Received: 11 October 2017 | Accepted: 26 December 2017

DOI: 10.1111/chd.12579

WILEY Congenital Heart Disease

ORIGINAL ARTICLE

Improving outpatient advance care planning for adults with congenital or pediatric heart disease followed in a pediatric heart failure and transplant clinic

Lindsay A. Edwards MD[1,2] | Christine Bui MD[2,3] | Antonio G. Cabrera MD[1,2] | Jill Ann Jarrell MD, MPH[2,4,5]

[1]Texas Children's Hospital, Lillie Frank Abercrombie Section of Pediatric Cardiology, Houston, Texas, USA

[2]Department of Pediatrics, Baylor College of Medicine, Houston, Texas, USA

[3]Department of Medicine, Baylor College of Medicine, Houston, Texas, USA

[4]Section of Academic General Pediatrics, Texas Children's Hospital, Houston, Texas, USA

[5]Texas Children's Hospital, Section of Palliative Care, Houston, Texas, USA

Correspondence
Jill Ann Jarrell, Baylor College of Medicine, Texas Children's Hospital, Address: 6651 Main St., Suite E.415-33, Houston, TX 77030.
Email: jajarrel@texaschildrens.org

Abstract

Objective: To improve outpatient advanced care planning (ACP) for adults with congenital/pediatric heart disease followed in a pediatric heart failure (HF) and transplant clinic through quality improvement (QI) methodology.

Design: A one-year QI project was completed. We conducted quarterly chart reviews and incorporated feedback from the providers to direct subsequent interventions.

Patients and Setting: Patients ≥18 years of age seen in the HF and Transplant Clinic for follow-up visit were included in analysis.

Interventions: Interventions focused on five main areas: identifying and training providers to have ACP discussions, standardizing the ACP discussion, standardizing ACP and advance directive (AD) documentation in the electronic medical record, preparing providers to have ACP conversations, and preparing patients to engage in ACP and AD completion.

Outcome Measures: The outcome measure was percent of adults seen in the HF and Transplant Clinic per month with documented AD (goal 50%). The process measure was percent of adults seen in the HF and Transplant Clinic per month with a documented ACP discussion (goal 100%).

Results: At baseline, no patients had a documented ACP discussion or AD. Fifty-eight adults (mean age 20.4 ± 2.1 years) were seen from March 2016 to February 2017 for a total of 130 visits. In the final month of our study, 75% of adult encounters had a documented ACP discussion and 42% had a documented AD.

Conclusions: The percentage of documented ADs in adults seen in the HF and Transplant Clinic at a quaternary children's hospital improved through a QI initiative. Over 50% of patients who were engaged in an ACP discussion completed an AD, suggesting this population is receptive to ACP and AD completion.

KEYWORDS
advance care planning, advance directive, congenital heart disease, heart failure, heart transplantation, quality improvement

1 | INTRODUCTION

As outcomes of pediatric heart disease continue to improve, an increasing proportion of children with chronic heart disease are reaching adulthood. This complex patient population is at increased risk for hospitalization and death.[1,2] In pediatrics, parents and the healthcare team typically make decisions for patients, but as these patients become adolescents and young adults, they should voice their own values, opinions, and healthcare goals. In no area is this more important than in end-of-life care.[3,4] Without knowing the patient's healthcare preferences in the case of advancing disease or imminent death, the family and healthcare team are forced to make decisions for the patient in an emotional and stressful time and in a culture that promotes life-sustaining measures.

Advance care planning (ACP) is the process by which patients, families, and healthcare teams share information about what to expect with the disease process, treatment options, possible outcomes, and what to do in these varying circumstances based on the patient's values and goals.[4] These discussions and decisions can be documented in a legal document called an advance directive (AD).

We developed an interdisciplinary quality improvement (QI) initiative between the cardiology and palliative care services at Texas Children's Hospital to improve outpatient ACP for adults followed in the Heart Failure and Transplant Clinic at the Heart Center. The global aim was to build a sustainable infrastructure within the Heart Failure and Transplant Clinic for routine ACP discussions and AD education for adult patients. The specific aim was that 50% of adults with congenital or pediatric heart disease seen in the Heart Failure and Transplant Clinic per month would have a documented AD by one year.

2 | METHODS

2.1 | Context

The Heart Center at Texas Children's Hospital (a large, quaternary children's hospital) encompasses a broad range of services including congenital heart surgery, cardiac catheterization, cardiovascular intensive care, and numerous subspecialty services under the umbrella of pediatric cardiology. The Heart Failure and Transplant Service cares for the cardiomyopathy, heart failure, and heart transplanted patients within the Heart Center from infancy to adulthood. While some of the patients cared for by the Heart Failure and Transplant Service are survivors of congenital heart disease, others were diagnosed with cardiomyopathy or heart failure as children.

The electronic medical record (EMR) was reviewed to identify the prevalence of documented ADs in adult patients admitted to the Texas Children's Heart Center Cardiovascular Intensive Care Unit (CVICU) from November 1st, 2014, to October 31st, 2015. Fifty-seven unique patients $\geq$18 years old were cared for during the yearlong period for a total of 69 admissions. Twenty-three percent carried the diagnosis of heart failure and/or transplant. Despite making up less than a quarter of the adult population cared for in the CVICU, they accounted for 83% (5/6) of adult patients with multiple CVICU admissions during that period and 100% (5/5) of deaths less than one year after CVICU discharge. Only 38% (5/13) of these heart failure and transplant patients had a documented advance directive prior to or during their admission(s). Given the relatively high proportion of patients, high proportion of readmissions, high proportion of mortality, and low proportion of advance directives in the heart failure and transplant patients, these patients were selected as the study population.

Our QI team included a pediatric cardiology fellow, a medicine-pediatrics resident, a pediatric cardiologist subspecialized in heart failure and transplantation as well as cardiac critical care, and a hospice and palliative care physician. During study design and implementation, the project was presented at the Baylor College of Medicine Fellows College Quality Improvement Module and the Heart Failure and Transplant Service monthly meetings. This initiative qualified as a quality improvement project and was exempt from the Baylor College of Medicine Institutional Review Board process.

2.2 | Patients

The inclusion criteria were established patients $\geq$18 years of age seen in the Heart Failure and Transplant Clinic. Baseline data was collected from visits in February 2016, with the study period spanning from March 1, 2016, to February 28, 2017. For patients seen multiple times per month, only the last visit in the month was included. New patient consultations were excluded.

2.3 | Interventions

This study focused on a series of interventions implemented during the study period from March 2016 (Month 1) to February 2017 (Month 12). Figure 1 is a modified key driver diagram depicting our intervention roadmap.

The first series focused on identifying a group of providers willing and able to conduct the ACP conversation. Once the transplant and cardiomyopathy coordinators (with nursing backgrounds) were identified, they underwent training. Based on their feedback, a second training session was held.

The second series included measures to standardize the ACP conversation. An ACP conversation script was introduced (Table 1), patient folders with information on advance directives were created, and the *Voicing My Choices* document (www.agingwithdignity.org) was obtained as a tool for patients completing the ACP process.[5]

The third series focused on standardizing the documentation for the ACP conversation and AD. In the background review of CVICU admissions, documentation of ACP and AD in the EMR (Epic^R) was not standardized. There was no documentation of the ACP conversation in the EMR unless it was included in a physician or social worker's note, and the AD was scanned into a generic "media" tab without a standard file name. To improve the ease of finding ACP and AD documentation, we introduced a "SmartPhrase" (Epic Systems, Verona, Wisconsin) to be completed in a standard "sticky note" location on the patient's chart, indicating the status of the ACP conversation and whether an AD had been completed (Table 2). We identified a standard location and file name for electronically filing the AD document. We then sent an email updating the entire Heart Center of these standardized EMR interventions.

The fourth series consisted of a single intervention: a reminder email to the coordinators stating the adult patients who would be seen in clinic the upcoming week and whether or not they had an AD.

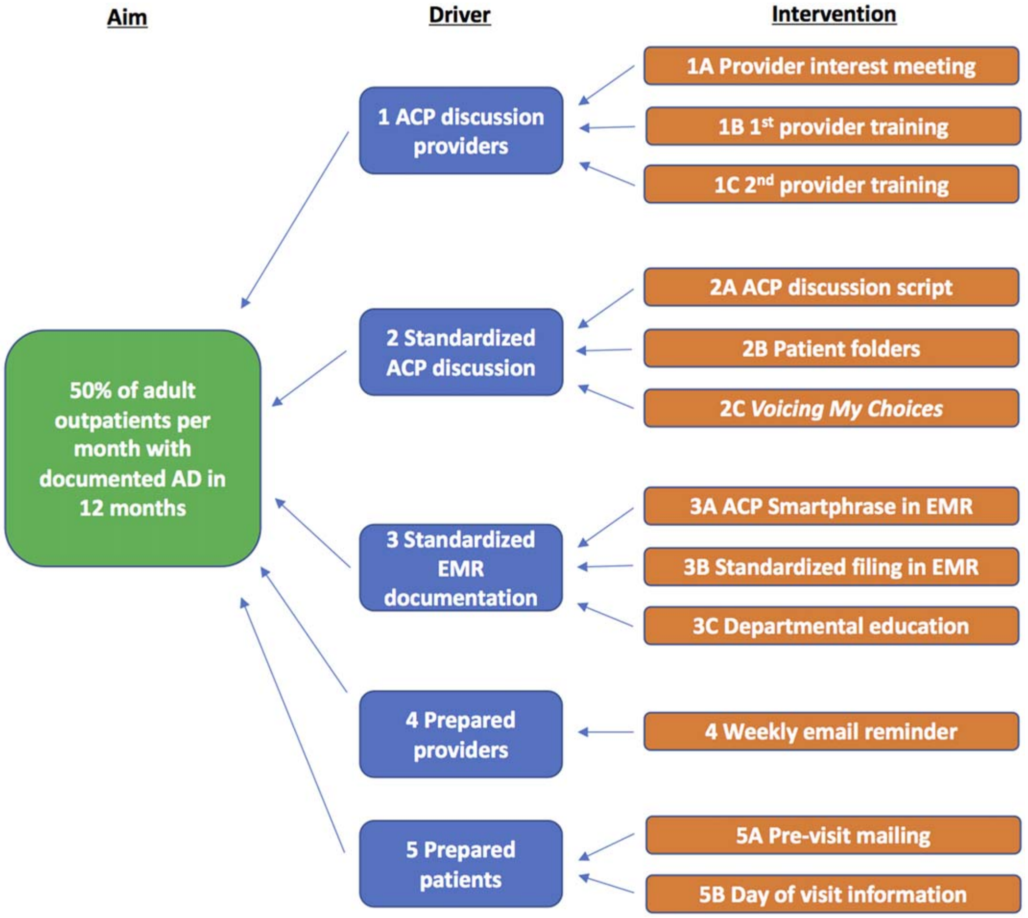

FIGURE 1 Modified key driver diagram. Abbreviations: AD, advance directive; ACP, advance care planning; EMR, electronic medical record.

The fifth and final series was designed to further prepare the patients for the ACP conversation. We introduced a previsit mailing so that patients would have the *Voicing My Choices* document prior to the visit to give them time to think about their preferences before discussion with a provider. We later began having the medical assistants hand a flyer on advance directives to the patients during their vital signs to peruse as they waited to be seen by the provider.

2.4 | Study measures

The outcome measure was percent of adults seen in the Heart Failure and Transplant Clinic per month with documented AD (goal 50%). The process measure was percent of adults seen in the Heart Failure and Transplant Clinic per month with a documented ACP discussion (goal 100%).

2.5 | Analysis

We conducted quarterly chart reviews assessing the study measures and incorporating feedback from the providers conducting ACP discussions to direct subsequent interventions. Demographic data including age, sex, race, and ethnicity was collected from the electronic medical record.

3 | RESULTS

At baseline, zero of the ten adults seen in February 2016 had a documented ACP discussion or AD. Fifty-eight unique patients $\geq$18 years of age (mean age 20.4 ± 2.1 years) at time of visit were seen in the Heart Failure and Transplant Clinic for a total of 130 visits from March 1st, 2016, to February 28th, 2017, and were included in analysis. Diagnosis and demographic data is summarized in (Table 3).

The outcome measure, the percent of adults seen in the Heart Failure and Transplant Clinic per month with documented AD, is shown in Figure 2. AD documentation peaked at 63% of adult patients seen in clinic in the seventh month of the study, and, in the twelfth month of our study, 42% of adult patients seen in clinic had a documented AD. The process measure, percent of adults seen in the Heart Failure and Transplant Clinic per month with a documented ACP discussion, is shown in Figure 3. Documentation of ACP discussion peaked in the seventh and twelfth months of our study, with 75% of adult encounters with a documented ACP discussion.

The timing of interventions is indicated in Figures 2 and 3. The first two interventions, identifying and training the transplant coordinators to have conversations, was met with a modest increase in ACP and AD documentation. Every patient that had an ACP discussion in the first three months of the study completed an AD. ACP conversations and AD

TABLE 1 Advance care planning script

I. Start the conversation
  a. "We are going to talk about advance care planning. This process involves a conversation with you, your healthcare team, and whomever else you choose about your future health and care. We will discuss and possibly complete documents to guide medical decision making to be used if someday you are unable to make or communicate your own decisions. This doesn't mean we think you are doing poorly; we try to talk about these things with all of our patients."
II. Introduce the components of advance directives
  a. Directive to physicians
    i. If you become very sick and your healthcare provider thinks that you have less than six months to live, even with all available treatments, would you want all of those treatments or would you want treatments to focus on your comfort?

    Examples: ECMO (heart/lung bypass), ventricular assist device (machine to pump the heart), dialysis (kidney replacement therapy), breathing tubes and machines, artificial nutrition through tubes or veins. These may keep you in the hospital instead of home and may cause discomfort.
    ii. If you are so sick that your death is near (hours, days, weeks) even with all available treatments and you cannot make your own decisions, would you want these treatments or would you want to focus on your comfort?
  b. Medical power of attorney/surrogate
    i. If you become so sick that you cannot make your own decisions, who do you want to make healthcare decisions for you?
    ii. Would you want them to make decisions exactly as you have stated or would you want them to make decisions that would give them peace, even if it goes against what you have said?
  c. Organ donation
    i. When you die do you want to try to donate your organs and/or tissue to others in need?
    ii. Do you have restrictions on how you would want your organs and/or tissues used? (transplant or research)
  d. Out of hospital "Do Not Resuscitate"
    i. If your heart stops suddenly at home or during normal life outside of the hospital, would you want your family, friends, or bystanders to call 911 and perform CPR (chest compressions and rescue breathing) or would you want to allow a natural death at home?
III. Complete the paperwork
  a. https://www.dads.state.tx.us/news_info/publications/handbooks/advancedirectives.html
  b. Out of hospital DNR must be signed by a notary or two witnesses
  c. Give original to patient, scan a copy into electronic medical record
IV. Document the conversation
  a. In "Specialty Comments" document conversation using Epic SmartPhrase
  b. Scan document in "media" tab as document type "Advance directive and living wills"
V. Plan the next steps
  a. Address specific medical or prognostic questions with healthcare provider
  b. Will revisit conversation at future visit
  c. Will review advance directive at future visit

documentation tapered in the third month as the QI team lessened their involvement. At this point, feedback was elicted from the transplant coordinators and numerous interventions were introduced to improve three areas: (1) provider comfort with the ACP discussion, including a second training session with an ACP discussion script; (2) standardized documentation, with an ACP SmartPhrase and standardized filing location for the AD in the EMR; and (3) provider compliance, with weekly reminder emails to the transplant coordinators with the names of their adult patients in clinic that week who did not have a documented AD. The following month, *Voicing My Choices* was introduced and the cardiology, cardiovascular surgery, and cardiac anesthesia teams were informed about the standardized location for ACP and AD documentation in the EMR. Both ACP discussions and AD documentation peaked in the seventh month of the study period. At this point, the department began mailing a packet to the patients two weeks before their clinic visit, to give the patient time to review the information and come prepared to discuss their wishes. We did not see a great impact from this mailing, as many patients would forget to complete the packet and bring it to clinic with them. Thus, in the final month of the study, the medical assistant provided handouts to the patients on ACP and ADs while they awaited their appointment, so that the patients who did not review the packets at home had an opportunity to review the material before their visit.

TABLE 2 Epic SmartPhrase for documenting advance care planning discussions

Provider/Social Worker Advance Care Planning Note
The following advance directive paperwork was discussed with the patient and/or his/her family:
[ ] Directive to Physicians
[ ] Medical Power of Attorney
[ ] Out of Hospital DNR
The patient/family was given the opportunity to ask questions.
[ ] Advance directive complete and scanned into Media tab as document type "Advance Directive and Living Wills"
[ ] Plan to discuss with patient/family again at next visit
[ ] Plan to discuss with patient/family again if clinical status worsens
[ ] Patient/family prefer not to discuss advance directive in the future

4 | DISCUSSION

In this study, we found that through a yearlong interdisciplinary QI project, we were able to improve the percentage of documented ADs in adults seen in the Heart Failure and Transplant Clinic per month from 0% at baseline to 42% at one year. Over 50% of patients who were engaged in an ACP discussion completed an AD, suggesting that if we had successfully discussed ACP with all adult patients, we would have

TABLE 3 Patient characteristics

Parameter *n* = 58	
Age in years (mean ± standard deviation)	20.4 ± 2.1
Diagnosis	
Heart transplanted, *n* (%)	28 (48)
Cardiomyopathy, *n* (%)	23 (40)
Ventricular assist device, *n* (%)	4 (7)
Failing Fontan, *n* (%)	3 (5)
Male, *n* (%)	43 (74)
Race	
Caucasian, *n* (%)	44 (76)
Black, *n* (%)	11 (19)
Asian, *n* (%)	3 (5)
Hispanic, *n* (%)	24 (41)

met our 50% AD documentation goal. To our knowledge, this is the first study describing the successful implementation of an advance care planning program in an adult population with congenital or pediatric heart disease as well as the first in a pediatric heart center.

The literature on ACP and ADs in adults with congenital or pediatric heart disease is sparse. Kovacs et al published an editorial discussing the "shifting mortality" of patients with pediatric heart disease from childhood and adolescence to adulthood and the importance of ADs to identify a surrogate decision maker and express end-of-life preferences.[4] Despite this recommendation, most adults with congenital or pediatric heart disease have not had ACP discussions and do not have ADs when they become critically ill. In a study of 48 adults with inpatient, non-perioperative death secondary to congenital heart disease, Tobler et al found documented ACP conversations for only five patients (10%).[6] Of these five, three occurred prior to admission. Surrogate decision makers were documented in 41%. Patients with a documented ACP conversation (either with the patient or a surrogate) were less likely to undergo attempted resuscitation than patients without ACP conversations (12% versus 100%).

The ultimate goal of advance care planning, in addition to preserving patient autonomy, is to provide an optimal end-of-life experience with minimal suffering and distress for the patient, family, and medical team.[4] Blume et al. surveyed parents of children and young adults less than 21 years of age with primary cardiac diagnoses who had died at Boston Children's Hospital nine months to four years prior to the survey date.[7] Forty-seven percent of the parents felt that their child suffered during the end-of-life period. Seventy-one percent described the quality of life of their child as "poor" or "fair" during the month preceding his/her death. Parents realized their child was dying a median of two days prior to death. This study highlights the importance of palliative care as well as improved communication between providers, patients, and families regarding prognosis and ACP.

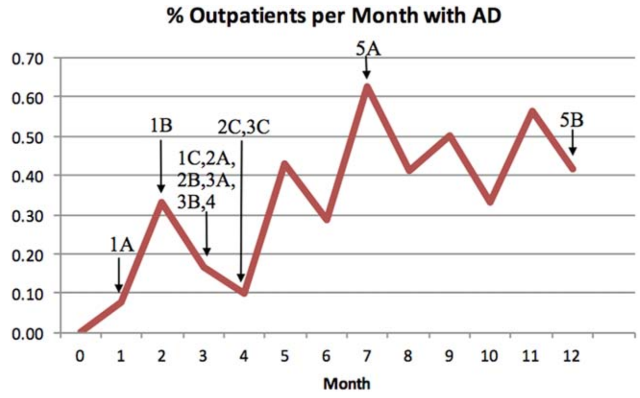

FIGURE 2 Percent adult outpatients seen per month with a documented advance directive (AD). Timing of interventions indicated with arrows

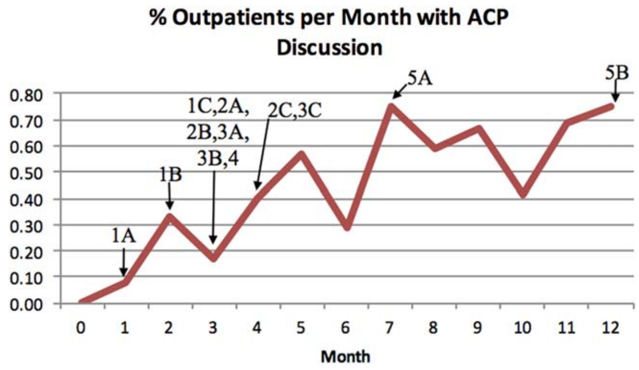

FIGURE 3 Percent adult outpatients seen per month with a documented advance care planning (ACP) conversation. Timing of interventions indicated with arrows

The official recommendation from the American College of Cardiology and the American Heart Association (ACC/AHA) 2008 guidelines are that all adults with congenital heart disease "should be encouraged to complete an AD, ideally at a time during which they are not extremely ill or hospitalized, so that they can express their wishes thoughtfully in a less stressful setting and communicate these wishes to their families and caregivers (*Level of Evidence: C*)."[8] A handful of studies have evaluated the prevalence of ACP and AD completion among the outpatient adult congenital heart disease population and patient preferences regarding ACP. In a survey of 200 adult patients living with congenital heart disease, Tobler et al found that only 5% had ADs, but 86% believed an AD would be helpful.[9] Fifty-six percent of the cohort had not heard of an AD before the time of survey. When this same cohort was questioned about their preferences for ACP, 78% of patients wanted their medical team to initiate ACP conversations, and this preference was independent of their disease complexity and sociodemographic factors.[10] Sixty-two percent of patients expressed a preference for early ACP, before diagnosis of life-threatening complications. Lin et al. similarly surveyed adults with congenital heart disease, reporting that of 165 responders, only 13% recalled having an ACP conversation with a provider and 21% had a documented AD.[11] Despite the relatively low percentage of ACP discussions, the responders indicated that ACP discussions had high importance (median score of 7 on a scale of 0 to 10) and preferred to initiate the conversation at a median age of 18 years. Female patients with lower complexity heart disease and those with more anxiety symptoms indicated higher scores for importance of ACP discussions.

When we were identifying the provider to lead the ACP conversations in clinic, the physicians and social workers expressed many concerns about conducting ACP discussions, including time, space, fear of painting a negative picture for families, and discomfort with having the conversation (social workers), and chose not to participate in the project. The transplant and cardiomyopathy nurse coordinators, while also acknowledging the above barriers championed this project because of their reported long-standing relationships with patients and families and belief that these conversations were in the patients' best interests. While the coordinators were able to take on this responsibility in our clinic, many settings may need to rely on physicians, social workers, or other team members to conduct ACP discussions. A national survey of physicians to determine perceived barriers to ACP conversations and AD documentation would be helpful in understanding and addressing prohibitive concerns. A recently published multicenter survey addressed a related topic: pediatric cardiology provider attitudes toward palliative care, and captures some of the same perceived barriers.[12] Balkin et al report that 45% of physicians reported concerns that "referring to palliative care services too early will undermine parents' hope" and 56% reported "concern that parents will think I am giving up on their child." Anecdotally, we asked several patients after the ACP discussion how they found the experience, and it was universally described as 'helpful.' Of note, we took care to normalize the experience, stating that we had this discussion with all adult patients in clinic as part of our ACP script. A survey documenting patients' perceptions of ACP and ADs may be helpful in addressing physician concerns.

Our next step is to expand the ACP program to other cardiology subspecialty clinics within the Heart Center. We also plan to begin having ACP conversations with adolescents. Kirkpatrick et al. discuss the importance of "progress in stages" in transitioning teenagers and young adults with pediatric heart disease to adult providers, emphasizing the importance of patient autonomy and patient shared decision-making for teenage and young adult patients.[13] Systematically empowering patients to participate in advance care planning conversations and advance directive documentation will contribute to a robust transition for patients with chronic pediatric heart disease. We hope this study will encourage members of the pediatric subspecialty community to empower their adolescent and adult patients to engage in ACP.

4.1 | Limitations

Our study has several limitations. It is limited by relatively small sample size. Our population was largely male, Caucasian, Hispanic, and heart transplanted. We do not know if our results are generalizable to other pediatric cardiology subspecialty or pediatric subspecialty populations. Furthermore, there may be regional differences in reception of ACP discussion by patients and their willingness to complete ADs. In addition, our study period was short, 12 months in duration, and we do not yet have follow-up data to demonstrate sustainability.

4.2 | Conclusions

We used quality improvement methodology to introduce provider-initiated, outpatient advance care planning for adult patients with congenital or pediatric heart disease followed in a pediatric heart failure and transplant clinic. Our results suggest that this population, if given the opportunity, will engage in advance care planning and advance directive documentation. Future research should focus on identifying and eliminating provider-perceived barriers to advance care planning.

ACKNOWLEDGMENTS

We would like to thank the outstanding transplant and cardiomyopathy coordinators, Carrie Brandenburger, Katherine Crockett, Corey Gates, Kimberly Gilbert, and Diana Harter, as well as Barbara Elias, our ventricular assist device nurse, for their hard work and tireless dedication to this initiative and their patients.

CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

Conceptualized and designed the study, performed data collection, carried out data analysis, drafted the initial manuscript: Lindsay A. Edwards
Collected data: Christine Bui
Participated in study design: Lindsay A. Edwards, Antonio Cabrera, Jill Ann Jarrell
Critically reviewed and revised the manuscript, and approves of the final version of the manuscript: Lindsay A. Edwards, Christine Bui, Antonio Cabrera, Jill Ann Jarrell

ORCID

Lindsay A. Edwards MD http://orcid.org/0000-0003-0555-0127

REFERENCES

[1] Agarwal S, Sud K, Menon V. Nationwide hospitalization trends in adult congenital heart disease across 2003–2012. *J Am Heart Assoc.* 2016;5(1):e002330.

[2] Diller G-P, Kempny A, Alonso-Gonzalez R, et al. Survival prospects and circumstances of death in contemporary adult congenital heart disease patients under follow-up at a large tertiary centre. *Circulation.* 2015;132(22):2118–2125.

[3] Bertaud S, Lloyd DFA, Laddie J, Razavi R. The importance of early involvement of paediatric palliative care for patients with severe congenital heart disease. *Arch Dis Childhood.* 2016;101(10):984–987.

[4] Kovacs AH, Landzberg MJ, Goodlin SJ. Advance care planning and end-of-life management of adult patients with congenital heart disease. *World J Pediatr Congenit Heart Surg.* 2013;4(1):62–69.

[5] Wiener L, Zadeh S, Battles H, et al. Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics.* 2012;130(5):897–905.

[6] Tobler D, Greutmann M, Colman JM, Greutmann-Yantiri M, Librach LS, Kovacs AH. End-of-life care in hospitalized adults with complex congenital heart disease: care delayed, care denied. *Palliat Med.* 2012;26(1):72–79.

[7] Blume ED, Balkin EM, Aiyagari R, et al. Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease: an exploratory study. *Pediatr Crit Care Med.* 2014;15(4):336–342.

[8] Warnes CA, Williams RG, Bashore TM, et al. ACC/AHA 2008 guidelines for the management of adults with congenital heart disease: executive summary: a report of the American college of cardiology/ American heart association task force on practice guidelines (writing committee to develop guidelines for the management of adults with congenital heart disease). *Circulation*. 2008;118(23):2395–2451.

[9] Tobler D, Greutmann M, Colman JM, Greutmann-Yantiri M, Librach SL, Kovacs AH. Knowledge of and preference for advance care planning by adults with congenital heart disease. *Am J Cardiol*. 2012;109(12):1797–1800.

[10] Tobler D, Greutmann M, Colman JM, Greutmann-Yantiri M, Librach LS, Kovacs AH. End-of-life in adults with congenital heart disease: a call for early communication. *Int J Cardiol*. 2012;155(3):383–387.

[11] Deng LX, Gleason LP, Khan AM, et al. Advance care planning in adults with congenital heart disease: a patient priority. *Int J Cardiol*. 2017;231:105–109.

[12] Balkin EM, Kirkpatrick JN, Kaufman B, et al. Pediatric cardiology provider attitudes about palliative care: a multicenter survey study. *Pediatr Cardiol*. 2017;18:459

[13] Kirkpatrick JN, Kim YY, Kaufman BD. Ethics priorities in adult congenital heart disease. *Prog Cardiovasc Dis*. 2012;55(3): 266–273.e3.

How to cite this article: Edwards LA, Bui C, Cabrera AG, Jarrell JA. Improving outpatient advance care planning for adults with congenital or pediatric heart disease followed in a pediatric heart failure and transplant clinic. *Congenital Heart Disease*. 2018;13:362–368. https://doi.org/10.1111/chd.12579