

# Pediatric Advance Directives: Parents' Knowledge, Experience, and Preferences



**WHAT'S KNOWN ON THIS SUBJECT:** As the number of chronically ill children grows in the United States, end-of-life discussions and advance directives (AD) will become increasingly important. Although pediatric palliative care is gaining interest, little is known about parental preferences regarding ADs for chronically ill children.



**WHAT THIS STUDY ADDS:** Knowledge about ADs is limited among caregivers of children who have chronic illness. However, interest in creating ADs is high, suggesting an unmet need and opportunity for health care providers to improve the care of children who have chronic illness.

## abstract

**OBJECTIVES:** To explore parents' and caregivers' experience, knowledge, and preferences regarding advance directives (ADs) for children who have chronic illness.

**METHODS:** We conducted a prospective, cross-sectional survey of parents and caregivers of children who have chronic illness. During ambulatory medical visits, participants were asked about previous AD experience and knowledge, future preferences regarding AD discussions, their child's past and current health status, and family demographics.

**RESULTS:** Among 307 participants surveyed, previous AD experience was low, with 117 (38.1%) having heard of an AD, 54 (17.6%) having discussed one, and 77 (25.1%) having known someone who had an AD. Furthermore, 27 (8.8%) participants had an AD or living will of their own, and 8 (2.6%) reported that their chronically ill child had an AD. Previous AD knowledge was significantly more likely among parents and caregivers who had a college degree than those who did not have a high school diploma, yet significantly less likely among primarily Spanish-speaking parents and caregivers than those primarily English-speaking. Interest in creating an AD for the child was reported by 151 (49.2%) participants, and was significantly more likely among families who had more frequent emergency department visits over the previous year.

**CONCLUSIONS:** The limited AD experience and knowledge of parents and caregivers of children who have chronic illness and their interest in creating an AD suggest an unmet need among families of children who have chronic illness, and an opportunity to enhance communication between families and medical teams regarding ADs and end-of-life care. *Pediatrics* 2014;134:e436–e443

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### KEY WORDS

advance care planning, special-needs children, palliative care, decision-making, end of life

### ABBREVIATIONS

AD—advance directive  
CPCT—comfort and palliative care team  
ED—emergency department  
 $\chi^2$ —chi-square

Dr Liberman conceptualized and designed the study, designed the data collection survey, coordinated and supervised data collection, supervised the data analyses, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Pham coordinated and supervised data collection, carried out the data analyses, and reviewed and revised the manuscript; Dr Nager contributed to the study design, assisted in design of the data collection survey, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

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Every year in the United States over 50 000 children die, and at any time >500 000 children are living with life-limiting illness.<sup>1</sup> A significant proportion of these pediatric deaths are in children who have chronic medical illnesses.<sup>2</sup> Rarely do children in the United States, including those who have chronic illness, have an advance directive (AD) or advanced care plan to communicate preferences for end-of-life care. Although pediatricians are well trained to take care of acutely ill children, the field of pediatric palliative care has only recently gained momentum.<sup>3–5</sup> As the number of chronically ill children rises in the United States, there will be a pronounced epidemiologic shift from acute to chronic pediatric care.<sup>6,7</sup>

The Patient Self Determination Act of 1991 has legislatively mandated that AD information and patient preferences be solicited and documented for all adult patients.<sup>8</sup> By encouraging and normalizing end-of-life discussions and by creating ADs, patients and their families are given an opportunity to examine and articulate their treatment preferences, particularly if patients become unable to speak or make decisions for themselves.<sup>9–11</sup> Literature on adult palliative care is expansive.<sup>12–17</sup> By comparison, research in pediatric palliative care and end-of-life planning is considerably more limited.<sup>3,18,19</sup> To date, most research evaluating pediatric palliative care has focused on adolescents who have HIV and cancer.<sup>20–22</sup>

The current study examined, among a broad range of children who have chronic illness, the experiences that their parents and caregivers have had with ADs. This study aimed to identify knowledge and preferences about ADs and characteristics associated with interest in creating ADs.

## METHODS

### Study Design

We conducted a prospective cross-sectional survey of parents and care-

givers of children who have chronic illness who were recruited from the emergency department (ED) and outpatient clinics at a children's hospital. The study was approved by the Institutional Review Board.

### Study Setting and Population

Using convenience sampling, parents and caregivers were non-randomly approached in the hospital's primary care pediatric clinic, pulmonary clinic, and ED between May 2012 and February 2013. The institution is an urban tertiary care pediatric medical center in Los Angeles, California, with over 300 000 annual outpatient clinic visits and an annual ED census of ~70 000. Study eligibility included parents and caregivers who spoke English or Spanish, the languages spoken by the majority of patients at the study site, and who were caring for a child who had a chronic illness (ie, defined by the US National Center for Health Statistics as a disease or condition existing for at least 3 months).

### Measures and Procedures

Potential subjects were identified by the treating physicians and research assistants, with eligibility ultimately determined by the treating physician. The ED tracking board and clinic schedules were continuously monitored for eligible patients by treating physicians and research assistants, with enrollment largely dependent on research assistant availability. After receiving participants' verbal consent, the investigator-developed survey was administered directly by the principal investigator and trained research assistants to study participants verbally in a private room to ensure confidentiality. Survey administration took ~10 to 20 minutes. Additional medical information was abstracted from the patients' medical records. If >1 parent

or caregiver was present, the survey was administered to the individual identified as the child's primary caregiver. Official certified hospital interpreters were used for Spanish-speaking participants.

The survey was developed specifically for use in this study. The survey was refined by ED physician colleagues, research specialists, and hospital diversity committee members, written at a third-grade reading level, and translated into Spanish. All complex terminology, such as ADs, advanced care guidelines, and living wills, were defined in layperson's terms within the survey. ADs and living wills were used interchangeably and defined as a document giving specific instructions about medical treatment to be administered when a patient is terminally ill or permanently unconscious. For the purposes of this survey, advanced care guidelines were defined as any plan prepared in advance outlining what therapies and interventions parents or caregivers would like administered to their child. The survey contained 4 sections. The first section included questions about the child's chronic medical illness. The second section included family demographics such as ethnicity and primary language spoken at home. The third section solicited information about the child's health status. The final section explored the caregiver's medical decision-making preferences and knowledge of ADs. All survey questions were closed-ended, primarily yes/no and multiple choice, with an "other" option for participants to provide open-ended responses.

Data were recorded directly onto a survey tool and subsequently transcribed into an Excel database. A trained research assistant performed all data entry. Ten percent of the data were randomly audited by the principal investigator to confirm accuracy of the data transcribed.

## Statistical Analyses

The Statistical Package for the Social Sciences (SPSS Version 17, SPSS Inc, Chicago, IL; 2008) was used to compute summary statistics and perform statistical analyses. Categorical variables were analyzed using chi-square ( $\chi^2$ ) test for association. Exact *P* values were conservatively reported for all contingency tables with and without expected cell counts  $>5$ . For each statistically significant  $\chi^2$  result, effect size (Cramer's *V*) was computed to measure the strength of the association (from 0 to 1, with 1 representing the strongest possible association). Finally, direct logistic multiple regression was used to further analyze 2 outcomes: whether parents and caregivers have heard of an AD, and their interest in creating an AD for their child.

## RESULTS

Of 383 families approached, 307 (80%) agreed to participate in the study. Among families who declined participation, 75% of children were male with a mean age of 9.03 years (SD = 5.99; range, 0.33 to 19). Overall, 60.6% of children in the final sample were male with a mean age of 8.95 (SD = 5.99; range, 0.08 to 21). Sixty-six of the 307 surveys completed (21.5%) were administered in Spanish.

Table 1 presents characteristics of the chronically ill children whose parents and caregivers were included in the final study sample (*n* = 307). Forty-five percent were diagnosed with a chronic illness at birth and 75.6% of the children were taking between 1 and 9 medications daily. Approximately two-thirds required the use of medical equipment, most commonly a feeding tube. Nearly half of the patients had 3 or more chronic conditions, most frequently genetic and metabolic disorders, epilepsy, chronic lung disease, and malignancy. Frequencies of outpatient visits over the previous 12

**TABLE 1** Characteristics of Children Who Have Chronic Illness

| Variables                                  | <i>n</i> (%) | Missing Data, <i>n</i> (%) |
|--|--------------|----------------------------|
| Age (years)                                |              | 0                          |
| 0 to 4                                     | 95 (30.9)    |                            |
| 5 to 8                                     | 66 (21.5)    |                            |
| 9 to 12                                    | 37 (12.1)    |                            |
| >12  | 109 (35.5)   |                            |
| Male gender                                | 186 (60.6)   | 1 (0.3)                    |
| Country of birth                           |              | 2 (0.7)                    |
| United States                              | 295 (96.1)   |                            |
| Other                                      | 10 (3.3)     |                            |
| Age at diagnosis (years)                   |              | 6 (2.0)                    |
| At birth                                   | 139 (45.3)   |                            |
| Before first birthday                      | 60 (19.5)    |                            |
| 2 to 5                                     | 59 (19.2)    |                            |
| >6   | 43 (14.0)    |                            |
| Chronic illnesses <sup>a</sup>             |              | 3 (1.0)                    |
| Genetic and metabolic disorders            | 73 (23.8)    |                            |
| Epilepsy                                   | 59 (19.2)    |                            |
| Chronic lung disease                       | 48 (15.6)    |                            |
| Feeding intolerance                        | 44 (14.3)    |                            |
| Malignancy                                 | 44 (14.3)    |                            |
| Hydrocephalus                              | 42 (13.7)    |                            |
| Chronic respiratory failure                | 32 (10.4)    |                            |
| Asthma                                     | 22 (7.2)     |                            |
| Congenital heart disease                   | 20 (6.5)     |                            |
| Sickle cell disease                        | 14 (4.6)     |                            |
| Cystic fibrosis                            | 6 (2.0)      |                            |
| Daily medications                          |              | 0                          |
| 0  | 37 (12.1)    |                            |
| 1 to 3                                     | 121 (39.4)   |                            |
| 4 to 6                                     | 70 (22.8)    |                            |
| 7 to 9                                     | 41 (13.4)    |                            |
| >9   | 38 (12.4)    |                            |
| Medical equipment <sup>a</sup>             |              | 19 (6.2)                   |
| Feeding tube                               | 115 (37.5)   |                            |
| Tracheostomy                               | 45 (14.7)    |                            |
| Ventriculoperitoneal shunt                 | 38 (12.4)    |                            |
| Ventilator                                 | 29 (9.4)     |                            |
| Central venous access                      | 21 (6.8)     |                            |
| Urinary catheter                           | 5 (1.6)      |                            |
| No medical equipment                       | 86 (28.0)    |                            |
| Ability to do the following <sup>a</sup>   |              | 1 (0.3)                    |
| Sit  | 229 (74.6)   |                            |
| Eat by mouth                               | 202 (65.8)   |                            |
| Attend school                              | 195 (63.5)   |                            |
| Walk                                       | 171 (55.7)   |                            |
| Eat unassisted                             | 154 (50.2)   |                            |
| Write                                      | 145 (47.2)   |                            |
| Read                                       | 134 (43.6)   |                            |
| Outpatient visits over past 12 mo          |              | 2 (0.7)                    |
| 1 to 5                                     | 120 (39.1)   |                            |
| 6 to 10                                    | 68 (22.1)    |                            |
| 11 to 20                                   | 58 (18.9)    |                            |
| >20  | 59 (19.2)    |                            |
| ED visits over past 12 mo                  |              | 1 (0.3)                    |
| 1 to 5                                     | 240 (78.2)   |                            |
| 6 to 10                                    | 45 (14.7)    |                            |
| 11 to 20                                   | 14 (4.6)     |                            |
| >20  | 7 (2.3)      |                            |
| Inpatient hospitalizations over past 12 mo |              | 3 (1.0)                    |
| 0 to 5                                     | 263 (85.7)   |                            |
| 6 to 10                                    | 23 (7.5)     |                            |
| 11 to 20                                   | 13 (4.2)     |                            |
| >20  | 5 (1.6)      |                            |

TABLE 1 Continued

| Variables                      | n (%)      | Missing Data, n (%) |
|--------------------------------|------------|---------------------|
| Child's primary caregiver      |            | 0                   |
| Mother                         | 290 (94.5) |                     |
| Father                         | 12 (3.9)   |                     |
| Other (eg, grandparent, nurse) | 5 (1.6)    |                     |

<sup>a</sup> Percentages do not add to 100 because children had more than 1 chronic illness, medical equipment, and functional ability.

months among children in the study sample varied substantially. In contrast, frequencies of ED visits were less varied, with 78.2% of children having had 1 to 5 visits over the previous 12 months. Similarly, most of the children had 0 to 5 inpatient hospitalizations over the previous 12 months.

Table 2 details the characteristics of the final sample of parents and caregivers. Seventy-two percent of parents and caregivers self-identified as Hispanic. Fifty-five percent of respondents were born outside of the United States, with approximately half of these respondents born in Mexico. In contrast, most of their children were US-born. Furthermore, nearly half of respondents had been told their child's life might be shorter than that of a normal child.

Table 3 shows frequencies of respondent knowledge and preferences about

ADs. When asked about familiarity with ADs, 61.6% of respondents reported that they had never heard of ADs and 81.8% had never discussed one previously. Only 3% reported that they had created an AD for their child, with a larger percentage, 28.7%, having advanced care guidelines or a medical care plan. Despite low previous experience with ADs, 49.2% of all parents and caregivers surveyed expressed interest in creating an AD for their child. Of note, 12% of parents and caregivers thought their child did not need an AD. When asked who should assist in creating an AD, 88 (28.7%) preferred their child's primary care physician, 68 (22.1%) their child's subspecialty physician, 32 (10.4%) their child's social worker or case manager, 80 (26.1%) their family, 13 (4.2%) their friends, and 18 (5.9%) their spiritual

advisor. Perceived advantages and disadvantages regarding the creation of an AD are described in Table 4.

Significant  $\chi^2$  associations between AD knowledge and preferences and demographic characteristics are presented in Table 5. Based on significant  $\chi^2$  results, a direct logistic multiple regression model was used to test education, language spoken at home, ethnicity, and religion (as simultaneous predictors) on whether parents and caregivers had heard of an AD (Table 6). Multicollinearity was low among all other predictors (tolerances  $\geq 0.81$ ) by excluding US-born (tolerance 0.67) owing to statistical redundancy with language. The model indicated that the primary determinants of AD knowledge were education and language, after controlling for ethnicity and religion. Specifically, AD knowledge was significantly more likely among parents and caregivers who had a college degree than those who did not have a high school diploma, yet significantly less likely among parents and caregivers primarily Spanish-speaking than those primarily English-speaking.

Another direct logistic multiple regression model based on significant  $\chi^2$  results was used to test ED visits, inpatient hospitalizations, and tracheostomy (as simultaneous predictors) on interest in creating an AD, among parents and caregivers whose child did not already have one (Table 6). Multicollinearity was low among all predictors (tolerances  $\geq 0.90$ ). The model showed that interest in creating an AD was significantly more likely among parents and caregivers of children who had 11 to 20 ED visits over the previous 12 months. However, interest in creating an AD was significantly less likely among parents and caregivers of children who had 11 to 20 inpatient hospitalizations over the previous 12 months. Tracheostomy was not a significant predictor.

TABLE 2 Characteristics of Parents and Caregivers

| Variables                           | n (%)      | Missing Data, n (%) |
|-------------------------------------|------------|---------------------|
| Country of birth                    |            | 1 (0.3)             |
| United States                       | 137 (45.0) |                     |
| Mexico                              | 86 (28.0)  |                     |
| Other                               | 83 (27.0)  |                     |
| Ethnicity                           |            | 1 (0.3)             |
| Hispanic                            | 223 (72.6) |                     |
| White                               | 34 (11.1)  |                     |
| Black/African American              | 25 (8.1)   |                     |
| Other                               | 24 (7.8)   |                     |
| Primary language spoken at home     |            | 1 (0.3)             |
| English                             | 168 (54.7) |                     |
| Spanish                             | 131 (42.7) |                     |
| Other                               | 7 (2.3)    |                     |
| Highest level of education obtained |            | 2 (0.7)             |
| No high school diploma              | 79 (25.7)  |                     |
| High school diploma or some college | 152 (49.5) |                     |
| College degree or higher            | 74 (24.1)  |                     |
| Religious affiliation               |            | 1 (0.3)             |
| Catholic                            | 181 (59.0) |                     |
| Christian                           | 88 (28.7)  |                     |
| None                                | 27 (8.8)   |                     |
| Other                               | 10 (3.3)   |                     |

**TABLE 3** Parent and Caregiver Knowledge and Preferences About Advance Directives

| Survey Item   | Yes, <i>n</i> (%) | No, <i>n</i> (%) | Missing Data, <i>n</i> (%) |
|---|-------------------|------------------|----------------------------|
| Would you like to create an AD for your child?  | 151 (49.2)        | 141 (45.9)       | 15 (4.9)                   |
| Have you ever heard of an AD?   | 117 (38.1)        | 189 (61.6)       | 1 (0.3)                    |
| Does your child have a medical care plan or advanced care guidelines?                   | 88 (28.7)         | 215 (70.0)       | 4 (1.3)                    |
| Do you know anyone with an AD or living will?   | 77 (25.1)         | 229 (74.6)       | 1 (0.3)                    |
| Have you ever wanted to discuss an AD with your physician?                              | 57 (18.6)         | 247 (80.5)       | 3 (1.0)                    |
| Have you ever discussed an AD?  | 54 (17.6)         | 251 (81.8)       | 2 (0.7)                    |
| Do you have an AD or living will?   | 27 (8.8)          | 278 (90.6)       | 2 (0.7)                    |
| Has your child's physician ever brought up an AD, but you refused to talk about it?     | 14 (4.6)          | 289 (94.1)       | 4 (1.3)                    |
| Have you ever wanted to discuss an AD for your child, but someone talked you out of it? | 6 (2.0)           | 299 (97.4)       | 2 (0.7)                    |
| Does your child have an AD?   | 8 (2.6)           | 297 (96.7)       | 2 (0.7)                    |

## DISCUSSION

In this study we found limited basic knowledge and previous experience with ADs among parents and caregivers of chronically ill children, with close to two-thirds of those surveyed never having heard of an AD. These findings are consistent with existing literature, which has described a poor understanding of ADs among the general US adult population. Furthermore, only

**TABLE 4** Frequencies of Perceived Advantages and Disadvantages of Advance Directives

| Survey Item  | <i>n</i> (%) |
|--|--------------|
| <b>Advantages</b>  |              |
| Ability to have more control over what happens to my child.                                | 180 (58.6)   |
| Opportunity to communicate to the medical team what I want for my child.                   | 172 (56.0)   |
| Opportunity to discuss and talk about what I want for my child.                            | 156 (50.8)   |
| Opportunity to think about what I want for my child.                                       | 155 (50.5)   |
| <b>Disadvantages</b>   |              |
| Too difficult to anticipate what might happen to my child in the future.                   | 98 (31.9)    |
| Might change my mind about what I want for my child.                                       | 92 (30.0)    |
| Afraid the medical team will not take care of my child if he/she has an advance directive. | 36 (11.7)    |
| Doubt the medical team will follow my child's advance directive.                           | 30 (9.8)     |
| Too time consuming to create an advance directive for my child.                            | 21 (6.8)     |
| My child does not need an advance directive.   | 36 (11.7)    |

a small percentage of US adults, and an even smaller number of chronically ill children, have ADs in place.<sup>15</sup> This literature and our study's results, however, contrast with a similar survey study done with attendees of a conference for parents of children who have special needs. Results from that study found that 63% of the 76 parents surveyed had heard of an AD, a number significantly higher than the 38.1% we found.<sup>23</sup> Additionally, they found that 21% of those surveyed had an understanding of ADs and 0.5% had actually completed their own AD. The population in the aforementioned study, however, differed substantially from ours, as 55% were college graduates and 98% were white.

We found that knowledge of ADs was significantly more likely among parents and caregivers with greater formal education, and significantly less likely among primarily Spanish-speaking parents and caregivers. It is possible that awareness about ADs may be linked to higher levels of medical literacy and heightened access to health care in the United States. As ADs are a complex concept, often requiring multiple in-depth conversations with a medical provider for accurate comprehension and informed decision-making, individuals who have greater health care literacy and access would likely have more opportunities to learn

about, discuss, and consider end-of-life issues and ADs.

Although only a small fraction of children in our study population had an AD, close to one-third of patients studied had a medical care plan or advanced care guidelines. A medical care plan or advance care guidelines tend to have broader definitions for both the medical and lay communities, and can be as simple as outlining a person's daily medication schedule, or as complex as defining a person's end-of-life wishes. It is possible that many of the children in our study had basic medical plans that described their daily care, but did not address decision-making for critical end-of-life circumstances. The concept of an AD in the United States is often considered a document to be created at the very end of life, when no further curative or therapeutic options exist, or to assist with final decisions related to resuscitative efforts, life support, and heroic measures.<sup>24</sup>

Contrary to our expectations, several proxies of complex health care needs (eg, feeding tube, ventilator) were not associated with previous AD knowledge or a preference to discuss or create an AD. Additionally, we found that interest in creating an AD was significantly less likely among parents and caregivers of children who had frequent inpatient hospitalizations over the previous 12 months. We speculate parents and caregivers of some of the sickest children have expressed directly through discussions or indirectly through previous medical decisions a desire to "do everything." They perhaps have grown tired of repeatedly being asked about their wishes for their child in different settings and by numerous providers. As a result, both caregivers and the medical team may be discouraged from pursuing discussions about ADs. Results from our analysis of interest in creating an AD for the child had a 58% prediction accuracy, suggesting that

**TABLE 5** Significant  $\chi^2$  Associations Between Knowledge and Preferences About Advance Directives and Demographic Characteristics

| Variables   | P Value, Exact | Effect Size, Cramer's V |
|---|----------------|-------------------------|
| Would you like to create an AD for your child?                        |                |                         |
| Frequency of ED visits  | 0.03           | 0.18                    |
| Frequency of inpatient hospitalizations                               | 0.05           | 0.16                    |
| Presence of tracheostomy  | 0.05           | 0.12                    |
| Have you ever heard of an AD?   |                |                         |
| Education of parent/caregiver   | <0.001         | 0.36                    |
| Ethnicity of parent/caregiver   | <0.001         | 0.25                    |
| Language spoken at home   | <0.001         | 0.30                    |
| Religion of parent/caregiver  | 0.02           | 0.18                    |
| US-born parent/caregiver  | <0.001         | 0.23                    |
| Does your child have a medical care plan or advanced care guidelines? |                |                         |
| Daily medications   | 0.004          | 0.22                    |
| Education of parent/caregiver   | 0.01           | 0.19                    |
| Do you know anyone with an AD or living will?                         |                |                         |
| Education of parent/caregiver   | <0.001         | 0.44                    |
| Ethnicity of parent/caregiver   | <0.001         | 0.35                    |
| Language spoken at home   | <0.001         | 0.34                    |
| Presence of ventriculoperitoneal shunt                                | 0.002          | 0.19                    |
| US-born parent/caregiver  | <0.001         | 0.24                    |
| Have you ever wanted to discuss an AD with your physician?            |                |                         |
| Daily medications   | 0.04           | 0.18                    |
| Education of parent/caregiver   | 0.01           | 0.19                    |
| Language spoken at home   | 0.004          | 0.21                    |
| Have you ever discussed an AD?  |                |                         |
| Education of parent/caregiver   | <0.001         | 0.32                    |
| Ethnicity of parent/caregiver   | 0.006          | 0.21                    |
| Language spoken at home   | 0.02           | 0.16                    |
| Presence of ventriculoperitoneal shunt                                | 0.04           | 0.13                    |
| US-born parent/caregiver  | 0.05           | 0.12                    |
| Do you have an AD or living will?                                     |                |                         |
| Education of parent/caregiver   | 0.002          | 0.22                    |
| Language spoken at home   | 0.03           | 0.16                    |
| Presence of ventriculoperitoneal shunt                                | 0.003          | 0.20                    |

this is a complex topic requiring further research.

Although the Patient Self Determination Act encourages advanced medical planning by competent adults in the United States, no such official system or legislation currently exists to support parents and children in making similar medical directives. At present, parents and children rely on a member of the medical team or their own initiative to begin the discussion.<sup>25</sup> Based on the results of this study, even among a subset of children most likely to need an AD, few parents had any knowledge of what an AD was, and even fewer had personal experience creating one. Despite this, nearly half of those surveyed expressed interest

in learning about and creating an AD for their child.

These results should encourage advancement in the field of pediatric palliative care. For over a decade, the American Academy of Pediatrics has advocated that pediatric health care providers have early and frequent discussions about palliative care with families of chronically ill children. The American Academy of Pediatrics policy statement on palliative care for children from 2000 expressed that, "the goal is to add life to the child's years, not simply years to the child's life."<sup>26</sup> More recently, a representative group of pediatricians from across North America came together to author a special article regarding children

who have medical complexity, which emphasized that the availability of palliative care, end-of-life care, ADs, and hospice is critical to the care of children who have life-limiting conditions.<sup>27</sup> Several studies looking specifically at advance care planning in pediatrics have reported the process to be helpful and beneficial to the family and child.<sup>20–22,28–32</sup>

At the conclusion of our survey, most participants were offered a basic information sheet about the hospital's Comfort and Palliative Care Team (CPCT) and a business card to contact the team. No respondents contacted the CPCT, which suggests that the parents or caregivers took the information without intention of following up with the CPCT, intended to follow-up but ultimately decided not to, or faced subsequent barriers arranging follow-up despite their intention to do so. Indeed, a study by Levetown et al found that discussions related to limitations and withdrawal of care were physician-initiated and not greatly influenced by the nature of the chronic disease. Rather, the expectation of imminent death was the most significant factor influencing placement of care restrictions on these patients.<sup>33</sup> Levetown's study supports the idea that parents prefer to have physicians initiate discussions, and that families of children who have chronic illness may delay discussions about limiting care until death is imminent.

Predicting patient outcomes and then communicating these predictions to families is difficult in medicine, particularly in pediatrics. This adds reluctance and uncertainty to the process of advance care planning.<sup>4,34</sup> In our study, the most common response to the question soliciting opinions about potential disadvantages to creating an AD was that it was too difficult to predict what might happen to the child. Future initiatives seeking to enhance

**TABLE 6** Direct Logistic Multiple Regression for Advance Directive Knowledge and Interest

| Outcome and Predictor Variables                             | P Value             | B (SE)       | Odds Ratio (95% Confidence Interval) |
|---|---------------------|--------------|--------------------------------------|
| Have you ever heard of an AD? <sup>a</sup>                  |                     |              |                                      |
| Education of parent/caregiver                               | <0.001 <sup>b</sup> |              |                                      |
| High school diploma vs no high school diploma               | 0.75                | 0.13 (0.40)  | 1.14 (0.52–2.48)                     |
| Some college vs no high school diploma                      | 0.26                | 0.48 (0.42)  | 1.61 (0.70–3.70)                     |
| College degree vs no high school diploma                    | <0.001 <sup>b</sup> | 1.54 (0.43)  | 4.66 (2.01–10.83)                    |
| Ethnicity of parent/caregiver                               | 0.58                |              |                                      |
| Hispanic/Latino vs white                                    | 0.18                | −0.61 (0.46) | 0.54 (0.22–1.32)                     |
| Black/African American vs white                             | 0.35                | −0.53 (0.57) | 0.59 (0.19–1.80)                     |
| Other ethnicity vs white                                    | 0.32                | −0.63 (0.64) | 0.53 (0.15–1.86)                     |
| Language spoken at home                                     | 0.02                |              |                                      |
| Spanish vs English  | 0.01 <sup>b</sup>   | −0.86 (0.34) | 0.42 (0.22–0.82)                     |
| Other language vs English                                   | 0.18                | −1.30 (0.98) | 0.27 (0.04–1.85)                     |
| Religion of parent/caregiver                                | 0.14                |              |                                      |
| Catholicism vs no religion                                  | 0.70                | −0.19 (0.48) | 0.83 (0.32–2.14)                     |
| Christianity vs no religion                                 | 0.66                | −0.21 (0.47) | 0.81 (0.33–2.03)                     |
| Other religion vs no religion                               | 0.07                | 1.61 (0.88)  | 4.99 (0.88–28.24)                    |
| Would you like to create an AD for your child? <sup>c</sup> |                     |              |                                      |
| Frequency of ED visits                                      | 0.04                |              |                                      |
| 6 to 10 visits vs 1 to 5 visits                             | 0.04                | 0.87 (0.43)  | 2.39 (1.04–5.54)                     |
| 11 to 20 visits vs 1 to 5 visits                            | 0.02 <sup>d</sup>   | 2.46 (1.09)  | 11.75 (1.38–100.23)                  |
| 21+ visits vs 1 to 5 visits                                 | 0.84                | 0.17 (0.85)  | 1.18 (0.22–6.26)                     |
| Frequency of inpatient hospitalizations                     | 0.04                |              |                                      |
| 6 to 10 hospitalizations vs 0 to 5 hospitalizations         | 0.37                | −0.50 (0.56) | 0.61 (0.20–1.81)                     |
| 11 to 20 hospitalizations vs 0 to 5 hospitalizations        | 0.01 <sup>d</sup>   | −3.62 (1.42) | 0.03 (0.002–0.44)                    |
| 21+ hospitalizations vs 0 to 5 hospitalizations             | 0.22                | −1.44 (1.18) | 0.24 (0.02–2.38)                     |
| Presence of tracheostomy                                    | 0.14                | 0.53 (0.36)  | 1.69 (0.84–3.40)                     |

<sup>a</sup> Model statistics: *n* analyzed = 304; *n* (%) missing data = 3 (1%); Hosmer-Lemeshow *P* = .10; Omnibus *P* < .001; Cox-Snell *R*<sup>2</sup> = 0.18; Nagelkerke *R*<sup>2</sup> = 0.24; and outcome prediction accuracy = 73%.

<sup>b</sup> Statistical significance according to criterion  $\alpha \leq 0.01$  to control for family-wise type I error rate among predictors.

<sup>c</sup> Model statistics: *n* analyzed = 270; *n* (%) missing data = 29 (10%); Hosmer-Lemeshow *P* = .88; Omnibus *P* = .001; Cox-Snell *R*<sup>2</sup> = 0.09; Nagelkerke *R*<sup>2</sup> = 0.12; and outcome prediction accuracy = 58%.

<sup>d</sup> Statistical significance according to criterion  $\alpha \leq 0.02$  to control for family-wise type I error rate among predictors.

palliative care and AD discussions must take potential barriers, reluctance, and uncertainty into consideration. Policies and guidelines should encourage providers to take a more active and proactive role in these in-depth and ongoing conversations with patients and families, rather than rely on families to initiate and maintain the discussion.<sup>9,35</sup> Alternatively, growing research suggests that specially trained and certified facilitators can successfully conduct conversations on end-of-life issues, alleviating dependence on the medical provider. This can potentially eliminate some of the barriers to these conversations, such as provider time constraints and discomfort.<sup>9,11,20,21</sup>

### Limitations

Our study has a number of limitations. The survey used in this study was developed specifically for this study and therefore not previously validated. Although not pilot-tested with parents, the survey was administered verbally by trained research assistants who were able to answer and clarify any questions that arose. Recall and social desirability biases are inherent in survey research.<sup>36</sup> Our data were collected primarily from the participating caregivers' responses, which meant that we relied on the respondents to report events to the best of their memories. Efforts were made to mitigate social desirability bias in our study by emphasizing anonymity, privacy, and confidentiality. Our analysis did not separate out children who had

no hospitalizations from those who had 1 to 5 to see if any significant findings arose. We used a convenience sample, dependent on treating physician and research assistant identification of eligible subjects, and research assistant availability, which may have introduced selection bias and reduced the generalizability of our results. Although not all eligible subjects were enrolled, given our high acceptance rate of 80%, large sample size, and multiple people identifying and enrolling subjects, discrepant demographics between participants and non-participants are likely minimal. Our study was conducted at 1 institution, which cares for a predominantly Hispanic, urban, and largely disadvantaged population from a single metropolitan area. Therefore, the results may not be generalizable to other settings and populations. Finally, although conclusions can be drawn regarding associations between AD knowledge and experience and characteristics of families of children who have chronic illness, it should be noted that these associations do not suggest causality.

### CONCLUSIONS

Previous knowledge and experience with ADs are limited among parents and caregivers of children who have chronic illness, thereby suggesting an unmet health care need. Parents' and caregivers' strong interest in creating ADs for their chronically ill children signifies a desire to evaluate and determine goals of care and quality of life preferences for their child.

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## Pediatric Advance Directives: Parents' Knowledge, Experience, and Preferences

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