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Transforming a Face-to-Face Legacy Intervention to a Web-Based Legacy Intervention for Children with Advanced Cancer

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Abstract

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Research is needed to examine new and innovative web-based intervention delivery methods that are feasible, cost-effective, and acceptable to children and their families to increase access to palliative care services in the home and community. Our previous work included the development of a legacy intervention using face-to-face digital storytelling for children with cancer that showed feasibility and strong promise to improve child outcomes. However, face-to-face intervention delivery techniques limited our recruitment, thus decreasing sample size and potential access to broader populations. Here we present the systematic steps of the development of a web-based legacy intervention for children (7 to 17 years of age) with relapsed or refractory cancer and their parent caregivers. Counts and frequencies for parent ($N = 81$) reports on satisfaction surveys are presented and parent suggestions for future work. Results suggest the web-based legacy intervention is feasible and acceptable, with parent perceived beneficial outcomes for the child, parent, and family. Results provide a foundation for web-based intervention development in palliative care and the implementation of a theoretically grounded intervention to reduce suffering of seriously-ill children and their family members, thereby advancing the science of symptom management in vulnerable palliative care populations.

Keywords

palliative care; palliative supportive care; terminal care; caregivers; pediatric nursing; hospice and palliative care nursing; children

Approximately 15,000 children aged five to 19 years die each year in the United States,[1] and an estimated 500,000 children are living with life-threatening conditions.[2] Seriously-ill children and their family members are a signifant and compelling population at high risk for suffering and distress. Children with life-threatening conditions not only have shown substantial physical symptom distress,[3–5] but also high levels of depression, sadness, distress, anxiety, and worry.[3,5,6] Mothers have reported sadness as one of the most burdensome symptoms for children.[3] Sadness, anxiety, and worry have been documented specifically in the last 4 weeks of life.[5] Children with life-threatening conditions are high risk for existential suffering, often manifested as questioning God and lack of meaning for their illness and concern for loved ones they will leave behind as they prepare for their impending deaths.[7–9] Seriously-ill children are likely to think about death even if they do not communicate that explicitly.[10]

Children's suffering during illness, and unfortunately sometimes death, can have immediate and long-term effects on parents. Parents of children with life-threatening conditions have reported anxiety, depression, and burden,[4] and below standard quality of life.[11] These consequences can lead to parent psychiatric distress,[12] marital disruptions,[13] family financial strain,[14] and job loss.[14,15] Ill children and parents may both experience psychological distress and strained family environments near end of life.[3–6,11,16,17]

Legacy-making is defined as actions or behaviors aimed at being remembered while comforting family members and thus can be beneficial during illness and end of life for patients and their families.[10, 18–20] Legacy activities can co-exist with curative care and be tailored to the goals of children and their families.[18,19,21] Although our previous work has documented that children naturally create legacies just by being who they are,[19] it is important to help children whose deaths can be anticipated to document their legacies to help reassure them that they will be remembered.

The majority of legacy interventions (e.g., dignity therapy) have been developed for and tested in adults with serious advanced illnesses.[20, 22–24] Few legacy interventions have been developed specifically for children, and those have included digital storytelling and artwork.[19, 21, 25] Some research has focused on legacy activities tailored to bereaved caregivers and families.[25–27] Formats of delivery have been in-person, aside from one legacy intervention for adults with terminal cancer using a web-based portal[24] and a pediatric palliative caregiver meaning-making intervention using a social media platform.[28]

Legacy-making in adults has been shown to increase patients' sense of dignity, purpose, meaning, will to live, generativity, and acceptance, while decreasing suffering, distress, and depressive symptoms.[20,22,23] Hospital staff have reported that legacy activities helped ill children cope and communicate and family members cope, communicate, and continue bonds after a child's death.[18] Our work has shown that legacy interventions can improve emotional quality of life, communication, and coping among children with cancer (aged 7 to 17 years).[18, 21] However, the potential impact of our work was limited by a face-to-face legacy intervention format and prompted us to examine web-based intervention delivery methods that are feasible, cost-effective, and acceptable to pediatric palliative care populations and their families. Here we describe the process of transforming a face-to-face format to a web-based legacy intervention for children with refractory or relapsed cancer and their parent caregivers.

Methods

Study recruitment took place via Facebook advertising over three years, targeting parents who: (a) were located in the United States, (b) were any gender, (c) and had interests related to pediatric oncology (e.g., expressed interest in or liked other Facebook pages related to childhood cancer).[29] Advertisements targeted parents aged 18 years and up because Facebook users must be at least 13 years of age to have an account. This allowed us to directly access parents via Facebook ads, with children aged 7 to 17 years accessed via their parents. The Facebook advertisement contained a REDCap link that included a brief study description and initial screening questions. Potentially eligible parents were then asked to complete basic demographic questions and provide their name and contact information to receive more study details. The study coordinator contacted interested individuals via phone or email within 1 week to describe the study and confirm eligibility. The Coordinator described the study as a "digital storytelling project;" the term "legacy" was not used to be sensitive to the treatment goals of children and not imply death was possibly imminent.

Eligible participants were: (a) children aged 7 to 17 years and their primary parent caregiver (i.e., legal parent guardian who spent the most number of hours per week with the eligible child); (b) patients with relapsed or refractory cancer determined by parent self-report; (c) able to speak, understand, read, and type English; (d) with internet access; and (e) without cognitive impairment as determined by the coordinator during the consent process. For eligible participants, the coordinator obtained verbal parental consent and confirmed contact information to email study documents. The study was approved by the Vanderbilt University Institutional Review Board (140622) for waiver of written consent, and consent was implied by participants' completion of surveys.

Intervention Overview

Development

Our team worked with a software design and development company to develop the web-based program. Original intervention content and format were based on components of the Dignity Model of Care previously used in adults,[20] child self-reports,[19] and our face-to-face legacy intervention.[21] In 2013, design work began and resulted in blueprints being created for the website design. Based on the blueprints, original website design with mobile access included 412 hours of work (192 hours of design, 220 hours of development). This original development of the web program occurred October 2014 through July 2015 and cost $50,000.

Intervention content (Table 1) was developed based on our preliminary face-to-face legacy-making intervention.[21] The web program included four major components that guided children to: (1) answer legacy questions about themselves; (2) upload photographs; (3) upload video; and (4) upload music. The final product was an electronic copy of the child's digital storyboard provided to the family to keep.

Our original intent was to model the web-based intervention product after our face-to-face intervention that provided families a digital story DVD to keep.[21] After study enrollment and intervention delivery was complete, we enhanced the final intervention product to play the digital stories in an automatic cinematic format, rather than storyboards requiring users to click each section to view content. Development of the new cinematic feature took approximately an additional 214 hours (30 hours of design, 184 hours of development) and cost $13,500.

Procedures

Data collection occurred over 3 years (2015-2018). Child-parent dyads were randomly assigned to either an intervention or usual care group by using a computer-generated randomization approach with a 1:1 permuted block scheme. All participants completed baseline (T1) measures. Within 1 week of baseline, the Coordinator emailed an electronic link to participants in the intervention group to access the password protected intervention website. Each family was provided a username and password to access and use the website. Children were asked to complete the storyboard within 2 weeks. Upon completion of each digital story, the website generated a unique electronic link to the final storyboard that the Coordinator then emailed to the child or parent. Only individuals with the link could view the child's digital story. Part of the assent process was to inform the child that their final story would be shared with the participating parent. Children and parents assigned to the intervention group completed T2 questionnaires post-intervention.

Children and parent assigned to the control group completed T2 questionnaires 2 months after baseline. The control group received usual care. Children and parents in the control group were offered the same intervention as the intervention group within 1 to 2 weeks after completing T2 measures.

Parents (both intervention and control group) of children who completed the intervention were also asked to complete a T3 follow-up survey to gather feedback on the intervention, and a T4 follow-up survey to gather feedback on the added cinematic feature. All children and parents completed study measures electronically via REDCap, a secure web-based application for building and managing online surveys and databases. The Coordinator made reminder calls or sent reminder emails for surveys not completed within 1 week. This paper presents T3 and T4 data related to parent reports on intervention implementation.

Measurement Tools

Follow-up parent surveys invited parents to answer survey questions regarding effects of the intervention and suggestions for future research. The questions were based on the follow-up survey used in our pilot study[21] and included multiple choice and open-ended questions.

Analysis

Independent sample *t*-tests and Chi-Square Tests of Independence were conducted to compare the demographic and clinical characteristics of those included in the study analysis to those excluded. Data coding and analysis of open-ended questions was managed by the Qualitative Research Core at Vanderbilt University. A hierarchical coding system was developed and refined by using the content of parent responses after the intervention was completed. Definitions and rules were written for the use of each category. Experienced qualitative coders first established reliability in using the coding system, then coded the remaining transcripts independently. Each statement was treated as a separate quotation, and each quotation could be assigned up to five independent codes. Transcripts were then combined and sorted by code. Analysis consisted of interpreting the sorted coded quotes and identifying higher-order themes and connections between themes. Management of transcripts, quotations, and codes was done using Microsoft Excel 2016 and SPSS version 25.0. Counts and frequencies were calculated for multiple choice survey responses.

Results

Of 273 individuals screened for eligibility, 123 were excluded (46 active refusals, 44 passive refusals, 23 ineligible, 10 other). Thus, 150 parents (55%) enrolled and began participation in the study. Forty-two (28%) parents dropped out prior to completing T2 (control=31, experimental=11), and 10 (7%) completed T2 more than 6 months after enrollment (control=7, experimental=3). Therefore, 98 families were included in the quantitative analysis for the study. See Tables 2 and 3 for complete demographic and clinical characteristics. Compared to the participants in the analysis group, those who did not complete the study were more likely to be married (73% vs. 51%) and less likely to have never married (6% vs. 26%). A higher percent of those who did not complete the study had a child with a bone marrow transplant (35%) compared to 14% of those who did complete ($p = 0.007$).

Of 98 child-parent dyads in the data analysis sample, 84 (85.7%) completed the intervention, and 81 (82.7%) completed T3 survey questions (median 16 days post-intervention) regarding effects of the intervention and suggestions for future research. At study end, parents ($n = 18$) completed additional open-ended questions at T4 regarding what they liked and disliked about the cinematic/movie-type format of their child's final digital story later added. Counts and frequencies for multiple choice survey responses are presented in Table 4.

Parental Feedback on the Intervention

When asked how the intervention could be more helpful to other families in the future, 23 (28.4%) parents expressed positive comments and appreciation for the intervention, such as it was "very helpful" or "an amazing experience." One parent said, "Awesome project. It's bittersweet to document the child's journey." Parents perceived positive intervention benefits for both the children and their family who were involved in creating their child's story. Five parents praised the *emotional expression and communication benefits for children and their family members*. Examples included positive recognition of the sharing aspects of the program and of how the intervention motivated the children to share their experiences. One parent said, "I believe it allows families to express their emotions, how treatment from this disease makes them feel. It allows the child to really evaluate how it makes them feel both emotionally and physically." Another parent shared, "It's helped this family realize some underlying issues."

Two parents reported liking how the intervention *strengthened the parent-child relationship.* Examples included bonding and quality time between parents and children in navigating the website, uploading pictures, and creating the storyboard. One parent reported, "This project was really a neat way for [ill child] to express himself and do something he felt would help others. He loved picking out photos and thinking about his favorites and even though we were not entirely sure how to go about doing things, we worked together, and it really did create a bond."

Parental Feedback on Timing for the Intervention

Parents provided feedback regarding the best timing for when to offer the intervention. Suggestions ranged from the beginning ($n = 11$; 13.6%) to end ($n = 12$; 14.8%) of the illness trajectory. One parent suggested that the intervention "be offered and available in the beginning of the journey for those parents that want to document as they go." Another parent suggested the beginning because of too many side effects after treatment began: "I believe that at the beginning is okay, but when it was offered to my son it was when he was fully into his treatment, and side effects didn't let him function much to begin with… now with him catching up on 'life' and school, he finds it hard to get back into it." While some parents thought early in the trajectory was best, others perceived later in the trajectory would be best. One parent said, "After treatment…gives time to reflect and open conversations." Some parents felt timing should be determined based on each individual child: "Hard to say, each situation is different. When the child is ready." Parent most frequently ($n = 33$; 40.7%) suggested that the intervention be offered throughout the children's cancer journey. One parent said timing would be best "when they are going through the process of the illness."

One parent felt any point in the illness trajectory was a good time: “I think given the opportunity, any time would benefit.”

Parental Feedback on Future Improvements for the Intervention

Some parents (n = 19; 23.5%) liked the intervention exactly as it was. Comments included parent reports such as this: “It was very helpful. I’m not sure what more they could add to make it better.” Another parent stated, “There is nothing I would change.”

Other parents offered recommendations for how the process could be more helpful to future families, including *involving family members more* (n = 9; 11.1%). One parent said, “Maybe also ask parent input on story.” Another parent suggested involving siblings: “I think it would be nice to have somewhere where siblings can also participate. Our youngest son always feels left out of things that have to do with his brother’s illness.” Fourteen (17.3%) parents suggested that more should be taken into account to *accommodate the individual needs of ill children*, including references to children’s age, stage of treatment, and how sick they were. One parent said, “Younger children or some that are not feeling well when completing this may require some assistance to complete.” Another said, “Some kids don’t understand what it means due to the chemotherapy and radiation damage.” Ten (12.3%) parents felt that *the program should be lengthened* to start sooner and last longer. One parent said, “I would have loved to have known about this in the beginning and keep being able to add to it as we go.” Another suggested they would have liked “more time to cover more of their journey.” Three (3.7%) parents desired *a sharing or community component* to allow the children to read others kids’ stories and increase their awareness of other patients. Parents reported this might “…help them communicate and understand what a cancer child goes through to bring awareness for other cancer kids and their families.”

The most frequent suggestion from parents (n = 19; 23.5%) was to *make the web program more user-friendly*. Parents reported the need to simplify the general process for the creation of storyboard and minimize technical issues encountered during the intervention. Parents had difficulty using the app on different devices and issues getting the program to work. One parent said, “The app itself was not user friendly. I had difficulty myself with the app.” Another parent shared, “The ease of creating was a little difficult.” Technical difficulties included logging in to the website, uploading pictures, and editing posts. One parent said, “It took me forever to be able to log in.” Another said, “We had technical problems. Also, it would be better to add pictures from device straight to [website]…some kids don’t feel like taking selfies or pics at times…but they may have pics on their devices already they can share.” Fourteen (17.3%) parents had suggestions for *improved intervention content and design*: One parent suggested: “I think some of the dropdown menu choices…[are] too limited. Maybe choices to change backdrop colors, etc.” Another parent said, “The questions were too vague. My daughter was confused about what to write. More detailed questions would help.”

Parent Feedback Regarding Cinematic Feature

All parents (*n* = 18, 100%) were positive about the movie format, specifically mentioning their appreciation for the coherent and automated flow of the entire story. Parents reported that the cinematic feature made the digital story more meaningful to themselves (n = 13, 81.3%) and their ill child (n = 10, 71.4%). Parents especially mentioned how they liked the music that played in the background. One parent said, “The music made it more emotionally significant. I really liked it a lot.” Parents reported that their children preferred the movie format as well. One parent said, “It made him feel special to be able to read his story and know that others will be able to see it also…” Other parents shared that the movie “gave her a starting point for talking” or their child “thought it was cool.” Parents perceived that the movie feature was easy and simple to use, and 13 (81.3%) of parents said that the new format make it easier to share their child’s story with others. A few parents provided feedback for future improvements, including options to select or change the music, rotate photographs, select full screen, and alter the speed of the movie progression.

One overall theme emerged from the data related to benefits of the cinematic feature, which was that parents perceived the new movie feature *facilitated family conversations*. Many parents reported how watching the movie caused them to remember and look back, such as one parent who said, “We talked about how much has changed. It was really nice to look back.” Another parent said, “I was able to have conversations with him that I otherwise wouldn’t have had.” Another participant shared, “My husband and I laughed and shed a few tears watching this, just thinking about how much has changed, what we have gone through…. We talked about how we are so much stronger because of what we have endured together.” One parent shared how the movie triggered a conversation between her and her ill child as well as her spouse: “[Ill child] and I talked about how the project made her feel about her cancer diagnosis and treatment…. My husband and I have had multiple conversations regarding the project and how [ill child]’s diagnosis has changed our lives and family goals.” A bereaved parent expressed, “I told people who [deceased child] had mentioned in the story. Since he’s gone, it means so much more.”

Discussion

This innovative study was the first to test a web-based intervention delivery method for legacy-making in a pediatric palliative care population. Here we described the systematic steps of transforming a face-to-face format to a web-based intervention and parent feedback on intervention effects and suggestions for future work. While previous studies have utilized face-to-face legacy-making intervention delivery mechanisms, computer and mobile intervention delivery may expand our potential impact and ultimately improve care for pediatric palliative care populations.

The intervention was feasible and acceptable to our sample representing parents who were mostly female, Caucasian, college-educated, and living in the Mid-Western region of the United States. The cinematic feature was feasible and especially appreciated. Interesting to note is that the children all had advanced (relapsed/refractory cancer) disease, yet very few had been notified of terminal status, been referred to hospice/palliative care, or a DNR in place. Although the term “legacy” risks the implication that death is imminent, results support feasibility and acceptability for children earlier in the illness trajectory to participate in legacy activities. Legacy interventions are not only for dying children, but also children who will be cured.

Parent perceived benefits of the intervention to children, parents, and families. Parent-child communication and child expression of feelings were the most frequently reported benefits. These findings are similar to previous studies noting potential benefits of legacy-making.[18,21] Areas of the intervention that need more emphasis include increasing user-friendliness of the web-program, intervention dose, and structured parent-child interactions. Intervention modifications already made include increased user-friendliness by simplifying the process for families to log in if they forget their account password. Future modifications will include: (a) more detailed guiding legacy questions; (b) increased intervention dose; (c) enhanced parent-child communication components; and (d) further revisions to maximize user-friendliness of the program (e.g., uploading materials).

Generalizability of our results are limited to children 7 to 17 years of age with advanced cancer and their parents recruited via Facebook. While Facebook recruitment provided a geographically diverse sample representing all regions of the United States, we subsequently could not access medical records for information such as how many children in our sample died. A major study limitation is the difference in participant numbers between intervention and control groups. Attrition in the intervention group was largely due to issues with user friendliness of the intervention web-program (e.g., difficulties logging into website) during Year 1 enrollment. Website issues and subsequent issues resolved the following year. However, other studies testing web-based interventions have similarly noted higher attrition in intervention versus control groups and dissatisfaction with online programs.[30, 31] Despite these limitations, our study demonstrated promising areas for future legacy-focused research studies.

In addition to intervention modifications, future research is needed to further develop and test legacy interventions in pediatric palliative care. Researchers should include measures related to child, parent, and family outcomes. More quantitative work is needed to test the effects of legacy interventions on family relationships, parent-child communication, and child emotional expression. Measures of psychological distress (e.g., anxiety, depression) could be considered, as well as physiological parameters such as salivary cortisol to measure stress. Researchers must also consider the effects of legacy interventions in diverse pediatric palliative care populations, rather than just cancer, to better understand how these supportive services could be accessible to all children and families who could benefit.

Nurses and other healthcare professions are in ideal positions to reassure children living with life-threatening conditions and their family members that they have already created a legacy just by being who they are. However, activities to help children document their legacies can be beneficial and improve parent-child communication and child expression of feelings. Although our web-based program is not yet available for public use, clinicians can use components of our intervention (provided in Table 1) to guide children and their families to consider legacy activities, such as talking about and documenting legacy topics (child’s personal characteristics [e.g., name, age, gender], things child likes to do [e.g., hobbies, interests], and connectedness with others [e.g., special message to a loved one]). Photographs, videos, and music can also help document children’s legacies. Clinicians can also help provide conceptual clarity to the term “legacy” by helping educate families and other providers that such services are not only for dying children but can co-exist with curative efforts.

Modifications to the web-program are currently in progress; the future plan is for our modified web-program to be available for public use after testing is complete and efficacy is established. While clinicians can help guide patients and families to document legacies without a web-program, electronic delivery of our legacy intervention will provide greater impact and access for seriously-ill children living in rural areas or those receiving home-based care. This study provides crucial information for future studies across all palliative care populations through the use of web-based research methodologies to improve sample diversity, increase sample sizes, improve generalizability of results, and ultimately enhance rigor in pediatric palliative care research. More work is needed to provide a foundation for the implementation of our intervention to reduce suffering of dying children and their family members, thereby advancing the science of symptom management in vulnerable populations.

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Table 1.

Intervention components and content

Intervention Components	Intervention Content
	1. Getting Started
Individualized structure • Text – child selects guiding legacy questions • Child selects photographs • Child selects music • Children can incorporate various activities and choose to complete content alone or with others (parent, sibling) **Self – who they are** • Child personal characteristics - children invited to answer questions about things that reflect their personal traits/characteristics • Things children like to do - children invited to answer questions about activities they enjoy or favorite memories. **Connectedness with others** • Child's relationships with others – children invited to share about important people in their lives. • Child's desire to express feelings towards others – children invited to give special messages.	- Coordinator emails family electronic tutorial to learn how to use the web-based program - Family creates online account (username and password)
	2. Enter Text/Answer Guiding Legacy Questions
	- Example *guiding legacy questions about self*: • Favorites: Color? Food? Sports team or athlete? Hobbies? TV show or movie? Music? Song or singer? Place to go? • What is your most special personal belonging and why? • Thinking way back to a long time ago, what is your favorite memory? • What is the funniest thing that you've ever done? • What's your most embarrassing moment? • Pretend you wrote a story about yourself. What is the story about? What part of the story would you want other people to remember the most? • What are the most important things you have done, and what do you feel most proud of? What are your goals for the future (e.g., what do you want to be when you grow up?) • Please share what you have done that makes you most happy. • Is there anything else that you would like to include in your story that we have left out? - Example *guiding questions about connectedness with others*: • Who are the important people in your life? (e.g., family, friends) Please share more about him or her. • Who is your hero? How would you describe him/her? • What special messages would you like to give to other people (mom, dad, sibs, grandparents, friends, teachers, other kids who may be sick or in the hospital) • If you could give your family anything, what would it be?
	3. Upload Photographs, Music, Video
	- Upload photographs - Upload music - Upload videos
	4. Finalize
	- Complete digital story - Unique link to final digital storyboard provided to family to keep - Enhanced cinematic feature of final story shared with families to keep

Table 2.

Demographic characteristics of groups ($N = 98$).

Characteristic	Overall (N=98)	Control (N=61)	Experimental (N=37)	*p*-value
Child with Cancer	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	
	N=95	*N=58*		
Age (years)	10.4 (3.0)	10.6 (3.1)	10.1 (3.0)	0.514
	N (%)	**N (%)**	**N (%)**	
Gender				0.826
Male	41 (41.8)	25 (41.0)	16 (43.2)	
Female	57 (58.2)	36 (59.0)	21 (56.8)	
Race	*N=96*	*N=60*	*N=36*	0.058
White	82 (85.4)	52 (86.7)	30 (83.3)	
Black or African American	4 (4.2)	4 (6.7)	0 (0.0)	
Asian	2 (2.1)	2 (3.3)	0 (0.0)	
American Indian or Alaska Native	2 (2.1)	1 (1.7)	1 (2.8)	
Other	6 (6.3)	1 (1.7)	5 (13.9)	
Ethnicity	*N=97*	*N=60*		0.596
Hispanic or Latino	11 (11.3)	6 (10.0)	5 (13.5)	
Not Hispanic or Latino	86 (88.7)	54 (90.0)	32 (86.5)	
Primary Language				0.718
English	96 (98.0)	60 (98.4)	36 (97.3)	
Spanish	2 (2.0)	1 (1.6)	1 (2.7)	
Parent Caregiver				
Relationship to Child				0.668
Biological parent	92 (93.9)	56 (91.8)	36 (97.3)	
Adoptive parent	4 (4.1)	3 (4.9)	1 (2.7)	
Foster parent	1 (1.0)	1 (1.6)	0 (0.0)	
Grandparent	1 (1.0)	1 (1.6)	0 (0.0)	
Gender	*N=96*	*N=60*	*N=36*	0.054
Male	7 (7.3)	2 (3.3)	5 (13.9)	
Female	89 (92.7)	58 (96.7)	31 (86.1)	
Race	*N=96*	*N=60*	*N=36*	0.239
White	89 (92.7)	55 (91.7)	34 (94.4)	
Black or African American	4 (4.2)	4 (6.7)	0 (0.0)	
American Indian or Alaska Native	1 (1.0)	0 (0.0)	1 (2.8)	
Other	2 (2.1)	1 (1.7)	1 (2.8)	
Ethnicity	*N=91*	*N=56*	*N=35*	0.942
Hispanic or Latino	5 (5.5)	3 (5.4)	2 (5.7)	
Not Hispanic or Latino	86 (94.5)	53 (94.6)	33 (94.3)	
Home Region	*N=96*	*N=60*	*N=36*	**0.015**

Characteristic	**Overall (N=98)**	**Control (N=61)**	**Experimental (N=37)**	***p*-value**
Child with Cancer	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	
Northeast	12 (12.5)	10 (16.7)	2 (5.6)	
Southeast	19 (19.8)	17 (28.3)	2 (5.6)	
Middle West	53 (55.2)	26 (43.3)	27 (75.0)	
Southwest	10 (10.4)	6 (10.0)	4 (11.1)	
West	2 (2.1)	1 (1.7)	1 (2.8)	
Primary Language	*N=95*	*N=59*	*N=36*	0.169
English	92 (96.8)	56 (94.9)	36 (100.0)	
Spanish	3 (3.2)	3 (5.1)	0 (0.0)	
Highest Grade Completed	*N=96*	*N=60*	*N=36*	0.558
Grade School (K-8)	1 (1.0)	1 (1.7)	0 (0.0)	
High School (9-12)	27 (28.1)	15 (25.0)	12 (33.3)	
GED	3 (3.1)	1 (1.7)	2 (5.6)	
College (Undergraduate)	53 (55.2)	36 (60.0)	17 (47.2)	
Graduate School	12 (12.5)	7 (11.7)	5 (13.9)	
Current Marital Status	*N=96*	*N=60*	*N=36*	0.230
Never Married	25 (26.0)	13 (21.7)	12 (33.3)	
Married	49 (51.0)	32 (53.3)	17 (47.2)	
Divorced	11 (11.5)	7 (11.7)	4 (11.1)	
Separated	1 (1.0)	0 (0.0)	1 (2.8)	
Widowed	6 (6.3)	6 (10.0)	0 (0.0)	
Other	4 (4.2)	2 (3.3)	2 (5.6)	
Current Annual Family Income	*N=96*	*N=60*	*N=36*	0.342
Under $25,000 per year	42 (43.8)	25 (41.7)	17 (47.2)	
$25,001-$50,000 per year	21 (21.9)	12 (20.0)	9 (25.0)	
$50,001-$75,000 per year	11 (11.5)	7 (11.7)	4 (11.1)	
$75,001-$100,000 per year	11 (11.5)	10 (16.7)	1 (2.8)	
$100,001 or more per year	11 (11.5)	6 (10.0)	5 (13.9)	

Table 3.

Clinical characteristics of groups ($N = 98$).

Characteristic	Overall (N=98)	Control (N=61)	Experimental (N=37)	*p*-value
	N (%)	N (%)	N (%)	
Cancer Relapse or Recurrence				0.631
No	29 (29.6)	17 (27.9)	12 (32.4)	
Yes	69 (70.4)	44 (72.1)	25 (67.6)	
Secondary Cancer				0.266
No	96 (98.0)	59 (96.7)	37 (100.0)	
Yes	2 (2.0)	2 (3.3)	0 (0.0)	
Surgery to Remove Tumor				0.521
No	57 (58.2)	37 (60.7)	20 (54.1)	
Yes	41 (41.8)	24 (39.3)	17 (45.9)	
Chemotherapy				0.292
No	5 (5.1)	2 (3.3)	3 (8.1)	
Yes	93 (94.9)	59 (96.7)	34 (91.9)	
Radiation				0.792
No	28 (28.6)	18 (29.5)	10 (27.0)	
Yes	70 (71.4)	43 (70.5)	27 (73.0)	
Bone Marrow Transplant	*N=97*		*N=36*	0.189
No	83 (85.6)	50 (82.0)	33 (91.7)	
Yes	14 (14.4)	11 (18.0)	3 (8.3)	
Phase I Study				0.329
No	63 (64.3)	37 (60.7)	26 (70.3)	
Yes	14 (14.3)	8 (13.1)	6 (16.2)	
Unsure	21 (21.4)	16 (26.2)	5 (13.5)	
Notified Cancer is Terminal				0.603
No	91 (92.9)	56 (91.8)	35 (94.6)	
Yes	7 (7.1)	5 (8.2)	2 (5.4)	
DNR Order in Place				0.067
No	96 (98.0)	61 (100.0)	35 (94.6)	
Yes	2 (2.0)	0 (0.0)	2 (5.4)	
Hospice				0.692
No	95 (96.9)	59 (96.7)	36 (97.3)	
Yes	2 (2.0)	1 (1.6)	1 (2.7)	
Unknown	1 (1.0)	1 (1.6)	0 (0.0)	
Palliative Care				0.200
No	85 (86.7)	51 (83.6)	34 (91.9)	
Yes	8 (8.2)	5 (8.2)	3 (8.1)	
Unknown	5 (5.1)	5 (8.2)	0 (0.0)	

Table 4.

Counts and Frequencies of Parent Responses to T3 Follow-up Survey (*N* = 81).

Why did you allow your child to participate in our project?	75 (92.6%)
I thought the study results could benefit other families in the future	38 (46.9%)
I wanted a digital storyboard of my child	48 (59.3%)
I thought it would help my child	2 (2.5%)
Other	
Why do you think your child wanted to participate?	55 (67.9%)
He/she wanted to make something to share with someone special	58 (71.6%)
He/she thought it would be a fun activity	11 (13.6%)
Other	
How did your child complete the digital storyboard?	52 (64.2%)
By him/herself	28 (34.6%)
With assistance from someone	1 (1.2%)
Other	
Since your child completed participation in our project, have you OR your child done anything with the digital storyboard?	56 (70.0%) 41 (51.3%)
We have watched the video again	13 (16.3%)
We gave the video to someone special	8 (10.0%)
We have never watched the video again	
Other	
How was/is the digital storyboard helpful to you?	50 (63.3%)
Provides me emotional comfort	36 (45.6%)
Is a coping strategy for me	57 (72.2%)
The process facilitated communication between me and my child	4 (5.1%)
Other	4 (5.1%)
The digital storyboard was not helpful to me	
How was/is the digital storyboard helpful to your child	70 (86.4%)
Helped him/her express their feelings	20 (24.7%)
Helped my child feel better physically	48 (59.3%)
Helped my child feel better emotionally	34 (42.0%)
Helped my child feel better socially	31 (38.3%)
Helped my child feel better spiritually	40 (49.4%)
Helped him/her cope	5 (6.2%)
Other	3 (3.7%)
The digital storyboard was not helpful to my child.	0 (0.0%)
Made me feel sad	1 (1.2%)
Made my child feel sad	2 (2.5%)
Other	