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Communication about prognosis and end-of-life in pediatric organ failure and transplantation

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Abstract

Background: Despite advancements in treatment and survival, pediatric organ failure and transplant populations continue to face significant risks of morbidity and mortality. Little scientific attention has been given to addressing the end-of-life care needs of this growing population of young people. This study characterized current practices, beliefs, and challenges specific to the disclosure of prognosis and end-of-life care topics among providers caring for pediatric organ failure and transplant populations.

Methods: This cross-sectional study included 144 healthcare providers actively caring for children, adolescents, and young adults with organ failure or solid organ transplant history. Participants completed an electronic survey measuring frequency and comfort in discussing the following topics with patients and parents: prognosis/survival statistics, re-transplantation, advance care planning (ACP), and death/dying. Descriptive statistics, two-sample *t* tests, and analysis of variance were used.

Results: Fewer than half of respondents regularly discuss prognosis/survival statistics and potential need for re-transplantation with their pediatric and young adult patients. Less than 20% of providers engage their pediatric patients in ACP discussions, and approximately 30% facilitate such discussions with young adult patients. Pediatric organ failure and transplant providers endorse a number of barriers specific to discussing these topics.

Conclusion: Pediatric organ failure and transplant providers do not regularly discuss prognosis or end-of-life care topics with this patient population. Communication-focused intervention research is needed to improve honest and compassionate discussion of these topics that is aligned with both patients' and parents' needs and preferences.

KEYWORDS

advance care planning, communication, end-of-life, pediatric, solid organ transplant

1 | INTRODUCTION

Five-year survival rates for pediatric heart, kidney, and liver transplant recipients have surpassed 85% due to significant advancements in pediatric solid organ transplantation.^{1,2} Despite noteworthy improvements in both the treatment and survival of pediatric patients with end-stage organ diseases, morbidity and mortality risks remain significant. For instance, pediatric intestinal and lung transplant recipients experience lower 5-year survival rates of 68%⁴ and 58%.⁵ One in ten pediatric heart transplant recipients die within the first year post-transplant,⁶ and a notable portion of children with some forms of end-stage organ disease die while waiting for a transplant.⁷

The Institute of Medicine has called for increased scientific investigation and the development of guidelines to improve the delivery of end-of-life care to pediatric patients with serious illnesses and their families.⁸ To improve the delivery of end-of-life care to pediatric organ failure and transplant patients, a population with very limited end-of-life care-focused research,⁹ it is necessary to understand current provider practices and barriers specific to discussing difficult topics, such as prognosis and ACP, with patients and families. Nearly two decades ago, the American Society of Clinical Oncology¹⁰ conducted a survey of pediatric oncologists assessing attitudes, clinical practices, and training in end-of-life care. Results showed that $\leq 10\%$ of pediatric oncologists received formal end-of-life care training and most learned through “trial and error.” Although pediatric oncologists rated their communication skills as strong, nearly 70% endorsed anxiety about having to tell parents of a child's nearing death and nearly half reported waiting for families to initiate conversations about ACP.¹⁰ This important work informed the development of end-of-life care-specific clinical practice guidelines¹¹ and provider trainings for pediatric oncology—a population with overall survival rates that exceed most solid organ transplant 5-year survival rates.

Guided by the extensive pediatric oncology end-of-life care literature, we developed a web-based survey of pediatric organ failure and transplant providers to (a) characterize current practices, beliefs, and challenges specific to the disclosure of prognosis and discussion of patient and family engagement in ACP, and (b) describe education and training experiences in caring for children with shortened life expectancies and at end-of-life. It was hypothesized that only a minority of healthcare providers will report regularly discussing engagement in ACP with patients and families with notable rates of discomfort specific to discussing death and dying with patients and families. In addition, we examined associations between provider communication practices and demographic, professional, and training characteristics.

2 | PARTICIPANTS AND METHODS

2.1 | Participants and recruitment

This study was reviewed and determined to be exempt by the local Institutional Review Board. Participants included healthcare providers (eg, nurses, transplant coordinators, physicians,

psychologists, social workers) actively caring for children, adolescents, and young adults with end-stage organ disease and/or solid organ transplant history. Participants were recruited from five Listserv managed by pediatric end-stage organ disease and/or solid organ transplant organizations. The number of Listserv members was unknown by some organizations. Eligible participants may have been members of multiple participating Listservs, but were instructed to complete the survey once. Thus, the total number of eligible participants could not be determined. Survey completion time was approximately 10 minutes. Following survey completion, participants could provide their email in order to receive a \$5 e-gift card.

2.2 | Inclusion criteria

Pediatric healthcare providers actively engaged in clinical care were eligible to participate in this study. Our age range guidelines for “pediatric” healthcare providers permitted the inclusion of those who care for young adult patients due to a tendency for pediatric transplant centers to care for patients into young adulthood. Healthcare providers of any professional background, including mental health professionals, were eligible to participate in this study. The survey was only available in English.

2.3 | Survey development

The survey was developed by a task force which included pediatric transplant and palliative care psychologists, a pediatric cardiologist, a pediatric liver/kidney transplant surgeon, and a pediatric palliative care physician. The task force drafted survey questions modeled from similar surveys developed by Hilden et al¹⁰ and Durall et al¹² for use with pediatric oncology providers. A pretest of the web-based survey was conducted with multidisciplinary pediatric providers. Feedback was obtained and integrated. The final survey included 32 items across the following domains: (a) provider demographics; (b) communication practices regarding prognostication, ACP, and end-of-life care; (c) comfort with and (d) perceived barriers to discussing these topics with patients and families; (e) education and training in end-of-life care; and (f) recent experiences with patients at end-of-life. See online supplemental material for sample of survey questions.

2.4 | Statistical analysis

Provider characteristics and survey responses in each domain are summarized as frequency and percentages for categorical variables and median (interquartile range) for continuous variables. To examine associations of provider characteristics and training experiences with communication practices, a 5-point Likert scale (ranging from “never”/“not comfortable” to “very often”/“very comfortable”) of each communication practice was linearly transformed to a 0- to 100-point scale, with higher scores indicating greater provider communication and comfort. The transformed continuous score of each communication practice was compared by provider characteristics and training

experiences, using two-sample *t* test or analysis of variance, as appropriate. The results from the comparison were reported as mean \pm SD. All analyses were performed using SAS version 9.4 (SAS Institute Inc, Cary, NC), with statistical significance set at *P*-value <0.05.

3 | RESULTS

3.1 | Participant characteristics

A total of 144 providers participated in the study with a larger proportion of female respondents (76%; Table 1). The vast majority of participants (87%) indicated United States of America as their country of origin. Participants represented a range of professional disciplines, with attending physicians (non-surgeons; 33%) and transplant coordinators/nurses/advanced practice providers (36%) representing the largest groups. Similarly, providers across various pediatric organ specialties participated, with the majority caring primarily for cardiac (56%), liver (30%), and/or renal populations (30%).

3.2 | Difficult communication practices

Table 2 details the frequency at which providers endorsed discussing the following topics with patients and parents: prognosis/survival statistics, potential need for re-transplantation, ACP, and death/dying.

3.2.1 | Communication of prognosis/survival statistics

Very few providers discuss prognostic or survival statistics with young patients (4-10 years old). A greater number of providers indicated that they communicate prognostic or survival statistics to their adolescent (11-17 years old) patients; yet, a portion (42%, pretransplant; 44%, post-transplant) never or rarely do. Prognostic and survival statistics are often or very often communicated to young adult patients (18-24 years old) by nearly half of participating providers (45%, pretransplant; 36%, post-transplant). Greater than half (56%) of providers indicated communicating these statistics to parents often or very often.

Only 42% of providers indicated that they often or very often discuss potential need for re-transplantation with their adolescent (11-17 years) pretransplant patients; rates were slightly higher for young adult patients (18-24 years) at 49%. The majority of providers (63%) often or very often discuss potential need for re-transplantation with parents.

3.2.2 | Communication about ACP and death/dying

Few providers regularly engage this population of patients and parents in ACP discussions. Less than 20% of providers engage their pediatric patients (<18 years) in ACP discussions, whereas approximately 30% facilitate ACP discussions with young adult patients and parents of pediatric patients. Similarly, providers reported that they

TABLE 1 Provider demographics (N = 144)

| | |
|---|------------|
| Female sex | 109 (75.7) |
| Provider country | |
| United States | 125 (86.8) |
| Canada | 12 (8.3) |
| Australia/New Zealand | 3 (2.1) |
| European Countries | 1 (0.7) |
| South American Countries | 1 (0.7) |
| Not reported | 2 (1.4) |
| Provider type | |
| Attending Physician | 48 (33.3) |
| Attending surgeon | 5 (3.5) |
| Resident/fellow | 6 (4.2) |
| Transplant coordinator, NP, PA, or RN | 52 (36.1) |
| Psychologist | 9 (6.3) |
| Social worker | 5 (3.5) |
| Other | 19 (13.2) |
| Years of practice (y) | |
| <5 | 42 (29.2) |
| 5-10 | 44 (30.6) |
| 11-20 | 29 (20.1) |
| >20 | 29 (20.1) |
| Provider age (y) | |
| <40 | 70 (48.6) |
| 41-50 | 49 (34.0) |
| 51-65 | 23 (16.0) |
| >65 | 2 (1.4) |
| Provider race | |
| White/Caucasian | 118 (81.9) |
| Black/African American | 1 (0.7) |
| Asian | 15 (10.4) |
| Hispanic/Latino | 7 (4.9) |
| Middle Eastern | 1 (0.7) |
| American Indian or Alaskan Native | 1 (0.7) |
| Pacific Islander | 0 (0.0) |
| Bi- or Multi-Racial | 1 (0.7) |
| %Time spent in direct patient care annually (N = 143) | 75 (60-90) |
| Pediatric organ failure/transplant population primarily cared for | |
| Cardiac | 81 (56.3) |
| Liver | 43 (29.9) |
| Lung | 24 (16.7) |
| Renal | 43 (29.9) |
| Intestinal | 16 (11.1) |
| Multivisceral | 16 (11.1) |
| Other | 3 (2.1) |

Data are presented as N (%) for categorical variables and median (25th percentile–75th percentile) for continuous variable.

TABLE 2 Difficult communication practices

| | Never | Rarely | Sometimes | Often | Very often |
|---|-----------|-----------|-----------|-----------|------------|
| How often do you talk about death and dying with | | | | | |
| Young patients (age 4-10) pretransplant | 46 (31.9) | 67 (46.5) | 24 (16.7) | 5 (3.5) | 2 (1.4) |
| Young patients (age 4-10) post-transplant | 41 (28.5) | 74 (51.4) | 24 (16.7) | 3 (2.1) | 2 (1.4) |
| Adolescent patients (age 11-17) pretransplant | 13 (9.0) | 37 (25.7) | 65 (45.1) | 22 (15.3) | 7 (4.9) |
| Adolescent patients (age 11-17) post-transplant | 12 (8.3) | 45 (31.3) | 59 (41.0) | 21 (14.6) | 7 (4.9) |
| Young adult patients (age 18-24) pretransplant | 17 (11.8) | 29 (20.1) | 58 (40.3) | 27 (18.8) | 12 (8.3) |
| Young adult patients (age 18-24) post-transplant | 17 (11.8) | 36 (25.0) | 53 (36.8) | 26 (18.1) | 11 (7.6) |
| Parents/family | 8 (5.6) | 30 (20.8) | 58 (40.3) | 33 (22.9) | 15 (10.4) |
| How often do you engage in ACP with | | | | | |
| Young patients (age 4-10) pretransplant | 68 (47.2) | 50 (34.7) | 14 (9.7) | 9 (6.3) | 3 (2.1) |
| Young patients (age 4-10) post-transplant | 67 (46.5) | 51 (35.4) | 17 (11.8) | 7 (4.9) | 2 (1.4) |
| Adolescent patients (age 11-17) pretransplant | 42 (29.2) | 42 (29.2) | 34 (23.6) | 22 (15.3) | 4 (2.8) |
| Adolescent patients (age 11-17) post-transplant | 42 (29.2) | 45 (31.3) | 35 (24.3) | 20 (13.9) | 2 (1.4) |
| Young adult patients (age 18-24) pretransplant | 37 (25.7) | 36 (25.0) | 29 (20.1) | 29 (20.1) | 13 (9.0) |
| Young adult patients (age 18-24) post-transplant | 36 (25.0) | 39 (27.1) | 30 (20.8) | 28 (19.4) | 11 (7.6) |
| Parents/family | 23 (16.0) | 34 (23.6) | 42 (29.2) | 26 (18.1) | 19 (13.2) |
| How often do you provide prognostic/survival stats to | | | | | |
| Young patients (age 4-10) pretransplant | 67 (46.5) | 39 (27.1) | 17 (11.8) | 11 (7.6) | 10 (6.9) |
| Young patients (age 4-10) post-transplant | 64 (44.4) | 46 (31.9) | 20 (13.9) | 6 (4.2) | 8 (5.6) |
| Adolescent patients (age 11-17) pretransplant | 35 (24.3) | 25 (17.4) | 32 (22.2) | 35 (24.3) | 17 (11.8) |
| Adolescent patients (age 11-17) post-transplant | 35 (24.3) | 28 (19.4) | 40 (27.8) | 26 (18.1) | 15 (10.4) |
| Young adult patients (age 18-24) pretransplant | 33 (22.9) | 20 (13.9) | 25 (17.4) | 35 (24.3) | 30 (20.8) |
| Young adult patients (age 18-24) post-transplant | 34 (23.6) | 23 (16.0) | 34 (23.6) | 26 (18.1) | 26 (18.1) |
| Parents/family | 23 (16.0) | 19 (13.2) | 21 (14.6) | 31 (21.5) | 50 (34.7) |
| How often do you discuss potential need for re-transplantation with | | | | | |
| Young patients (age 4-10) pretransplant | 36 (25.0) | 47 (32.6) | 36 (25.0) | 14 (9.7) | 11 (7.6) |
| Young patients (age 4-10) post-transplant | 31 (21.5) | 50 (34.7) | 38 (26.4) | 12 (8.3) | 13 (9.0) |
| Adolescent patients (age 11-17) pretransplant | 16 (11.1) | 16 (11.1) | 51 (35.4) | 34 (23.6) | 27 (18.8) |
| Adolescent patients (age 11-17) post-transplant | 12 (8.3) | 16 (11.1) | 47 (32.6) | 46 (31.9) | 23 (16.0) |
| Young adult patients (age 18-24) pretransplant | 19 (13.2) | 14 (9.7) | 39 (27.1) | 30 (20.8) | 40 (27.8) |
| Young adult patients (age 18-24) post-transplant | 16 (11.1) | 13 (9.0) | 37 (25.7) | 39 (27.1) | 38 (26.4) |
| Parents/family | 10 (6.9) | 10 (6.9) | 34 (23.6) | 42 (29.2) | 48 (33.3) |

Data are presented as N (%). N = 144.

do not regularly discuss death and dying with their pediatric organ failure and transplant patients and families. Very few (<5%) discuss such topics with patients 10 years old and under. Approximately ¼ or less (20%-27%) of respondents indicated often or very often discussing death and dying with adolescent and young adult patients. One-third (33%) of providers reported often or very often discussing death and dying with parents.

3.2.3 | Comfort in communicating difficult topics

Provider comfort ratings specific to discussing each of these topics are detailed in Table 3. As a whole, about half of respondents reported feeling comfortable or very comfortable discussing

the majority of these difficult topics with patients ≥11 years old. Discussing potential need for re-transplantation was found to be a topic that providers are especially comfortable discussing, even with young patients.

3.3 | Barriers and challenges

Providers endorsed a number of barriers and challenges to discussing difficult topics with pediatric organ failure and transplant populations (Table 4). The most frequently endorsed patient- and family-specific barriers and challenges included the following: Parents do not want difficult news discussed with their child (59%), patients (56%) and parents (55%) do not remember information that was communicated

TABLE 3 Comfort in communicating difficult topics

| | Not comfortable | Not very comfortable | Somewhat comfortable | Comfortable | Very comfortable |
|--|-----------------|----------------------|----------------------|-------------|------------------|
| How comfortable are you in talking about death and dying with | | | | | |
| Young patients (age 4-10) | 27 (18.8) | 42 (29.2) | 36 (25.0) | 26 (18.1) | 10 (6.9) |
| Adolescent patients (age 11-17) | 10 (6.9) | 21 (14.6) | 46 (31.9) | 46 (31.9) | 18 (12.5) |
| Young adult patients (age 18-24) | 10 (6.9) | 13 (9.0) | 45 (31.3) | 48 (33.3) | 24 (16.7) |
| Parents/family | 6 (4.2) | 20 (13.9) | 39 (27.1) | 44 (30.6) | 32 (22.2) |
| How comfortable are you in engaging in ACP with | | | | | |
| Young patients (age 4-10) | 32 (22.2) | 39 (27.1) | 35 (24.3) | 24 (16.7) | 9 (6.3) |
| Adolescent patients (age 11-17) | 18 (12.5) | 29 (20.1) | 35 (24.3) | 41 (28.5) | 16 (11.1) |
| Young adult patients (age 18-24) | 15 (10.4) | 21 (14.6) | 44 (30.6) | 34 (23.6) | 25 (17.4) |
| Parents/family | 9 (6.3) | 25 (17.4) | 36 (25.0) | 43 (29.9) | 24 (16.7) |
| How comfortable are you in providing prognostic/survival stats to | | | | | |
| Young patients (age 4-10) | 38 (26.4) | 33 (22.9) | 33 (22.9) | 26 (18.1) | 9 (6.3) |
| Adolescent patients (age 11-17) | 28 (19.4) | 21 (14.6) | 24 (16.7) | 44 (30.6) | 22 (15.3) |
| Young adult patients (age 18-24) | 25 (17.4) | 16 (11.1) | 24 (16.7) | 38 (26.4) | 36 (25.0) |
| Parents/family | 22 (15.3) | 16 (11.1) | 25 (17.4) | 35 (24.3) | 42 (29.2) |
| How comfortable are you in discussing potential need for re-transplantation with | | | | | |
| Young patients (age 4-10) | 15 (10.4) | 23 (16.0) | 44 (30.6) | 37 (25.7) | 22 (15.3) |
| Adolescent patients (age 11-17) | 9 (6.3) | 11 (7.6) | 26 (18.1) | 59 (41.0) | 36 (25.0) |
| Young adult patients (age 18-24) | 8 (5.6) | 7 (4.9) | 19 (13.2) | 60 (41.7) | 46 (31.9) |
| Parents/family | 7 (4.9) | 6 (4.2) | 22 (15.3) | 54 (37.5) | 52 (36.1) |

Data are presented as N (%). N = 144.

to them, parents have unrealistic expectations about the treatments available to their child (50%), and parents are often in denial about the life-threatening nature of their child's condition (49%). Nearly half of providers (48%) agreed that prognostic information is difficult to provide due to unknown disease trajectories. Providers also acknowledged their own personal challenges with balancing hopefulness and realism (49%) and limited training specific to communicating difficult news (46%). Lack of time to discuss ACP or end-of-life care was not considered a barrier for most providers.

3.4 | Training and education

Overall, the majority of providers received training in caring for pediatric patients with shortened life expectancy through informal clinical experiences and mentoring (81%) and/or didactic lectures (70%) only. Very few completed formal palliative care or hospice-based clinical rotations (15%) or fellowships (3%).

3.5 | Associations between provider characteristics and provider practices

There were no associations between provider sex and communication practices or comfort when controlling for provider role (MD vs. non-MD) ($P = 0.77$). Provider race/ethnicity was not associated with communication practices or comfort ($P = 0.65$).

Overall, attending physicians and surgeons were more likely than transplant coordinators or advanced practice providers to discuss prognosis/survival statistics, potential need for re-transplantation, ACP, and death/dying with patients and parents. Despite their increased frequency in having such conversations, there were no differences in provider-reported comfort in discussing difficult topics between attending physicians and surgeons and transplant coordinators and advanced practice providers, with the exception that attending physicians and surgeons did endorse increased comfort in providing prognosis/survival statistics (mean 69.6 vs. 50.4, $P = 0.0003$).

Providers with greater years of practice were both more likely to discuss and more comfortable discussing potential need for re-transplantation and death/dying with patients and families (Figure 1). Providers who cared for pediatric patients with heart failure or transplant history were more likely than all other organ groups to engage patients and parents in ACP discussions (mean 40.0 vs. 24.4, $P < 0.0001$) and discuss death/dying (mean 47.2 vs. 32.2, $P < 0.0001$), yet those caring for young people with advanced lung disease or transplant history were most comfortable discussing death/dying with patients and parents (mean 70.0 vs. 52.1, $P = 0.004$). Providers who received any type of training in caring for pediatric patients with shortened life expectancy, both formal and informal, were more comfortable discussing death/dying with patients and parents.

TABLE 4 Barriers and challenges

| | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|---|-------------------|-----------|-----------|-----------|----------------|
| I feel anxious discussing death and dying w/pediatric patients | 14 (10.0) | 42 (30.0) | 33 (23.6) | 44 (31.4) | 7 (5.0) |
| Parents/families are often in denial about the life-threatening nature of their child's condition | 0 (0.0) | 31 (22.1) | 40 (28.6) | 54 (38.6) | 15 (10.7) |
| Parents/families often have unrealistic expectations about the treatments that are available | 0 (0.0) | 24 (17.1) | 46 (32.9) | 57 (40.7) | 13 (9.3) |
| I don't have sufficient time to adequately discuss end-of-life issues or ACP w/my patients and families | 27 (19.3) | 53 (37.9) | 31 (22.1) | 28 (20.0) | 1 (0.7) |
| There is insufficient reimbursement for the time required to discuss difficult topics, such as end-of-life or ACP w/patients and families | 17 (12.1) | 30 (21.4) | 41 (29.3) | 36 (25.7) | 16 (11.4) |
| It's difficult to provide prognostic information due to unknown disease trajectory for most of my patients | 6 (4.3) | 30 (21.4) | 36 (25.7) | 61 (43.6) | 6 (4.3) |
| I received limited training/experience in communicating difficult news to patients and families | 12 (8.6) | 33 (23.6) | 30 (21.4) | 47 (33.6) | 18 (12.9) |
| Cultural and/or language barriers often limit effective communication of difficult news w/my patients and families | 5 (3.6) | 48 (34.3) | 31 (22.1) | 47 (33.6) | 9 (6.4) |
| It's challenging to balance hopefulness and realism when talking w/patients and families | 2 (1.4) | 43 (30.7) | 27 (19.3) | 55 (39.3) | 13 (9.3) |
| Patients often don't understand information that was communicated | 4 (2.9) | 36 (25.7) | 40 (28.6) | 51 (36.4) | 8 (5.7) |
| Parents/families often don't understand that was communicated | 5 (3.6) | 44 (31.4) | 38 (27.1) | 49 (35.0) | 4 (2.9) |
| Patients often don't remember information that was communicated | 2 (1.4) | 27 (19.3) | 32 (22.9) | 67 (47.9) | 11 (7.9) |
| Parents/families often don't remember information that was communicated | 2 (1.4) | 27 (19.3) | 34 (24.3) | 68 (48.6) | 9 (6.4) |
| I don't know the right time in disease course to discuss end-of-life care w/patients and families | 8 (5.7) | 57 (40.7) | 48 (34.3) | 22 (15.7) | 4 (2.9) |
| Patients and parents have conflicting preferences for what information is discussed | 2 (1.4) | 21 (15.0) | 60 (42.9) | 51 (36.4) | 5 (3.6) |
| Parents don't want difficult news discussed w/their child | 1 (0.7) | 14 (10.0) | 42 (30.0) | 69 (49.3) | 14 (10.0) |

Data are presented as N (%). N = 140.

Providers own experiences with the death of a spouse, child, parent, or sibling in the past 5 years were unrelated to communication practices and comfort ($P = 0.57$); however, those with a greater number of patient deaths in the past year were more likely to engage in and more comfortable having discussions with patients and parents about ACP and death/dying.

4 | DISCUSSION

To our knowledge, this is the first study to assess communication practices among pediatric organ failure and transplant providers. Overall, results highlight significant gaps in provider communication about prognosis and end-of-life care topics with pediatric and young adult patients. For example, less than half of providers discuss prognosis/survival statistics and potential need for re-transplantation directly with their pediatric and young adult patients. Fewer than 1/3 of providers engage their patients in ACP discussions or discuss death/dying. For some providers, it may be that the prospect of solid organ transplantation, a potentially life-extending intervention, is in direct contrast to discussions about prognosis and end-of-life care planning.

Findings also bring to the forefront issues surrounding informed consent and assent for pediatric and young adult organ transplant populations. Only 56% of providers stated that they often or very often provide parents with prognosis/survival statistics, and 63% regularly discuss potential need for re-transplantation with parents. Understanding of the risks and benefits of solid organ transplantation, an intervention associated with daily treatment demands, life-threatening complications, and mortality, is critical to one's decision making.

Discussion of these challenging, yet important topics, may be met with obstacles. The most frequently reported communication barrier experienced by organ failure and transplant providers was parents not wanting difficult information communicated to their child. This finding is consistent with previous research that suggests pediatric cardiologists worry about reducing hope in patients and families by discussing or consulting palliative care,¹³ while parents also endorse wanting to "protect" their children from difficult information.¹⁴ Similarly, others have found that teen and young adult patients desire involvement in communication and decision making about end-of-life care.^{15,16} Discussions of this nature can be uncomfortable, however. Similar to findings reported by Contro and colleagues¹⁹ in their survey of over 400 pediatric providers, fewer than half of respondents in the current

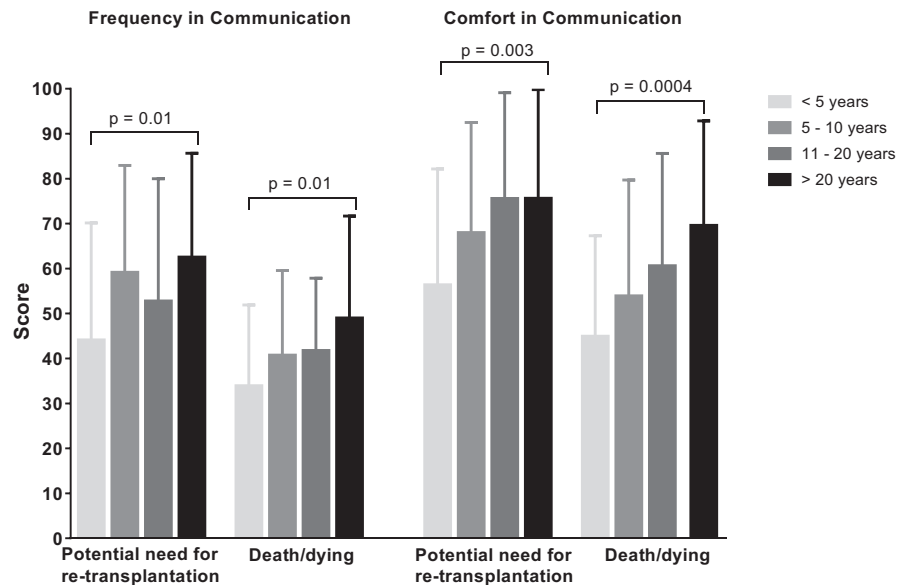


FIGURE 1 Provider communication and comfort by years of practice. Provider mean ratings of frequency of and comfort in communication about potential need for re-transplantation and death/dying by years of practice

study reported feeling comfortable or very comfortable discussing ACP and death/dying with patients under 18 years old. Very few of our respondents received formal training in caring for children with shortened life expectancies and acknowledged their own struggles with balancing hopefulness and realism.

Nearly half of providers reported that prognostic or survival information is difficult to provide due to unknown disease trajectories, as the progression of organ failure is variable and death often occurs suddenly. Despite the challenges associated with prognostication in pediatric organ failure, parents of seriously ill children often desire this information. For example, in a study of parents of children with cancer, 87% of parents wanted as much information about their child's prognosis as possible with a strong preference (85%) for numerical/statistical information.²⁰

Thus, findings underscore a number of opportunities for improvement in how we communicate with pediatric organ failure and transplant patients and their families. Based upon pediatric oncology research,^{20,21} pediatric organ failure and transplant providers are encouraged to discuss prognosis/survival statistics and re-transplantation with young adult patients and parents. This information is critical to informed decision making. Providers should work carefully with pediatric patients and their parents to balance communication preferences. Not all pediatric patients desire communication about prognosis or end-of-life care, and some parents may request that these topics not be discussed even when a child asks for this information. However, it is important for providers and parents to remain aware that conversations of this nature may actually reduce a young person's worries and better equip parents to support and protect their child.²³ Early engagement in ACP has also been found to be beneficial for young people. In adolescent and young adults with HIV or cancer, involvement in ACP was associated with increased positive emotions following discussion, decreased decisional regret, increased family understanding of patient's end-of-life wishes, reductions in invasive interventions at end-of-life, and increased likelihood of home death.^{24,25} Clinical tools, such as My CHATT,¹⁴ or direct questioning of a pediatric

patient about their communication needs can help providers navigate and plan for these more difficult conversations.

The results of the study also highlight a need for provider communication trainings specific to pediatric organ failure and transplantation. Providers with more years of practice, greater patient deaths in the past year, and training experiences in the care of patients with shortened life expectancy discuss difficult topics with pediatric patients and families with increased frequency and comfort. In addition, the development of research-informed clinical practice guidelines, like those in pediatric oncology¹¹ and adult heart failure,²⁷ would further assist organ failure and transplant providers in discussing ACP and end-of-life care with this population.

Results and implications must be considered in light of study limitations. First, findings and conclusions are subject to selection bias. Providers most interested in communication practices may have been more likely to complete the web-based survey. In addition, only organ failure and transplant providers who were active Listserv members of the societies and organizations who agreed to send the survey were offered study participation. Second, communication practices vary across transplant centers and disciplines. Transplant surgeons may be most likely to provide the prognosis/survival information, yet our sample only included five surgeons. ACP discussions may be initiated by social workers at some centers, and our study included only five social workers. Despite our attempt to provide an overview of communication practices among multidisciplinary pediatric organ failure and transplant providers, the varying distribution in participation among disciplines may have limited our ability to fully capture the multidisciplinary team-based approach in communicating with pediatric organ failure and transplant patients and their families. Due to the lack of other related measures for determining construct validity, the survey questionnaire was not psychometrically studied. Lastly, although the survey was sent to Listservs with international members, the respondents were largely United States-based, preventing examination of cultural and regional differences in communication practices.

5 | CONCLUSION

Despite risks of morbidity and mortality for pediatric organ failure/transplant patients, providers do not regularly discuss prognosis/survival statistics, re-transplantation, ACP, and death and dying with patients and their families. Communication-focused intervention research is needed to improve honest and compassionate discussion of these topics that is aligned with both patients' and parents' needs and preferences.

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AUTHORS' CONTRIBUTIONS

Melissa K. Cousino: Conceptualized and designed the study, designed the data collection instrument, collected data, participated in interpretation of data, drafted the initial manuscript, and reviewed and revised the manuscript; Kurt R. Schumacher, Emily M. Fredericks, and Sally J. Eder: Conceptualized and designed the study, designed the data collection instrument, collected data, participated in interpretation of data, and reviewed and revised the manuscript; Sunkyung Yu: Completed statistical analyses, participated in interpretation of data, drafted the initial manuscript, and reviewed and revised the manuscript; John C. Magee and Joanne Wolfe: Conceptualized and designed the study, participated in interpretation of data, and critically reviewed the manuscript for important intellectual content; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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REFERENCES

- Hart A, Smith JM, Skeans MA, et al. OPTN/SRTR 2016 annual data report: kidney. *Am J Transplant.* 2018;18:118-113.
- Kim WR, Lake JR, Smith JM, et al. OPTN/SRTR 2016 annual data report: liver. *Am J Transplant.* 2018;18:172-253.
- Colvin M, Smith JM, Hadley N, et al. OPTN/SRTR 2016 annual data report: heart. *Am J Transplant.* 2018;18:291-362.
- Smith JM, Weaver T, Skeans MA, et al. OPTN/SRTR 2016 annual data report: intestine. *Am J Transplant.* 2018;18:254-290.
- Valapour M, Lehr CJ, Skeans MA, et al. OPTN/SRTR 2016 annual data report: lung. *Am J Transplant.* 2018;18:363-433.
- Dipchand AI, Rossano JW, Edwards LB, et al. The Registry of the International Society for Heart and Lung Transplantation: Eighteenth Official Pediatric Lung and Heart-Lung Transplantation Report—2015; focus theme: early graft failure. *J Hear Lung Transplant.* 2015;34:1255-1263.
- Almond C, Thiagarajan RR, Piercey GE, et al. Waiting list mortality among children listed for heart transplantation in the United States. *Circulation.* 2009;119:717-727.
- Institute of Medicine. Dying in America: improving quality and honoring individual preferences near the end of life. 2014.
- Fowler A, Freiburger D, Moonan M. Palliative and end-of-life care in pediatric solid organ transplantation. *Pediatr Transplant.* 2015;19:11-17.
- Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology Survey. *J Clin Oncol.* 2001;19:205-212.
- Hinds PS, Oakes L, Furman W, et al. End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology: research to evidence-based practice guidelines. *Cancer Nurs.* 2001;24:122-126.
- Durall A, Zurakowski D, Wolfe J. Barriers to conducting advance care discussions for children with life-threatening conditions. *Pediatrics.* 2012;129:e975-e982.
- Balkin EM, Kirkpatrick JN, Kaufman B, et al. Pediatric cardiology provider attitudes about palliative care: a multicenter survey study. *Pediatr Cardiol.* 2017;38:1324-1331.
- Cousino MK, Rea KE, Mednick LM. Understanding the healthcare communication needs of pediatric patients through the My CHATT tool: a pilot study. *J Commun Healthc.* 2017;10:16-21.
- Jacobs S, Perez J, Cheng YI, Sill A, Wang J, Lyon ME. Adolescent end of life preferences and congruence with their parents' preferences: results of a survey of adolescents with cancer. *Pediatr Blood Cancer.* 2015;62:710-714.
- Dunsmore J, Quine S. Information, support, and decision-making needs and preferences of adolescents with cancer. *J Psychosoc Oncol.* 1996;13:39-56.
- Wiener L, Ballard E, Brennan T, Battles H, Martinez P, Pao M. How I wish to be remembered: the use of an advance care planning document in adolescent and young adult populations. *J Palliat Med.* 2008;11:1309-1313.
- Wiener L, Zadeh S, Battles H, et al. Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics.* 2012;130:1-9.
- Contro NA, Larson J, Scofield S, Sourkes B, Cohen HJ. Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics.* 2004;114:1248-1252.
- Mack JW, Wolfe J, Grier HE, Cleary PD, Weeks JC. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J Clin Oncol.* 2006;24:5265-5270.
- Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Oncol.* 2007;25:5636-5642.
- Mack JW, Cronin AM, Kang TI. Decisional regret among parents of children with cancer. *J Clin Oncol.* 2016;34:4023-4029.
- Rosenberg AR, Wolfe J, Wiener L, Lyon M, Feudtner C. Ethics, emotions, and the skills of talking about progressing disease with terminally ill adolescents a review. *JAMA Pediatr.* 2016;170:1216-1223.
- Lyon ME, Garvie PA, McCarter R, Briggs L, He J, D'Angelo LJ. Who will speak for me? Improving end-of-life decision-making for adolescents with HIV and their families. *Pediatrics.* 2009;123:e199-e206.

25. Me L, Jacobs S, Briggs L, Cheng Y, Wang J. Family-centered advance care planning for teens with cancer. *JAMA Pediatr.* 2013;167:460-467.
26. Lyon ME, Garvie PA, Briggs L, He J, McCarter R, D'Angelo LJ. Development, feasibility, and acceptability of the family/adolescent-centered (FACE) advance care planning intervention for adolescents with HIV. *J Palliat Med.* 2009;12:363-372.
27. Hunt SA, Baker DW, Chin MH, et al. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: executive summary: a report of the American college of cardiology/American heart association task force on practice guidelines. *J Am Coll Cardiol.* 2001;38:2101-2113.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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