



Advance Care Planning in Adults with Congenital Heart Disease: A Patient Priority[☆]



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ABSTRACT

Background: Adult congenital heart disease (ACHD) patients with moderate or great defect complexity are at risk for premature death. Although early engagement in advance care planning (ACP) is recommended, previous research suggests that it seldom occurs.

Methods: This study investigated ACHD patient preferences for ACP and factors that impact preferences. ACHD patients completed an ACP preferences questionnaire, the Hospital Anxiety and Depression Scale and a measure of attachment styles.

Results: Of 152 ACHD patients (median age 33 years, 50% female), 13% reported previous ACP discussions with providers and 21% had completed advance directives. On a 0–10 scale, the median rating for the importance of discussing ACP with providers was 7; 18 years was identified as the most appropriate age to initiate this dialogue. Higher ratings for the importance of discussing ACP with providers was observed in patients who were female ($p = 0.03$), had lower disease complexity ($p = 0.03$), and had elevated anxiety symptoms ($p = 0.001$); elevated anxiety remained significant in a multivariable model. Interest in receiving information about life expectancy (61% overall) was greater among patients with lower disease complexity ($p = 0.04$) and a history of ≥ 2 cardiac surgeries ($p = 0.01$); disease complexity remained significant in a multivariable model.

Conclusions: As a group, ACHD patients value the opportunity for ACP discussions and prefer earlier communication. Although some clinicians might avoid ACP discussions in patients who are generally more anxious or have less complex CHD, such avoidance does not appear to be warranted.

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1. Introduction

Almost 90% of children born with congenital heart disease (CHD) will reach adulthood and adults now comprise almost 60% of the American CHD population [1,2]. However, adults with moderate or complex CHD continue to have substantial morbidity and mortality and the annual number of deaths within this group is projected to markedly increase [3,4,5,6]. As mortality has largely shifted to the

adult setting, American guidelines for the management of adult CHD (ACHD) patients recommend that “all ACHD patients should be encouraged to complete an advance directive, ideally at a time during which they are not extremely ill or hospitalized” [7].

Advance care planning (ACP) is the process of planning for future medical care and typically includes the completion of advance directives and the appointment of a health care power of attorney. Canadian research documented that three-quarters of ACHD patients wanted to discuss end-of-life planning with health care providers, although only 1% recalled such discussions and only 5% had completed advance directives [8,9]. It is unknown whether Canadian findings are generalizable to an American setting. The objectives of this study were to (1) describe the ACP experiences and preferences in a sample of American ACHD patients, and (2) investigate whether patient preferences differ as a function of sociodemographic, medical or psychosocial factors.

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¹ This author takes responsibility for all aspects of the reliability and freedom from bias of the data presented and their discussed interpretation.

2. Methods

2.1. Study population

This study was approved by our institutional ethics review board and written informed consent was obtained from all participants. Patients were consecutively enrolled at the outpatient clinic of an American northeastern tertiary ACHD center and inclusion criteria included age ≥ 18 years, documented history of CHD, and cognitive and language abilities to complete study questionnaires in English.

2.2. Study measures

Patients completed a questionnaire focused on ACP and life expectancy that included questions used previously [9,10] and others written by our study team. ACP was defined as “the process of thinking about your preferences for future health care (including the kinds of treatment you would and would not want) and letting other people know your preferences should you get very sick and become incapable of speaking for yourself.” Patients were asked whether (and at what age) they had discussed ACP with a health care provider. Patients were also asked with whom, if anyone, they had talked about wishes for end-of-life care. In addition, patients were asked whether they had completed an advance directive or had identified a healthcare power of attorney who would make decisions about their health care should they be unable to do so for themselves. Patients were then asked the following questions: (1) On a scale of 0–10 (with 0 being least important and 10 being most important), how important is it to you to discuss advance care planning with your health care provider? (2) When do you think is the right age for a health care provider to start discussing advance care planning with a patient with congenital heart disease? (3) What is the best time to bring up ACP discussion? Response options to this third question included (a) Before getting sick, while healthy, (b) When first diagnosed with a life-threatening illness or complication from heart disease, (c) When first symptomatic with a life-threatening illness or complication from heart disease, (d) when first hospitalized with a life-threatening illness or complication from heart disease, and (e) If dying [9,10].

Next, patients were asked (yes or no) whether they wanted information about the estimated life expectancy of patients with their heart condition. They were also asked to rate how likely they were to have a shorter life expectancy compared to healthy people without CHD. Response options were: (a) a lot less likely, (b) slightly less likely, (c) about the same, (d) slightly more likely, and (e) a lot more likely.

The Hospital Anxiety and Depression Scale (HADS), a 14-item measure, was used to measure symptoms of anxiety and depression [11]. Subscale scores for anxiety (HADS-A) and depression (HADS-D) range from 0 to 21 with scores ≥ 8 indicating clinically elevated symptoms of anxiety or depression [12]. Attachment style refers to the security of an individual's interpersonal relationships and was assessed using the Relationship Questionnaire, which is a self-report measure based on a 4-category model of attachment: secure, preoccupied, dismissing, and fearful [13]. People with a *secure* attachment style are comfortable with both intimacy and independence. Individuals with a *preoccupied* style are characterized as emotionally dependent on others. People with *dismissing* style are extremely self-reliant, and *fearful* individuals simultaneously desire and are afraid of emotional intimacy.

Medical records were reviewed and CHD was categorized as being of simple, moderate, or great complexity [7]. Study data were collected and managed using REDCap (Research Electronic Data Capture), a secure web-based data capture application [14].

2.3. Statistical analyses

Data are summarized as medians with ranges or percentages as appropriate. With a univariate approach, we first evaluated whether

patient-reported importance of discussing ACP and interest in information about life expectancy varied as a function of sociodemographic factors, disease complexity, clinically elevated anxiety, clinically elevated depression, and attachment style. Correlation analyses, Chi-square tests and Mann Whitney tests were performed as appropriate. Effect sizes (eta-squared for importance of discussing ACP and phi and Cramér's V for interest in life expectancy) were also computed. Multivariable models were then performed to predict importance of discussing ACP and interest in information about life expectancy using variables selected on an a priori basis: age, sex, CHD complexity, HADS-A, HADS-D, and attachment style [15]. In multivariable models, HADS-A and HADS-D scores were entered as continuous variables and attachment style was dichotomized into secure vs. not secure. Missing values were excluded from analyses and given the exploratory nature of this research, significance was defined as $p \leq 0.05$ for all analyses. Analyses were conducted using SPSS (Version 22.0. Armonk, NY: IBM Corp).

3. Results

3.1. Participants

Of 321 patients invited to participate in the study, 165 consented, 26 declined, and 130 were unable to participate due to timing or scheduling issues. A total of 13 patients were excluded from the final analysis, thus generating a final study sample of 152.

Table 1 summarizes the demographic and clinical characteristics of the study sample. The most common defects were tetralogy of Fallot ($n = 29$; 19%), d-transposition of the great arteries ($n = 18$; 12%), bicuspid aortic valve disease ($n = 13$; 9%), and coarctation of the aorta ($n = 13$; 9%). The median (range) HADS-A score was 7 (0–19), and the median (range) HADS-D score was 2 (0–14). The proportion of patients with elevated symptoms of depression, elevated symptoms of anxiety, and a secure attachment style did not differ between the three categories of defect complexity.

3.2. Advance care planning: Recalled discussions and communication preferences

Nineteen patients (13%) recalled previous ACP discussions with their health care provider. The median (range) age of the first discussion occurred at 25 years (16–50). Most patients ($n = 106$, 70%) had discussed end-of-life wishes with other people, most commonly their spouse/partner ($n = 61$, 40%) and friends and family ($n = 46$, 51%). Thirty-two patients (21%) had completed advance directives and 28 (18%) had a healthcare power of attorney.

Table 1
Demographic and clinical characteristics of study sample (N = 152).

	n (%)
Age in years (mean & range)	33 (19–67)
Female	76 (50)
White	126 (83)
Partnered	60 (40)
College education or above	117 (77)
Disease complexity	
Simple	25 (16)
Moderate	74 (49)
Great	53 (35)
Total number of cardiac surgeries	2 (0–8)
Elevated anxiety symptoms (HADS-A ≥ 8)	67 (46)
Elevated depressive symptoms (HADS-D ≥ 8)	15 (11)
Attachment Style	
Secure	82 (57)
Dismissing	30 (21)
Fearful	17 (12)
Preoccupied	15 (10)

Data are counts (percentages) or medians (range).

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