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To cite this article: Terrah Foster Akard , Mary S. Dietrich , Debra L. Friedman , Cynthia A. Gerhardt , Barbara Given , Verna Hendricks-Ferguson , Pamela S. Hinds , Sheila H. Ridner , Nicole Beckmann & Mary Jo Gilmer (2020): Improved parent–child communication following a RCT evaluating a legacy intervention for children with advanced cancer, Progress in Palliative Care, DOI: [10.1080/09699260.2020.1826778](https://doi.org/10.1080/09699260.2020.1826778)

To link to this article: <https://doi.org/10.1080/09699260.2020.1826778>



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Published online: 20 Oct 2020.



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# Improved parent–child communication following a RCT evaluating a legacy intervention for children with advanced cancer

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Although legacy-building is a priority for quality palliative care, research has rarely examined effects of legacy interventions in children, particularly their impact on parent–child communication. We examined the impact of a web-based legacy intervention on parent–child communication. Facebook advertisements were used to recruit families of children (ages 7–17) with relapsed/refractory cancer. Parent–child dyads were randomly assigned to the intervention or usual care group. The intervention website guided children to create digital storyboards over 2 weeks by directing them to answer legacy questions about themselves and upload photographs, videos, and music. Families received a copy of the child's final digital story. Children and parents completed the Parent–Adolescent Communication Scale pre- (T1) and post-intervention (T2). Linear regressions tested for differences in change from T1 to T2 between the groups controlling for T1 values using an alpha of  $P < 0.05$ . Intervention effects were measured using Cohen's  $d$ . Ninety-seven parent–child dyads were included for analysis. Changes in parent–child communication were not statistically significantly different between the groups, yet meaningful intervention effects were observed. The strongest effects were observed for improving father–child communication (Cohen's  $d = -0.22-0.33$ ). Legacy-making shows promise to facilitate improved parent–child communication, particularly for fathers. Clinical Trials Registry: Number NCT04059393.

**Keywords:** Parent–child relationship, Father–child relationship, Family relationships, Parent–child communication, Web-based intervention, Pediatric, Palliative care, Cancer

## Introduction

Approximately 15,800 children ages 0–19 years are newly diagnosed with cancer each year in the United States.<sup>1</sup> Despite survival rates exceeding 80%,<sup>1</sup> the burden of cancer and its treatment for children and their caregivers is substantial.<sup>2–9</sup> Despite evidence supporting the value and feasibility of ill children being able to self-report on their cancer-related symptoms and experience,<sup>10</sup> research has shown that parents may avoid cancer-related discussions with their child and do not seek children's input about treatment options to

protect their child from additional distress.<sup>11,12</sup> The avoidance occurs even though parents and their ill child may spend more time together due to frequent appointments and hospitalizations, providing opportunities for discussion of physical and emotional effects from treatment and very difficult topics related to the worry about their child's mortality.<sup>13</sup> Some parents have described engaging in more intimate communication and purposefully maintaining an open relationship with their child after diagnosis.<sup>13</sup>

The quality of parent–child communication following relapse may predict children's adjustment over time.<sup>14</sup> Higher openness and fewer problems in

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communication between children and their parents have predicted lower withdrawn/depression scores for children with advanced cancer.<sup>14</sup> Communication quality between children and their parents near the time of relapse has also been found to strongly predict future adjustment a year later for children with advanced cancer. A commonly reported barrier to parent–child communication involves avoiding conversations about making necessary healthcare decisions as the child’s health declines near the end of life.<sup>15,16</sup> Parents often feel responsible for choosing how and when to disclose potentially upsetting information in an attempt to protect their child from emotional distress.<sup>13</sup> However, some parents have described increased openness in communication when the child’s diagnosis is definitively terminal.<sup>15</sup>

Although parents may initiate communication about their child’s cancer and prognosis, children often use avoidance or adjust their communication with others, particularly about their prognosis, to minimize parental sadness.<sup>17–19</sup> Children may outwardly mask physical symptoms of illness or emotional distress by portraying a positive and cheerful mood.<sup>18</sup> Some parents have described children openly sharing plans for the future, even when children recognize such plans are unlikely to occur.<sup>15</sup> Expressiveness in communication is important to adaptation, but both parents and their children recognize barriers to communication and a strong desire to protect each other against emotional distress.

Legacy-making (i.e. actions or behaviors aimed at being remembered<sup>20</sup>) is a palliative care intervention to improve communication outcomes for children with serious illnesses and their families. Legacy-making has been explored in both adult and pediatric populations.<sup>20–32</sup> Legacy-making in adults has been shown to increase patients’ sense of dignity, purpose, meaning, and will to live, while decreasing suffering and depressive symptoms.<sup>22,28,32</sup> In our previous work, hospital staff and parents reported that legacy-making improved quality of life (QOL), communication, and coping among children with cancer (ages 7–17).<sup>21,24</sup> Research has rarely examined effects of legacy-making on parent–child communication outcomes, and randomized controlled trials in this area are particularly lacking. Thus, this paper examines the impact of a web-based legacy intervention on parent–child communication among children with relapsed or refractory cancer. We hypothesized that compared to customary care, legacy-making would improve the quality of communication between children and their parents from pre- to post-intervention.

## Methods

### *Conceptual approach*

We developed the conceptual framework based on synthesis of components from existing theories and

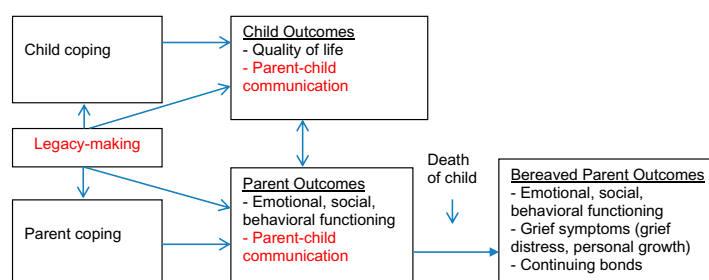
evidence<sup>22,25,33</sup> to guide the proposed study (see Fig. 1). Briefly, this conceptual framework provided a basis for examining the direct effects of our legacy intervention on the quality of communication between children living with refractory or relapsed cancer and their parent caregivers. This paper reports results related to the study outcome of parent–child communication.

### *Procedures*

This single-site research was part of a larger randomized clinical trial examining the effects of a legacy intervention on child and parent outcomes. Institutional review board approval was obtained prior to participant enrollment using Facebook advertisements. Because Facebook users must be at least 13 years of age to have an account, our advertisements targeted parents of children with cancer. Advertisements were placed on Facebook over 3 years, targeting parents who (a) were 18 years of age or older; (b) were located in the United States; (c) were any gender; and (d) had interest in pediatric oncology (liked other Facebook pages related to childhood cancer, cure childhood cancer, etc.). Parents could click on an electronic REDCap link in the Facebook ad that briefly described the study and included initial screening questions. Potentially eligible parents were then asked to complete basic demographic questions, including their names and contact information to receive more details about the study. The study coordinator contacted interested parents via phone or email within 1 week to describe the study and confirm eligibility. Eligible participants were (a) children 7–17 years of age, (b) children with relapsed or refractory cancer determined by parent self-report, (c) able to speak, understand, read, and type English, (d) those with internet access, and (e) without cognitive impairment as determined by the coordinator during the consent process. Primary parent caregivers included the legal parent guardian who spent the most number of hours per week with the eligible child. For all eligible child–parent dyads, the coordinator obtained verbal parent consent and child assent and confirmed contact information to send study documents.

### *Legacy intervention*

Upon consent, child and parent dyads were randomly assigned to either the web-based intervention ( $n = 75$ ) or usual care ( $n = 75$ ) group by using a computer-generated randomization approach with a permuted block scheme. The coordinator emailed an electronic link to an intervention website to families in the *intervention group* within 1 week after children and parents completed baseline (T1) measures. Detailed description of the legacy intervention is presented in another



**Figure 1 Conceptual framework (red font notes outcomes reported in this paper).**

article.<sup>34</sup> In brief, each child–parent dyad created a username and password for the website. The website guided children to create a personal digital storyboard by directing them to: (a) *answer legacy-making questions*, (b) *upload photographs*, (c) *upload video*, and (d) *upload music*. Children were asked to complete the intervention within 2 weeks. When children completed the storyboard, the website generated a unique electronic link that the coordinator emailed to the child or parent. The *control group* received usual care. The intervention was offered to children in the control group after each child–parent dyad completed T2 measures.

### Data collection

Data collection occurred over three years (2015–2018). Participants in the intervention group completed T1 baseline and T2 post-intervention questionnaires related to parent–child communication, child quality of life, and child and parent coping outcomes. The median time between T1 and T2 was 69 days (range 7–176) for the children, and 68 days (range 7–176) for parents. At the end of the study, parents were asked to complete a T3 concluding survey about the intervention process, including what they liked and did not like (Akard et al.<sup>34</sup>). Participants completed all the study measures electronically online via REDCap, a secure web-based application for building and managing online surveys and databases. The study coordinator conducted reminder calls or sent reminder emails to enrolled participants for any surveys that were not completed within 1 week. This paper presents T1 and T2 quantitative data related to parent–child communication. The length of time to complete T1 and T2 child assessments was approximately 30 minutes.

### Measurement tools

Parents completed a background survey to report child and parent demographic characteristics and child clinical characteristics. Children and parents completed the Parent–Adolescent Communication Scale (PACS) to assess parent–child communication.<sup>35</sup> Children completed 20 items about communication in relation to each parent (mother and father), and parents answered 20 items about communication

with their ill child. Although child and parent participants were asked to self-report independently, younger children may have received parent assistance to complete the measure electronically. Responses were rated on a 5-point Likert scale from ‘strongly disagree’ to ‘strongly agree’. Summary scores reflect open communication, problems in communication, and overall communication. Higher scores for open and overall communication, and lower scores for problems in communication, reflect better quality of parent–child communication. The internal consistency of the scores used in this study ranged from 0.67 to 0.80 for the parental scales and 0.73–0.92 for the child scales.

### Analysis

Data analyses were conducted using IBM SPSS Statistics (Version 25). Frequency distributions were generated for summarizing the nominal and ordinal variables. Means and standard deviations were used to summarize the normally distributed continuous variables; medians and inter-quartile ranges (IQR) described the skewed distributions. Independent sample *t*-tests and Chi-Square Tests of Independence were conducted to compare the demographic and clinical characteristics of the participants in the two study data analysis groups. Comparisons between the study groups in the amount of change in each of the study outcome variables from baseline were conducted using generalized linear models that included the respective baseline scores as a covariate. Cohen’s *d* statistics quantifying the effect of the intervention on PACS outcome variables were generated by transforming the regression coefficient for the group effect after controlling for the baseline value. Interpretations of statistical significance maintained a maximum alpha of 0.05 ( $P < 0.05$ ). Given that effect sizes were generated and presented, no adjustment for multiple outcomes to the critical alpha level was made.

### Results

Two hundred seventy-three child–parent dyads were screened for eligibility (see Consort Diagram Fig. 2). Of those, 150 dyads (55%) were deemed eligible and enrolled in the study. Forty-two (28%) dyads dropped out, including deaths, prior to completing

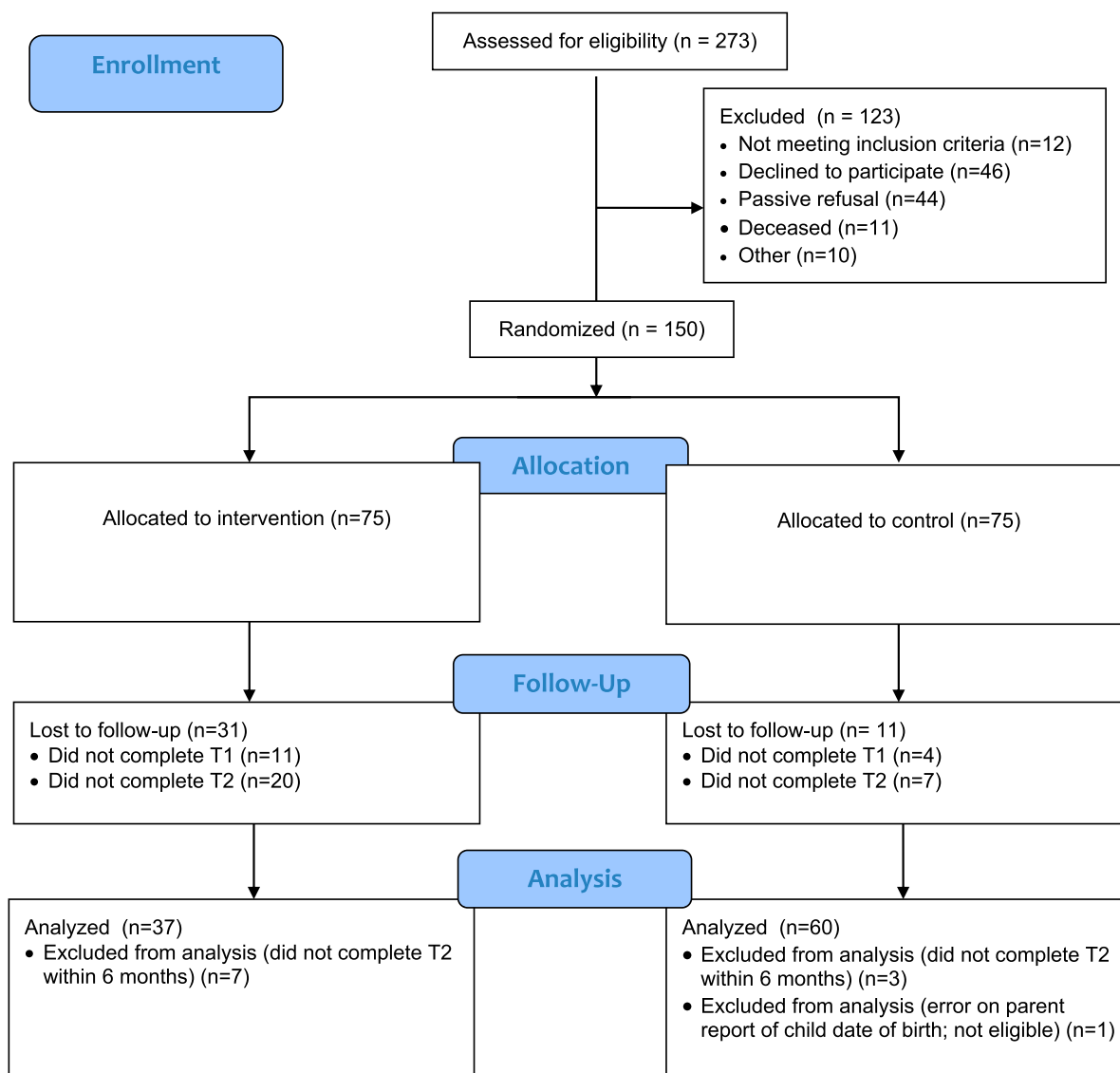


Figure 2 CONSORT flow diagram.

T2 (control = 31, experimental = 11). Ten (7%) completed T2 more than 6 months after enrollment (control = 7, experimental = 3). One additional dyad in the control group was excluded from analysis after noting a discrepancy during analysis on parent report of child age compared to date of birth, making the child participant ineligible. Therefore, 97 dyads were included in analyses. Summaries of the demographic and clinical characteristics of those completing the study and those excluded have been previously published.<sup>34</sup> Region of the country and marital status were the only statistically significant differences observed ( $P < 0.05$ ).

Other than home region, no statistically significant differences in demographic or clinical characteristics were observed between the groups (experimental versus control group) of participants who completed the study (see Tables 1 and 2). The sample of 97 ill children averaged 10 years of age. The majority were female ( $n = 57, 59%$ ) and Caucasian ( $n = 81, 85%$ ). Most had

experienced a cancer relapse ( $n = 69, 71%$ ). Few had (a) been notified that their cancer was terminal ( $n = 7, 7%$ ), (b) a DNR in place ( $n = 2, 2%$ ), (c) received a hospice referral ( $n = 2, 2%$ ), or (d) received a palliative care consult ( $n = 7, 7%$ ). The majority of caregivers were biological parents ( $n = 91, 94%$ ), female ( $n = 88, 93%$ ), Caucasian ( $n = 88, 93%$ ), living in the Midwest ( $n = 53, 56%$ ), married ( $n = 49, 52%$ ), and college educated ( $n = 64, 67%$ ), and had an annual family income of  $> \$25,000$  ( $n = 53, 56%$ ) (see Tables 1 and 2).

Descriptive summaries of the PACS scores at baseline (T1) and changes in those scores between T1 and end of study (T2) are shown in Table 3. Communication scores were generally moderate to good at baseline with no statistically significant differences between the groups reported at T1. As reported by the child, communication was generally better with mother than with father (Table 3). Tests of differences between the groups in the amount of change from T1 to T2 (after controlling for T1 scores) revealed no

**Table 1** Demographic characteristics by study group (N = 97)

Characteristic	Overall (N = 97)	Control (n = 60)	Experimental (n = 37)	P-value
Child with Cancer	Mean (SD) N = 94	Mean (SD) n = 57	Mean (SD)	
Age (years)	10.4 (3.0) N (%)	10.6 (3.0) N (%)	10.1 (3.0) N (%)	0.435
Gender				0.753
Male	40 (41.2)	24 (40.0)	16 (43.2)	
Female	57 (58.8)	36 (60.0)	21 (56.8)	
Race	N = 95	N = 59	N = 36	0.059
White	81 (85.3)	51 (86.4)	30 (83.3)	
Black or African American	4 (4.2)	4 (6.8)	0 (0.0)	
Asian	2 (2.1)	2 (3.4)	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 = 96	N = 59		0.617
Hispanic or Latino	11 (11.5)	6 (10.2)	5 (13.5)	
Not Hispanic or Latino	85 (88.5)	53 (89.8)	32 (86.5)	
Primary Language				0.727
English	95 (97.9)	59 (98.3)	36 (97.3)	
Spanish	2 (2.1)	1 (1.7)	1 (2.7)	
Caregiver				
Relationship to Child				0.659
Biological parent	91 (93.8)	55 (91.7)	36 (97.3)	
Adoptive parent	4 (4.1)	3 (5.0)	1 (2.7)	
Foster parent	1 (1.0)	1 (1.7)	0 (0.0)	
Grandparent	1 (1.0)	1 (1.7)	0 (0.0)	
Gender	N = 95	N = 59	N = 36	0.057
Male	7 (7.4)	2 (3.4)	5 (13.9)	
Female	88 (92.6)	57 (96.6)	31 (86.1)	
Race	N = 95	N = 59	N = 36	0.238
White	88 (92.6)	54 (91.5)	34 (94.4)	
Black or African American	4 (4.2)	4 (6.8)	0 (0.0)	
American Indian or Alaska Native	1 (1.1)	0 (0.0)	1 (2.8)	
Other	2 (2.1)	1 (1.7)	1 (2.8)	
Ethnicity	N = 90	N = 55	N = 35	0.958
Hispanic or Latino	5 (5.6)	3 (5.5)	2 (5.7)	
Not Hispanic or Latino	85 (94.4)	52 (94.3)	33 (94.3)	
Home Region	N = 95	N = 59	N = 36	0.019
Northeast	12 (12.6)	10 (16.9)	2 (5.6)	
Southeast	18 (18.9)	16 (27.1) <sup>a</sup>	2 (5.6) <sup>b</sup>	
Middle West	53 (55.8)	26 (44.1) <sup>a</sup>	27 (75.0) <sup>b</sup>	
Southwest	10 (10.5)	6 (10.2)	4 (11.1)	
West	2 (2.1)	1 (1.7)	1 (2.8)	
Primary Language	N = 94	N = 58	N = 36	0.165
English	91 (96.8)	55 (94.8)	36 (100.0)	
Spanish	3 (3.2)	3 (5.2)	0 (0.0)	
Highest Grade Completed	N = 95	N = 59	N = 36	0.587
Grade School (K-8)	1 (1.1)	1 (1.7)	0 (0.0)	
High School (9–12)	27 (28.8)	15 (25.4)	12 (33.3)	
GED	3 (3.2)	1 (1.7)	2 (5.6)	
College (Undergraduate)	52 (54.7)	35 (59.3)	17 (47.2)	
Graduate School	12 (12.6)	7 (11.9)	5 (13.9)	
Current Marital Status	N = 95	N = 59	N = 36	0.201
Never Married	24 (25.3)	12 (20.3)	12 (33.3)	
Married	49 (51.6)	32 (54.2)	17 (47.2)	
Divorced	11 (11.6)	7 (11.9)	4 (11.1)	
Separated	1 (1.1)	0 (0.0)	1 (2.8)	
Widowed	6 (6.3)	6 (10.2)	0 (0.0)	
Other	4 (4.2)	2 (3.4)	2 (5.6)	
Current Annual Family Income	N = 95	N = 59	N = 36	0.319
Under \$25 000 per year	42 (44.2)	25 (42.4)	17 (47.2)	
\$25 001–\$50 000 per year	20 (21.1)	11 (18.6)	9 (25.0)	
\$50 001–\$75 000 per year	11 (11.6)	7 (11.9)	4 (11.1)	
\$75 001–\$100 000 per year	11 (11.6)	10 (16.9)	1 (2.8)	
\$100 001 or more per year	11 (11.6)	6 (10.2)	5 (13.9)	

statistically significant differences ( $P > 0.05$ , Cohen's  $d$  ranged from  $-0.20$  to  $0.33$ ). The strongest effects were observed for improving open communication (child report related to father:  $d = 0.33$ ; parent report:  $d =$

$0.21$ ), decreasing child report of problems with mother ( $d = -0.20$ ), and overall communication (child report related to father:  $d = 0.20$ ; parent report:  $d = 0.25$ ) (Table 3).



**Table 2 Clinical characteristics by study group (N = 97)**

Characteristic	Overall (N = 97)	Control (N = 60)	Experimental (N = 37)	P-value
	N (%)	N (%)	N (%)	
Advanced Cancer Type				0.543
Refractory disease	28 (28.9)	16 (26.7)	12 (32.4)	
Relapsed	69 (71.1)	44 (73.3)	25 (67.6)	
	Median (IQR)	Median (IQR)	Median (IQR)	
If relapsed, months since	8.6 (3.7, 19.4)	8.7 (4.5, 14.0)	8.1 (3.3, 19.6)	0.694
Time (years since first cancer diagnosis)	4.1 (2.2, 6.0)	3.9 (2.3, 6.2)	4.2 (1.8, 5.3)	0.891
	N (%)	N (%)	N (%)	
Type of cancer	N = 94	N = 59	N = 35	0.063
Hematologic	47 (50.0)	31 (52.5)	16 (45.7)	
Solid tumor	28 (29.8)	13 (22.0)	15 (42.9)	
Central Nervous System	19 (20.2)	15 (25.5)	4 (11.4)	
Secondary Cancer				0.262
No	95 (97.9)	58 (96.7)	37 (100.0)	
Yes	2 (2.1)	2 (3.3)	0 (0.0)	
Surgery to Remove Tumor				0.565
No	56 (57.7)	36 (60.0)	20 (54.1)	
Yes	41 (42.3)	24 (40.0)	17 (45.9)	
Chemotherapy				0.302
No	5 (5.2)	2 (3.3)	3 (8.1)	
Yes	92 (94.8)	58 (96.7)	34 (91.9)	
Radiation				0.754
No	28 (28.9)	18 (30.0)	10 (27.0)	
Yes	69 (71.1)	42 (70.0)	27 (73.0)	
Bone Marrow Transplant	N = 96		N = 36	0.248
No	83 (86.5)	50 (83.3)	33 (91.7)	
Yes	13 (13.5)	10 (16.7)	3 (8.3)	
Phase I Study				0.395
No	63 (64.9)	37 (61.7)	26 (70.3)	
Yes	14 (14.4)	8 (13.3)	6 (16.2)	
Unsure	20 (20.6)	15 (25.0)	5 (13.5)	
Notified Cancer is Terminal				0.588
No	90 (92.8)	55 (91.7)	35 (94.6)	
Yes	7 (7.2)	5 (8.3)	2 (5.4)	
DNR Order in Place				0.069
No	95 (97.9)	60 (100.0)	35 (94.6)	
Yes	2 (2.1)	0 (0.0)	2 (5.4)	
Hospice				0.692
No	94 (96.9)	58 (96.7)	36 (97.3)	
Yes	2 (2.1)	1 (1.7)	1 (2.7)	
Unknown	1 (1.0)	1 (1.7)	0 (0.0)	
Palliative Care				0.195
No	85 (87.6)	51 (85.0)	34 (91.9)	
Yes	7 (7.2)	4 (6.7)	3 (8.1)	
Unknown	5 (5.2)	5 (8.3)	0 (0.0)	

## Discussion

This study is the first of its kind to examine changes in parent–child communication following a web-based legacy intervention for children with advanced cancer. Using a two-group (legacy intervention versus usual care) randomized design, we examined the effects of the intervention on the quality of communication between children with relapsed or refractory cancer and their parents. Compared to usual care, legacy-making showed trends for improving the quality of communication between children and their parents across time, especially father–child communication.

Results revealed positive trends in intervention effects on the quality of communication between children and fathers but not for the mothers. This difference could be due to low quality father–child communication in the presence of advanced pediatric

cancer at baseline. Studies have shown that fathers may not be adequately equipped to communicate well with children. For example, fathers of children whose mothers were diagnosed with breast cancer have been shown to sometimes misinterpret children's distress as 'bad behavior' and benefit from more information about the relationship between their spouse's illness and how children may react emotionally.<sup>36</sup> Although fathers are typically involved in the day-to-day care of children with life-threatening conditions, fathers' perspectives are often not sought or only measured via mother proxy-reports due to recruitment and retention challenges.<sup>37</sup> For example, our study sample of primary parent caregivers included 7.3% fathers. Fathers have offered rich and unique insights in pediatric oncology studies.<sup>25,38,39</sup> Although the American Academy of Pediatrics emphasizes fathers' perspectives as critical components in the care of

**Table 3** Summaries of change in communication scores from baseline (T1) to study end (T2)

Measure	Baseline Median [IQR]	Change Median [IQR]	P-value	Effect size*
<b>PACS (child reports)</b>				
Open communication with mother			0.623	−0.09
Control ( <i>n</i> = 57)	4.3 [3, 5]	0.1 [−0.3, 0.2]		
Intervention ( <i>n</i> = 32)	4.2 [4, 5]	0.0 [−0.1, 0.2]		
Problems in communication with mother			0.341	−0.20
Control ( <i>n</i> = 57)	2.5 [2, 3]	0.0 [−0.3, 0.5]		
Intervention ( <i>n</i> = 32)	2.6 [2, 3]	−0.1 [−0.4, 0.2]		
Overall communication with mother			0.637	0.10
Control ( <i>n</i> = 57)	3.9 [3, 5]	−0.1 [−0.3, 0.3]		
Intervention ( <i>n</i> = 32)	3.8 [3, 5]	0.1 [−0.1, 0.2]		
Open communication with father			0.248	0.33
Control ( <i>n</i> = 27)	4.0 [3, 5]	−0.1 [−0.6, 0.4]		
Intervention ( <i>n</i> = 17)	3.7 [3, 5]	0.2 [−0.2, 0.4]		
Problems in communication with father			0.877	0.05
Control ( <i>n</i> = 27)	3.0 [2, 4]	0.0 [−0.4, 0.4]		
Intervention ( <i>n</i> = 17)	2.1 [2, 4]	−0.1 [−0.3, 0.5]		
Overall communication with father			0.502	0.20
Control ( <i>n</i> = 27)	3.5 [3, 4]	0.1 [−0.4, 0.3]		
Intervention ( <i>n</i> = 17)	3.7 [3, 4]	0.1 [−0.4, 0.5]		
<b>PACS (parent reports)</b>				
Open communication with child			0.260	0.21
Control ( <i>n</i> = 60)	3.9 [3, 5]	0.0 [−0.3, 0.3]		
Intervention ( <i>n</i> = 37)	3.9 [3, 5]	0.0 [−0.2, 0.3]		
Problems in communication with child			0.372	−0.18
Control ( <i>n</i> = 60)	2.7 [2, 3]	0.1 [−0.1, 0.4]		
Intervention ( <i>n</i> = 37)	2.6 [2, 3]	0.0 [−0.2, 0.2]		
Overall communication with child			0.201	0.25
Control ( <i>n</i> = 60)	3.6 [3, 4]	−0.1 [−0.3, 0.2]		
Intervention ( <i>n</i> = 37)	3.6 [3, 4]	0.0 [−0.1, 0.2]		

\*Cohen's *d* estimate transformed from regression coefficient, after controlling for baseline values.

seriously-ill children,<sup>40</sup> pediatric oncology research that includes fathers' reports remains lacking.

Although PACS results lacked statistically significant intervention effects for changes in parent–child communication between T1 and T2 and displayed only small to moderate effect sizes, additional qualitative data collected post-intervention suggested different intervention effects. In the T3 concluding survey, 72% (*n* = 57) of parents reported that the intervention improved parent–child communication, and 86% (*n* = 70) reported that the intervention improved children's expression of feelings.<sup>34</sup> Such findings highlighted the potential for legacy interventions to facilitate opportunities to acknowledge and document the 'child's voice' within parent–child communication during palliative and end-of-life care.<sup>10</sup> The contrast in quantitative and qualitative data was also seen in our pilot study.<sup>21</sup> These results could be due in part to the PACS not being sensitive to intervention effects related to communication. Rather than quality of communication, the intervention may influence other components of parent–child interactions, such as parenting, relationships between family members, or family environment, such as adaptability or cohesion.

Demographic results of our study are important to note. Although few children with cancer and their parents oppose palliative care services,<sup>41</sup> only 8.2%

of children with advanced cancer in our sample were receiving palliative care services at the point of relapse or refractory cancer. It's possible that families with little access to palliative care services, or those who have not yet been referred to palliative care, may be more likely to respond to Facebook recruitment and participate in web-based activities. Our intervention appeared to especially attract White, highly educated families living in the Midwest. Researchers can use this knowledge about potential participants, who may be attracted to such interventions, to guide future studies.

### Limitations

We acknowledge that study results only generalize to children with advanced cancer and their parents. Participants reflected a volunteer sample, including only those with access to Facebook. Parents included 92.7% mothers and 7.3% fathers, thus, parent reports are likely biased towards mothers' perceptions. A major study limitation was the significant attrition in the intervention group (41%) compared to usual care (15%). As discussed in more detail in our previous publication,<sup>34</sup> this participant drop-out likely somewhat reflects intervention feasibility issues (e.g. user-friendliness of the website) experienced early in the study that were later resolved. However, greater drop out at T1 was also seen for participants allocated to



the intervention group (15%) compared to the control group (5%). Differences in demographic and clinical characteristics by sample status could explain this in part.<sup>34</sup> For example, a higher percent of participants who dropped out of the study had a child with a bone marrow transplant (35%) compared to 14% of participants who completed the study ( $P=0.007$ ). Further, the intervention allowed children to complete the activity alone or with assistance from others. Parents reported that more than half (62%) of children completed the activity alone; thus, the lack of structured parent–child interaction during the intervention could have decreased potential effects on parent–child communication.

### *Implications for research and practice*

Future pediatric palliative care studies will benefit from considering fathers as important participants to enroll. Web-based legacy interventions may be a good strategy to facilitate improved father–child communication, thus future studies should include fathers as participants and specific recruitment strategies to enroll and retain fathers. In addition to the quality of parent–child communication, family relationships and cohesion may be important outcome variables for researchers to consider when testing interventions that include parent–child dyads. Observational methods may be an alternative strategy to measure parent–child communication. Secondary analyses from our data will examine potential correlations among demographic characteristics (e.g. child age and gender) and parent–child communication.

Providers should remain ever mindful that differences may exist in the quality of communication between children with cancer and their mothers compared to fathers. Nurses are ideally positioned to help identify families who may be at risk for poor quality of communication. Development of a family communication assessment tool and formal integration of such an assessment into nursing practice would provide a standardized mechanism for such identification to occur. Creation of family communication aids designed to facilitate communication, especially between fathers and children, is indicated. Nurses can also help guide families with communication challenges to appropriate resources or referrals when needed.

### **Conclusion**

Children with advanced cancer receiving standard treatments are at a high risk of receiving limited communication about elements of palliative and end-of-life care support from their providers and parents.<sup>42</sup> Future research is needed to better understand how family-based legacy activities may impact parent–child communication patterns and preferences to

develop interventions to assist parents in initiating open and clear discussions with their child with cancer. Such research would help provide a strong foundation for future development of standardized guidelines for parents related to parent–child communication patterns during a child’s cancer care.

### **Acknowledgements**

We thank the children and parents who generously participated in this study. We acknowledge Sodium Halogen for their design and hosting of the intervention website and Paramore Digital for assisting in Facebook advertising.

### **Disclaimer statements**

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**Funding** This work was supported by the National Institute of Nursing Research under grant number 1R01NR015353; and the NIH/National Center for Advancing Translational Sciences under grant number UL1 TR000445. This project collaborated with the Palliative Care Research Cooperative Group, supported by the National Institute of Nursing Research under grant number U24NR014637.

**Conflicts of interest** None.

**Ethics approval** None.

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