or life-limiting illness	3 (7.0%)
Patients with neurodegenerative diseases	2 (4.7%)
Other (Patients who have lost a close family member/parent)	1 (2.3%)
Timing of Activities At what point in the illness trajectory are patients and/or families offered opportunities to engage in legacy building in your outpatient setting? Please select all that apply.	
As a standard of care for outpatients	10 (23.3%)
Before the death of the patient: soon after diagnosis	13 (30.2%)
Before the death of the patient: when further treatment is no longer being pursued	31 (72.1%)
After the death of the patient	15 (34.9%)
Only if specifically requested by the patient or family	3 (7.0%)
Other (Other meaningful points in the illness experience based on family preference/Depends on modality and patient/family)	2 (4.7%)
What is the intended goal of providing legacy building opportunities to outpatients at your facility? Please select all that apply.	
To benefit the patient	3 (7.9%)
To benefit the family while the child is receiving care	10 (26.3%)
To benefit bereaved families	14 (36.4%)
*Other	11 (29.0%)

All of the above Depends on modality No answer provided	9 (23.7%) 1 (2.6%) 1 (2.6%)
Barriers What do you perceive as the most difficult part of engaging in legacy building for patients and/or families in the outpatient setting?	
Emotional burden on patients and/or families	21 (55.3%)
Physical limitations of sick patients	3 (7.9%)
Developmental limitations of patients understanding intended meaning of activities	2 (5.3%)
*Other Staffing/schedules All of the above N/A Illness decline/timeline accelerating	12 (31.6%) 5 (13.2%) 1 (2.6%) 3 (7.9%) 3 (7.9%)

the implementation of legacy building in pediatric outpatient settings. Overall, the findings demonstrate that 86% of the hospitals are offering legacy-building activities to patients and their families in the outpatient setting. When legacy-building interventions are offered, it is typically by a child life specialist. Barriers identified for implementing these interventions include lack of resources, limited staffing, timing, and buy-in from medical team members.

Legacy building is a critical aspect of pediatric care that has evolved and become more widely implemented over the past few decades (Akard et al., 2021). While such activities have been instituted as an intervention for inpatients and their families, hospitals and clinics continue to recognize more deeply the importance of legacy building for outpatients to benefit coping for both patients and families during healthcare encounters (Akard et al., 2021). Research continues to support that the goal of legacy-building interventions is to benefit children who are receiving medical care and their families throughout an illness or injury, at the end of life, and following death (Akard et al., 2021). However, all empirical evidence before this study regarding legacy building has focused on inpatient settings.

This study found that some pediatric institutions excluded outpatients (n = 6) from legacy-building opportunities while others did not offer any legacy building (n = 3), indicating that legacy-building interventions were reserved for patients who are inpatient and/or further along in an illness trajectory as opposed to being part of a patient and family's entire medical journey. Reserving legacy-building services for inpatients and their families remains a missed opportunity in patient-and-family-centered care. By waiting until hospitalization or end of life to facilitate legacy-building interventions, patients lose out on many benefits associated with legacy building (Foster et al., 2012). A shift in thinking to view legacy-building interventions as celebrations of what a patient and their family have conquered throughout their healthcare journey allows for greater delivery of holistic, psychosocial care. This type of shift in thinking can also hopefully help non-psychosocial staff members shift their perspective on what it means to "create a legacy" for patients and families.

In comparing types of legacy-building activities offered, the results of this study suggest that patients and families are being offered the same types of interventions regardless of location, indicating that the location of an intervention alone does not affect what is being offered to patients or families. However, barriers exist to facilitating these interventions specifically in outpatient clinic settings, with time constraints and limited staffing being identified as the key barriers to engaging in legacy-building interventions in an outpatient setting.

An additional barrier indicated that a lack of support from non-psychosocial staff hinders earlier engagement in legacy-building interventions. Pediatric primary care clinicians cite a lack of confidence in their ability to implement social-emotional interventions as a barrier to providing social-emotional care in a primary care setting (Merle et al., 2023). A similar lack of confidence may be a reason why multidisciplinary team members are hesitant to participate in legacy-building interventions. This highlights the importance of educating multidisciplinary team members on the importance of legacy building, including benefits to patients and families. Furthermore, barriers of time constraints, limited staffing, and lack of support from non-psychosocial team members are likely to be the reason legacy-building interventions are most often only being offered and facilitated by a child life specialist when present in a clinic setting. Buy-in from multidisciplinary team members could increase opportunities for all healthcare providers to feel comfortable and confident in offering legacy-building opportunities even when child life staff are not available.

Because this study found that child life specialists are the clinical staff members who offer legacy-building interventions, it is possible that legacy-building interventions will not be offered or facilitated when a child life specialist is not present. For institutions that do have a child life department, those departments must assess their coverage structure to ensure that outpatient clinic areas have dedicated coverage by a child life specialist. Once child life coverage in an outpatient clinic has been established, child life specialists should actively identify opportunities in which they may incorporate legacy-building interventions with patients and families. These opportunities may include discussing an intent for legacy building with the patient and/or family or an opportunity for legacy building as a byprod-

uct of an intervention that was implemented with other primary goals.

More research is needed to understand the short-term and long-term effects on patients and families who engage in legacy-building interventions in an outpatient setting, whether a child lives to adulthood or dies. Additionally, more research is needed to understand the best way to approach patients and families regarding perceptions about how legacy-building interventions are presented and offered.

The results of this study provide the opportunity to explore ways for child life professionals and other members of the healthcare team to overcome barriers to increase legacy-building opportunities for patients and families in outpatient clinic settings. Such action can include multidisciplinary education and communication, increased outpatient clinic child life staffing within departmental coverage models, and incorporating legacy building as a byproduct of interventions with other primary goals. Although survey results indicate that child life specialists most often offer legacy-building interventions, opportunities for legacy building can be increased and accomplished without child life by increasing education among multidisciplinary teams and readily available access to appropriate resources. Based on this study's findings, more research is needed to better understand how to expand these services earlier in an illness trajectory to more outpatient pediatric patients living with chronic conditions and their families. Additionally, the costs and benefits of outpatient clinic legacy building should also be investigated.

Limitations

Limitations of this study included the nature of the survey, which led to a lower participation rate. This is consistent with many survey studies, especially those completed via email (51% average response rate) and specifically by doctors or healthcare professionals (53% average response rate; Meyer et al., 2022). Second, selection bias might have favored survey completion by those institutions with greater infrastructure and those that regularly offer legacy building. Children's hospitals that were contacted but did not respond or complete a survey may have been more likely to offer no defined legacy building opportunities, may not prioritize legacy building, or may not have appropriate resources to do so. Additionally, the survey did not capture data on characteristics of healthcare institutions as respondents, such as location or size of an institution, which could have influenced responses. Likewise, as this study only surveyed hospitals that are members of CHA and have self-reported contact information on the Association of Child Life Professionals' Child Life Program Directory, participants may not be representative of all pediatric healthcare institutions, and therefore there may be limited generalizability of findings. Last, survey questions were not tested for validity or reliability before the study, therefore, the accuracy and comprehensiveness of questions may be limited.

Implications for Practice

Because this study found that child life specialists are the clinical staff members who most often offer legacy-building interventions, it is possible legacy-building interventions might not be offered or facilitated when a child life specialist is not present. Legacy-building opportunities should be offered as a standard of care to all outpatients, regardless of a child life specialist's availability. Clinic settings without child life coverage should explore partnerships with nonprofit programs that help to promote legacy and tell stories of patients and families to aid in addressing time and resource constraints. These nonprofit programs exist in several different capacities, including promoting legacy through a collection of beads, creating personalized plates, or providing stuffed animals with a heartbeat recording inside of them. Nonprofit partnerships provide space for clinic settings to ensure that legacy opportunities are available to patients and families, even when a clinic has fewer resources and less time for in-depth interventions.

For institutions that do have a child life department, those departments must assess their coverage structure to ensure outpatient clinic areas have dedicated coverage by a child life specialist. Once child life coverage in an outpatient clinic has been established, child life specialists should actively seek opportunities to incorporate legacy-building interventions with patients and families. These opportunities may be discussing an intent for legacy building with a patient and/or family or interventions in which legacy building is a byproduct of interventions with other primary goals. Furthermore, to address the lack of support from non-psychosocial team members, child life professionals should educate team members about the positive effects of legacy building throughout a patient's healthcare journey, rather than reserving these interventions for end-of-life. Multidisciplinary rapport building and ongoing education opportunities can increase buy-in from multidisciplinary team members, leading to less pushback in offering these interventions earlier in an illness trajectory and increasing the number of patients and families who receive this service.

Conclusion

This study provides survey data on legacy building in the outpatient setting. The types of legacy-building interventions offered are similar whether inpatient or outpatient, including photography, memory boxes/journals, hand molds, writing and music opportunities, and "remembrance keepsakes." Additionally, this study identified that legacy-building interventions, even in an outpatient setting, are often occurring late in a patient's illness trajectory, including after death. Barriers to offering legacy building in an outpatient setting included time and resource constraints, short staffing, and limited support from non-psychosocial clinic staff members. These findings identify the continued need to educate the healthcare team on the importance of individualized legacy building throughout the healthcare journey, including during outpatient visits, and the need

for dedicated child life coverage and psychosocial support in the outpatient setting to support legacy-building interventions. Future research is needed to explore what legacy-building interventions look like in hospitals and outpatient settings that do not have child life programs. Additionally, future research is needed to better understand how to expand legacy-building interventions to a greater number of outpatient pediatric patients and their families, as well as to understand how a shift in thinking about legacy-building interventions in the outpatient setting impacts perception of these interventions by non-psychosocial staff members.

Submitted: November 26, 2024 EDT. Accepted: March 16, 2025 EDT. Published: July 31, 2025 EDT.

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