


# Establishing Feasibility of Early Palliative Care Consultation in Pediatric Hematopoietic Stem Cell Transplantation

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**Deborah A. Lafond, DNP, PPCNP-BC, CPON, CHPPN<sup>1</sup>,  
Katherine Patterson Kelly, PhD, RN<sup>2</sup>, Pamela S. Hinds, PhD, RN, FAAN<sup>2</sup>,  
Ann Sill, BS, MSHS<sup>1</sup>, and Michele Michael, PhD, CRNP, RN<sup>3</sup>**

## Abstract

Children and adolescents undergoing hematopoietic stem cell transplantation (HSCT) encounter a number of distressing physical symptoms and existential distress but may not be afforded timely access to palliative care services to help ameliorate the distress. This feasibility study investigated the acceptability and outcomes of early palliative care consultation to promote comfort in this population. A longitudinal, descriptive cohort design examined both provider willingness to refer and willingness of families to receive palliative care interventions as well as satisfaction. Feasibility was demonstrated by 100% referral of eligible patients and 100% of patient and family recruitment (N = 12). Each family received 1 to 3 visits per week (ranging from 15 to 120 minutes) from the palliative care team. Interventions included supportive care counseling and integrative therapies. Families and providers reported high satisfaction with the nurse-led palliative care consultation. Outcomes included improvement or no significant change in comfort across the trajectory of HSCT, from the child and parental perspective. Early integration of palliative care in HSCT is feasible and acceptable to families and clinicians.

## Keywords

pediatric palliative care, stem cell transplant, comfort, patient- and parent-reported outcomes, satisfaction, translation, evidence-based practice

Children and adolescents undergoing hematopoietic stem cell transplantation (HSCT) encounter a number of distressing physical symptoms and existential distress but may not be afforded timely access to palliative care services to help ameliorate their distress (Foster, Lafond, Reggio, & Hinds, 2010; Johnson et al., 2008). Care in the pediatric HSCT setting could be improved by adopting a palliative care holistic perspective that extends beyond treating physical symptom distress and symptom intensity to helping these seriously ill children and adolescents transcend the distress and intensity of HSCT. Early integration of palliative care into the HSCT care trajectory could function in this way. This study evaluated the feasibility and outcomes of early palliative care consultation for children and adolescents with high-risk or advanced cancers and other potentially life-limiting nonmalignant diseases undergoing HSCT.

## Background

The comfort needs of children or adolescents with advanced life-limiting cancers or other nonmalignant diseases stem

from physical, psychospiritual, environmental, and socio-cultural symptoms that manifest by unique diagnosis and stage. The most common symptoms in children with advanced cancer include pain, fatigue, dyspnea, nausea/vomiting, anxiety, weight loss/cachexia, fever, sore throat, alopecia, drowsiness, bruising, pain, and infections (Baggott, Dodd, Kennedy, Marina, & Miaskowski, 2009; Hinds, Quargnenti, & Wentz, 1992; Cohen & Maruice, 2010; Hongo et al., 2003; Houlahan, Branowicki, Mack, Dinning, & McCabe, 2006; Pritchard et al., 2009; Ullrich et al., 2010; Walker, Gedaly-Duff, Miaskowski, & Nail, 2010; Woodgate, Degner, & Yanofsky, 2003). Parents reported

<sup>1</sup>Children's National Health System, Washington, DC, USA

<sup>2</sup>Department of Nursing Research and Quality Outcomes, Children's National Health System, Washington, DC, USA

<sup>3</sup>University of Maryland School of Nursing, Baltimore, MD, USA

## Corresponding Author:

Deborah Lafond, DNP, Children's National Health Systems, PANDA Palliative Care Team, Department of Hospitalist Medicine, 111 Michigan Avenue, NW, Washington, DC 20010, USA.  
Email: dlafond@childrensnational.org

“suffering” in their seriously ill child secondary to these symptoms and say that interventions were not available or adequate to relieve the related symptom distress (Wolfe et al., 2000). The presence or absence of symptoms does not determine existential distress; what is a minor inconvenience to one child or family may be a profound source of existential distress to another (Pritchard et al., 2010).

Acute and chronic graft versus host disease (GVHD) accounts for the most commonly reported symptoms in HSCT. Symptoms of GVHD include rash, cramp-like abdominal pain, diarrhea, persistent nausea/vomiting, and hepatitis (Jacobsohn, 2008). Other commonly experienced symptoms or conditions during HSCT include pain, mucositis, infection, pancytopenia, fluid imbalance, veno-occlusive disease, pulmonary hypertension, and alterations in nutrition (Gassas et al., 2011; Maltezou et al., 2000; Rawlinson et al., 2011; Reggio, 2011). Symptom distress interferes with the ability of the affected child or adolescent to perform activities of daily living, including school, play, and peer activities, which in turn adversely affects health-related quality of life (HRQOL) (Barrera & Atenafu, 2008; Roeland et al., 2010).

Burdens of treatment include toxicities and related monitoring required during HSCT, the actual symptom experience, and family efforts to address distress secondary to these cancer experiences. This burden can negatively affect the patient’s health related quality of life (HRQOL) and parental/patient decision making about proceeding with HSCT (Roddenberry & Renk, 2008). Parents and children often report different degrees of distress for the burdens of treatment, including symptom distress and quality of life (Chambers, Reid, Craig, McGrath, & Finlay, 1998; Chang et al., 2012). Children with cancer often report their quality of life to be quite good, while parents may view the burdens of treatment as indicators of decreased quality of life (Fortier et al., 2013). Prior to transplant, consideration must be made of the additional burdens of treatment toxicity and continued adaptive functioning needs of these children (Gassas et al., 2011). Fortunately, both symptom distress and HRQOL can improve with integration of palliative care (Wolfe et al., 2008).

Children and their families experience suffering in a variety of ways (physical, social, emotional, existential, and/or spiritual) and in varying degrees during the trajectory of a serious, life-limiting illness. Existential distress is suffering that affects the integrity of the person, integrating into every domain of human existence, affecting quality of life and activities of daily living (Cassell, 1999). Providing palliative care for children undergoing HSCT and their families is one way to eliminate suffering by promoting comfort and ameliorating symptom and existential distress (Mayer et al., 2009; O’Neill & Mako, 2011).

Palliative care seeks to “prevent, relieve, reduce, or soothe the symptoms produced by serious medical conditions or their treatment and to maintain patients’ quality of life” (Field & Behrman, 2003, p. 33). The primary focus of palliative care is to ease the burden by providing holistic interventions that promote comfort by relief, ease, and transcendence of the illness experience (American Academy of Pediatrics AAP Committee on Bioethics, 2000).

Data are lacking regarding the impact on quality of life and overall long-term distress for children with advanced cancers or nonmalignant diseases who undergo HSCT. Improvement in these areas through early integration of palliative care services may provide patients, parents, and the health care team with strategies to promote transcendent comfort throughout the HSCT experience, whether the outcome leads to cure or to death. In this study, *transcendent comfort* was conceptually defined as a state of ease and well-being influenced by the caring and actions of nursing, which lead to transcendence of the circumstances of symptom distress, functional status, and quality of life to promote a sense of well-being despite the circumstances of HSCT.

The primary aim of this study was to establish the feasibility of integrating palliative care early in the trajectory of HSCT (at the time of referral or admission to the HSCT program) and to measure the outcomes of such care including the easing symptom distress and provision of additional supportive quality-of-life care for patients and families to promote transcendent comfort in the HSCT experience. Secondary study aims included assessing comfort levels of children and adolescents with high-risk or advanced cancers and determining concordance of their reported comfort levels with the parent or guardian’s report of the child or adolescent’s comfort levels. This is significant to note, because previous studies in several chronic illnesses of childhood show that there are low to moderate levels of agreement of symptom distress, responses to distress may change over time with developmental changes, and children may report greater improvement in symptom distress and quality of life than their parents do (Brinksma et al., 2014; Gallo et al., 2014).

## Methods

### Design

This prospective, longitudinal cohort, feasibility study examined the willingness of patients and families of a vulnerable population of children scheduled to receive HSCT to receive palliative care interventions, the willingness of clinicians to refer HSCT patients and families for palliative care, the estimated resource allocation required for HSCT palliative care (time and activities

needed to provide the interventions), and the perceived value added of the interventions as evidenced by family and provider satisfaction. Data points included  $T_0$  (baseline, prior to undergoing HSCT),  $T_1$  (14 days post HSCT), and  $T_2$  (approximately 30 days post HSCT or time of discharge, whichever came first). Secondary aims included assessing comfort levels of children and adolescents with high-risk or advanced cancers and determining concordance of their reported comfort levels with the parent or guardian's report of the child or adolescent's comfort levels. These outcomes are hallmarks of feasibility studies (Arain, Campbell, Cooper, & Lancaster, 2010).

### Sample and Setting

The study was conducted in an urban, tertiary care, free-standing children's hospital. All patients and families admitted for HSCT were considered for enrollment on this study. Only English-speaking families were recruited, as the assessment questionnaires were not available in other languages.

### Measures

**Resource Allocation.** Resource allocation included the time required for palliative care team personnel and prescribed interventions. The number of visits required, time (minutes) required by the palliative care team practitioners for care interventions, the types of interventions requested by patients and families, and whether the requested interventions were available and provided in a timely manner were the included variables. These data were tracked on a time and activity log, noting the number and dates of visits made, time in and out of each visit or intervention, the types of interventions requested by patients and families, and the date and time each intervention was provided or the reason why an intervention was not provided. The goal was to provide each intervention as soon as possible or within 24 hours for those services requiring equipment or other care providers.

**Family Survey and Provider Satisfaction Survey.** A Family Satisfaction Survey and a Provider Survey, adapted from a Center to Advance Palliative Care (CAPC) satisfaction survey, consisted of 6 questions answered on a 5-point Likert scale. Pretesting with parents of children with serious life-limiting illnesses established face and content validity of the Family Survey, and the Provider Satisfaction Survey was pretested with oncology providers at the study site (excluding HSCT team staff) to establish face and content validity. Family satisfaction was measured at the end of the 30-day data collection period or at the time of discharge and was coordinated with timing of standard HSCT satisfaction surveys by the HSCT nurse

coordinator. Provider satisfaction was measured at the end of the 6-month study period by the unit director to avoid bias.

**General Comfort Questionnaire–Parent/Guardian Form.** The General Comfort Questionnaire (GCQ) was originally developed as a 48-item self-report and observational scale to measure comfort in the domains of relief, ease, and transcendence of physical, psychospiritual, sociocultural, and environmental stressors (Kolcaba, 1992). The GCQ, written at a 6.1 grade level, has been widely used in multiple patient populations including pediatrics. A shorter, 28-item form of the GCQ improved reliability on all subscales with an overall Cronbach's alpha of 0.90. The shorter form was used in this study. For children under the age of 3 years, parent-report alone was used.

**Children's Comfort Daisies and Comfort Line Visual Analog Scale.** Self-report of comfort from the child's perspective was measured using a 1-question assessment on the Comfort Daisies, a 4-point Likert scale that has been validated with children ages 3 to 7 years. This tool is similar in format to the widely used Faces Pain scales (Kolcaba & DiMarco, 2005). For older children and adolescents, ages 7 to 21 years, the Comfort Line Visual Analog Scale was used. The Comfort Line is a standard visual analog scale with ratings from 1 (very comfortable) to 10 (very uncomfortable). The visual analog scale has been validated in children as young as 5 years of age (McGrath et al., 1966; Miro & Huguet, 2004). In this study, visual analog scale ratings were grouped into 4 ranges of scores to correspond to similar ratings of the Comfort Daisies scale for ease in analysis. Correlation between the 2 scales was adequate ( $r = 0.94$ ) (Tomlinson, Von Baeyer, Stinson, & Sung, 2010). Methods of data collection were standardized and the data were collected by the principal investigator, with the exception of satisfaction data, to avoid threats to validity and reliability.

### Study Procedures

All children and families who were admitted for HSCT during the 6-month study period who met the eligibility criteria were approached by the HSCT team and referred to the study team for enrollment. A minimum of 10 new HSCT patient/families, who completed all 3 design points, was deemed an appropriate estimate to establish feasibility. After enrollment, formal palliative care consultation and interventions were provided by the palliative care team attending physician and/or nurse practitioner. Interventions were provided using a standardized approach as outlined in the COG/APHON Pediatric Oncology Palliative Care Resource (Ethier, Rollins, & Stewart, 2010) and individualized to the needs

of each patient and family. Patient- and parent-reported comfort measures were administered at the same time point for each participant: at baseline or study enrollment ( $T_0$ ), approximately 2 weeks after the HSCT conditioning regimen was completed ( $T_1$ ), and at the time of discharge or the first outpatient clinic follow-up visit ( $T_2$ ), approximately 30 days after HSCT. Satisfaction was assessed at the time of discharge or first outpatient clinic follow-up visit for families and at the completion of the study for clinicians.

### Human Participants Protection

The study was approved by both the clinical institution and the university institutional review boards. The potential risks and benefits of sharing any information were discussed with the participants in advance of sharing any information with other members of the health care team and were shared for clinical care purposes only.

### Analysis

Data were descriptively analyzed, and group means, medians, and proportions were used to characterize feasibility, study participants, and palliative care outcomes. PASW Statistics GradPack18 software was used (SPSS Inc, 2009). Nonparametric analysis techniques were applied because of the small sample size. The results of the Comfort Line Visual Analog Scale were regrouped into 4 categories, similar to the categories on the Comfort Daisies instrument, so that scores on the 2 instruments could be compared over time. Measures of comfort from the parental perspective were analyzed using an overall score and with individual scores for each subscale: Physical (6 items), Psychospiritual (9 items), Environmental (7 items), and Sociocultural (6 items). Negative comfort items were recoded to reflect the same direction of comfort report as the positive comfort items. Total comfort scores, as well as scores in each subscale, were recoded to reflect an overall score comparable to the 6-point scale of the General Comfort Questionnaire–Parent/Guardian Form. Mean scores of parental ratings of their child's baseline comfort were also analyzed by diagnosis and type of HSCT.

A Kruskal-Wallis test, a nonparametric alternative to 1-way between-group analysis of variance (ANOVA), was used to compare parental reports of comfort at baseline  $T_0$ ,  $T_1$ , and  $T_2$  by diagnosis and type of HSCT. The Friedman test, a nonparametric alternative to the 1-way repeated-measures ANOVA, was used to measure differences in parents' reports of their child's overall comfort over time from baseline  $T_0$  (prior to beginning conditioning) to  $T_1$  (~14 days after HSCT) to  $T_2$  (~30 days after HSCT). An additional secondary aim was to investigate

**Table 1.** Demographic Characteristics (N = 12).

Measure	n	%	Range	Mean	SD
Gender					
Male	6	50			
Female	6	50			
Primary caretaker during HSCT					
Mother	7	58.3			
Father	2	16.7			
Both equally	3	25			
Age			1.2-20	8.8	5.87
0-3 years	3	25.0			
4-6 years	2	16.7			
7-10 years	3	25.0			
11-13 years	2	16.7			
14-18 years	1	8.3			
>18 years	1	8.3			
Diagnosis					
Leukemias	3	25			
Solid tumors	4	33.3			
Genetic disorders	4	33.3			
Other	1	8.3			
Type of transplant					
Allogeneic	7	58.3			
Autologous	3	25			
Cord blood	2	16.7			

and describe concordance of assessment of comfort as reported by parent or guardian on the General Comfort Scale–Parent/Guardian Form, as reported by the child (ages 3-6 years) on the Children's Comfort Daisies form and as reported by older children and adolescents (ages 7-21 years) on the Comfort Line Visual Analog Scale. Parental reports of total comfort were recoded to a 4-point scale to better correlate with the child and adolescent's self-reports of comfort.

## Results

### Establishing Feasibility of Early Palliative Care Consultation in HSCT

Feasibility was established by 100% referral and recruitment, provision of nearly 100% of interventions requested by families, and high family and provider satisfaction.

**Recruitment.** The HSCT team referred all 12 eligible participants, and 100% of these eligible participants enrolled, thus achieving 100% referral and enrollment of all eligible participants. See Table 1 for sample demographics.

**Availability of Interventions.** Needed palliative care interventions were provided nearly 100% of the time. Only

**Table 2.** Palliative Care Interventions Requested By Patients and Families.

Type of Intervention	Requested, n (%)	Provided, n (%)	% Provided per Request	Comments
Initial family meeting/assessment	12 (100)	12 (100)	100	Required by study
Supportive care counseling	12 (100)	12 (100)	100	
Acupuncture/acupressure	8 (66.7)	4 (33.3)	50	Community referral
Advanced directive	2 (16.7)	2 (16.7)	100	
Aromatherapy	5 (41.7)	4 (33.3)	80	Equipment need
Art therapy	10 (83.3)	10 (83.3)	100	Standard referral
Biofeedback	0 (0)	0 (0)	N/A	
Complementary-alternative medicine approaches	0 (0)	0 (0)	N/A	
Dietary modifications	12 (100)	12 (100)	100	Standard HSCT care
Guided imagery/relaxation techniques	5 (41.7)	5 (41.7)	100	
In-house consults				
• Child life	12 (100)	12 (100)	100	Standard referral
• Pastoral care	3 (25)	3 (25)	100	
• Pain team	6 (50)	6 (50)	100	Standard HSCT care
• Social work	12 (100)	12 (100)	100	Standard referral
• Other	2 (16.7)	2 (16.7)	100	
Hospice referral	2 (16.7)	2 (16.7)	100	Community referral
Massage therapy	7 (58.3)	7 (58.3)	100	Community referral
Music therapy	11 (91.7)	11 (91.7)	100	Standard referral
Nonpharmacological interventions (not otherwise specified)	8 (66.7)	8 (66.7)	100	
Oxygen	3 (25)	3 (25)	100	
Palliative chemotherapy	1 (8.3)	1 (8.3)	100	
Palliative radiation therapy	0 (0)	0 (0)	N/A	
Pharmacological interventions	12 (100)	12 (100)	100	Standard HSCT care
Psychology/psychiatry	7 (58.3)	7 (58.3)	100	
Team meeting	3 (25)	3 (25)	100	Standard referral
Others, not otherwise specified	2 (16.7)	2 (16.7)	100	

<sup>a</sup>There were no biofeedback, CAM, palliative radiation requests so therefore none were provided.

1 requested intervention, acupuncture (58%), fell below the 70% benchmark due to availability of the outside consultant. A variety of interventions were provided (Table 2). The average number of interventions per participant was 13. The most frequent additional palliative care intervention, requested by 100% of families, was supportive care counseling, which is a time-intensive intervention, defined as extended time at the bedside bearing witness to the unique journey of each child and family, including time spent in patient/family education as well as active listening.

**Staffing Metrics.** The number of visits for each participant ranged from 6 to 18, with a mean of 11 visits over the 30-day data collection period per participant. The time required for each visit ranged from 15 to 120 minutes and was dependent on each participant's needs (Table 2). Rarely was an intervention provided without time spent in additional supportive care counseling, as requested by participants. Staff included a pediatric palliative care board-certified nurse practitioner and/or attending physician.

**Parental and Provider Satisfaction.** Descriptive provider and parent satisfaction survey reports are provided in Table 3. Missing data occurred longitudinally from 2 families: 1 family had a child who was still hospitalized, and 1 child had died and the family asked to defer filling out the questionnaire due to the immediacy of the death experience. Overall, families were very satisfied with integration of palliative care services.

Families (90%) indicated they were very comfortable with receiving care from the palliative care team. Families (100%) also rated the palliative care team as helpful or very helpful in managing symptoms and stresses during their child's admission for HSCT. Families (100%) were satisfied or very satisfied with access to services. All families indicated it was very important to offer palliative care services and that they were very likely to recommend the palliative care team to others. Families (70%) were also very likely to recommend the institution to other patients and families based upon their experiences with the palliative care team.

**Table 3.** Family Satisfaction.

Family Satisfaction Questions <sup>a</sup>	n (%)	Mean Score	Median	SD
How comfortable were you in getting care from the [palliative] care team? 5 = Very comfortable 4 = Comfortable	10 9 (90) 1 (10)	4.90	5.00	0.316
How helpful was the [palliative] care team to you in helping your child to be as comfortable as possible by managing the symptoms and other stresses of your child's transplant? 5 = Very helpful 4 = Helpful	10 8 (80) 2 (20)	4.80	5.00	0.422
How helpful was the [palliative] care team in improving your access to services at Children's National? 5 = Very helpful 4 = Helpful 3 = Neutral	10 7 (70) 2 (20) 1 (10)	4.60	5.00	0.699
How important is it to you that [this institution] offers the services of the [palliative] care team? 5 = Very important	10 10 (100)	5.00	5.00	0.000
How likely are you to recommend the [palliative] care team to others? 5 = Very likely	10 10 (100)	5.00	5.00	0.000
How did your experience with the [palliative] care team influence your likelihood to recommend [this institution] to others? 5 = Very likely 4 = Likely	10 7 (70) 3 (30)	4.70	5.00	0.483
Overall total satisfaction scores (total possible score = 30) Actual scores: 30 (100% satisfaction) 28 (93% satisfaction) 27 (90% satisfaction)	10 6 (60) 2 (20) 2 (20)	29.00	30.00	1.333

<sup>a</sup>Possible scores from 1 (very uncomfortable/unhelpful/unimportant, unlikely) to 5 (very comfortable/helpful/important/likely).

Overall, providers (n = 20) indicated satisfaction, with a mean score of 4.40 on a 5-point Likert scale (Table 4). Providers including physicians, physician assistants, and nurse practitioners indicated that they were comfortable or very comfortable with referring patients for palliative care consultation prior to the implementation of this study. Licensed independent providers (physicians, physician assistants, and nurse practitioners) were more comfortable in making palliative care referrals prior to this study than were other providers (staff nurses and social work). Of note, some staff nurses (50%) did not respond to this question. At the conclusion of the study, clinicians indicated that the palliative care team was helpful in managing symptoms and other stressors and in improving access to services for patients and families during the trajectory of HSCT admission. Additionally, clinicians indicated that it was very important that the institution offer palliative care services and that they were very likely to recommend the palliative care team to other patients and families.

There was no significant difference in satisfaction scores by types of HSCT clinician for comfort in palliative care referral, importance of offering palliative care services, and

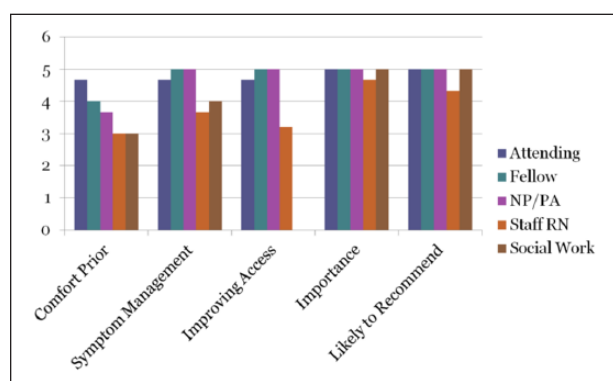
likelihood to recommend palliative care services. Significant differences in satisfaction scores by types of HSCT clinician were noted for managing symptoms and other stressors ( $\chi^2_{4(n=17)} = 12.360, P = .015$ ), improving access to services ( $\chi^2_{4(n=17)} = 9.388, P = .025$ ), and total satisfaction scores ( $\chi^2_{4(n=20)} = 14.773, P = .005$ ). Licensed independent providers rated these areas with higher satisfaction than did other providers (see Figure 1).

### Comfort and Concordance of Child Self-Report With Parent Report

*Child's Self-Report of Comfort by Diagnosis and Type of HSCT.* Means trended toward a decrease in comfort scores from baseline but showed no statistical difference. Diagnostic groups did not differ at baseline ( $P = .091$ ) or at  $T_1$  ( $P = .591$ ) in comfort scores, nor were there significant differences in reports of comfort between type of HSCT groups at baseline ( $P = .625$ ) or at  $T_1$  ( $P = .812$ ). Child and adolescent self-reports of comfort at  $T_2$  were consistent (100%) at "very good" for all diagnoses and types of HSCT (Tables 5 and 6).

**Table 4.** Descriptive Statistics for Parental Report of Their Child's Comfort.

Comfort Domain	Baseline T <sub>0</sub> (N = 12)			T <sub>1</sub> (N = 11)			T <sub>2</sub> (N = 9)		
	n (%)	Mean (Median)	SD	n (%)	Mean (Median)	SD	n (%)	Mean (Median)	SD
Physical		4.25 (4.00)	1.055		4.09 (4.00)	1.045		5.22 (6.00)	0.972
Strongly agree	2 (16.7)			1 (9.1)			5 (55.6)		
Agree	2 (16.7)			2 (18.2)			4 (44.4)		
Somewhat agree	5 (41.7)			6 (54.5)			0		
Somewhat disagree	3 (25)			1 (9.1)			0		
Disagree	0			1 (9.1)			0		
Strongly disagree	0			0			0		
Psychospiritual		5.50 (6.00)	0.674		5.55 (6.00)	0.688		6.00 (6.00)	0.000
Strongly agree	7 (58.3)			7 (63.6)			9 (100)		
Agree	4 (33.3)			3 (27.3)			0		
Somewhat agree	1 (8.3)			1 (9.1)			0		
Somewhat disagree	0			0			0		
Disagree	0			0			0		
Strongly disagree	0			0			0		
Environmental		5.33 (5.00)	0.779		5.55 (6.00)	1.009		5.86 (6.00)	1.191
Strongly agree	6 (50)			6 (54.5)			8 (88.9)		
Agree	4 (33.3)			3 (27.3)			1 (11.1)		
Somewhat agree	2 (16.7)			1 (9.1)			0		
Somewhat disagree	0			1 (9.1)			0		
Disagree	0			0			0		
Strongly disagree	0			0			0		
Sociocultural		4.83 (5.00)	1.115		4.72 (5.00)	1.191		5.43 (6.00)	0.787
Strongly agree	4 (33.3)			3 (27.3)			5 (55.6)		
Agree	4 (33.3)			4 (36.4)			2 (22.2)		
Somewhat agree	2 (16.7)			3 (27.3)			2 (22.2)		
Somewhat disagree	2 (16.7)			0			0		
Disagree	0			1 (9.1)			0		
Strongly disagree	0			0			0		
Total		4.67 (5.00)	0.888		4.55 (5.00)	0.820		5.44 (6.00)	0.726



**Figure 1.** Provider satisfaction. This graph illustrates the 5 major areas measured on the Provider Satisfaction Survey using a 5-point Likert scale, with 1 indicating low satisfaction with palliative care services addressing this need and 5 indicating very high satisfaction. NP, nurse practitioner; PA, physician assistant.

**Table 5.** Parental Report of Child's Comfort by Diagnosis.

Diagnosis	Baseline T <sub>0</sub>	T <sub>1</sub>	T <sub>2</sub>
	n (%) Mean/Median/SD	n (%) Mean/Median/SD	n (%) Mean/Median/SD
Leukemia	3 (30) 3.33/4/1.155	3 (33.3) 2.67/3/1.528	2 (25) 4.00
Solid tumor	4 (40) 3.5/4/1.000	3 (33.3) 3.33/4/1.155	3 (37.5) 4.00
Genetic disorder	3 (30) 3.67/4/0.577	3 (33.3) 3.67/4/0.577	3 (37.5) 4.00
Difference Between Groups	Kruskal Wallis		
Baseline	$\chi^2_{2(n=10)} = 0.80, P = .961$		
T <sub>1</sub>	$\chi^2_{2(n=9)} = 1.051, P = .591$		
T <sub>2</sub>	n = 8: all participants rated as 4.00		

**Table 6.** Parental Reports of Child's Comfort by Type of HSCT.

Type of HSCT	Baseline T <sub>0</sub> n (%) Mean/Median/ SD	T <sub>1</sub> n (%) Mean/Median/SD	T <sub>2</sub> n (%) Mean/ Median/SD
Allogeneic	5 (50) 3.4/4.0/0.894	4 (44.4) 3.5/ 4.0/0.577	3 (37.5) 4.0
Autologous	3 (30) 3.33/4.0/1.155	3 (33.3) 3.33/4.0/1.155	3 (37.5) 4.0
Cord blood	2 (20) 4.0/4.0/0.00	2 (22.2) n = 1 and n = 4	2 (25) 4.0
Difference Between Groups		Kruskal-Wallis	
Baseline		$\chi^2_{2(n=10)} = 0.939, P = 0.625$	
T1		$\chi^2_{2(n=9)} = 0.418, P = 0.812$	
T2		n = 8: all participants rated as 4.0	

**Parental Report of Their Child's Comfort by Diagnosis and Type of HSCT.** All parents felt that their child was comfortable at baseline. Parental reports of their child's comfort did not differ by diagnostic group ( $P = .752$ ). When compared for type of HSCT, parents of children who underwent allogeneic HSCT rated their child's baseline comfort slightly lower (mean = 4.43) compared with parents of children who underwent autologous or cord blood HSCT, where both groups agreed that their child was comfortable at baseline (mean = 5). However, this was not significant ( $P = .638$ ). The majority of parents "agreed" ( $n = 5, 45.5\%$ ) or "strongly agreed" ( $n = 1, 9.1\%$ ) that their child was comfortable at T<sub>1</sub> (14 days after completing conditioning); however, parents of children with leukemia reported a slightly higher mean level of comfort for their child than did parents of children with solid tumors or genetic disorders, and children who underwent allogeneic HSCT had slightly higher reported comfort levels than children who underwent cord blood or autologous HSCT. There was no significant difference at T<sub>1</sub> by diagnosis ( $P = .341$ ) or by type of HSCT ( $P = .762$ ). At T<sub>2</sub> (30 days after completing conditioning and HSCT), overall parental reports indicated their child was comfortable. Parental reports of comfort did not differ at T<sub>2</sub> across the 4 diagnostic groups ( $P = .620$ ). No significant difference was noted in parental reports of comfort at T<sub>2</sub> across the 3 types of HSCT ( $P = .459$ ); however, the allogeneic HSCT group had slightly higher levels of comfort at T<sub>2</sub> (Table 4).

**Parental report of their child's comfort over time.** There was statistical significance in parental reports of comfort across the 3 time points ( $\chi^2_{2(n=9)} = 9.750, P = .008$ ). Inspection of the mean values showed a decrease in comfort scores from baseline (mean = 4.89) to T<sub>1</sub> (mean

= 4.67) and an increase at T<sub>2</sub> (mean = 5.44), and trends confirmed using a Wilcoxon signed rank test. No statistical significance for parental report of their child's comfort was noted from baseline to T<sub>1</sub> ( $P = .317$ ); however, this value statistically significantly increased from T<sub>1</sub> to T<sub>2</sub> ( $z = -2.646, n = 9, P = .008$ ).

#### Parental Report of Physical, Psychospiritual, Environmental, and Sociocultural Comfort Subscales

**Parental report of physical comfort.** At baseline, parents rated their child's physical comfort level as somewhat comfortable; however, the range was broad: "somewhat disagree" (25%), "somewhat agree" (41.7%), "agree" (16.7%), and "strongly agree" (16.7%). At T<sub>1</sub>, parents overall rated their child's physical comfort as somewhat comfortable; however, the range was very broad, with ratings from "disagree" to "strongly agree." The majority of parents somewhat agreed that their child was physically comfortable at T<sub>1</sub> (54.5%); however, some parents disagreed or somewhat disagreed that their child was comfortable (18.2%) and others agreed or strongly agreed that their child was comfortable at T<sub>1</sub> (27.3%). At T<sub>2</sub>, parents overall agreed that their child was comfortable; however, the reports were less polar, with ratings of "somewhat agree" (33.3%), "agree" (11.1%), and "strongly agree" (55.6%) (Table 4).

**Parental report of psychospiritual comfort.** At baseline, all parents strongly agreed their child was comfortable in the psychospiritual domain. At T<sub>1</sub>, parents continued to strongly agree that their child had overall psychospiritual comfort; however, the range was broader, with ratings of "somewhat agree" (7.7%), "agree" (15.4%), and "strongly agree" (38.5%). At T<sub>2</sub>, all parents strongly agreed that their child had psychospiritual comfort.

**Parental ratings of environmental comfort.** At baseline, all parents rated their child's environmental comfort as comfortable. At T<sub>1</sub>, parents overall agreed that their child was comfortable in the environmental domain (mean = 5.27, SD = 1.00); however, the range was broader, with ratings of "strongly disagree" (0.09%), "somewhat disagree" (0.09%), and "strongly agree" (81.8%). At T<sub>2</sub>, all parents strongly agreed that their child was comfortable.

**Parental reports of sociocultural comfort.** At baseline, all parents agreed their child was overall comfortable in the sociocultural domain; however, the range was broad: "somewhat disagree" (16.7%), "somewhat agree" (16.7%), "agree" (33.3%), and "strongly agree" (33.3%). At T<sub>1</sub>, all parents overall continued to agree that their child experienced sociocultural comfort; however, the range was again broad, with ratings of "disagree" (0.1%), "somewhat agree" (27.3%), agree (36.3%), and



“strongly agree” (27.3%). At  $T_2$ , parents overall agreed that their child was comfortable, although ratings were not close: “somewhat agree” (22.2%), “agree” (22.2%), and “strongly agree” (55.6%).

*Parental reports of comfort over time per each subscale.* When analyzed by subscale, there was no statistical significance in parental reports of their child’s psychospiritual comfort ( $P = .105$ ), environmental comfort ( $P = .143$ ), or sociocultural comfort ( $P = .069$ ) across the 3 time points. Statistical significance was demonstrated in physical comfort ( $\chi^2_{2(n=9)} = 6.462$ ,  $P = .040$ ), which is expected in the natural history of acute recovery from HSCT.

### Concordance of Child and Parent Reports of Comfort

At baseline and at  $T_1$ , there was no significant difference between parental and child reports of comfort (baseline,  $\chi^2_{6(n=10)} = 4.881$ ,  $P = .559$ ;  $T_1$ ,  $P = .300$ ). Correlation of parent to child reports of comfort at baseline showed a moderate correlation by the Spearman rho ( $\rho = 0.305$ ,  $n = 10$ ,  $P = .391$ ). Comparison of parent to child reports of comfort at  $T_1$  showed large correlation by the Spearman rho ( $\rho = 0.534$ ,  $n = 10$ ,  $P = .138$ ). At  $T_2$ , all children reported their comfort levels as “very good,” whereas parents had greater range of responses: “sort of bad” (12.5%), “sort of good” (12.5%), and “very good” (75%).

There was no statistical significance in reports of comfort across the 3 time points ( $P = .202$ ). A Wilcoxon signed rank test confirmed no statistical significance in differences in child and parent level of agreement over time from baseline to  $T_1$  ( $P = .655$ ) and from  $T_1$  to  $T_2$  ( $P = .564$ ). Analyses of concordance revealed no significant differences between child self-report and parental reports of their child’s comfort at the 3 time points (baseline,  $T_1$ , and  $T_2$ ) or over time.

## Discussion

This study established the feasibility and acceptability of providing early palliative care consultation and intervention to promote transcendent comfort for children and adolescents with advanced or life-limiting cancers or other nonmalignant diseases undergoing HSCT. The primary aims of enrollment and satisfaction were met. This study achieved 100% referral and enrollment; however, these results should be interpreted with caution, as the principal investigator was well known to the HSCT team, which may have biased referral patterns positively. Enrollment at 100% is unbiased, as the principal investigator was not known to patients and families; thus, this supports feasibility that families are accepting of early

palliative care consultation. Integration of palliative care consultation achieved high levels of patient and family satisfaction as well as provider satisfaction in resource availability to augment care for these children and their families. The use of the palliative care team early in the HSCT trajectory, prior to critical life-threatening events, facilitated difficult discussions regarding goals of care and in some cases foregoing further life-sustaining treatment. Fostering a more homelike setting also assisted in promoting an environment that was conducive to decreasing existential distress.

Integration of palliative care consultation for children and adolescents with high-risk or advanced cancers undergoing stem cell transplantation, as implemented by this feasibility study, was able to maintain adequate comfort levels from baseline through conditioning and transplant for children and adolescents undergoing HSCT as well as high levels of family satisfaction and clinician satisfaction in resource availability to augment care for these children and their families. The use of the palliative care team early in the HSCT trajectory, prior to critical life-threatening events, facilitated difficult discussions regarding goals of care and in some cases foregoing further life-sustaining treatment. Fostering a more homelike setting also promoted an environment that was conducive to decreasing existential distress.

The time commitment to provide these intense services was substantial. In the context of a study, there was vested interest in ensuring that visits and interventions were provided; however, without a dedicated palliative care team, these types of services may be less feasible. The time spent in supportive care counseling was substantial, and it was imperative to make time as the family needed. This was difficult to do in the face of other clinical responsibilities. Interventions aimed at demonstrating compassionate care are integral to the profession of nursing; thus, improving the communication skills of HSCT staff nurses may be one way of improving satisfaction for nursing and the families who receive this care. Nursing in the modern age is a technical profession; although therapeutic listening is desired, nurses are often unable to dedicate extended time for this. In this study, all families desired supportive care counseling, operationally defined as time taken by the palliative care team provider to listen to their fears and concerns. Training in therapeutic communication regarding the comfort needs of patients undergoing HSCT and their families may increase the competency level of nurses to provide more efficient communication, particularly when the palliative care team is not readily available. A dedicated palliative care team would improve access to this model of care delivery. The institution has made a commitment to improving access to palliative care services, so inclusion of palliative care consultation is now a standard of care for all HSCT patients.

The intervention was well received by families as well as providers. Families indicated high overall satisfaction with early integration of palliative care services. Families were comfortable in receiving palliative care interventions and felt that the service helped them manage symptoms and other stressors of HSCT. They indicated that provision of palliative care services was very important and that they not only were very likely to recommend these types of interventions to other families but were very likely to recommend the institution to others due to the influence of this service. Providers were also very satisfied with the intervention.

The promotion of comfort embodies the art as well as the science of nursing. Improving patient outcomes, such as patient comfort and patient satisfaction, documents the productivity and value of nursing (Kolcaba, 2003; Novack, Kolcaba, Steiner, & Dowd, 2001). In addition, integration of palliative care services in high-stress environments will allow planning for interventions to relieve compassion fatigue for nursing and other staff as well. Both families and providers indicated that early palliative care intervention was a value-added service that was very beneficial for patients and families. In this study, there was no change in comfort over time, which in itself is a significant finding as the impetus for this evidence-based practice change was rooted in the declaration of moral distress of staff nurses bearing witness to the apparent existential distress of children undergoing HSCT and their families. Specific symptoms were not investigated in this pilot study; however, these findings of general comfort support the need for future research of early integration of palliative care in mitigation of specific symptoms such as pain, stress, and fatigue inherent to the trajectory of pediatric HSCT.

### **Strengths and Limitations**

Strengths of the study design were that the participants underwent similar treatment (HSCT) despite having differing underlying diagnoses and were in the same setting throughout the intervention. Standardized interventions were provided using the COG/APHON Pediatric Oncology Palliative Care Resource and standardized training of the palliative care practitioners. Since the primary aims measured feasibility, the threats to validity were somewhat tempered as an effect on comfort was not expected due to the small sample and short period of data collection.

For a feasibility study, this sample size is sufficient to establish our *a priori* feasibility parameters: These included at least 70% of children undergoing HSCT being referred and consented for participation, provision of at least 70% of interventions identified by families as needed to promote comfort, and at least 70% of families

and HSCT clinicians indicating high satisfaction with the palliative care consult process. In a feasibility study, the effects of interventions are not the focus; however, multiple studies of symptom distress in pediatric advanced cancers have been reported with as few as 1 to 5 participants (Cohen, 1992; Jaing et al., 2011; Pallant, 2007; Rawlinson et al., 2011; Wilson, Mazhar, Rojas-Cooley, DeRosa, & Van Cleve, 2011). The potential for selection bias and the inability to generalize to the population of children with advanced cancer or other serious nonmalignant disease at large should be considered; however, the availability of potential subjects was limited in this setting and would be in most pediatric HSCT clinical sites. This feasibility work sets the stage for a similar approach in a multi-institutional study or as a routine part of assessment for children and adolescents undergoing HSCT.

Participants received standard care to address pain and suffering as part of the HSCT process, so the palliative care interventions may not have caused the effects. In addition, counts usually recover by the time of discharge so participants may have felt better regardless of the palliative care interventions and distress may have improved simply because of time (Trochim, 2006). Other considerations of validity were that families did interact within the intimate setting of the HSCT inpatient unit, so treatments or suggestions of improvement may have been communicated between families.

The sample was representative of the pediatric HSCT population—slightly more patients had solid tumors and underlying genetic disorders and some patients had leukemia—so the results can be representative of the pediatric HSCT population. The sample size was small, and given that this was a single-site study, findings are not generalizable to other settings. This sample was young (many patients were <7 years of age); thus, the findings may not be as applicable to an older adolescent and young adult population.

### **Summary**

This study demonstrated the feasibility of early integration of palliative care interventions with curative-intent therapy of HSCT for children and adolescents with advanced cancers and other nonmalignant diseases and their families. Feasibility was evidenced by 100% enrollment and recruitment, the ability to provide interventions requested by families (>70% of the time), and high satisfaction of families and providers. This approach to care was implemented at the study site as a standard of care, with further data collection to aid in understanding of the phenomena of transcendent comfort and improve credibility of the findings. This feasibility study is one of the first to examine palliative care consultation and intervention in the pediatric HSCT population, a curative intent

therapy. The impact of the findings may reach further than the initial setting, and consideration of multisite studies across HSCT centers is another future direction of this work.

Stem cell transplantation is not without substantial risks, thus increasing stress upon the child and family (Jobe-Shields, Alderfer, Barrera, Vannatta, Currier, & Phipps, 2009). Higher levels of distress may impact the psychosocial and emotional outcomes as well as the medical outcomes of stem cell transplantation (Jobe-Shields, Alderfer, Barrera, Vannatta, Currier, & Phipps, 2009). Promotion of comfort may decrease levels of distress with the potential of fostering more positive outcomes in a population at high risk for morbidity and mortality.

*Existential distress* is suffering that affects the integrity of the person, integrating into every domain of human existence and influencing quality of life and activities of daily living (Cassell, 1999). Providing palliative care for the child or family experiencing existential distress is one way of promoting comfort (O'Neill & Mako, 2011). Palliative care is not about dying, as historically thought. It is about helping children and families to live well in the midst of a potentially life-limiting illness or treatment, such as HSCT.

Palliative care no longer means helping children die well. It means helping children and their families to live well and then, when the time is certain, to help them die gently. (Mattie Stepanek 1990-2007)

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### Author Biographies

**Deborah A. Lafond** is the Clinical Coordinator of the PANDA Care Team at Children's National Health Systems in Washington, DC. This project was completed as part of her Doctorate of Nursing Practice capstone project.

**Katherine Patterson Kelly** is a Nurse Scientist in the Department of Nursing Research and Quality Outcomes at Children's National Health System in Washington, DC.

**Pamela S. Hinds** is the Director of the Department of Nursing Research and Quality Outcomes and the Co-Director of the Center for Translational Science at Children's National Health System in Washington, DC.

**Ann Sill** is a biostatistician in the Center for Clinical and Translational Research at Children's National Health System in Washington, DC.

**Michele Michael** is an Assistant Professor in Family and Community Health at the University of Maryland, School of Nursing in Baltimore, MD.