Original Article

Provision of Palliative and Hospice Care to Children in the Community: A Population Study of Hospice Nurses

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Abstract

Context. Approximately 500,000 children in the United States suffer from life-limiting illnesses each year, many of whom are hospice eligible each year. Few hospice agencies, however, offer formal pediatric programs.

Objective. To determine the levels of experience and comfort of hospice nurses who provide care to children and families in the community.

Methods. A cross-sectional survey was developed to assess hospice nurse experience/comfort across the domains of symptom management, end-of-life care, goals of care, family-centered care, and bereavement. The survey was pilot tested and distributed to hospice nurses across a tristate region.

Results. A total of 551 respondents across 71 hospices completed surveys. The majority of nurses reported no training in pediatric palliative or hospice care (89.8%), with approximately half reporting <5 years of hospice experience (53.7%) and no pediatric hospice experience (49.4%). Those with pediatric hospice experience reported limited opportunities to maintain or build their skills, with the majority providing care to children several times a year or less (85.7%). Nurses reported feeling somewhat or very uncomfortable providing services to children during the illness trajectory and at the end of life across all domains.

Conclusion. Children with serious illness who receive care from local hospices often interface with nurses who lack training, experience, and comfort in the provision of palliative and hospice care to pediatric patients. These findings should inform future development and investigation of educational resources, training programs, and child- and family-centered policies to improve the delivery of palliative and hospice care to children in the community. J Pain Symptom Manage 2019;57:241−250. © *2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Pediatric, palliative care, hospice, community, training

Introduction

Approximately 500,000 children in the U.S. suffer from life-limiting illnesses each year, 10% of whom die annually.[1] Provision of home-based supportive resources and services through hospice care has been shown to ameliorate symptom burden and improve quality of life for children with serious illness,[2−5] mitigate parental burden and psychosocial stress,[3] reduce costs,[4,6] and even improve the experiences of health care providers regarding interdisciplinary collaboration, communication, and family support.[2] Based on these and other data, the Institute of Medicine and the American Academy of Pediatrics strongly endorse the integration of palliative and hospice care for children with life-limiting illness.[7−9]

Unfortunately, hospice services only reach about 10% of children who die in the U.S.,[10] with the majority receiving hospice services through adult organizations.[11]

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In 2007, the National Hospice and Palliative Care Organization conducted a national survey to ascertain the extent of pediatric services available, in which 78% of responding hospices reported serving pediatric patients yet few had a formal pediatric program in place.[11] Data from the 2013 National Summary of Hospice Care showed that only 14% of participating hospice programs have formal pediatric palliative care (PPC) services with specialized staff.[11]

Arguably, the provision of hospice care to children with life-limiting illness, particularly at the end of life, is one of the most sensitive and stressful responsibilities that a clinician can undertake.[12,13] Despite this, very little is known about the level of pediatric expertise available through the majority of community-based hospice agencies. No prior studies have investigated levels of clinician training, experience, and comfort in the delivery of care to children with life-limiting illness and their families in the community. To address these deficits, we conducted a cross-sectional survey study of hospice nurses employed by all accredited hospice organizations across Tennessee, Arkansas, and Mississippi, with the goal of identifying perceived barriers to provision of optimal community-based care. Ultimately, we hope that these findings will inform the development and investigation of educational resources, training programs, and supportive interventions to improve delivery of palliative and hospice care to children with serious illness and their families in the community.

Methods

The authors' Institutional Review Board reviewed and approved this study.

State-Specific Hospice Identification

Our research team collaborated with Hospice Analytics to interrogate the National Hospice Locator and aggregate a roster of all accredited hospice organizations in the tristate region of Tennessee, Arkansas, and Mississippi. This list was cross-checked with rosters derived from the Tennessee Hospice Organization, Arkansas Department of Health, Hospice and Palliative Care Organization of Arkansas, and the Louisiana-Mississippi Hospice and Palliative Care Organization. Discrepancies between the National Hospice Locator roster and state-specific lists were reconciled by phone calls to hospice agencies to ascertain current status of eligibility.

Rationale for Regional Selection

The geographic area of interest in this study was selected for two reasons. First, the states of Tennessee, Mississippi, and Arkansas fall within the lowest quartile of states regarding hospice access, with approximately one-quarter to one-third of individuals lacking services within a 30-minute drive.[14] Second, this tristate region serves as a large catchment area for children with serious illness referred to our institution, and little is known about the needs and limitations of hospice provision within this region. Over the past decade, our institutional PC program has observed limitations related to delivery of hospice services to children with life-limiting conditions within this catchment area, and this needs assessment was designed as a first step toward developing educational services and interventions to improve provision of pediatric palliative and hospice care within this under-resourced tristate region.

Eligibility Criteria

Hospice organizations were eligible to participate in this study if they offered PC and/or hospice services to patients in Tennessee, Mississippi, and Arkansas, and if they employed nurses who could be asked to provide care to a pediatric patient if a need arose within their catchment area. Hospices that had a policy precluding provision of care to patients under the age of 18 years were ineligible. All hospice nurses employed by a participating organization were eligible to complete the survey if their job description included possible provision of palliative or hospice care to pediatric patients and their families.

Recruitment and Enrollment

Prescreened state-specific hospices were contacted by telephone to confirm eligibility and determine interest in participation. For sites that enrolled, a member of the hospice leadership (i.e., medical director, nursing director, or program coordinator) was appointed as the on-site study facilitator, and this individual distributed an electronic survey to all eligible nurses at the participating site and confirmed the total number of nurses who received the survey. Paper surveys were provided at several sites by request.

Survey Development and Content

Initial development of survey items was conducted by an expert team of PPC and hospice clinicians and researchers after review of literature related to barriers to provision of pediatric palliative and hospice care to children in the community.[15–25] To enhance face and content validity, items subsequently underwent revision by a panel of key stakeholders employed by community-based hospice programs, including two hospice medical directors, four hospice nurse practitioners, and two expert PC methodologists. Panel participants conducted iterative review of the survey, with serial testing of questions conducted in three rounds until final consensus was achieved. Then the survey was pilot tested with a cohort of seven pediatric hospice nurses affiliated with a local community-based hospice organization, to ensure optimal question clarity, construct, and survey structure logic. The final survey included items to ascertain current status and extent of provision of PPC and hospice services to children and families in the community, as well as items to evaluate levels of prior training, experiences, and self-perceived comfort across the following domains: pain control, nonpain symptom management, communication around goals of care and advance directives, end-of-life management, bereavement support, debriefing, and self-care.

Statistical Analysis

Respondent demographics, hospice demographics, and hospice nurse experience and comfort levels with provision of care to pediatric patients were summarized using descriptive statistics (number and percentage). Hospice nurse experiences were summarized for the subgroup of respondents who answered in the affirmative with regard to any history of prior practice in provision of palliative or hospice care to infants, children, or adolescent patients. All statistical analyses were conducted using SAS 9.4 (SAS Institute, Cary, NC).

Results

A total of 221 accredited hospices were identified in Tennessee, Arkansas, and Mississippi, of which 83 were found to have combined with other agencies or gone out of business and 47 were ineligible because of policies precluding provision of services to pediatric patients. Enrollment rates were high across the remaining 91 eligible hospices, with 91.7% (22/24) participation in Tennessee, 78.6% (22/28) in Arkansas, and 69.2% (27/39) in Mississippi. A total of 1366 nurses were eligible to receive the survey across 71 participating hospice sites, and a total of 551 surveys were completed for a response rate of 40.3%.

Hospice and individual respondent demographics are described in Tables 1 and 2. More than half of respondents (53.7%) had fewer than 5 years of experience working as a hospice nurse, and nearly half (49.4%) had no experience providing palliative or hospice care to an infant, child, or adolescent patient. The majority reported that their agencies lacked formal training or resources on providing care to children (77.1%); those who reported a lack of training/resources also reported a desire for educational strategies to improve their comfort/competency in provision of care to children (64.9%).

Table 1
Hospice Demographics ($N = 551$)

Survey Item	N (%)
Location of hospice agency	
Tennessee	184 (33.4)
Arkansas	181 (32.8)
Mississippi	144 (26.1)
Other	4 (0.7)
Missing	38 (6.9)
Number of nurses on staff at each hospice	
1–9	208 (37.7)
10–19	150 (27.2)
20–29	46 (8.3)
30 or more	107 (19.4)
Missing	40 (7.3)
Number of children per year served by each hospice	
0–4	406 (73.7)
5–9	51 (9.3)
10–19	18 (3.3)
20–29	10 (1.8)
>30	24 (4.4)
Missing	42 (7.6)
Does hospice provide debriefings for staff to discuss the stress of caring for children at the end of life?	
Yes	253 (45.9)
No	116 (21.1)
Not sure	140 (25.4)
Missing	42 (7.6)
Does hospice offer training or resources for nurses on providing palliative/hospice care to children?	
Yes	84 (15.2)
No	190 (34.5)
Not sure	235 (42.6)
Missing	42 (7.6)
Interest in receiving training or resources on providing palliative/hospice care to children[a]	
Yes	276 (64.9)
No	51 (12)
Not sure	96 (22.6)
Missing	2 (0.5)

[a] Answered "no" or "not sure" to the question "Does hospice offer training or resources for nurses on providing palliative/hospice care to children?"

Hospice Nurse Self-Reported Experience With Provision of Palliative and Hospice Care to Pediatric Patients

Table 3 summarizes the experience levels of the 279 respondents who reported any experience with provision of pediatric palliative or hospice care. Within this subgroup, the majority (85.7%) reported currently taking care of pediatric patients infrequently (i.e., several times a year, every couple of years, or never) and were considered to have little to no experience for the purposes of this analysis. The majority of these respondents (89.8%) had never received formal training in pediatric palliative or hospice care and reported little to no experience with assessing pain (73.1%) or nonpain symptoms (73.1%) or giving medications for management of pain (75.6%) or nonpain symptoms (75.2%). Likewise, the majority reported little to no experience with caring for children who are

Table 2
Respondent Demographics ($N = 551$)

Survey Item	N (%)
Gender	
Female	476 (86.4)
Male	33 (6)
Missing	42 (7.6)
Race	
White	470 (85.3)
Black	24 (4.4)
Asian/Pacific Islander	2 (0.4)
Arabic/Middle Eastern	0 (0)
Native American Indian/Alaskan Native	4 (0.7)
Other	9 (1.6)
Missing	42 (7.6)
Ethnicity	
Hispanic	4 (0.7)
Non-Hispanic	502 (91.1)
Missing	45 (8.2)
Age	
≤19 years	0 (0)
20−29 years	40 (7.3)
30−39 years	121 (22)
40−49 years	143 (26)
50−59 years	141 (25.6)
≥60 years	64 (11.6)
Missing	42 (7.6)
Years as a nurse	
<1 year	5 (0.9)
1−4 years	56 (10.2)
5−9 years	128 (23.2)
10−19 years	170 (30.9)
≥20 years	192 (34.8)
Missing	
Years as a hospice nurse	
<1 year	97 (17.6)
1−4 years	199 (36.1)
5−9 years	148 (26.9)
10−19 years	93 (16.9)
≥20 years	13 (2.4)
Missing	1 (0.2)
Any prior experience providing palliative or hospice care to an infant, child, or adolescent patient	
Yes	279 (50.6)
No	272 (49.4)
Any prior training in pediatric palliative care or pediatric hospice	
Yes	56 (10.2)
No	495 (89.8)

actively dying (80.3%) or managing pain, dyspnea, or seizures at the end of life (78.8%).

Regarding communication, the majority of respondents reported little to no experience with asking children about their hopes and goals of care (77.1%), talking with children about death and/or dying (79.6%), or using a tool (e.g., My Wishes or Voicing my Choices) that helps children express their views, hopes, or wishes about end-of-life care (83.1%). The majority also reported little to no experience with asking family members about their hopes and goals of care for their child (73.8%) or talking with family members about death and/or dying (55.6%).

Nearly two-thirds of respondents also reported little to no experience with assessing the psychosocial needs of parents and/or siblings (62.7%), providing supportive care or other interventions for parents and/or siblings (64.1%), or assessing family members for risk factors for complicated grief (61.3%). The majority of respondents rarely, if ever, provided bereavement support and/or resources for family members after the child's death (78.5%).

Hospice Nurse Self-Reported Comfort Level With Provision of Palliative and Hospice Care to Pediatric Patients

Table 4 summarizes the self-reported comfort levels of hospice nurses with provision of care to children and families in the community. Nearly half of respondents reported feeling somewhat or very uncomfortable providing PC or hospice services to children during the illness trajectory (46.5%) or during the active dying process (46.6%). Specifically, nurses felt somewhat or very uncomfortable taking care of children with common symptoms at the end of life, including severe pain (48.2%), dyspnea (47.7%), or seizures (51.0%).

One-third to half of respondents also felt somewhat or very uncomfortable talking with children about how they define their quality of life (37.8%), asking children about their hopes and goals of care (30.3%), talking with children about death and/or dying (47.2%), or using a document or tool to help children express their views, hopes, or wishes about end-of-life care (33.7%). A sizable minority of respondents felt somewhat or very uncomfortable discussing these topics with family members as well. About one-third of nurses felt somewhat or very uncomfortable providing bereavement support and/or resources for family members in the first 12 months after a child's death (30.4%), more than 12 months after a child's death (30.3%), or bereavement support specifically for siblings (32.3%).

Discussion

Among hospice nurses in the community employed by agencies that offer services to pediatric patients, preliminary descriptive analysis has demonstrated that the majority of nurses have fewer than 5 years of hospice experience, have never received formal training in pediatric palliative or hospice care, and have no personal experience providing palliative or hospice care to pediatric patients. Given this finding, it is unsurprising that the majority of these nurses reported feeling somewhat or very uncomfortable providing PC or hospice services to children.

Even those nurses with prior pediatric hospice experience have limited opportunities to maintain or increase their skills, with the majority providing care to pediatric patients in the community several times a

Table 3

Hospice Nurse Experiences With Provision of Care to Pediatric Patients ($N = 279$)[a]

Item	Daily	Several times a week	Several times a month	Several times a year	Every Couple of years	Never	Missing
How often do you…							
Provide palliative care or hospice services to infants, children, or adolescents?	10 (3.6%)	17 (6.1%)	12 (4.3%)	68 (24.4%)	147 (52.7%)	24 (8.6%)	1 (0.4%)
Symptom management							
Assess children for pain?	21 (7.5%)	13 (4.7%)	11 (3.9%)	59 (21.1%)	133 (47.7%)	12 (4.3%)	30 (10.8%)
Give opioids to children to help with pain?	10 (3.6%)	18 (6.5%)	8 (2.9%)	53 (19%)	118 (42.3%)	40 (14.3%)	32 (11.5%)
Assess children for nonpain symptoms (e.g., dyspnea, nausea, delirium, sleep issues, anxiety, depression)?	20 (7.2%)	16 (5.7%)	10 (3.6%)	58 (20.8%)	132 (47.3%)	14 (5%)	29 (10.4%)
Give medications to children to help with nonpain symptoms?	14 (5%)	14 (5%)	12 (4.3%)	59 (21.1%)	125 (44.8%)	26 (9.3%)	29 (10.4%)
Offer complementary alternative therapies to children to improve quality of life (e.g., Reiki, aromatherapy, guided imagery, massage)?	5 (1.8%)	6 (2.2%)	12 (4.3%)	39 (14%)	98 (35.1%)	91 (32.6%)	28 (10%)
End-of-life care							
Provide care to children who are actively dying?	6 (2.2%)	7 (2.5%)	9 (3.2%)	59 (21.1%)	143 (51.3%)	22 (7.9%)	33 (11.8%)
Take care of children with severe pain, dyspnea, or seizures at the end of life?	7 (2.5%)	9 (3.2%)	10 (3.6%)	52 (18.6%)	139 (49.8%)	29 (10.4%)	33 (11.8%)
Goals of care							
Ask children about their hopes and goals of care?	5 (1.8%)	11 (3.9%)	14 (5%)	41 (14.7%)	97 (34.8%)	77 (27.6%)	34 (12.2%)
Talk with children about death and/or dying?	1 (0.4%)	8 (2.9%)	14 (5%)	44 (15.8%)	101 (36.2%)	77 (27.6%)	34 (12.2%)
Use a document or tool that helps children express their views, hopes, or wishes about end-of-life care (e.g., "My Wishes" or "Voicing My Choices")?		5 (1.8%)	8 (2.9%)	28 (10%)	75 (26.9%)	129 (46.2%)	34 (12.2%)
Ask family members about their hopes and goals of care for their child?	7 (2.5%)	17 (6.1%)	13 (4.7%)	62 (22.2%)	127 (45.5%)	17 (6.1%)	36 (12.9%)
Talk with family members about death and/or dying?	38 (13.6%)	26 (9.3%)	23 (8.2%)	50 (17.9%)	97 (34.8%)	8 (2.9%)	37 (13.3%)
Family-centered care							
Assess the physical and psychosocial needs of parents and/or siblings?	20 (7.2%)	22 (7.9%)	21 (7.5%)	53 (19%)	110 (39.4%)	12 (4.3%)	41 (14.7%)
Provide supportive care or other interventions for parents and/or siblings?	19 (6.8%)	20 (7.2%)	20 (7.2%)	55 (19.7%)	113 (40.5%)	11 (3.9%)	41 (14.7%)
Assess family members for risk factors for complicated grief (e.g., loss of a child, multiple losses, sudden/unexpected death, traumatic/violent death, lack of support systems, mood disorder, childhood abuse/neglect, other major life stressors)?	23 (8.2%)	23 (8.2%)	21 (7.5%)	48 (17.2%)	104 (37.3%)	19 (6.8%)	41 (14.7%)
Bereavement care							
Attend the viewing, memorial, and/or funeral service after you take care of a child who died?	3 (1.1%)	1 (0.4%)	8 (2.9%)	39 (14%)	90 (32.3%)	94 (33.7%)	44 (15.8%)
Provide bereavement support and/or resources for family members after the child's death (as part of your job, and not on your own personal time)?	3 (1.1%)	3 (1.1%)	10 (3.6%)	47 (16.8%)	85 (30.5%)	87 (31.2%)	44 (15.8%)

[a] $N = 279$ represents all respondents who answered "yes" to the question "Any prior experience providing palliative or hospice care to an infant, child, or adolescent patient?"

Table 4

Hospice Nurse Comfort With Provision of Care to Pediatric Patients ($N = 551$)

Survey Item	Very Comfortable	Somewhat Comfortable	Somewhat Uncomfortable	Very Uncomfortable	Missing
How comfortable do you feel…					
Providing palliative care or hospice services to children?	73 (13.2%)	200 (36.3%)	162 (29.4%)	94 (17.1%)	22 (4%)
Symptom assessment					
Assessing children for pain?	156 (28.3%)	233 (42.3%)	98 (17.8%)	40 (7.3%)	24 (4.4%)
Assessing children for dyspnea?	185 (33.6%)	220 (39.9%)	85 (15.4%)	38 (6.9%)	23 (4.2%)
Assessing children for nausea?	192 (34.8%)	230 (41.7%)	71 (12.9%)	36 (6.5%)	22 (4%)
Assessing children for delirium?	126 (22.9%)	212 (38.5%)	127 (23%)	64 (11.6%)	22 (4%)
Assessing children for sleep issues?	147 (26.7%)	222 (40.3%)	112 (20.3%)	47 (8.5%)	23 (4.2%)
Assessing children for anxiety?	153 (27.8%)	228 (41.4%)	103 (18.7%)	45 (8.2%)	22 (4%)
Assessing children for depression?	121 (22%)	212 (38.5%)	137 (24.9%)	58 (10.5%)	23 (4.2%)
Symptom management					
Giving opioids to children to help with pain?	138 (25%)	219 (39.7%)	105 (19.1%)	64 (11.6%)	25 (4.5%)
Giving opioids to children to help with dyspnea?	144 (26.1%)	208 (37.7%)	110 (20%)	64 (11.6%)	25 (4.5%)
Giving medications to children to help with nausea?	214 (38.8%)	214 (38.8%)	63 (11.4%)	35 (6.4%)	25 (4.5%)
Giving medications to children to help with delirium?	138 (25%)	208 (37.7%)	118 (21.4%)	62 (11.3%)	25 (4.5%)
Giving medications to children to help with sleep issues?	148 (26.9%)	228 (41.4%)	102 (18.5%)	47 (8.5%)	26 (4.7%)
Giving medications to children to help with anxiety?	159 (28.9%)	215 (39%)	96 (17.4%)	56 (10.2%)	25 (4.5%)
Giving medications to children to help with depression?	144 (26.1%)	211 (38.3%)	111 (20.1%)	58 (10.5%)	27 (4.9%)
Offering complementary alternative therapies to improve quality of life (e.g., Reiki, aromatherapy, guided imagery, massage)?	151 (27.4%)	205 (37.2%)	110 (20%)	55 (10%)	30 (5.4%)
End-of-life care					
Providing care to children who are actively dying?	105 (19.1%)	162 (29.4%)	161 (29.2%)	96 (17.4%)	27 (4.9%)
Taking care of children with severe pain at the end of life?	103 (18.7%)	154 (27.9%)	155 (28.1%)	111 (20.1%)	28 (5.1%)
Taking care of children with severe dyspnea at the end of life?	104 (18.9%)	157 (28.5%)	152 (27.6%)	111 (20.1%)	27 (4.9%)
Taking care of children with seizures at the end of life?	91 (16.5%)	151 (27.4%)	169 (30.7%)	112 (20.3%)	28 (5.1%)
Goals of care					
Asking children about how they define quality of life?	103 (18.7%)	213 (38.7%)	143 (26%)	65 (11.8%)	27 (4.9%)
Asking children about their hopes and goals of care?	139 (25.2%)	218 (39.6%)	111 (20.1%)	56 (10.2%)	27 (4.9%)
Talking with children about death and/or dying?	86 (15.6%)	177 (32.1%)	166 (30.1%)	94 (17.1%)	28 (5.1%)
Asking children about their spirituality?	141 (25.6%)	216 (39.2%)	116 (21.1%)	49 (8.9%)	29 (5.3%)
Using a document or tool that helps children express their views, hopes, or wishes about end-of-life care (e.g., "My Wishes" or "Voicing My Choices")?	113 (20.5%)	225 (40.8%)	122 (22.1%)	64 (11.6%)	27 (4.9%)
Asking family members about how they define quality of life for their child?	167 (30.3%)	213 (38.7%)	102 (18.5%)	42 (7.6%)	27 (4.9%)
Asking family members about their hopes and goals of care for their child?	177 (32.1%)	211 (38.3%)	95 (17.2%)	41 (7.4%)	27 (4.9%)
Talking with family members about death and/or dying?	193 (35%)	207 (37.6%)	81 (14.7%)	41 (7.4%)	29 (5.3%)
Asking family members about their spirituality?	189 (34.3%)	231 (41.9%)	71 (12.9%)	32 (5.8%)	28 (5.1%)
Family-centered care					
Assessing the physical needs of parents?	244 (44.3%)	213 (38.7%)	43 (7.8%)	21 (3.8%)	30 (5.4%)
Assessing the psychosocial needs of parents?	213 (38.7%)	226 (41%)	57 (10.3%)	25 (4.5%)	30 (5.4%)
Providing supportive care or other interventions for parents?	234 (42.5%)	220 (39.9%)	41 (7.4%)	24 (4.4%)	32 (5.8%)
Assessing the physical needs of siblings?	177 (32.1%)	221 (40.1%)	87 (15.8%)	35 (6.4%)	31 (5.6%)
Assessing the psychosocial needs of siblings?	160 (29%)	219 (39.7%)	102 (18.5%)	38 (6.9%)	32 (5.8%)
Providing supportive care or other interventions for siblings?	179 (32.5%)	223 (40.5%)	87 (15.8%)	32 (5.8%)	30 (5.4%)
Assessing family members for risk factors for complicated grief (e.g., loss of a child, multiple losses, sudden/unexpected death, traumatic/violent death, lack of support system, mood disorder, childhood abuse/neglect, other major life stressors)?	163 (29.6%)	208 (37.7%)	109 (19.8%)	40 (7.3%)	31 (5.6%)

(*Continued*)

Table 4
Continued

Survey Item	Very Comfortable	Somewhat Comfortable	Somewhat Uncomfortable	Very Uncomfortable	Missing
Bereavement care					
Attending the viewing, memorial, and/or funeral service after you take care of a child who died?	170 (30.9%)	180 (32.7%)	111 (20.1%)	55 (10%)	35 (6.4%)
Providing bereavement support and/or resources for family members in the first 12 months after the child's death?	153 (27.8%)	197 (35.8%)	116 (21.1%)	51 (9.3%)	34 (6.2%)
Providing bereavement support and/or resources for family members more than 12 months after the child's death?	144 (26.1%)	206 (37.4%)	111 (20.1%)	56 (10.2%)	34 (6.2%)
Providing bereavement support and/or resources specifically for siblings?	138 (25%)	200 (36.3%)	122 (22.1%)	56 (10.2%)	35 (6.4%)

year or every couple of years. Given that community-based hospice nurses infrequently assessed and managed pediatric patients, it follows that a substantial number of nurses reported feeling uncomfortable with assessment and management of common symptoms; communication around the hopes, wishes, and goals of care of patients and families; evaluation and management of the psychosocial and spiritual needs of family members; assessment of family members for risk factors for complicated grief; and provision of bereavement support.

These findings are concerning for several reasons. First, a clear malalignment exists between the needs of children with serious illness in the community and the availability of trained providers. Each year, approximately 50,000 children in the U.S. die in the context of life-limiting illnesses,[1] yet only 1 in 10 of these children receive hospice services.[10] Data in the context of oncology suggest that many parents prefer for their child to receive end-of-life care in the home,[26–29] and this preference is supported by the majority of clinicians.[27] Yet fewer than 1 in 5 hospice programs in the U.S. offer formal PPC services with specialized staff,[11] and nearly one-third of existing hospices in the region have policies in place prohibiting provision of care to pediatric patients.

Second, in the absence of accessible pediatric programs, children with serious illnesses typically receive care from organizations geared toward providing care to adult patients.[11] These findings substantiate prior National Hospice and Palliative Care Organization data that suggest most children enrolled in hospice access services and resources through adult-centric organizations, most of which have little to no experience with provision of pediatric care.[11] Our data reveal that this stop-gap system places highly vulnerable children and families at risk of receiving services from clinicians with inadequate experience and comfort with provision of pediatric palliative and hospice care in the community.

Third, clinicians who provide care to children with serious illness are at high risk for experiencing moral distress and burnout.[30,31] Nurses, in particular, are at high risk for burnout in the context of provision of palliative and hospice care to children.[12,13,32] Interestingly, interviews with nurses have revealed an awareness of the profound responsibility of providing care to a child at the end of life, with "you've only got one chance to get it right" emerging as a common theme.[12] In the face of these inherent stressors, nurses who care for children with serious illness may struggle with job satisfaction and retention in the context of burnout.[33] Presently, little is known about how nursing levels of experience and confidence influence rates of moral distress/burnout. Based on our collective clinical experience, we hypothesize that nurses who lack experience and/or confidence in their ability to care for pediatric patients may be at higher risk for moral distress/burnout, and we advocate for further prospective study of this potential adverse association.

Fourth, the literature suggests that nurses who provide care in stressful environments benefit from participation in debriefing opportunities, with improvement in resilience and mitigation of burnout.[34–36] Notably, fewer than half of the nurses who participated in this study reported access to debriefings through their hospice agency. These data highlight opportunities for improvement with regard to provision of reflective debriefing and other supportive interventions to promote caregiver well-being within community-based hospice organizations.

Ultimately, the findings from this study highlight existing discordance between the physical, psychosocial, and spiritual needs of children with serious illness and their families and the availability of providers trained to respond to these critical needs in the community. Further studies are needed to investigate how provider inexperience and discomfort impact physical and psychosocial outcomes for patients and families across the illness experience, at end-of-life, and into the bereavement period, as well as how these variables influence provider burnout and job retention.

We believe that the findings of this study necessitate a call to action for increased collaboration between hospital-affiliated PPC programs and surrounding community-based hospice organizations. Fortuitously, nearly two-thirds of surveyed hospice nurses desired additional pediatric-specific training. We advocate for coordination of regional PPC nursing didactics (e.g., ELNEC[37]), facilitated by PPC experts in the community and at academic centers, with the goal of extending educational and training opportunities to hospice providers in the community. Training should target pediatric-specific symptom management, end-of-life care, communication around goals of care and advance directives, psychosocial support for parents and siblings, and grief and bereavement support, given the deficits in these domains identified in this study.

In addition, standardized resources specific to pediatric palliative and hospice care should be developed and shared with regional hospice networks, with opportunities to modify templates to best align with the needs of local programs. Development of pediatric hospice intake processes, policies, and standardized operating procedures may further assist community-based providers with their delivery of hospice care to children in the home. Similarly, high-yield guidelines reflecting current standards of care for symptom assessment/management for children with serious illness may be helpful for hospice providers who provide services to pediatric patients. Finally, telemedicine shows promise for improving provision of pediatric palliative and hospice care and bereavement support[38]; this technology should be harnessed and studied to improve community-based hospice care to children and families.

Each of the above strategies warrants thoughtful conversation and further investigation among palliative and hospice clinicians in the field. However, it is important to acknowledge the real-life challenges inherent to providing educational resources and support to adult hospice nurses who rarely take care of children. For hospice programs with infrequent pediatric enrollments, one option might be to identify a core pediatric team in which a subset of nurses receives specialized pediatric training and assume clinical responsibility of pediatric patients. Ultimately, consensus quality metrics applicable to community-based pediatric palliative and hospice care must be developed and studied to move the field forward in a meaningful way. Such metrics would enable hospices across the nation to track the impact of interventions on physical and psychosocial outcomes for pediatric hospice patients and their families.

This study has several limitations. First, it represents the experience of a specific tristate region and is not inherently generalizable across all states. Second, although we achieved high levels of hospice participation (78.0%), it is not possible to ascertain the impact of data from missing sites. Third, the nurse-specific response rate (40.3%) is lower than typically desired for survey studies; however, significant efforts were conducted to achieve this degree of response, and, based on the authorship's collective clinical and research experiences working with local hospice providers, we believe it would be challenging to exceed this degree of response rate within this targeted population. Furthermore, given the relatively low numbers of hospice nurses employed across the country, we believe that a survey comprising the perspectives of more than 550 nurses is a valuable addition to the literature.

In summary, children and families who receive care from local hospices in this tristate region frequently interface with nurses who lack training, experience and comfort in the provision of palliative and hospice care to pediatric patients. These findings should sound an alarm for hospice agencies, academic centers, local municipal leaders, and national hospice and palliative medicine organizations. We hope that the results from this study will inform the development of policies, standardized programmatic resources and processes, and educational interventions to improve provision of palliative and hospice care to children with serious illness in the community and their families.

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