Cardiology in the Young

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Advance care planning for adolescents and young adults with congenital heart disease: the adult patient perspective

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Abstract

Introduction: Although the importance of advance care planning (ACP) for individuals with adult congenital heart disease (ACHD) has been established, there is no consensus regarding the optimal age to initiate ACP discussions. We asked ACHD patients their opinions about the timing of the first ACP discussion. *Materials/methods:* Adult patients seen in an outpatient ACHD clinic from April to August 2018 completed a self-administered questionnaire that evaluated opinions regarding the content and timing of ACP discussions, end-of-life communication preferences, and anticipated emotional responses to ACP discussions. *Results:* Ninety-five patients participated. Median age was 34.8 years (Q1 – Q3: 28.4 - 47.1 years), 53% ($n = 50$) were female, and 91% ($n = 86$) had great or moderate disease complexity. Although 75% ($n/N = 69/92$) thought ACP was important, only 37% ($n/N = 35/94$) had completed advance directives. Most (79%, $n/N = 72/91$) preferred ACP conversations early, either before getting sick (44%, $n = 40/91$) or when first diagnosed with a life-threatening illness (35%, $n = 32/91$). Responses varied regarding the appropriate age for first ACP conversations: 28% ($n/N = 25/88$) chose options $\leq$ 15 years, 23% ($n/N = 20/88$) 16–17 years, 32% ($n/N = 28/88$) 18–20 years, and 17% ($n/N = 15/88$) $\geq$ 21 years old. *Discussion:* ACHD patients value ACP discussions and think they should occur early in the disease course, before patients face a life-threatening disease complication, yet most think these conversations should wait until later adolescent or young adult years. ACP readiness should be assessed to determine the optimal timing of ACP discussions.

Introduction

Individuals with adult congenital heart disease (ACHD) have an increased incidence of medical and psychosocial morbidity[1] and an increased risk for hospitalisation and premature death.[2–8] Patients who have had advance care planning (ACP) discussions are more likely to die at home with less invasive, futile, and costly treatments.[9] ACP supports patient autonomy and decision-making; reduces stress, anxiety, and the decision-making burden of family members; helps ensure that delivered care better aligns with desired care;[10] improves the quality of life at end-of-life; and improves end-of-life communication and care.[11,12] The American College of Cardiology and American Heart Association (AHA/ACC) 2008 guidelines recommend that individuals with ACHD "should be encouraged to complete an advance directive (AD), ideally at a time during which they are not extremely ill or hospitalised, so that they can express their wishes thoughtfully in a less stressful setting and communicate these wishes to their families and caregivers".[13] The 2018 guidelines note that "early discussion of end-of-life issues is consistent with patient-centered care and patient satisfaction".[14] It is recommended that ACP conversations occur in a structured process across life stages and are revisited annually.[15] European guidelines for ACP in ACHD similarly recommend that ACP be delivered to patients as a "structured process across different stages, with content dependent upon the anticipated disease progression".[15] Physician concerns about patient readiness for ACP conversations and challenges related to prognostication have been cited as barriers to initiating ACP conversations.[16] However, most ACHD patients report wanting to have these discussions with their medical team and family[17,18] independent of disease complexity,[16] but few have had them.[17,19–21]

Some patients with congenital heart disease (CHD) face life-threatening disease states prior to adulthood. While these patients are unable to complete an AD, their end-of-life wishes can still be heard and respected, and they stand to derive similar benefits to adults from ACP conversations. ACP conversations, however, require them to have the maturity to engage in in-depth conversations where they express clear end-of-life care preferences with family members and the healthcare team. While it is appreciated that these conversations should occur before the patient is critically ill, the optimal age for these sensitive conversations in adolescents with complex CHD is unknown. Adolescence is a time of significant development, maturation, and growing independence. Ideally, during this time, patients with CHD gain increasing knowledge of their heart condition and gradually increase their autonomy and decision-making when it comes to their medical care. We previously described the ACP preferences of adolescents and their caregivers seen in the heart failure and transplant clinic at a West Coast American tertiary care centre.[22] The majority of adolescents and caregivers reported that the adolescent was old enough to make end-of-life decisions, although there was no consensus as to the appropriate age to initiate ACP conversations. In this study, we asked individuals with ACHD to reflect on the timing of and anticipated emotional responses to ACP conversations to inform if and when ACP conversations are appropriate for adolescents.

Material and methods

Study design and sample

We performed a descriptive, cross-sectional survey to assess the ACP preferences of ACHD patients. The questionnaire and study methodology were approved by the Stanford University Institutional Review Board. Patients 18 years and older seen for a follow-up visit in an ACHD clinic in our tertiary care centre situated along the West Coast of the United States from April to August 2018 were eligible for inclusion. The monthly clinic volume is approximately 250 patients. Patients who were unable to read in English or Spanish, those with cognitive limitations prohibitive to survey understanding/completion (subjectively determined by the patient's cardiology provider), and those without CHD were excluded. Eligible patients were approached by a study coordinator during their clinic visit and offered three modalities for questionnaire completion: paper, tablet, or an emailed questionnaire link. All patients consented to study participation.

Study tool

Participants completed a questionnaire that inquired into their ACP preferences (Supplement 1). The questionnaire drew from previously published research and included 46 items assessing patient identifiers, demographic characteristics, self-perceived health status, experience with ACP, preferences for ACP, emotions surrounding ACP, and open-ended feedback for investigators.[17,21,23–26] A version of this questionnaire was previously utilised to assess ACP preferences for adolescents with heart failure/orthotopic heart transplantation and their caregivers.[22]

Data and statistical analysis

Questionnaires were distributed electronically and by paper by a study coordinator, and responses were manually entered and stored in a Research Electronic Data Capture (REDCap) database, a secure and HIPAA-compliant web-based survey and database design and management application.[27,28] Clinical characteristics were collected from the electronic medical record and manually entered into the corresponding record in REDCap. Responses from participants who completed <50% of the questionnaire items were excluded. Standard descriptive statistics were performed using R (Version 4.3.2, R Foundation for Statistical Computing, Vienna). Clinical and demographic characteristics and survey responses were reported as percentage *n* for items with a response rate of 100%, percentage *n/N* for items with less than 100% response rate where N is the total number of item respondents, or median (Q1, Q3).

Results

Ninety-nine patients filled out the survey instrument. Two participants were followed for cardiomyopathy and did not carry a diagnosis of CHD; these were excluded. Two terminated the survey before completing 50% of the questionnaire items and were excluded. Responses from the remaining 95 participants were included.

Demographic and clinical characteristics are shown in Table 1. Complete clinical data was available for all participants. Most participants (91%, *n* = 86) had moderate or great complexity disease by ACHD AP Classification.[14] The majority (75%, *n* = 71) self-reported their health as *very good* or *good* and were assigned by their physician to New York Heart Association Functional Class[29] I or II (62%, *n* = 59, and 27%, *n* = 26, respectively). Median age at survey completion was 34 years (Q1 – Q3: 28.4 - 47.1 years;), and 63% (*n/N* = 55/88) of respondents identified as white/non-Hispanic.

Of the 95 patients analysed, 54% (*n* = 51) had engaged in ACP discussions, most informal with family members or friends (43/51 positive respondents). Only 13% (n = 16) had ACP discussions with a physician, despite 75% (*n/N* = 69/92) indicating that ACP with a healthcare provider was *moderately important* or *extremely important*. Most participants indicated that ACP should be performed early in the disease course—*before getting sick, while healthy* or *when first diagnosed with a life-threatening illness* [44% (*n/N* = 40/91) and 35% (*n/N* = 32/91)], respectively. Responses varied as to what age is old enough to know what kind of end-of-life care one would want if terminally ill and the optimal age for provider-initiated ACP conversations (Figure 1), but the majority of respondents [62% (*n/N* = 58/93)] felt that an individual needed to be 16 or older before they knew their end-of-life wishes. Only 28% (*n/N* = 25/88) thought that healthcare providers should first engage in ACP with individuals with CHD less than 16 years of age. Ninety-five percent (*n/N* = 86/91) indicated they were currently old enough to know their end-of-life care preferences. Most had heard of ADs [71% (*n/N* = 65/92)], and 37% (*n/N* = 35/94) had completed one. Only 17% (*n/N* = 16/94) had written down their wishes outside of an AD.

When asked if they would like to know the expected life expectancy for someone with their heart condition, 13% (*n/N* = 12/93) already knew this information, and of the remaining respondents, 94% (76 of 81 remaining respondents) desired this information. All participants (100%, *n* = 95) indicated they would want to be told if they were terminally ill, and 98% (*n/N* = 92/94) would want to be involved in end-of-life medical care decisions.

Anticipated emotional responses to ACP discussions are shown in Figure 2. Respondents were split as to whether they thought discussing ACP would induce worry about their health or stress

Table 1. Patient demographic and disease characteristics

Disease characteristics $N = 95$		
Congenital heart disease complexity category[a]	Great	42 (44)
	Moderate	44 (46)
	Simple	9 (9)
Congenital heart disease diagnosis classification	**Single ventricle**	**15 (16)**
	Tricuspid atresia	7 (7)
	Hypoplastic left heart	0 (0)
	Other	8 (8)
	Biventricular repair	**64 (67)**
	D-transposition of the great arteries	12 (13)
	Tetralogy of Fallot	11 (12)
	Coarctation of the aorta	6 (6)
	Anomalous pulmonary venous return	6 (6)
	Pulmonary valve/artery stenosis	6 (6)
	Septal defect	5 (5)
	Other	18 (19)
	Unrepaired CHD	**11 (12)**
	Septal defect, anomalous pulmonary venous return	5 (5)
	L-transposition of the great arteries	2 (2)
	Ebstein's anomaly	1 (1)
	Bicuspid aortic valve	3 (3)
	Eisenmenger	**5 (5)**
New York Heart Association functional classification	I	59 (62)
	II	26 (27)
	III	10 (11)
	IV	0 (0)
Patient-reported health status	Excellent	8 (8)
	Very good	34 (36)
	Good	37 (39)
	Fair	14 (15)
	Poor	2 (2)
Demographic characteristics		
Age, years		34.8 (28.4, 47.1)
Male		45 (47)
White/non-Hispanic		55 (63, $N = 88$)
Christian		43 (48, $N = 90$)
Bachelor or advanced degree		49 (52, $N = 94$)
Married/domestic partnership		47 (53, $N = 88$)

Median (Q1, Q3) or n (%) when $N = 95$ and n (%, n) when $n \neq 95$

[a] Adult congenital heart disease anatomic and physiological (ACHD AP) classification [Stout 2018]

about making important healthcare decisions. Most anticipated relief that their family and medical team would know their wishes [79% ($n/N = 73/92$)], confidence that these individuals would respect their wishes [74% ($n/N = 64/86$)], and happiness in making important healthcare decisions [86% ($n/N = 76/88$)].

Discussion

We demonstrated that ACP discussions with providers are greatly desired, rarely had, and that anticipated emotional responses to ACP discussions are overall positive. We importantly found that while ACP discussions are preferred earlier in the disease course, before life-threatening disease complications, there was no consensus regarding optimal age for first ACP discussion, although few adults with ACHD felt that these conversations should be initiated with children less than 16 years old.

ACP discussions with providers are wanted but seldom had

ACP discussions were described as moderately or extremely important by 75% of respondents. However, only 13% had had a prior ACP discussion with their physician. Notably, more respondents indicated having conversations about ACP with people who were close to them, such as family and friends, suggesting a willingness to engage in ACP discussions and an unmet need and opportunity for the medical team to inform these conversations. It was important to respondents that their medical team communicate if their prognosis is poor, and 94% of respondents wanted to know about life expectancy despite only 13% reporting that they had this information. Cousino et al. studied the ACP preferences of an adolescent and young adult advanced heart failure population and similarly found that 79% of participants preferred to discuss prognosis, with a stronger preference for decision-making involvement in

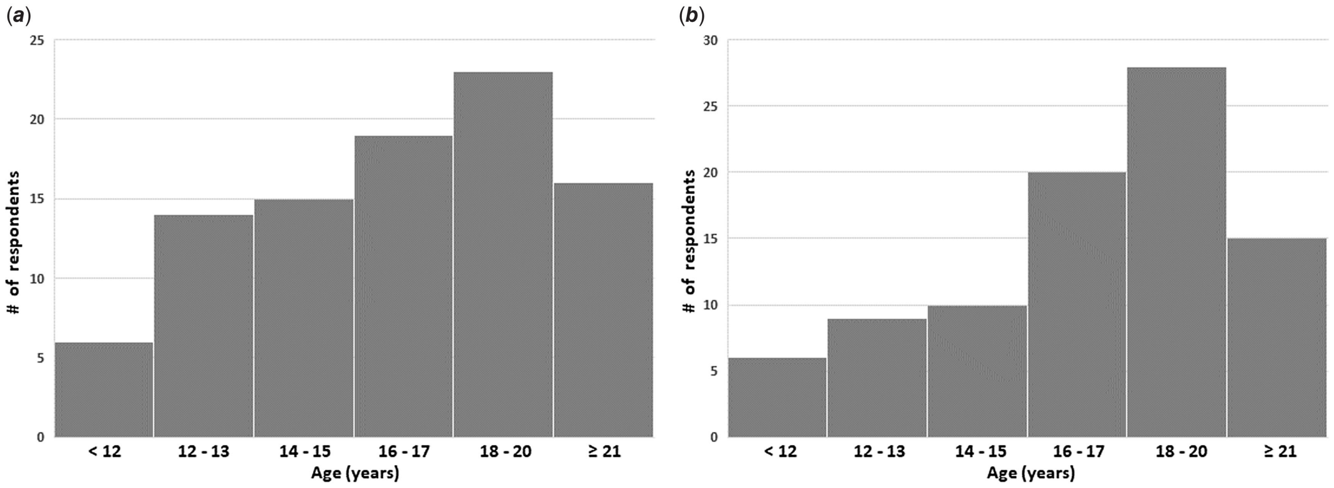

Figure 1. a) At what age is a person with a heart condition old enough to know what kind of care they would want if they were very sick? b) At what age should a health care provider start discussing advance care planning with a patient with a heart condition?

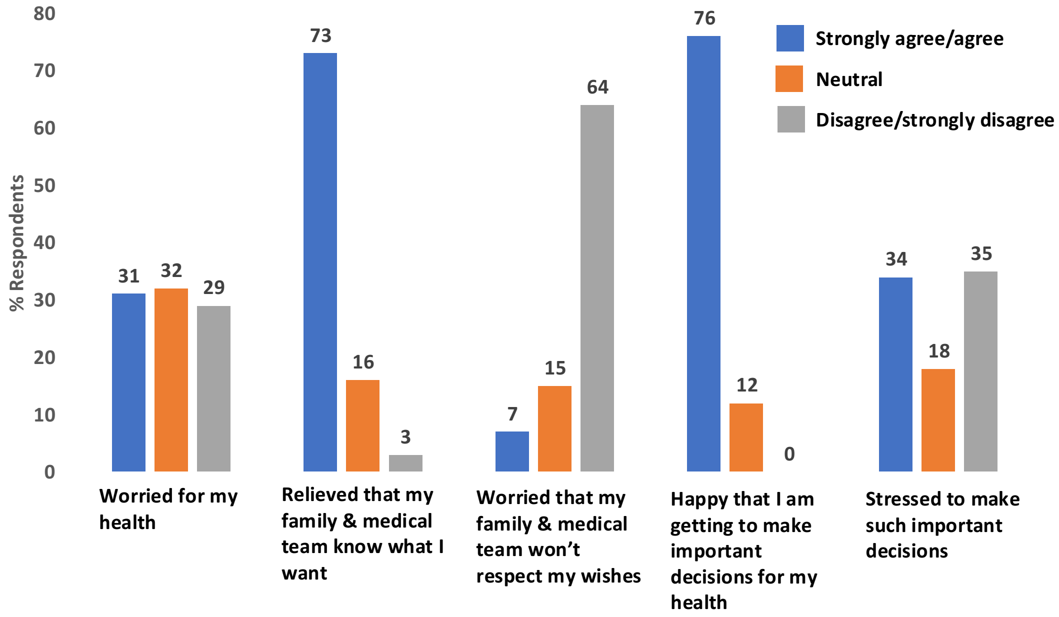

Figure 2. Emotional response to talking about advance care planning.

patients who had a worse functional status or longer time since cardiac diagnosis.[30]

While the outcomes for patients with CHD have dramatically improved, the life expectancy remains substantially lower than the general population, with a median age of death of 50 years.[31] Additionally, a perception of being "cured" has been described, which has implications for compliance and may leave patients vulnerable to psychosocial challenges.[32] ACP discussions provide another opportunity for education about the anticipated disease course (e.g., possible complications, including sudden cardiac death and the development of arrhythmia and heart failure) and prognosis, which patients have repeatedly reported wanting.[19,22] Medical team members can also discuss the components of an AD, which may help guide the conversation.

While most respondents (71%) had heard of an AD, only 37% had completed one despite a median respondent age of 34 years, well beyond the age at which ADs are legally recognised and older than the age recommended for individuals with ACHD to have an AD in place.[13,33] These findings are consistent with prior inquiries into reported interest in ACP conversations among individuals with ACHD; most preferred to have an AD in place if they are no longer able to speak for themselves, yet few had completed an AD or had appointed a healthcare representative.[17–19,21] While completing an AD during an acute decompensation may be useful, it is preferred that ACP conversations occur during routine visits with the patient's trusted longitudinal medical team before the patient becomes acutely ill.[34] A staged implementation of ACP discussions as part of standard care for all ACHD patients provides a forum for having these important discussions gradually over time and as an iterative process with an opportunity for reflection and re-evaluation.[15] The European Society for Cardiology recommendations for ACP in ACHD outline barriers to ACP discussions in the clinical setting. A primary barrier is a lack of knowledge about ACP amongst patients.[15] If patients don't know that their life expectancy may be shorter than their peers[2,7,35] and do not know that ACP discussions provide a mechanism for better understanding prognosis, empowering decision-making, and reducing decision-making burden on loved ones,[36] they are unlikely to initiate the conversation. It is important that the healthcare team recognise their essential role in initiating and continuing longitudinal ACP discussions. Ideally, for patients who are cared for throughout childhood by their paediatric cardiology medical team, a trusting and longitudinal relationship with that team may provide the foundation to initiate these conversations prior to transitioning to adult care.

ACP conversations are empowering

Most individuals with ACHD anticipated that ACP discussions would leave them feeling relieved that their preferences would be communicated to the medical team and to their family and happy to have the opportunity to make important decisions about their health. These results were similar to our previously reported adolescent responses.[22] Respondents with ACHD were divided as to whether having ACP discussions would make them feel worried or stressed, though few worried that their family and medical team would not respect their end-of-life wishes. Deng et al. reported that higher participant anxiety was associated with high ratings of ACP importance and concluded that ACP discussions should not be avoided due to anxiety, as anxious patients may welcome the conversation.[17] While our study did not collect data on the mental health of participants, it does support a generally positive anticipated emotional response to ACP across participants while suggesting that the actual process of ACP may be stressful for some patients. Future research is needed to evaluate the experience and perspectives of patients with CHD who complete ACP.

ACP discussions should occur early in the disease course, but not when the patient is too young

Similar to prior studies, our study supports that ACP should occur early in the disease course, before a patient is symptomatic from a life-threatening diagnosis.[17,20] In our prior study of adolescent heart failure/transplant patients and their caregivers, we found that adolescents and caregivers similarly preferred ACP earlier in the disease course. This timing allows for thoughtful, less pressured decision-making when the patient is not hospitalised or critically ill. The 2023 AHA guidelines for palliative care for patients with CHD suggest that ACP discussions should begin in adolescence.[37] This recommendation comes despite the study by Deng et al. that reported that ACHD patients prefer initiating ACP at 18 years of age.[17] In our current study, responses from individuals with ACHD were split as to whether conversations should occur in adolescence or adulthood. More evident was the sentiment that conversations should not occur at too young an age; 72% indicated that an adolescent needed to be at least 16 years old before first engaging in ACP. Correspondingly, most indicated that an adolescent needed to be at least 16 years old before they could know their end-of-life wishes. In our prior study describing the ACP preferences of adolescents with heart failure/transplant and their caregivers, we similarly observed varied responses as to the appropriate age of first ACP.[22] The lack of consensus likely reflects that age is an inadequate surrogate for readiness for ACP, which relies on maturity, decision-making capacity, autonomy, and health awareness. The AHA palliative guidelines acknowledge that age at ACP readiness may differ and suggest an individualised approach with assessment of readiness.[37] These assessments may occur concurrently with the transition (i.e., from paediatric to adult provider) readiness assessment. Transition readiness can be measured by the Transition Readiness Assessment Questionnaire, a validated assessment of healthcare self-management skills.[38] Transition clinic visits may serve as a valuable opportunity to gauge maturity to handle ACP discussions. Our findings support that ACP readiness assessment should ideally begin at 16 years and early in the disease course. These timing factors are sometimes mutually exclusive, and consequently, there are nonideal situations where children <16 years present in more advanced disease stages. These complex situations are unfortunately often encountered in acquired diseases like cancer and trauma and best navigated with the early involvement of palliative care experts.[39] Even outside of these challenging situations, palliative care involvement may be helpful for ACP readiness assessment in all adolescents and young adults with CHD.

Limitations

Limitations of this study include the limited nature of short questionnaires and survey-based research; there is much nuance and individualisation to ACP, and this study design only provides limited insights into respondents' perspectives on ACP. Our study was also limited in that it was a single-centre, small sample size study of patients in Western North America with primarily complex CHD with little or no heart failure symptoms, limiting the generalisability of our findings. ACP is a culturally informed process, and an individual's ACP decisions may reflect their level of trust in local and national health care systems, and thus these findings may not apply to populations in other regions or countries. Self-selection by patients that elected to participate may have introduced selection bias. Our sample included a high proportion of White/non-Hispanic individuals relative to our catchment population, which is concerning for some degree of sampling bias that may further limit generalisability. Additionally, our sample had a high degree of educational attainment reflective of our catchment population, which may limit generalisability to other populations.

In designing our survey, we included many questions with Likert and other ordinal scale responses, which may be subject to various forms of response bias.[40] Additionally, the age ranges we selected for questions about the age when a child is old enough to know their end-of-life wishes and the optimal age for the first ACP discussion were narrow, potentially contributing to the variability of responses. It is recommended that the transition process for children with CHD begin at 12 years of age and the transfer of care between 18 and 21 years of age; thus, <12 years old and ≥ 21 years old were chosen as the end ordinal responses, and the intervening ages were divided into 2–3 year intervals. This granularity was intended to be most informative for clinical teams looking for guidance on when to initiate ACP but may have led to choice overload, making it more difficult for participants to choose.

Conclusion

Adults with heart disease prefer that ACP conversations begin early in the disease course, but the optimal age for initiating ACP is harder to define, likely reflecting that there is no one age that fits all and that individualising the timing of ACP discussions is essential. Our study suggests that medical teams should take into consideration disease state and ACP readiness when initiating ACP discussions. Sixteen years is the optimal age for care teams to begin assessing readiness for ACP. For children less than 16 years old with more advanced disease states, early involvement of palliative care experts is recommended. Future study into how ACP preferences may vary by patient-specific factors (e.g., cardiac disease complexity, illness severity, and mental health) and best practices for the conduct of ACP conversations in the clinical setting are warranted.

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