


Perspectives on advance care planning and palliative care among adults with congenital heart disease

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Funding information

Funding was provided by a training grant from the National Heart Lung and Blood Institute (T32 HL 125195) and the Cambia Health Foundation.

Abstract

Background: Patients with adult congenital heart disease (ACHD) report that advance care planning (ACP) is important, and that they want information about prognosis. However, recognizing importance and being willing to participate are different constructs, and how and when to begin ACP and palliative care discussions remains ill-defined.

Methods: We conducted a cross-sectional survey of 150 consecutive outpatients to assess willingness to participate in ACP, with whom, and important barriers and facilitators to these discussions.

Results: The majority of participants (69%) reported being willing to participate in ACP; 79% to have a meeting to discuss goals and care preferences; and 91% to speak to a clinician who specializes in palliative care. Being married and anticipating a shorter lifespan were associated with increased reported willingness to participate in ACP. The health care provider with whom most participants preferred to have these discussions was their ACHD clinician. Participants identified important barriers and facilitators to these discussions.

Conclusion: Patients with ACHD report being willing to participate in ACP and palliative care discussions. Patients prefer to have these discussions with their ACHD clinicians, thus ACHD clinicians need to be prepared to address these issues as part of routine care.

KEYWORDS

adult congenital heart disease, advance care planning, palliative care

1 | BACKGROUND

Symptom management, advance care planning (ACP), and palliative care are gaining recognition as critical components of comprehensive care for adults with congenital heart disease (ACHD). Previous research suggests patients want information on life expectancy and think ACP is important.¹ Patients report they want their health care providers to initiate end-of-life conversations, preferably before they become ill.^{1,2} However, determination of prognosis in ACHD is difficult,³ and patients' desire for information does not always correlate with disease complexity.^{1,2} Patients with ACHD are

younger than many patients with chronic, life-limiting illnesses and may consequently have different emotional and physical needs. Evidence for when or how best to proactively address these concerns is limited.

The aim of this study was to explore, among patients with ACHD, (1) their willingness to participate in ACP and with whom; (2) whether prior discussions with clinicians or family met their needs and preferences; and (3) most common and important barriers and facilitators to discussing care preferences. We conducted a cross-sectional survey of patients cared for at a single large ACHD clinic in the United States to address these aims.

2 | METHODS

2.1 | Sample and procedure

We recruited consecutive outpatients scheduled for an appointment in the ACHD Clinic at a large, west coast, and quaternary medical center. To introduce the project, we contacted potential participants via phone prior to the appointment. Patients were eligible if they were at least 18 years of age, had a confirmed diagnosis of ACHD, and were able to complete a written or electronic survey in English. Patients were not eligible if they carried a diagnosis of another life-limiting condition (such as cancer) or if they were inpatients at the time of contact. If contact with the patient was not possible during the outpatient visit or if the patient agreed to participate but was unable to do so at the time of the visit, up to 3 phones or email attempts were made after the visit.

This study was approved by the University of Washington Human Subjects Committee. All participants gave verbal informed consent and written permission for health record review.

2.2 | Study measures

The survey included questions regarding ACP and care preferences (see Appendix). Survey questions were adapted from a prior study of patients with cystic fibrosis.⁴ Palliative care was defined as “specialized medical care that focuses on providing relief from the symptoms, pain, and stress of a serious illness, whatever the diagnosis.” ACP was described as a plan for the future that “includes discussion about the medical care you would want if you were too sick to speak for yourself (for example, whether you would want cardiopulmonary resuscitation [CPR], nutrition through a feeding tube, or care in the intensive care unit or a nursing home).”

Participants were asked how willing they would be to meet together with family members or friends and their ACHD doctor (defined for this study as a physician, nurse practitioner, or physician assistant) to discuss their goals and preferences for care in the future. They were asked how willing they would be to participate in ACP, which includes an opportunity to complete ACP documents, such as a living will or health care directive, specifying their wishes and values regarding treatment and care. They were asked how willing they would be to see a clinician who specializes in palliative care. For each of these questions, they were given the options of “Not at all willing,” “A little willing,” “Moderately willing,” “Very willing,” and “Don’t know.” Participants were asked if they had ever discussed with their doctors the kind of medical care they would want if they were too sick to speak for themselves, and if yes, they were asked to rate on a 0-10 scale to what extent these discussions met their needs for information about their medical care.

Based on prior literature,³⁻⁶ a list of 10 barriers and 4 facilitators for talking about care preferences were provided to survey participants in table format. Participants were asked to identify whether each listed barrier does or does not keep them from talking to their doctors about their care. They were then asked to identify whether each listed facilitator does or does not make it easier to talk with their doctors about

their care. Participants were asked to identify which was the most important factor from each list (barriers and facilitators). Next, participants were asked questions about disease and health self-perception and life expectancy. Examples of these questions include (1) “In general, would you say your health is:” with answer options “Excellent,” “Very Good,” “Good,” “Fair,” and “Poor;” (2) “On a daily basis, how physically limited are you by your heart condition?,” with answer options “Very limited,” “Somewhat limited,” “Not too limited,” and “Not at all limited;” and (3) “How worried are you about your heart condition?,” with answer options “Very worried,” “Somewhat worried,” “Not too worried,” and “Not at all worried.” Participants were asked if they consider their heart problem to be “Severe or complex,” “Moderate,” or “Mild, not a big deal.” They were also asked whether they thought they would live “longer than,” “as long as,” or “a shorter life” than other people their age without heart problems.

Finally, participants were asked questions about demographic information not available in the electronic health record (EHR), such as highest level of school completed, employment status, and whether they considered themselves religious in a way that might affect their views on health care. Additional demographic information and ACHD diagnoses were obtained from the EHR. Congenital heart disease lesion type was categorized as being of simple, moderate, or great complexity.⁷ Hospitalizations in the last year were counted if they were cardiac-related based on supporting documentation, such as progress notes and telephone notes. These did not include same-day procedures. Cardiology clinic visits in the last year were counted if they were with the ACHD or Heart Failure teams, since at our institution those services share “primary” care of patients with ACHD, depending on whether they have a diagnosis of heart failure.

2.3 | Statistical analysis

Numerical data were described as means with standard deviations or medians with interquartile ranges as appropriate. Categorical data were described using percentages and 95% confidence intervals. We used multivariate logistic regression to identify factors associated with being “very willing” to participate in ACP. Participants with missing values (3%) were excluded from regression analyses. A significance level of .05 was used for all analyses. Data analyses were performed using Stata version 15 (StataCorp. 2017. Stata Statistical Software: Release 15, StataCorp LLC, College Station, Texas).

3 | RESULTS

A total of 304 patients were screened for involvement in this study, and 206 met eligibility criteria. Of the eligible patients, 56 declined or did not follow-up. This resulted in 150 patients who completed surveys, for a participation rate of 73%. Demographics for the study population are shown in Table 1. Survey participants were an average age of 37 ± 13 years old, 46% were male, and 85% were Caucasian. Forty-five percent were married, and 35% considered themselves religious in a way that affected their care wishes.

The mean number of clinic visits in the last year was 2.6 ± 2.2 , and 40% had at least one hospitalization in the last year. Participants were significantly more likely to report their race/ethnicity as non-Hispanic white and to have had more cardiology clinic visits in the prior year than those who declined to participate, but patients who declined to participate were not significantly different from those who agreed to participate on age, gender, marital status, severity of congenital heart disease (CHD), diagnosis of heart failure,

or hospitalizations in the prior year (Table A1, see Appendix). There were no differences in results between surveys completed on paper (84%) vs electronically (16%).

TABLE 1 Participant characteristics

Characteristic ^a	Categories	Participants
Age, mean (SD)		37 ± 13
Male sex, n (%)		69 (46)
Married, n (%) (n = 149)		67 (45.0)
Consider self religious, n (%) (n = 148)		51 (34.5)
Race/ethnicity, n (%)	Caucasian	127 (84.7)
	Black	3 (2)
	Asian	9 (6)
	Hispanic	7 (4.7)
	Other	4 (2.7)
Education, n (%) (n = 147)	8th grade or less	2 (1.4)
	High school or GED	60 (40.8)
	College	59 (40.1)
	Graduate school	26 (17.7)
Employment, n (%) (n = 149)	Employed	95 (63.8)
	Unemployed	24 (16.1)
	Unable to work	11 (7.4)
	Retired	6 (4.0)
	Student	13 (8.7)
CHD lesion Severity, n (%)	Simple	25 (16.7)
	Moderate	86 (57.3)
Diagnosis of heart failure, n (%)	Complex/severe	39 (26)
		36 (24)
Prior advance care planning, n (%)	No	107 (71.3)
	Yes	43 (28.7)
	- Appointed DPOA	6 (14)
	- Completed AD	6 (14)
	- Completed LW	5 (11.6)
	- More than one	26 (60.5)
Hospitalizations in last year, n (%)		0.8 ± 1.5
Cardiology clinic visits in last year, n (%)		2.6 ± 2.2

N = 150 unless otherwise specified. Abbreviations: CHD, congenital heart disease, DPOA, designated power of attorney; AD, advance directive; LW, living will.

^aAs reported by participants or as documented in the electronic health record.

3.1 | Patient perspectives and clinical assessment of severity of ACHD

In self-assessments of the severity of their ACHD, 28.2% of participants considered their heart condition to be mild, 40.9% moderate, and 30.9% severe or complex. This is in contrast to lesion severity as classified by the 2008 ACC/AHA guidelines,⁷ where 17% of participants had simple lesions, 57% moderate, and 26% complex. Only 41% of participants reported disease perception that agreed with diagnosed lesion severity (Table 2). Very good or excellent health was reported by 38.9% and 10.1% of participants, respectively. At least some physical limitation attributed to their heart condition was reported by 57.7% of participants, and 54.4% reported being at least somewhat worried about their heart condition. When asked about life expectancy, 37.4% of participants thought they would have a shorter life than a peer without heart disease, 45.6% thought they would live as long, and 17% thought they would live longer. This was independent of CHD lesion complexity.

3.2 | Using ACP and palliative care services

Less than a third of participants (28.7%) had done some prior ACP, either by naming a designated health care power of attorney or by completing an advance directive or living will. However, 78.9% reported they were at least moderately willing to meet together with family or friends and their ACHD doctor to discuss goals and care preferences, and 69.1% reported they were at least moderately willing to participate in ACP. The vast majority (91.3%) reported they were at least moderately willing to speak to a clinician who specializes in palliative care; only 4 (2.7%) had met with one in the past (Figure 1).

In multivariate analysis, being married and believing one would have a shorter lifespan than peers without heart disease were factors associated with reported willingness to participate in ACP (Table 3). The remaining potential factors were not associated with

TABLE 2 Discordance between patient-perceived and diagnosed heart lesion severity

Clinical severity from EHR	Patient perception of severity			Total
	Mild/simple	Moderate	Complex	
Mild/simple	6 ^a	13	6	25 ^b
Moderate	30	35 ^a	20	85
Complex	6	13	20 ^a	39
Total	42	61	46	

^aPatients' disease perception was in agreement with diagnosed heart lesion severity for 41% of patients. However, substantial discordance was present, with 8% of patients off in their perception by more than 1 category.

^bOne person with a simple lesion did not answer the question about perceived severity.

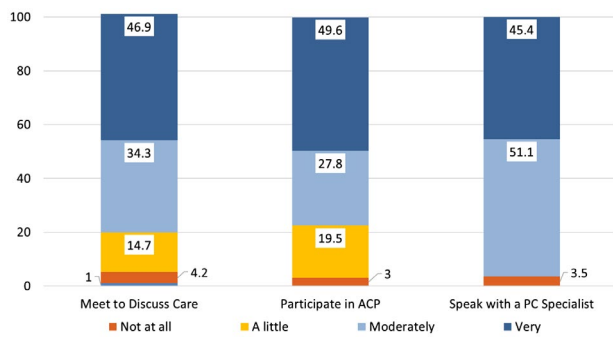


FIGURE 1 Participant willingness to meet to discuss care, participate in ACP,* and speak with a palliative care specialist

reported willingness to participate in ACP, including CHD lesion severity, self-perceived disease severity, religiosity, and hospitalizations in the past year. Concordance in self-assessment of ACHD lesion severity was not associated with perception of ACP or sense of illness. We did not identify any factors associated with reported willingness to meet to discuss goals and care preferences or to speak with a clinician who specializes in palliative care.

3.3 | Prior discussions about care preferences

Only 10 participants (6.7%) indicated they had previously discussed their future care preferences with their ACHD doctor. Of those who had not had prior conversations, 42.5% reported they would like to have such a discussion in the future. Six participants (4%) reported having prior care preference discussions with another cardiologist, and 5 (3.4%) with their primary care physician. When asked which provider they would prefer to have future discussions, 48.6% chose

TABLE 3 Factors associated with willingness to participate in advance care planning

Predictor	Multivariate analysis results	
	Odds ratio (95% CI)	P value
Older age	0.98 (0.95-1.01)	.19
Male sex	1.45 (0.71-2.94)	.31
Education beyond high school	1.43 (0.68-3.03)	.35
Being married	2.16 (1.01-4.59)	.047
CHD lesion severity	0.95 (0.55-1.63)	.84
Perceived CHD lesion severity	1.02 (0.62-1.67)	.95
Anticipating shorter lifespan	0.52 (0.30-0.89)	.02

Bold font indicates a statistically significant value ($P < .05$).

their ACHD doctor, 6.9% indicated another cardiologist, and 12.5% preferred their primary care physician (Table 4).

When asked about discussions with family or friends, 48.5% of participants indicated they had previously discussed their care preferences. Of those who had not had prior conversations, 58.4% indicated they would like to have a future discussion of this type with a family member or friend.

3.4 | Facilitators and barriers

We asked participants whether any of the 10 barriers or 4 facilitators presented in the survey applied to them in terms of making it harder or easier, respectively, to talk with their doctors about their care preferences. Their responses are described in Table 5. The most commonly identified barrier was "I have not felt sick enough to talk with my doctor about end-of-life care," endorsed by 42% of study participants. It was also chosen as the most important barrier. The most commonly identified facilitator was "I worry about the quality of life in my future," endorsed by 58% of study participants. The most important facilitator was "I worry that I could be a burden on my friends and family if I were to become very sick."

4 | DISCUSSION

We evaluated outpatients' views on ACP and palliative care in the context of having ACHD. The majority of participants reported being willing to meet together with family or friends and their ACHD doctor to discuss care preferences, to participate in ACP, and to speak to a clinician who specializes in palliative care. Being married and believing one would have a shorter lifespan than one's peers without heart disease were factors associated with reported willingness to participate in ACP. About half of participants had expressed their care preferences to family, and some had taken part in ACP previously, but less than 10% had discussed their care preferences with their ACHD clinician. However, almost half chose their ACHD clinician as the health care provider with whom they'd prefer to have future conversations. We also found that less than half of the patients described the severity of their ACHD in a way concordant with guideline classification, suggesting important opportunities for patient education.

Advance care planning and palliative care are likely to be beneficial in the care of patients with ACHD based on studies of patients with other serious illnesses,⁸⁻¹⁰ but no studies have specifically evaluated these services in ACHD. Prior studies show low rates of ACP in ACHD.^{1,2,11} Even in severely ill patients who died during an index hospitalization, one study found that only 6% had end-of-life care discussions documented prior to that admission.¹¹ Health care directives (living wills) had been completed by outpatients for only 5% of participants in 1 study² and 21% in another.¹ In both studies, 18% had designated a health care power of attorney. Discussion of future care preferences with the provider had occurred in 1% and 13%, respectively.^{1,2} In our study, a similar percentage of participants reported having discussed their wishes with family (48%), appointing a

TABLE 4 Care planning discussions by type of provider

	Had prior discussion with (n = 21)	Discussion met needs* (n = 21)	Preferred provider for future discussion (n = 144)
ACHD clinician	10 (47.6)	5.8 ± 4.3	70 (48.6)
Other cardiologist	6 (28.6)	7.4 ± 3.0	10 (6.9)
Primary care physician	5 (23.8)	8.8 ± 1.6	18 (12.5)
Multiple providers	n.a	n.a	25 (17.4)

Values displayed as n (%) or mean ± SD on a 0-10 scale.

TABLE 5 Barriers and facilitators to talking about care preferences

Barriers to talking about care preferences	N (%)
I have not felt sick enough to talk with my doctor about end-of-life care ^a	60 (42)
I'm not sure which doctor would be taking care of me if I were to get very sick	42 (29.4)
I would rather concentrate on staying alive than talk about death	42 (29.2)
I'm not ready to talk about the care I would want if I were to get very sick	33 (22.8)
My ideas about the kind of medical care I want may change	32 (22.4)
I don't like to talk about getting very sick	30 (20.8)
I don't know what kind of care I would want if I were to get very sick	23 (15.9)
My doctor never seems to have the time to talk about issues like end-of-life care	19 (13.3)
I feel that talking about death can bring death closer	13 (9.1)
I have a living will, and that means I don't need to talk with my doctor about the care I would want if I were too sick to speak for myself	7 (5)
Facilitators for talking about care preferences	N (%)
I worry about the quality of my life in the future	80 (57.6)
I worry that I could be a burden on my friends and family if I were to become very sick ^a	76 (55.1)
I have had family or friends who have died so it is easier to talk about ^a	68 (48.9)
I have been very sick, so it is easier to talk about	59 (42.8)

^aIdentified by participants as the most important factor.

health care power of attorney (14%), and completing living wills (12%). Although less than 20% of participants in our study had discussed future care preferences with health care providers, and less than 10% had had this discussion with their ACHD clinician, the ACHD clinician was the person with whom most participants preferred to have these discussions. These findings suggest that additional work needs to be done to promote ACP for patients with ACHD.

Prior studies suggest that patients with ACHD are interested in receiving information about prognosis,^{1,2} and they recognize the importance of discussing ACP with their health care providers.¹ Interestingly, in almost all cases, patients thought the provider should raise the subject.¹² However, supporting the importance of something like ACP is different than being willing to personally participate in the process. Our study assessed patients' reported willingness

to engage in specific types of discussions and planning activities. Interestingly, we found that almost 80% reported they were willing to meet together with family or friends and their ACHD doctor to discuss goals and care preferences, and a slightly smaller proportion (70%) reported they were willing to participate in ACP. This difference may reflect some reservation about formal participation in ACP activity, such as fear, denial, or questions about relevance.

We also attempted to identify characteristics that may affect reported willingness to engage in ACP and found, in multivariate analysis, that being married and believing one would have a shorter lifespan than peers without heart disease were associated with being more willing to participate in ACP. Perhaps this reflects more of a desire to plan ahead if family members could be adversely affected by the consequences of severe illness. This is supported by our finding that the facilitator identified as most important for discussing care preferences was worrying about being a burden on friends and family. Tobler and colleagues² likewise found that nonsingle patients had more advance directives. In contrast to our study, Deng and colleagues¹ reported that females and those with lower disease complexity were more likely to recognize ACP as important. In populations with noncongenital cardiac illness, factors other than marital status and sex, such as older age and prior hospitalization, have been associated with a higher chance of having advance directives.^{13,14}

Identifying ways to encourage patients with ACHD to consider acting on ACP is perhaps one of the largest challenges in providing palliative care in this population. The barriers and facilitators most relevant in our study were not the same as those identified in a study of Canadian patients.³ In our study, the most commonly endorsed barrier to talking with doctors about care preferences and the barrier identified as most important was not feeling sick enough to discuss end-of-life care. The percentage of patients who endorsed this barrier was similar in this study and a prior Canadian study (42% vs 47%), as was not being ready to talk about care preferences (23% vs 24%). The preference to focus on staying alive (29% vs 66%) and not knowing what kind of care they would want (16% vs 55%) were endorsed by a smaller percentage of patients in our study. Exposure to someone else who died, which may increase the personal relevance of ACP, was endorsed by a smaller percentage of patients in our study than in the Canadian study (49% vs 63%). Facilitators endorsed similarly in both were worrying about future quality of life (58% vs 68%) and becoming a burden to family/friends (55% vs 58%). However, it is noted that direct comparison between these studies is limited by the fact that the barriers and facilitators queried were not identical.

Together, these study results suggest a few options for ways to improve the incorporation of palliative care and ACP into outpatient ACHD visits. Visits separate from planned medical follow-up can be scheduled for the purposes of discussing ACP and palliative care and could include time to work through an advance directive. Palliative care and ACP information may be included in clinic Welcome materials or the medical after-visit summary so patients can familiarize themselves with them ahead of time. Topic-specific training in palliative care and ACP for ACHD clinicians, such as through seminars or as part of fellowship training, may be important since patients preferred to plan with their ACHD clinicians. Alternatively, institutions can develop outpatient cardiac palliative care clinics, perhaps led by palliative care specialists with ACHD clinicians present to answer questions.

Our study has important strengths, as the first study in the United States to explore facilitators and barriers to discussions about future care preference in patients with ACHD and reported willingness to actively participate in ACP and see a palliative care specialist. Our study also has several limitations. First, this is a cross-sectional study, and therefore, associations cannot be assumed to be causal. We did not offer discussions or consultations to see how many patients followed through with those visits as part of this study. Therefore, we describe patients' reported willingness to engage, in the absence of being able to know if willingness would translate into action. Second, our study took place in a single ACHD clinic in a single location and may not be generalizable to other geographic areas. Our sample was predominantly non-Hispanic white and may not generalize to other races and ethnicities. Third, although our participation rate was high for this type of study, participation bias may limit generalizability to the population, as participants were more likely to be non-Hispanic whites and to have had more cardiology clinic visits in the prior year. Finally, answers regarding prior conversations were by self-report and potentially subject to recall bias.

In summary, this study describes facilitators and barriers to ACP for patients with ACHD and found that the majority of patients reported being willing to participate in ACP or see a clinician who specializes in palliative care. In addition, we found that patients with ACHD were most likely to prefer having ACP discussions with their ACHD clinician, suggesting education is needed regarding ACP and goals-of-care discussions for all clinicians caring for patients with ACHD. Recognizing common barriers and facilitators may facilitate this process. Further studies are needed to explore the best ways to integrate ACP and palliative care into the care of patients with ACHD.

DISCLOSURES

None (all authors).

AUTHOR CONTRIBUTIONS

Concept/design, data analysis/interpretation, drafting of article, revision and approval of the article: Steiner

Concept/Design, Revision and approval of the article: Stout, Soine, Kirkpatrick

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REFERENCES

- 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.
- 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;109:1797-1800.
- Greutmann M, Tobler D, Colman JM, Greutmann-Yantiri M, Librach SL, Kovacs AH. Facilitators of and barriers to advance care planning in adult congenital heart disease. *Congenit Heart Dis.* 2013;8:281-288.
- Hobler MR, Engelberg RA, Curtis JR, et al. Exploring opportunities for primary outpatient palliative care for adults with cystic fibrosis: a mixed-methods study of patients' needs. *J Palliat Med.* 2018;21(4):513-521.
- Curtis JR, Patrick DL, Caldwell ES, et al. Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Arch Intern Med.* 2000;160(11):1690-1696.
- Knauff E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest.* 2005;127:2188-2196.
- Warnes CA, Williams RG, Bashore TM, et al. ACC/AHA 2008 guidelines for the management of adults with congenital heart disease. *J Am Coll Cardiol.* 2008;52(23):e143-263.
- Higginson IJ, Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *Cancer J.* 2010;16:423-435.
- Rogers JG, Patel CB, Mentz RJ, et al. Palliative care in heart failure: the PAL-HF randomized, controlled clinical trial. *J Am Coll Cardiol.* 2017;70:331-341.
- Smallwood N, Thompson M, Warrender-Sparkes M, et al. Integrated respiratory and palliative care may improve outcomes in advanced lung disease. *ERJ Open Res.* 2018;4(1). pii:00102-2017.
- Tobler D, Greutmann M, Colman JM, Greutmann-Yantiri M, Librach SL, Kovacs AH. End-of-life care in hospitalized adults with complex congenital heart disease: care delayed, care denied. *Palliat Med.* 2012;26:72-79.
- Tobler D, Greutmann M, Colman JM, Greutmann-Yantiri M, Librach SL, Kovacs AH. End-of-life in adults with congenital heart disease: a call for early communication. *Int J Cardiol.* 2012;155:383-387.
- Merchant FM, Binney Z, Patel A, et al. Prevalence, predictors, and outcomes of advance directives in implantable cardioverter-defibrillator recipients. *Hear Rhythm.* 2017;14:830-836.
- Butler J, Binney Z, Kalogeropoulos A, et al. Advance directives among hospitalized patients with heart failure. *JACC Hear Fail.* 2015;3:112-121.

How to cite this article: Steiner JM, Stout K, Soine L, Kirkpatrick JN, Curtis JR. Perspectives on advance care planning and palliative care among adults with congenital heart disease. *Congenital Heart Disease.* 2019;14:403-409. <https://doi.org/10.1111/chd.12735>

APPENDIX

Table A1. Characteristics of survey participants and available characteristics of nonparticipants

Characteristic*	Categories	Participants	Nonparticipants	P value
Age, mean (SD)		37 ± 13	34 ± 12	.13
Male sex, n (%)		69 (46)	27 (48.2)	.78
Married, n (%) (n = 149)		67 (45.0)	22 (39.3)	.25
Consider self religious, n (%) (n = 148)		51 (34.5)	n/a	n/a
Race/ethnicity, n (%)	Caucasian	127 (84.7)	42 (75)	.04
	Black	3 (2)	2 (3.6)	
	Asian	9 (6)	4 (7.1)	
	Hispanic	7 (4.7)	3 (5.4)	
	Other	4 (2.7)	1 (1.8)	
Education, n (%) (n = 147)	8th grade or less	2 (1.4)	n/a	n/a
	High school or GED	60 (40.8)		
	College	59 (40.1)		
	Graduate school	26 (17.7)		
Employment, n (%) (n = 149)	Employed	95 (63.8)	n/a	n/a
	Unemployed	24 (16.1)		
	Unable to work	11 (7.4)		
	Retired	6 (4.0)		
	Student	13 (8.7)		
CHD lesion Severity, n (%)	Simple	25 (16.7)	13 (23.2)	.07
	Moderate	86 (57.3)	22 (39.3)	
	Complex/severe	39 (26)	21 (37.5)	
Diagnosis of heart failure, n (%)		36 (24)	13 (23.2)	.26
Prior advance care planning, n (%)	No	107 (71.3)	n/a	n/a
	Yes	43 (28.7)		
	- Appointed DPOA	6 (14)		
	- Completed AD	6 (14)		
	- Completed LW	5 (11.6)		
	- More than one	26 (60.5)		
Hospitalizations in last year, n (%)		0.8 ± 1.5	0.8 ± 1.4	.87
Cardiology clinic visits in last year, n (%)		2.6 ± 2.2	1.7 ± 2.2	.007

For participants, N = 150 unless otherwise specified. For nonparticipants, N = 56. Abbreviations: CHD, congenital heart disease; DPOA, designated power of attorney; AD, advance directive; LW, living will.

*As reported in survey by participants, and, when available, as documented in EHR for nonparticipants.