

Perceptions of the Pediatric Hospice Experience among English- and Spanish-Speaking Families

Rachel Thienprayoon, MD,^{1,2} Emily Marks, MS,³ Maria Funes, MPH,³ Louizza Maria Martinez-Puente, BA,³ Naomi Winick, MD,^{4,5,*} and Simon Craddock Lee, PhD, MPH^{3,6,*}

Abstract

Objective: Many children who die are eligible for hospice enrollment but little is known about parental perceptions of the hospice experience, the benefits, and disappointments. The objective of this study was to explore parental perspectives of the hospice experience in children with cancer, and to explore how race/ethnicity impacts this experience.

Study Design: We held 20 semistructured interviews with 34 caregivers of children who died of cancer and used hospice. Interviews were conducted in the caregivers' primary language: 12 in English and 8 in Spanish. Interviews were recorded, transcribed, and analyzed using accepted qualitative methods.

Results: Both English and Spanish speakers described the importance of honest, direct communication by medical providers, and anxieties surrounding the expectation of the moment of death. Five English-speaking families returned to the hospital because of unsatisfactory symptom management and the need for additional supportive services. Alternatively, Spanish speakers commonly stressed the importance of being at home and did not focus on symptom management. Both groups invoked themes of caregiver appraisal, but English-speaking caregivers more commonly discussed themes of financial hardship and fear of insurance loss, while Spanish-speakers focused on difficulties of bedside caregiving and geographic separation from family.

Conclusions: The intense grief associated with the loss of a child creates shared experiences, but Spanish- and English-speaking parents describe their hospice experiences in different ways. Additional studies in pediatric hospice care are warranted to improve the care we provide to children at the end of life.

Introduction

HOSPICE, considered to be the model for quality, compassionate care for people facing life-limiting illness, is both a philosophy and a system of care and is defined by the Institute of Medicine as “a comprehensive, socially supportive, pain-reducing, and comforting alternative to technologically elaborate, medically centered interventions.”¹⁻⁴ Hospice focuses on “caring, not curing” and may be provided in free-standing hospice centers, hospitals, or nursing homes, but in most cases is provided in patient homes.³ Home-based care often affords the dying person greater emotional and physical comfort, and therefore, enhanced quality of life during the terminal phase.⁵ Many children who

die are eligible for hospice care and many parents of children who die of cancer report home as a preferred location of death.⁶⁻⁹ Regardless of whether a child died at home or elsewhere, parents who are able to plan their child's location of death are more likely to report feeling prepared for their child's end of life and comfortable with the location of death than those who did not plan.¹⁰ Thus, high-quality communication surrounding end-of-life care, and the opportunity to plan the location of death, may represent more relevant predictors for parental outcomes than the actual location in which a child dies.¹⁰

While multiple studies have documented racial/ethnic disparities in hospice enrollment in adults,¹¹⁻¹⁷ to our knowledge only one study has addressed this question in the

¹The Pediatric Palliative and Comfort Care Team, Division of Pain, Department of Anesthesiology and ²Cancer and Blood Disease Institute, Department of Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio.

³Department of Clinical Sciences, ⁴The Pauline Allen Gill Center for Cancer and Blood Disorders, Department of Pediatrics, ⁶Harold C. Simmons Cancer Center, University of Texas at Southwestern Medical Center, Dallas, Texas.

⁵Children's Medical Center Dallas, Dallas, Texas.

*Co-senior authors

Accepted August 21, 2015.

pediatric population.¹⁸ In a retrospective cohort study of 95 children with cancer who enrolled on hospice in Texas over 5 years, we found that Latinos were significantly more likely to enroll on hospice than children of other racial/ethnic groups.¹⁸ A 2008 survey of Children's Oncology Group institutions indicated that although approximately 60% had hospice programs available, hospice services were underutilized, with the median number of hospice enrollments less than half of the number of patient deaths.¹⁹ Experts in the field of pediatric end of life (EOL) care have found that less than 10% of eligible children receive hospice care, and a study of children with complex chronic conditions in California at the end of life found that less than 25% accessed care designed to meet the physical and psychosocial needs of terminally ill children.^{20,21} Pediatric provider perceptions of barriers to hospice enrollment have been explored, but parental perspectives about hospice care and those factors that may impact hospice enrollment and revocation have not.^{22,23} How children and their families experience hospice, and how race/ethnicity may modify this experience, remain unknown. Therefore, the aim of this pilot study was to qualitatively explore parental perspectives on the hospice experience among those whose children died as a result of cancer. Specifically, we sought to explore potential differences in this experience using Spanish-language preference as a proxy for acculturation in a diverse sample of pediatric patients with cancer.

Methods

Participants

Potential participants, mainly bereaved parents, were identified upon chart review of patients treated for cancer who died between 2006–2010 while under the care of a primary oncologist at Children's Medical Center Dallas. This cohort was then cross-referenced with the two local hospice agencies that service the catchment area (unpublished data). Caregivers of children with cancer who were enrolled in hospice prior to the child's death were considered for inclusion in this study. Exclusion criteria included any child who was older than 18 at the time of diagnosis, or whose death was the result of an event unrelated to cancer. Participants were recruited through an initial mailed invitation letter including an opt-out card, followed by an invitation phone call. Of the 98 families to whom recruitment letters were mailed, 3 returned opt-out cards. Thirty-two (33%) caregivers were reached by phone; 21 families had at least one caregiver who agreed to participate, but one family who consented was unable to complete the interview because of scheduling conflicts. Participants provided written consent and completed a brief demographic survey at the time of the interview. Interviews were held in the spring 2013; time since the child's death ranged from 3 to 7 years. Participants received an honorarium for each interview in the form of a gift card (\$30).

Institutional Review Board approval was obtained from the University of Texas at Southwestern (STU 012012-158).

Interviews

A 16-item interview moderator's guide (Fig. 1) was developed based on domains drawn from the literature regarding parental decision making in pediatrics, parental decision-making in children with cancer and at the end of life,

and medical decision-making in Latinos. The guide was reviewed with an ethnically diverse focus group of eight bereaved parents of children who died of cancer, and revised according to their recommendations. It was edited to an eighth-grade reading level by a specialist in medical education, and translated into Spanish by a bilingual research assistant. Last, it was reviewed and edited for cultural validity by the University of Texas at Southwestern Language Validation Services.

Each interview was held at a location that was selected by the participant. Given the exploratory nature of this research, participants included whoever was designated as a primary caregiver to the child during hospice enrollment. Participants were therefore interviewed based on family preference: individually, as mother–father dyads, as entire families including siblings, and in one case with two cousins and an uncle. Interviews were conducted by the principal investigator or by research team members trained in qualitative research methods. Interviews were conducted in English or Spanish based on participant preference and were approximately 60 minutes each. Interviews were digitally recorded and transcribed, and Spanish transcripts were translated by a bilingual research assistant.

Data analysis

Transcripts of each interview were reviewed by three members of the research team using an inductive, text-driven approach to thematic content analysis.^{24,25} After reading through all transcripts, team members developed and applied initial open codes in NVivo 9 (QSR International, Victoria, Australia). This line-by-line coding led to the understanding and development of thematic categories of codes. The analysis team members, principal investigator (R.T.), master's-level qualitative analyst (E.M.), and bilingual research assistant (M.F.), met weekly to discuss emergent themes and resolve any coding discrepancies. In an iterative process, codes were reconstructed, refined, and revised.^{26,27}

Once coding was completed, the team reviewed results by participant demographics and determined that comparison based on participant interview language was most appropriate to examine differences. Team members then reviewed English- and Spanish-coded utterances individually and met with coinvestigators (S.C.L., N.W.) to discuss findings until consensus was reached regarding broad themes.

Results

Thirty-four adult caregivers participated in 20 interviews, including one self-identified as African American, 18 self-identified as Hispanic/Latino, and 15 self-identified non-Hispanic Caucasians. Thirty-one participants were parents; one patient's parents remained in Mexico for the duration of his cancer treatment and death, so his uncle and two cousins participated as primary caregivers. Participant and interview demographic characteristics are summarized in Table 1. All participants who identified as Caucasian or African American and 3 who identified as Hispanic/Latino were English-speaking; all remaining participants were Spanish-speaking. Twelve interviews were conducted in English and 8 were conducted in Spanish.

Overall, English-speaking families reported higher levels of education than Spanish-speaking families, and their

Moderator's Guide (script)**Topic: Cancer journey/Introduction**

1. Please begin by telling me a little bit about NAME.
(Follow up) What kind of cancer did NAME have?
2. Can you tell me about the first time that you talked about the possibility that NAME was going to die?
(Follow up) Who led this conversation with you?

Topic: Understanding and expectations of hospice

3. Before NAME was on hospice, what did the word "hospice" mean to you?
(Follow up) Did you have any prior experiences with hospice or expectations of being on hospice?
4. Tell me about the first conversation in which hospice was mentioned as an option.
(Follow up) Who was involved in that conversation? What did you talk about?
5. What were some reasons that you decided that hospice was the best option for NAME?
(Follow up) Tell me about how you came to make that decision.

Topic: Hospice experience

6. Tell me about the hospice experience. What was that like for your family and for NAME?
7. Did your family talk in advance about where hospice care would happen?
Is that where NAME died, or did he/she go back to the hospital?

Topic: Quality of care

8. Looking back, what would you have done differently?
(Follow up) What advice would you give to another family facing a similar situation?
9. What could we have done better in taking care of NAME and your family during that time?

Prompts for cultural factors, should these topics arise**Trust of the healthcare system**

10. While AME was being treated, did you have a good relationship with at least one person on the team taking care of your child?
(Follow up) Tell me more about that. (Doctor, social worker, chaplain? Anyone else?)
11. How well did NAME's care team listen to you and respect your opinion?
(Follow up) How could we have listened better?

Health literacy

12. Many families tell us they have difficulty understanding what we're telling them because they are worried about their child. Tell me what it was like for you.

Discrimination

13. Did you ever feel as though NAME or your family were treated differently than other families?
(Follow up) Why might that be the case? (Race/Ethnicity)

Religiousness

14. Who did you look to outside the hospital for help in making decisions for NAME at that time?
(Family, Pastor, Healthcare provider)
15. What kind of support did you get from a faith community? How important was that?

Topic: Conclusion

16. Is there anything else that you would like to share with us?

FIG. 1. Moderator's guide.

TABLE 1. PARTICIPANT DEMOGRAPHIC AND INTERVIEW CHARACTERISTICS

<i>Participant and interview characteristics</i>			
<i>Characteristics</i>	<i>English n = 12</i>	<i>Spanish n = 8</i>	<i>Total n = 20</i>
Age of child at death			
Less than 2 years	0	1	1
2 years to 5 years	4	1	5
6 years to 12 years	3	2	5
13 years to 18 years	5	4	9
Gender of child			
Female	7	3	10
Male	5	5	10
Payer status of child			
Medicaid/CHSCN	3	7	10
Private insurance	9	1	10
Race/ethnicity of participant			
Black	1	0	1
Hispanic/Latino	3	8	11
Non-Hispanic white	8	0	8
Location of interview			
Participant home	10	6	16
Medical center	1	1	2
Other location	1	1	2
Highest level of education of participants			
Grade school	0	1	1
Some high school	0	2	2
High school graduate	0	3	3
Some college	3	1	4
College graduate	5	1	6
Graduate level or higher	4	0	4
Number of other children in the family			
None	1	0	1
1	6	3	9
2	2	3	5
3 or more	3	2	5
Retention on hospice at death			
Exited hospice	5	1	6
Remained on hospice	7	7	14
Interview participant relationship to child			
Mother and father	6	6	12
Mother only	5	1	6
Father only	1	0	1
Parent and/or other family members	0	1	1
Religion			
Christian-Catholic	3	7	10
Christian-Other	7	0	7
Non-Christian other	1	0	1
Unassigned	1	1	2
Siblings or other family present at interview			
Yes	4	7	11
No	8	1	9
Location of interview			
Participant home	10	6	16
Cancer support center	1	0	1
Children's Medical Center	1	1	2
Other (Local library)	0	1	1

children were much more likely to carry private insurance versus Medicaid or charity care (Children with Special Healthcare Needs), which may indicate higher socioeconomic status than parents in Spanish-speaking families. More of the children of English-speaking families (5) than Spanish-speaking families (1) exited hospice before death. Spanish-speaking families were much more likely to involve other siblings or family members in the study interviews (7 of 8 interviews) than were English-speaking families (4 of 12 interviews).

Themes that emerged include: communication with medical providers, which includes the subthemes honesty and trust in communication; hospice expectations and utilization, which includes the subthemes transition to hospice care, retention, quality of care, symptom control, prior familiarity with hospice, and types of services and staff utilized; and caregiver appraisal, which includes the subthemes geographic difficulties, financial difficulties, family dynamics, and social support. These themes, and similarities and differences that emerged between English-speaking and Spanish-speaking participants, are summarized in Table 2.

Communication with medical providers

We found that receiving honest, truthful, direct prognostic information was important to both English- and Spanish-speaking families. English-speaking families more commonly indicated that they may have been unwilling or unable to receive bad news early on.

It took the second set of opinions for me to understand she's not gonna make it...We all heard the same thing...I just couldn't believe it.

Spanish-speaking families were consistently satisfied with the use and quality of interpreters in the majority of their care. As exhibited in the quotations that follow, some families did discuss culture-related frustrations with communication in the emergency department and the receipt of bad news in the presence of their child, and a few also described inconsistent use of interpreters for day-to-day bedside matters when the child or siblings spoke English.

The doctor knew that, she came in and spoke to him [Dad] but he [child] was to one side. But [child] paid attention, although he was over there, he paid attention. He told me, "I heard the doctor told dad that I was going to die."

At the beginning, what I didn't like was the ER, yes very crude, in other words, she tells me "It can be an infection or cancer." That yes, I say that if it is something like that they let it hit you very badly.

Hospice care

Both English-speaking and Spanish-speaking families said that the decision to enroll in hospice was driven primarily by the recommendation of the primary oncologist. English-speaking families often framed the decision to transition to hospice care as the only option, whereas Spanish-speaking families more commonly discussed this as a choice provided by their oncologist.

[English-speaking]Yeah I mean she was on hospice care, she was going to die, we needed it...because we wanted her anywhere we were, at home, and that was really the thing, if she was going to be sick we wanted to keep her home.

TABLE 2. IMPORTANT THEMES AND DIFFERENCES AND SIMILARITIES BETWEEN ENGLISH AND SPANISH PARTICIPANTS

<i>English</i>	<i>Spanish</i>
<i>Trust in the provider/medical communication</i>	
<i>Differences</i>	
Parents would have preferred to be given difficult news honestly, clearly, directly from the beginning	Parents would have preferred to hear difficult news before the child; some were told simultaneously due to the language barrier
Some parents heard bad news more directly from a second opinion and may have been unprepared or unwilling to receive bad news early on	Sometimes, the child or sibling overheard difficult news due to the language barrier
Some parents expressed regret in that had they understood sooner, they may have done more enjoyable things with the time they had left	Patterns of communication were at times different between the family, patient and team due to language barrier
Having a doctor that you trust is very important; this person does not necessarily have to be the primary oncologist	Parents appreciated all efforts to make sure they understood news during “big” conversations, but on a minute-to-minute or day-to-day basis at the bedside, language was frequently an issue
If any doctor came to the funeral, was present at the death, or acknowledged the death in some way, this was very special to the family	Communication in the emergency department was very poor
	Many participants received honest, truthful communication from providers, and felt that doctors were forthcoming
	Overall, though, many felt communication was good, used interpreters, explained things clearly to the patient and the parents
<i>Hospice</i>	
<i>Prior familiarity with hospice</i>	
<i>Differences</i>	
Most participants had heard of hospice, and thought it was for the very old, to provide care at home	Most had heard of it, but no strong themes
Most never considered the notion that a child would need hospice	
<i>Hospice conversation: Transition</i>	
<i>Differences</i>	
Families seemed feel to that hospice was next step, there were no other options	Families were aware that they could go home or stay in hospital
Most parents knew prognosis was poor early on	Parents felt that their options were explained well by physicians
Transitions were described as following a progression of attempts at chemotherapy, cancer progression, and then hospice	The child’s preferences often drove the choice to go home
Family wanted to be home	
<i>Similarities</i>	
<i>Hospice was chosen because it was recommended by the doctor</i>	
<i>Hospice nurse communication</i>	
<i>Differences</i>	
Many parents disliked the personality of the hospice nurse and felt that she made a negative first impression; these families often felt that they did not get along well with nurse	Most families felt that the communication with the hospice nurse was overall very positive, despite the language barrier
Some parents, when asked about coming to the hospital, were told to stay home and not return to the hospital	Most families felt that the nurse explained hospice care very well
The doctor’s high opinion of the nurse influenced the decision to continue hospice care	
Some families had a very positive impression of their hospice nurses	
Some families felt that communication with the nurse was broadly very positive	

(continued)

TABLE 2. (CONTINUED)

<i>English</i>	<i>Spanish</i>
<i>Similarities</i>	
<i>Hospice providers normalized the death and dying experience, which was very helpful to caregivers</i>	
<i>Quality of hospice care</i>	
<i>Differences</i>	
Variable, but overall families described positive experiences	Most families felt that experiences were overall very positive
If families complained, it had to do with the personality of the hospice nurse, being told they were not able to return to the hospital, or pain and symptom control	If families complained, it was that they would like more time after the death before hospice arrived to pick up the equipment
<i>Symptom control</i>	
<i>Differences</i>	
Many families felt that pain and symptom control was poor, with a few notable exceptions who felt that the hospice provided excellent pain and symptom control	Overall families felt symptoms were well controlled, with few exceptions
<i>Services and staff provided</i>	
<i>Differences</i>	
Many described that child life was critical in the hospice experience	Some described extra support in terms of hospice helping with planning the funeral
<i>Retention on hospice</i>	
<i>Differences</i>	
Many families needed to go back to hospital due to poor pain or symptom control	Many families described that it was most important to be home, no matter the quality of symptom control
Some families believed that insurance would not cover returning to the hospital, or were told by the hospice that this was not an option	The child preferred to be home
The family wanted to be home	
<i>Similarities</i>	
Many families described a sense of panic and fear in anticipating the moment of their child's death, or just after the death; a hospice provider frequently was not present with these families when the child died	
<i>Caregiver appraisal</i>	
<i>General</i>	
<i>Differences</i>	
Those who understood that their child was dying were able to, and would recommend to other families in a similar situation, to stop and smell the roses, live every minute, appreciate the time you have	Many participants described themes of being the bedside nurse to their child
Those who did not realize that their child was dying regret that they had not made more memories	Many participants described that not speaking English was a barrier to feeling like an effective parent, and fear of not being able to do what was needed due to language
<i>Similarities</i>	
Many families described the difficulty of bearing witness to child's suffering and, in retrospect, thought, "How did we do it?"	
<i>Geography</i>	
<i>Differences</i>	
There were no strong themes	Many participants described having family in Mexico who were unable to help and limited by immigration status In one family, the patient, a teenager, was cared for by a group of second-degree relatives because his parents

(continued)

TABLE 2. (CONTINUED)

<i>English</i>	<i>Spanish</i>
	remained in Mexico, yet he remained in the United States to die because he believed his pain control would be poor in Mexico One family moved from out of town to be closer to the hospital One family described that a charitable foundation refused to provide them a car with air conditioning, and they felt that this would have provided considerably more relief and comfort to their ill child than a wish or a party
<i>Financial</i>	
<i>Differences</i>	
Some families described the difficulty of maintaining a job with a sick child Some families discussed concerns about being able to maintain insurance and to also be present to care for the child Many parents shared the responsibility of caring for the child and working Some described that they would have paid anything to cure their child and were thus vulnerable to scams	Most participants described that father maintained a job and the mother was the primary caregiver
<i>Spirituality/Religiosity</i>	
<i>Differences</i>	
There were no strong themes	Many described that the child's death was the will of God or God's plan
<i>Family Dynamics</i>	
<i>Differences</i>	
Many families described having honest and open, poignant conversations with the child about his or her death and were very thoughtful about how to discuss this with the child Many families also described having open and honest conversations with siblings Parents were concerned about the short- and long-term impact of the child's death on their siblings	Many parents described not wanting to be honest with child and protecting the child from the truth, although doctors encouraged the family to be honest and were willing to facilitate those conversations Some described situations where the child may have been protecting them and was very mature, particularly when children were teenagers and bilingual Many described the child's wishes drove their decision making, particularly in the desire to be at home
<i>Similarities</i>	
Many parents described being "in different places" during the journey of the child's illness and death	
<i>Social support</i>	
<i>Differences</i>	
Some families described deriving strength from the school community Many wish they were able to connect with other families who had been through it	Many parents derived support from other families they met in the hospital Some needed resources not well understood by charity organizations
<i>Similarities</i>	
Many described social isolation from friends and family who	"couldn't handle it" or from "normal" families and friends
<i>Systems Issues</i>	
<i>Positive Experiences</i>	
<i>Differences</i>	
Many described that it was special when doctors acknowledged the child's death	Many described that the care received by their child was no different than that received by other patients

(continued)

TABLE 2. (CONTINUED)

<i>English</i>	<i>Spanish</i>
Some felt that the hospital was an important source of support	
<i>Similarities</i>	
Many parents believed that their child was a special patient to all caregivers, who was well-loved by the entire team	
<i>Negative Experiences</i>	
<i>Differences</i>	Some parents described language barriers at the bedside in being able to access interpreters
<i>Similarities</i>	
Many families described the negative impact of long wait times in the oncology clinic and the emergency department	
Many felt that communication in the emergency department was broadly poor	

[Spanish-speaking]They gave me the option of letting [child] stay at the hospital if he wanted to, or if he wanted, to come to the house. And he told the doctor that he wanted to come home.

[Spanish-speaking]But I think that he was comfortable being at home, that he was with his family rather than if he were at the hospital. I feel that in the hospital, well perhaps the nurse would have been there, the doctor there at his side, but he was much calmer at home. He liked being there at home, he didn't like being admitted very much.

Both mentioned a sense of panic and anxiety surrounding the moment of their child's death, and that hospice providers, when present, were able to normalize the changes they witnessed as the child died.

[Mother]But as soon as she got there we all felt a whole lot better because you know I've never experienced somebody dying let alone my own child, and so just not knowing.

[Father]I said is this normal? It's like yes don't worry about it, his body is shutting down.

Some English-speaking families voiced discomfort with the hospice nurse who cared for their child; frequently these families relied on the positive recommendation of the primary oncologist in continuing hospice care. English-speaking families were also more likely to describe frustrations with hospice when they compared care delivered to their child to that delivered to older relatives.

You know, she didn't even know our names sometimes, but maybe that was just a personal thing... if this is who Dr. [Oncologist] worked best with then you know we'll accept that.

With parents on hospice, I've seen people that have 24-hour care, you know, three shifts, seven days a week, but with our child, she only came by when she had to.

Spanish-speaking families consistently commented that they were pleased with what they perceived to be a high quality of care provided by the hospice group.

[Mother]And if she wasn't here, she'd send another person.
[Father]She'd send another person. Or she'd come and look over him and she would call [the doctor], "Hey, I need this medicine." Within half an hour they'd knock the door and there would be the medicine. It's to say it was a good service, really a very good service. We don't have a single complaint. They provided us with everything, I tell you.

Here too we'd call [hospice nurse] and this or that and she'd come. Sometimes she'd come by to see how she was. "I came to see another child around here" and like that. She wanted to check on [child] to see how she was.

Six families of 20 in this study revoked hospice care, 5 due to uncontrolled symptoms and 1 due to fear of caring for the child in the home at the moment of death. All 5 who revoked hospice due to poor pain and symptom control were English-speaking, and the parents of one additional English-speaking child described terrible suffering through her death, but expressed a belief that having elected the hospice benefit, they were unable to return to the hospital for care.

I'm still—I look back and I don't know what I was thinking. I would have hired private duty, but the response I got, "Well you're the mother, you're the parents, don't you want to take care of your child?" Cause I was thinking I needed to bring her to the hospital because she was having trouble breathing.

[Mother]Her death was bad. I can't say she had a good death.

[Father]She cried and cried and the Saturday before she passed. I held her, she held her. She [mother]—She was inconsolable.

Caregiver appraisal

Both English-speaking and Spanish-speaking participants in our study discussed themes of caregiver appraisal, including the physical strain of caring for a dying child, family stresses, and the need for social support. English-speaking families were more likely to describe caregiver appraisal in terms of the financial cost of caring for their children, and to highlight concerns about maintaining their jobs specifically to maintain insurance coverage for their child.

I carried our insurance so I had to go to work each day. My company is really known for firing people that take leaves or after so we just thought I'd better, I maintained my job and I had the flexibility to go in when I, you know I still had to put my 40 hours in, but I would go back and spend the night at the hospital... but then he stayed with her during the day.

I can tell you I don't think I slept very much. There was you know you're up all night and then you have to go to work...with the stress of knowing that you know, well, my child is going to die...so I think for some parents it might be very difficult to try to do that and try to maintain a job and, you know, bills and all the same stuff and it's, it's you know it's hard financially.

These parents also described that the stress of balancing work with the care of a terminally ill child frequently led to physical strain and near-exhaustion. Yet concerns about financial strains and insurance loss were not described by our Spanish-speaking families, who more commonly focused on concerns about their role in providing bedside nursing care to the child, or who discussed geographic restraints in living far from family or only having one car for transportation.

We didn't live here in Dallas, we lived in Sherman. We didn't have any family here. He, my son, the big one, and I were there at the hospital. We practically lived in the hospital the first months.

Many of our Spanish-speaking families described being far from family in Mexico; seven of eight Spanish-speaking interviews specifically mentioned Mexico as the country of origin. They did not describe involving their extended families in the decision-making and instead discussed making decisions as a small unit, often mentioning a lack of understanding by other family members who were not directly experiencing the loss. Consistent with prior research, themes of withholding bad news from the patient and of not discussing death openly as a family were reported.²⁸

We didn't want to [tell her] because, um, because we have always known that she is very, um, is very, how can I tell you? That they know because if they are fighting to live, and then if the doctors go and tell them, for example, "No, well, you have this, and this and this." So I think that [the child thinks], "Well, enough."

However, Spanish-speaking families did mention being encouraged by providers to be honest with their child, and that at times, they allowed older children to discuss difficult news with providers in English. English-speaking families were more likely to discuss death openly as a family and to prepare the child for his or her death, which is consistent with studies examining communication at the end of life in Caucasian adults.²⁸

Obviously there were scary times and when we started talking about those, but he got to a point where he, he knew he was going to die and we talked openly about that and you know we tried to prepare him as best that we could with our religious beliefs and what we believe would happen after he died...so we have some really amazing memories of, associated with those kind of experiences.
Most parents teach their child how to live. We taught ours how to die.

Many English-speaking families mentioned the importance of the child life specialist in facilitating these conversations and their disappointment when child life services were cut from those provided by hospice either during or after the child's care.

We need the medical, but if I had to name one person that made the most significant difference it was Child Life, it was [therapist] and the chaplain.

The child life really made a difference because she worked with my son too because [child] and our son are, were very close in age and very tight.

Discussion

Public health scientists have investigated language preference as a marker of acculturation, a construct for the pro-

cess by which foreign-born individuals and their children acquire and accommodate the values, beliefs, language, customs and mannerisms of the new society in which they live.^{29,30} We explored the hospice experience, from the perspective of bereaved parents whose children had died of cancer and were enrolled in hospice, to gain an understanding of hospice care for children and to ascertain whether any major differences exist in the hospice experience between Latino and Caucasian families. In our study context, acculturation theory would suggest that family preference to interview in Spanish or English may act as a proxy for other sociocultural factors shaping parent perspectives on the hospice experience.^{31,32}

Previous studies have highlighted tremendous communication barriers to receiving adequate pediatric palliative care for Mexican American and Chinese American parents who did not speak English, leading to long-lasting distress and dissatisfaction with care.³³ Based on this, we anticipated that our Spanish-speaking families might express frustrations in communication with oncology and hospice providers and describe significant language barriers to providing adequate care for their children. While we did learn of instances of poor communication from Spanish-speaking families, these instances were not more common among the Spanish-speaking versus English-speaking families. Models for the provision of culturally competent care are available and our data further support incorporating them into oncology and palliative care training.^{34,35} However, while it is imperative for providers to receive training in culturally sensitive communication, we are also mindful that individual patient considerations also matter. Our findings indicate a distinction between language barriers with quality communication and poor communication with providers, regardless of patient language preference.³⁴

Prior retrospective interviews with bereaved parents of children who died of cancer have indicated that many of these children suffered from pain and other symptoms at the end of life.³⁶ Yet our study is the first to describe inadequate symptom management specifically among children receiving hospice care, and the first to link hospice revocation with poor pain and symptom control. This phenomenon was more commonly reported by English-speaking families. During our interviews, we did question our Spanish-speaking parents about pain and symptom management, and some responded that "It was more important to be home" and did not further elaborate on symptom control for their children. Thus, we are not convinced that these children had superior pain and symptom control, only that the family's priority was to experience the death of the child in the comfort of their home.

Caregiver appraisal has been defined as the "physical, psychological or emotional, social, and financial problems that can be experienced by family members," and the experience of caregiving is viewed as having both positive and negative dimensions.^{37,38} Financial burdens, psychological distress, and emotional hardships borne by parents and family members of children receiving treatment for cancer have been previously described.³⁹⁻⁴⁵ Prior to this research, studies have yet to examine such burdens in families of children receiving hospice care or at the end of life. Importantly, English-speaking and Spanish-speaking families here described differing themes of caregiver burden that invoked

issues of socioeconomic status. Our English-speaking families were more likely to have attained a higher level of education and to carry private insurance coverage for their child, which may indicate a higher socioeconomic status than parents in Spanish-speaking families. English-speaking parents were more likely to describe the strain of maintaining a job through the child's illness and death, such that insurance coverage would be protected. Spanish-speaking families did not mention concerns regarding insurance and instead focused on the difficulties of bedside caregiving and distance from family in Mexico. More studies are warranted to describe all constructs of caregiver burden in parents of children receiving hospice care, to understand the impact of socioeconomic status in caregiver burden, and to explore how hospice providers may best allocate resources to ameliorate this burden. Because the Affordable Care Act allows for concurrent hospice and curative care in children, more children may be eligible for hospice care than ever before; this may challenge existing resources and further impact the quality of care provided to children at the end of life.^{21,46}

In 2012, Latinos represented the largest minority group in the United States, comprising 17% of the population; this number is expected to rise to 31% by 2060.⁴⁷ Contro et al.⁴⁸ described the experiences of Mexican American immigrants who moved to the United States and then experienced the death of a child; challenges faced by these families in being far from home included a backdrop of poverty, absence of traditional social support, and challenges in caring for healthy siblings. Other studies about the influence of culture in hospice care have highlighted the importance of the family in EOL decision-making in Latino families, the belief that truth telling about prognosis was harmful to the patient, and a preference to not discuss death openly.^{29,49} While some of these themes were reflected in our interviews, they were not universally shared. As the Latino population of the United States grows, research in EOL care must also evolve to engage children, adolescents, and young adults that reflect both the breadth and unique needs of this population.

This is the first pilot study to examine differences in the racial/ethnic experiences in pediatric hospice care. Because of the exploratory nature of this analysis in a single institution with a small number of patient participants, findings may not be generalizable, but we believe these data are noteworthy in light of significant shifts in population diversity nationally. It is possible that parents who participated in the study represent a different group from those who opted out or refused study participation, but it is impossible to know whether participants represent families who had a "better" or "worse" experience with hospice. Recall bias may have been introduced in that studies were conducted months to years after the child's death. Our study found differences in parents' experience of hospice care varied by language preference. Language preference as a marker of acculturation processes may be mediated by education or other socioeconomic factors; however, our study design did not allow us to differentiate among these variables.

Conclusions

Hospice is an important provider of care for children with cancer at the end of life. While the intense grief as-

sociated with the loss of a child creates common shared experiences, we identified areas where Spanish-speaking and English-speaking families differ in their description of the hospice experience. While parents in both groups described caregiver strain, English-speaking families were more likely to highlight concerns about finances and insurance loss, while Spanish-speaking families described the difficulty of bedside caregiving and geographic hardship. Five English-speaking children in this study revoked hospice because of poor pain and symptom management; an additional English-speaking child died at home with uncontrolled pain because her parents believed they could not return to the hospital. Additional prospective research is warranted to improve the care we provide to children at the end of life, and to establish best practices for the care of those children for whom hospice is an appropriate option. Infrastructure has been created for researchers to conduct outcomes research in adults who receive hospice care, but pediatric researchers lack a comparable vehicle for national research.^{50,51} Establishing the infrastructure to accomplish such research in pediatric populations should be a priority for pediatric palliative and hospice providers nationally.

Acknowledgments

Dr. Thienprayoon received 100% salary support for this project from the St. Baldrick's Foundation Fellows Grant. The St. Baldrick's Foundation had no involvement in study design; the collection, analysis, and interpretation of data; the writing of the report; or the decision to submit the paper for publication. Dr. Lee is supported in part by the UT Southwestern Center for Patient-Centered Outcomes Research through a grant from the Agency for Healthcare Research and Quality (R24 HS022418). Additional support provided by the UTSW Center for Translational Medicine, through the NIH/National Center for Advancing Translational Sciences (UL1TR001105) and the Harold C. Simmons Cancer Center (1P30 CA142543).

Drs. Thienprayoon, Lee, and Winick conceptualized and designed the study, contributed to data analysis, drafted the initial manuscript, and approved the final manuscript as submitted. Dr. Thienprayoon also contributed to data collection (conducted or attended all interviews). Ms. Marks coordinated data collection, participated in data analysis, helped to draft the initial manuscript, and approved the final manuscript as submitted. Ms. Martinez and Ms. Funes contributed to data collection and data analysis, critically reviewed the manuscript, and approved the final manuscript as submitted. Dr. Thienprayoon wrote the first draft of the manuscript and no form of payment was given to any author relative to preparation of the manuscript. Each author takes full responsibility for the research reported herein; all authors have participated in concept and design, analysis and interpretation of data, drafting or revising of the manuscript, and all have approved the manuscript as submitted.

Author Disclosure Statement

No competing financial interests exist.

References

- DuBois PM: The Hospice Way of Death. New York: Human Sciences Press, 1980.
- Smith DH, Granbois JA: The American way of hospice. *Hastings Cent Rep* 1982;12:8–10.
- Hospice Care. National Hospice and Palliative Care Organization. www.nhpco.org/about/hospice-care (Last accessed July 21, 2015).
- Institute of Medicine: *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, D.C.: National Academies Press, 2015.
- Cooper B, Kinsella GJ, Picton C: Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psychooncology* 2006;15:613–622.
- Grinyer A: The importance of place of death for young adults with cancer. *EJC Suppl* 2005;3:475.
- Heath JA, Clarke NE, Donath SM, et al.: Symptoms and suffering at the end of life in children with cancer: An Australian perspective. *Med J Aust* 2010;192:71–75.
- Hechler T, Blankenburg M, Friedrichsdorf SJ, et al.: Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klinische Padiatrie* 2008;220:166–174.
- Vickers J, Thompson A, Collins GS, et al.: Place and provision of palliative care for children with progressive cancer: A study by the Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. *J Clin Oncol* 2007;25:4472–4476.
- Dussel V, Kreicbergs U, Hilden JM, et al.: Looking beyond where children die: Determinants and effects of planning a child's location of death. *J Pain Symptom Manage* 2009;37:33–43.
- Cohen LL: Racial/ethnic disparities in hospice care: A systematic review. *J Palliat Med* 2008;11:763–768.
- Hardy D, Chan W, Liu CC, et al.: Racial disparities in the use of hospice services according to geographic residence and socioeconomic status in an elderly cohort with non-small cell lung cancer. *Cancer* 2011;117:1506–1515.
- Enguidanos S, Yip J, Wilber K: Ethnic variation in site of death of older adults dually eligible for Medicaid and Medicare. *J Am Geriatr Soc* 2005;53:1411–1416.
- Ngo-Metzger Q, Phillips RS, McCarthy EP: Ethnic disparities in hospice use among Asian-American and Pacific Islander patients dying with cancer. *J Am Geriatr Soc* 2008;56:139–144.
- Smith AK, Earle CC, McCarthy EP: Racial and ethnic differences in end-of-life care in fee-for-service Medicare beneficiaries with advanced cancer. *J Am Geriatr Soc* 2009;57:153–158.
- Givens JL, Tjia J, Zhou C, et al.: Racial and ethnic differences in hospice use among patients with heart failure. *Arch Intern Med* 2010;170:427–432.
- Colon M, Lyke J: Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *Am J Hosp Palliat Care* 2003;20:182–190.
- Thienprayoon R, Lee SC, Leonard D, Winick N: Racial and ethnic differences in hospice enrollment among children with cancer. *Pediatr Blood Cancer* 2013;60:1662–1666.
- Johnston DL, Nagel K, Friedman DL, et al.: Availability and use of palliative care and end-of-life services for pediatric oncology patients. *J Clin Oncol* 2008;26:4646–4650.
- Children's International Project on Palliative/Hospice Services Administrative/Policy Workgroup of the National Hospice and Palliative Care Organization. A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions. Alexandria, VA: National Hospice and Palliative Care Organization, 2001.
- Lindley LC, Lyon ME: A profile of children with complex chronic conditions at end of life among Medicaid beneficiaries: implications for health care reform. *Journal of palliative medicine* 2013;16:1388–1393.
- Davies B, Sehring SA, Partridge JC, et al.: Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics* 2008;121:282–288.
- Dalberg T, Jacob-Files E, Carney PA, et al.: Pediatric oncology providers' perceptions of barriers and facilitators to early integration of pediatric palliative care. *Pediatric Blood Cancer* 2013;60:1875–1878.
- Creswell JW, Miller DL: Determining validity in qualitative inquiry. *Theor Pract* 2000;39:124–130.
- Miles MB, Huberman AM: *Qualitative Data Analysis: An Expanded Sourcebook, 2nd ed.* Thousand Oaks, CA: Sage Publications, 1994.
- Cohen DJ, Crabtree BF: Evaluative criteria for qualitative research in health care: Controversies and recommendations. *Ann Fam Med* 2008;6:331–339.
- Mays N, Pope C: Rigour and qualitative research. *Br Med J* 1995;311:109–112.
- Kreling B, Selsky C, Perret-Gentil M, et al.: "The worst thing about hospice is that they talk about death." Contrasting hospice decisions and experience among immigrant Central and South American Latinos with US-born White, non-Latino cancer caregivers. *Palliat Med* 2010;24:427–434.
- Arcia E, Skinner M, Bailey D, et al.: Models of acculturation and health behaviors among Latino immigrants to the US. *Soc Sci Med* 2001;53:41–53.
- Hunt LM, Schneider S, Comer B: Should "acculturation" be a variable in health research? A critical review of research on US Hispanics. *Soc Sci Med* 2004;59:973–986.
- Unger JB, Cruz TB, Rohrbach LA, et al.: English language use as a risk factor for smoking initiation among Hispanic and Asian American adolescents: Evidence for mediation by tobacco-related beliefs and social norms. *Health Psychol* 2000;19:403–410.
- Lee S, Hoang AN, Tsui J: Interview language: A proxy measure for acculturation among Asian Americans in a population-based survey. *J Immigr Minor Health* 2011;13:244–252.
- Davies B, Contro N, Larson J, et al.: Culturally-sensitive information-sharing in pediatric palliative care. *Pediatrics* 2010;125:e859–865.
- Wiener L, McConnell DG, Latella L, et al.: Cultural and religious considerations in pediatric palliative care. *Palliat Support Care* 2013;11:47–67.
- Flores G: Culture and the patient-physician relationship: achieving cultural competency in health care. *J Pediatr* 2000;136:14–23.
- Wolfe J, Grier HE, Klar N, et al.: Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000;342:326–333.
- George LK, Gwyther LP: Caregiver well-being: A multi-dimensional examination of family caregivers of demented adults. *Gerontologist* 1986;26:253–259.
- Given CW, Given B, Stommel M, et al.: The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health* 1992;15:271–283.

39. Lansky SB, Cairns NU, Clark GM, et al.: Childhood cancer: Nonmedical costs of the illness. *Cancer* 1979;43:403–408.
40. Miedema B, Easley J, Fortin P, et al.: The economic impact on families when a child is diagnosed with cancer. *Current Oncol* 2008;15:173–178.
41. Aung L, Saw SM, Chan MY, et al.: The hidden impact of childhood cancer on the family: a multi-institutional study from Singapore. *Ann Acad Med Singapore* 2012;41:170–175.
42. Heath JA, Lintuuran RM, Rigguto G, et al.: Childhood cancer: its impact and financial costs for Australian families. *Pediatr Hematol Oncology* 2006;23:439–448.
43. Barr RD, Sala A: Hidden financial costs in the treatment for childhood cancer. *J Pediatr Hematol Oncol* 2003;25:842–844.
44. Dockerty JD, Skegg DC, Williams SM: Economic effects of childhood cancer on families. *J Paediatr Child Health* 2003;39:254–258.
45. Rosenberg AR, Dussel V, Kang T, et al.: Psychological distress in parents of children with advanced cancer. *JAMA Pediatr* 2013;167:537–543.
46. Patient Protection and Affordable Care Act, 42 U.S.C. § 18001 (2010).
47. US Census Bureau: U.S. Census Bureau Daily Feature for September 15: Hispanic Heritage Month 2013.
48. Contro N, Davies B, Larson J, et al.: Away from home: experiences of Mexican American families in pediatric palliative care. *J Soc Work End Life Palliat Care* 2010;6:185–204.
49. Taxis JC, Keller T, Cruz V: Mexican Americans and hospice care. Culture, control, and communication. *J Hosp Palliat Nurs* 2008;10:133–141.
50. NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, October 2013..
51. NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, April 2009.

Address correspondence to:
Rachel Thienprayoon, MD
Pediatric Palliative and Comfort Care Team
Cincinnati Children's Hospital Medical Center
3333 Burnet Avenue, ML-2001
Cincinnati, OH 45229-3039

E-mail: rachel.thienprayoon@cchmc.org