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Advance Care Directives Among a Population-Based Sample of Young Adults with Congenital Heart Defects, CH STRONG, 2016–2019

Sherry L. Farr[1], **Karrie F. Downing**[1], **Anthony Goudie**[2], **Scott E. Klewer**[3], **Jennifer G. Andrews**[3], **Matthew E. Oster**[1,4]

[1]National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 4770 Buford Highway, MS 106-3, Atlanta, GA 30341, USA

[2]Department of Pediatrics, Center for Applied Research and Evaluation, College of Medicine, Little Rock, AR, USA

[3]Department of Pediatrics, University of Arizona, Tucson, AZ, USA

[4]Children's Healthcare of Atlanta and Emory University School of Medicine, Atlanta, GA, USA

Abstract

Little is known about advance care planning among young adults with congenital heart defects (CHD). Congenital Heart Survey to Recognize Outcomes, Needs, and well-beinG (CH STRONG) participants were born with CHD between 1980 and 1997, identified using active, population-based birth defects surveillance systems in Arkansas, Arizona and Atlanta, and Georgia, and surveyed during 2016–2019. We estimated the percent having an advance care directive standardized to the site, year of birth, sex, maternal race, and CHD severity of the 9312 CH STRONG-eligible individuals. We calculated adjusted odds ratios (aOR) and 95% confidence intervals (CI) for characteristics associated with having advance care directives. Of 1541 respondents, 34.1% had severe CHD, 54.1% were female, and 69.6% were non-Hispanic white. After standardization, 7.3% had an advance care directive (range: 2.5% among non-Hispanic blacks to 17.4% among individuals with "poor" perceived health). Individuals with severe CHD (10.5%, aOR = 1.6, 95% CI: 1.1–2.3), with public insurance (13.1%, aOR = 1.7, 95% CI: 1.1–2.7), with non-cardiac congenital anomalies (11.1%, aOR = 1.9, 95% CI: 1.3–2.7), and who were hospitalized in the past year (13.3%, aOR = 1.8, 95% CI: 1.1–2.8) were more likely than their counterparts to have advance care directives. Individuals aged 19–24 years (6.6%, aOR = 0.4, 95% CI: 0.3–0.7) and 25–30 years (7.6%, aOR = 0.5, 95% CI: 0.3–0.8), compared to 31–38 years (14.3%), and non-Hispanic blacks (2.5%), compared to non-Hispanic whites (9.5%, aOR = 0.2,

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Sherry L. Farr, sfarr@cdc.gov.

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95% CI: 0.1–0.6), were less likely to have advance care directives. Few young adults with CHD had advance care directives. Disparities in advance care planning may exist.

Keywords

Congenital heart defect; Congenital heart disease; Advance care directive; Living will

Over one million adults are living with congenital heart defects (CHD) in the U.S [1]. and most children born with CHD will live into adulthood [2]. Yet, adults with CHD may require additional surgeries in adulthood [3], acquire comorbidities [3, 4], and die prematurely [2, 5]. Compared to the age and sex-matched general U.S. population, 25 year mortality after initial surgery was 4 times higher among individuals with milder heart defects and up to 35 times higher among individuals with severe defects [2]. In another study of patients at a single adult CHD clinic in London, mortality was 10.9 times higher among patients with Bethesda classification of great complexity, but still 1.3 to 1.6 times higher among those with simple defects or with New York Heart Association functional class 1 [5].

Due to this increased risk of premature mortality and because advance care directives may result in care more consistent with patient preferences, the American Heart Association (AHA) and American College of Cardiology (ACC) recommend that clinicians discuss end-of-life care and establishment of advance care directives with adult patients with CHD, when cognitively and culturally appropriate and before the patient is extremely ill or hospitalized [6, 7]. However, the majority of existing studies examining the percentage of adults with CHD with advance care directives have had small sample sizes and were conducted among adults receiving care at adult congenital cardiac clinics [8-12]. These results may not be generalizable to the larger population of adults living with CHD in the United States, many of whom are not receiving specialized cardiac care [13]. Therefore, we used population-based data from the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG (CH STRONG) to examine the percentage of young adults with CHD who reported having an advance care directive and factors associated with having one.

Methods

Data for this analysis were from CH STRONG, the methods of which have been previously described in detail [14]. Briefly, individuals recruited for CH STRONG were identified through population-based birth defects surveillance systems with active case-finding methods in Arkansas (AR), Arizona (AZ), and metropolitan Atlanta, Georgia (GA). Individuals with CHD were identified by British Paediatric Association (BPA) codes within the range 745–747, with some exceptions for codes with low specificity for CHD. Each site identified individuals born in a 10-year time period between 1980 and 1997. Using probabilistic matching by date of birth, sex, and name, sites linked these individuals to their respective state death records through 2015 to determine eligible individuals presumed alive at time of recruitment. Sites then tracked and traced 9312 individuals for current contact information and mailed surveys to 6943 eligible individuals, following up with non-responders up to three times with reminder postcards and another mailed survey. From 2016 to 2019, 1656 eligible individuals, or their proxies (e.g., parent), completed a CH

STRONG survey, for an overall response rate of 17.8% and a survey response rate of 23.9%. Survey data were then linked to birth defects surveillance system information. CH STRONG was funded by the Centers for Disease Control and Prevention (CDC) and approved by the Institutional Review Boards (IRB) of the CDC and the University of Arkansas for Medical Sciences. The University of Arizona relied on the CDC's IRB.

The CH STRONG survey included questions on demographic characteristics, quality of life, perceived health status, and healthcare utilization. As part of the survey respondents were asked "Have you completed an advance health care directive, living will, or health care power of attorney?"(hereafter referred to as an advance care directive), with possible answers of "Yes", "No" and "Don't know/not sure". We provide prevalence estimates for the three response options, but for all other analyses we dichotomized responses as "Yes" and "No/Don't know/not sure".

We examined associations between having an advance care directive and several demographic and health characteristics based on data from the birth defects surveillance system and the CH STRONG survey. Variables from the birth defects surveillance systems included, CHD type based on BPA codes, year of birth to calculate age at survey completion, site (i.e., location of birth: AZ, AR, and metro-Atlanta), sex, and diagnosis codes to identify non-cardiac congenital anomalies (a co-occurring birth defect or chromosomal anomaly falling outside of the BPA 745.000–747.9XX code range). CHD type was categorized as severe (defects typically requiring intervention in the first year of life) and non-severe, based on an established hierarchical algorithm for native anatomic severity and modified for use with BPA codes [15].

All other variables of interest were based on survey data only. We examined race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and non-Hispanic other race), insurance type (private only, any public (Medicaid, Medigap and Medicare), and other/none), whether the person has ever been married (yes, no), education level (≤ high school, > high school), number of healthcare visits in the past year (0, ≥ 1), number of hospitalizations in the past year (0, ≥ 1), and receipt of care by a cardiologist in the past 2 years (yes, no). We also examined number of disabilities (0, ≥ 1), based on the 6-item set of Department of Health and Human Services Standard Disability Status Questions [16]. Number of cardiovascular comorbidities (0, ≥ 1) was tabulated from positive indication for each of the following conditions: congestive heart failure, hypertension, stroke, myocardial infarction, and/or arrhythmia. Among women, we examined number of live births (0, ≥ 1). We also examined respondents' concern about their future health and, separately, their heart health, with response options of "not at all", "not very", "somewhat", and "very". Lastly, we examined a respondent's perceived health, based on the question: "In general, would you say your health is excellent, very good, good, fair, or poor?".

For all analyses, we excluded from the analytic sample all individuals who did not respond to questions on advance care directive, race/ethnicity, marital history, education, number of disabilities, number of hospitalizations, and receipt of cardiology care and compared demographic characteristics on included and excluded individuals. For the analytic sample, we examined the prevalence of all demographic and health characteristics overall and by CHD severity. We calculated having an advance care directive overall and by CHD severity in two ways. First, we calculated the overall prevalence of having an advance care directive among respondents. To reduce bias associated with non-response and adjust for differences in characteristics between respondents and non-respondents, we also calculated the prevalence of having an advance care directive standardized to the site, year of birth, sex, maternal race, and CHD severity distribution of the 9312 eligible individuals (i.e., the prevalence of having an advance care directive was calculated as if CH STRONG respondents had the same distribution of site, year of birth, sex, maternal race, and CHD severity as all CH STRONG-eligible individuals). For all other analyses, we calculated unstandardized estimates. We calculated prevalence of having an advance care directive by all demographic and health characteristics listed above. For education, we excluded individuals with non-cardiac congenital anomalies, since this variable was highly correlated with educational status. For all variables except concern about future health and heart health and perceived health status, we calculated crude and adjusted odds ratios (aOR) and 95% confidence intervals (CI) for associations between each demographic and health characteristic and having an advance care directive, the dependent variable. Models were adjusted for site, age, CHD severity, and presence of non-cardiac congenital anomalies. In three sensitivity analyses we excluded from the models, individuals with proxy report, those with non-cardiac congenital anomalies, and those who answered “don’t know/not sure” to having an advance care directive. All analyses were conducted in SAS-callable SUDAAN and were independently replicated by two analysts.

Results

Of the 1656 CH STRONG survey respondents aged 19 to 38 years, 45 (2.7%) were missing data on advance care directives. Another 70 (4.2%) were missing data on race/ethnicity, marital history, education, number of disabilities, number of hospitalizations, and receipt of cardiology care. Compared to the 1541 (93.1%) individuals in the analytic sample, a disproportionate percentage of the 115 respondents excluded from the analysis had public insurance (35.4%) or other/no insurance (34.3%), ≥ 1 disabilities (65.2%), and self-perceived fair/poor health (30.0%) ($p < 0.05$ for all; Appendix 1).

A descriptive profile of the 1541 respondents in the analytic sample is presented overall and by CHD severity in Table 1. The majority of respondents in the analytic sample had non-severe CHD (65.9%), were female (54.1%), were non-Hispanic white (69.6%), had no non-cardiac congenital anomalies (65.4%), had never been married (74.2%), had more than a high school education (62.9%), had no disabilities (60.6%), had no cardiac comorbidities (84.6%), had ≥ 1 healthcare visits in the past year (81.8%), had not been hospitalized in the past year (87.8%), and had not received cardiology care in the past 24 months (52.9%). Among women, most had never given birth (70.8%). The distribution of site, sex, number of disabilities, number of cardiac comorbidities, heart failure, healthcare visits in past 12 months, cardiology care in past 24 months, and ever had a live birth differed by CHD severity (p-value < 0.05 for all).

Having an advance care directive was reported by 8.2% of the CH STRONG analytic sample; 4.9% were unsure or didn’t know if they had an advance care directive, and 86.8%

did not have an advance care directive. After standardizing to the CH STRONG-eligible population of young adults with CHD born in AR, AZ, and Atlanta, GA, 7.3% overall, 10.5% of those with severe CHD, and 6.1% of those with non-severe CHD had an advance care directive (Fig. 1).

Individuals with the highest point prevalence of having an advance care directive were ages 31–38 years (14.3%), those with one or more hospitalizations in the past 12 months (13.3%), those with public insurance (13.1%), and those with non-cardiac congenital anomalies (11.1%; Table 2). Among individuals with heart failure, only 10.1% reported having an advance care directive. Individuals with the lowest point prevalence of having an advance care directive were non-Hispanic black (2.5%) and had no insurance or indicated insurance other than private or public (4.5%). Of non-Hispanic black young adults with CHD, the group with the lowest percentage with advance care directives, 74% reported one or more healthcare encounters in the previous year and 41% reported a cardiology encounter in the past 2 years (data not shown).

Individuals with severe CHD (aOR = 1.6, 95% CI: 1.1–2.3), with public insurance (aOR = 1.7, 95% CI: 1.1–2.7) compared to private, with non-cardiac congenital anomalies (aOR = 1.9, 95% CI: 1.3–2.7), with one or more disabilities (aOR = 1.5, 95% CI: 1.0–2.2), who were hospitalized in the past 12 months (aOR = 1.8, 95% CI: 1.1–2.8), and who received cardiology care in the past 24 months (aOR = 1.4, 95% CI: 1.0–2.2) were more likely than their counterparts to have an advance care directive, although the lower limit of some 95% confidence intervals was 1.0 (Table 2). Individuals who were ages 19–24 years (aOR = 0.4, 95% CI: 0.3–0.7) and 25–30 years (aOR = 0.5, 95% CI: 0.3–0.8), compared to those ages 31–38 years; and non-Hispanic black, compared to non-Hispanic white individuals (aOR = 0.2, 95% CI: 0.1–0.6) were less likely to have an advance care directive. After excluding 321 individuals with proxy report, the percent with an advance care directive dropped to below 10% for all groups except 31- to 38-year-olds and those with ≥ 1 hospitalization in the past year; however, associations were similar, except for public insurance coverage, presence of non-cardiac congenital anomalies, and number of disabilities, which were attenuated to the null (Appendix 2). Associations also remained largely the same after excluding 533 individuals with non-cardiac congenital anomalies, except for public insurance, which was also attenuated toward the null. Associations did not change after excluding 76 individuals who answered “don’t know/not sure” to having an advance care directive. When stratifying associations by CHD severity, associations between having an advance care directive and disability status, number of healthcare visits, and receipt of cardiology care were stronger among adults with non-severe CHD, compared to the same associations among those with severe CHD (Appendix 3).

Prevalence of having an advance care directive varied by perceived health and concern about future health, although differences were not statistically significant (Fig. 2). Of individuals with poor perceived health, 17.4% had an advance care directive, compared to less than 10% of individuals with fair to excellent perceived health (range: 6.9–9.2%; *p*-value = 0.30). One in nine (11.2%) individuals who were “very concerned” about their future health had an advance care directive, compared to 6.8% of individuals who were “not concerned at all” (*p*-value = 0.19). Only 8.2% of individuals who were “very concerned” about their heart health had an advance care directive, compared to 6.4% who were “not concerned at all” (*p*-value = 0.43). After restricting the analysis to individuals who self-reported perceived health status and concern about future health (1212 to 1216 individuals), prevalence estimates of having an advance care directive were on average one to three percentage points lower than among the entire sample, but patterns did not change (Appendix 4).

Discussion

Results from this population-based survey of young adults with CHD born in AR, AZ and metropolitan Atlanta, Georgia, showed that only one in 13 had an advance care directive. Furthermore, we found disparities in having an advance care directive, with only one in 40 non-Hispanic black young adults with CHD and less than one in 20 adults with CHD without health insurance having an advanced directive. While estimates were higher for individuals with CHD who were ages 31–38 years, hospitalized in the past 12 months, reported poor health, or had public insurance, still fewer than one in 5 in these subgroups reported having an advance care directive. Among adults with severe CHD or heart failure, those who may be at greatest risk for premature death, only one in 10 had established an advance care directive.

Advance care directives may reduce in-hospital deaths, increase the likelihood of care provision according to patient preferences, and improve communication between family members and physicians near the end of life [17]. Studies have shown that individuals with complex CHD, as well as less severe forms of CHD, are at increased risk for premature mortality [2, 5] and that many CHD patients prefer to discuss end-of-life care when entering adulthood [8] and before they become ill [8, 12, 18]. One quality improvement project at a heart failure and transplant clinic found that over 50% of young adults who discussed advance care directives with their cardiac provider ultimately completed one [19]. In CH STRONG, respondents who had received cardiac care within the 2 years before completing the CH STRONG survey were 40% more likely to have an advance care directive than those who had not, yet only one in 10 had an advance care directive. While 75% of adults with severe CHD had seen a cardiologist in the past 2 years, only one in 10 had an advance care directive. Our findings show that cardiologists may not be discussing end-of-life care and establishment of advance care directives with a large percentage of young adults with CHD or that young adults with CHD (even those with severe CHD, with heart failure, who have been hospitalized, or with poor perceived health) are not establishing advance care directives after a discussion with their healthcare provider.

Our population-based estimates of young adults with CHD who reported having an advance care directive, living will, and/or healthcare power of attorney (7%) are slightly lower than previous estimates of patients seeking care at adult CHD clinics in the United States and Canada, showing 5% to 14% of patients had an advance care directive and 14% to 18% had a healthcare power of attorney [8, 10, 12]. While these studies included patients as young as 19 to 24 years, the upper age limit was 50 years [10, 12] and 67 years [8], older than the upper age limit of CH STRONG participants (38 years). Additionally, in these studies, all patients had received recent care at an adult congenital cardiology clinic, over 80% were non-Hispanic white, and half to three-quarters were college educated. CH STRONG estimates may better approximate the percentage of younger adults with CHD born in the three sites who have an advance care directive, since recruitment was not based on receipt of congenital cardiology care, or any healthcare. Further, CH STRONG participants represent a more diverse segment of individuals living with CHD, with 30% a race/ethnicity other than non-Hispanic white and 37% with a high school degree or less.

It is difficult to compare our results to those from a systematic review of studies from the U.S. general population, among whom one-third had an advance care directive [17]. The median participant age in the included studies in the review was 65 years, older than the CH STRONG population of 19 to 38 year-olds. This systematic review found that having an advance care directive varied by presence and type of chronic condition, from 17% in individuals with HIV/AIDS to 57% in individuals with neurologic disease [17]. CH STRONG estimates are higher than one qualitative study exploring knowledge, attitudes and preferences of a convenience sample of 56 healthy university students, that reported only one student (1.8%) had created an advance care directive or healthcare power of attorney [20].

We found that individuals with indicators of poorer health or more health issues (e.g., severe CHD, heart failure, non-cardiac congenital anomalies, one or more disabilities, a hospitalization in the past 12 months, and self-perceived poor health) were more likely than their counterparts to have an advance care directive. Individuals who were younger and non-Hispanic black were less likely to have an advance care directive. Contrary to our findings, the one study among adults ages 18 to 79 years attending a CHD clinic found no statistically significant association between having an advance care directive or healthcare power of attorney and defect severity or health status (estimates not provided) [12]. However, similar to our findings, the same authors reported an association with older patient age [12]. Whereas we saw no strong associations with having ever been married or given birth (among women), the authors of the referenced study found that individuals with partners and those with children were more likely to have an advance care directive. Differences in findings may be due to the underlying population surveyed and differing age ranges, as mentioned above, as well as a larger sample size of 1541 in this analysis, compared to 200 individuals in the study by Tobler et al. [12], limiting its power to detect associations.

Participants with public insurance were more likely to have an advance care directive than individuals with private insurance. Since 2016, the Centers for Medicare & Medicaid Services has reimbursed clinicians for voluntary advance care planning with their patients covered by Medicare [21]. Additionally, by virtue of their eligibility for these programs, individuals covered by public insurance may have more advanced disease or disability than individuals with private insurance, leading these individuals to consider and establish advance care directives at a younger age.

The greatest disparity seen in having an advance care directive was for non-Hispanic blacks, among whom only one in 40 reported having one, compared to one in ten among non-Hispanic whites and one in 12 among Hispanics. Some of this disparity may be due to lower access to healthcare, yet three out of four non-Hispanic blacks with CHD had at least one healthcare encounter in the past year and over 40% had seen a cardiologist in the past 2 years, representing opportunities to discuss advance care planning. We found no other studies among individuals with CHD examining racial/ethnic differences in having an advance care directive, although this association has been seen in the general population, even after adjusting for demographic characteristics [22, 23], and among individuals with cancer [24]. Reviews examining end-of-life care in the general population [25] and among cancer patients [24] reported religious or cultural differences, access barriers, and knowledge of end-of-life care as possible reasons for these disparities by race and ethnicity. More information, specific to adults with CHD, may help elucidate why differences in advance care planning exist among different racial and ethnic groups and if CHD patients of different racial and ethnic groups are receiving end-of-life care according to their preferences.

CH STRONG provides the first population-based estimates of young adults living with CHD and their planning for end-of-life care. Estimates are inclusive of all individuals living with CHD, not limited to those receiving congenital cardiac care, any healthcare or with health insurance. Over 1500 individuals provided information on advance care planning, allowing us to examine associations with many demographic and health characteristics. However, this analysis also has limitations. Only 18% of eligible individuals completed CH STRONG surveys, and respondents were more likely than non-respondents to be female, non-Hispanic white, have severe CHD, and not have a non-cardiac congenital anomaly, which may lead to non-response bias [14]. To reduce non-response bias, we standardized the overall and CHD severity-specific prevalence estimates to the CH STRONG-eligible population and the standardized and unstandardized prevalence estimates did not differ substantially. Additionally, to limit survey length, participants answered one question on whether they have an advance care directive, living will, or healthcare power of attorney, and, therefore, we are unable to examine prevalence of different types of tools for end-of-life care. Additionally, we may have misclassified some individuals’ advance care directive status because data on advance care directives were self- or proxy-reported, not validated, and we grouped the approximately 5% of individuals reporting “don’t know/not sure” with those reporting not having an advance care directive. In one systematic review, self-report of having an advance care directive (39.5%) was higher than that documented in medical records (32.0%) [17]. However, associations with demographic and health characteristics did not change when individuals unsure about having an advance care directive were excluded from analyses.

Few young adults with CHD reported having an advance care directive, even those with indicators of more severe disease or poorer health. Over 45% of all individuals with CHD surveyed and 75% of those with severe CHD had received cardiac care in the past 2 years, yet only one in 10 reported having an advance care directive, indicating that there may be missed opportunities to engage young adults in discussing end-of-life care and establishing advance care directives when young and relatively healthy. Additionally, understanding why there are racial and ethnic disparities in having an advance care directive may help ensure opportunities for non-Hispanic blacks to discuss end-of-life options and establish advance care directives, if desired.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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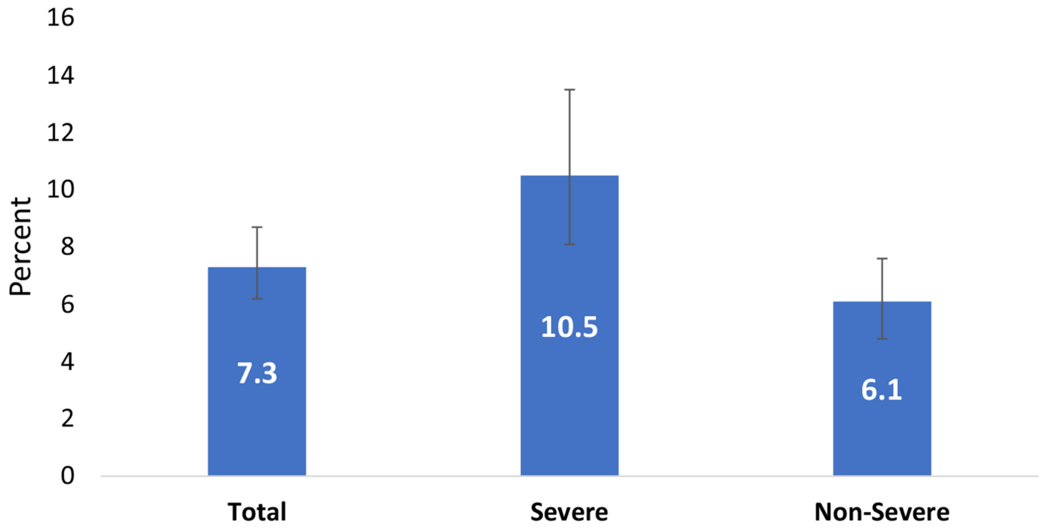

Fig. 1.

Standardized prevalence of advance care directives, overall and by heart defect severity among young adults with congenital heart defects, CH STRONG, 2016–2019 Abbreviations: CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; CHD: congenital heart defect. Notes: Standardized to the distribution of place of birth, year of birth, sex, maternal race, and congenital heart defect severity in the 9312 individuals eligible for CH STRONG

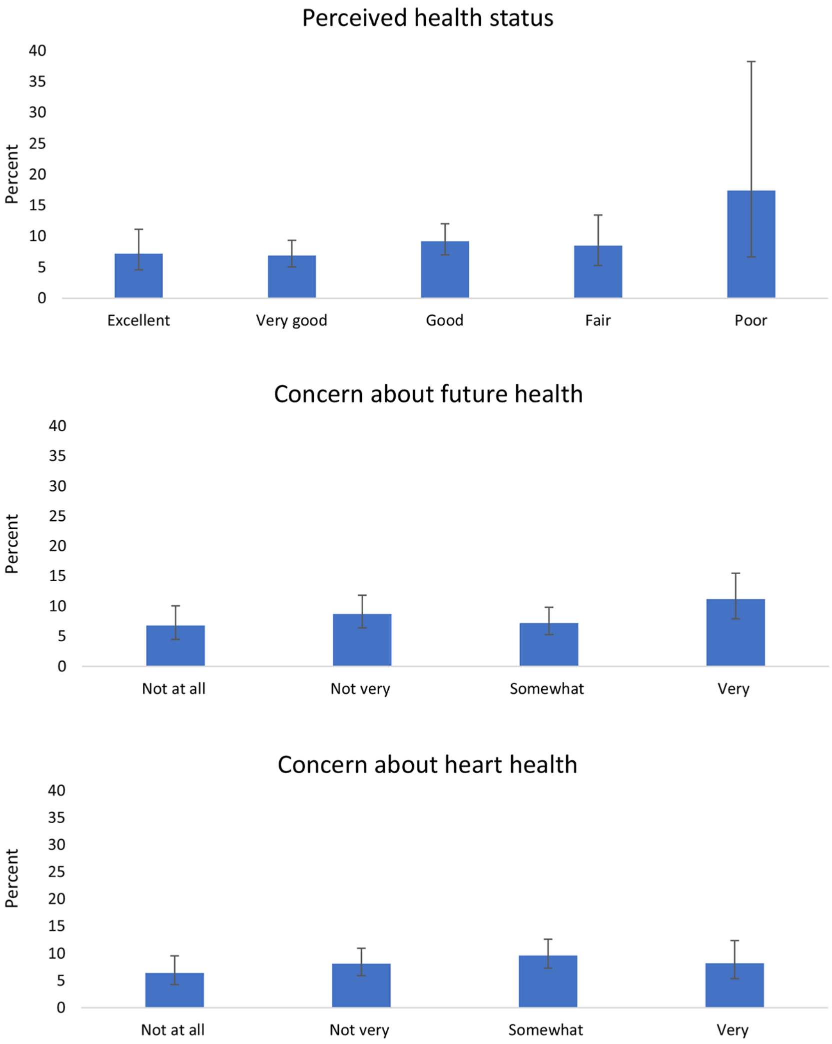

Fig. 2.

Prevalence of having an advance care directive by perceived health and concern about health among young adults with congenital heart defects, CH STRONG, 2016–2019 Abbreviations: CH STRONG: Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG

Table 1

Demographic and health characteristics of young adults with congenital heart defects, CH STRONG, 2016–2019

	Total		**Severe CHD**		**Non-severe CHD**		
	***N* = 1541 (100%)**		***N* = 525 (34.1%)**		***N* = 1016 (65.9%)**		
Characteristic	***N***	**%**	***N***	**%**	***N***	**%**	**Chi-square *p*-value**
Age at survey completion							0.40
19–24	670	43.5	228	43.4	442	43.5	
25–30	620	40.2	220	41.9	400	39.4	
31–38	251	16.3	77	14.7	174	17.1	
Site							< .0001
AR	587	38.1	135	25.7	452	44.5	
AZ	484	31.4	233	44.4	251	24.7	
GA	470	30.5	157	29.9	313	30.8	
Sex							< .0001
Male	708	45.9	286	54.5	422	41.5	
Female	833	54.1	239	45.5	594	58.5	
Race/ethnicity							0.13
Hispanic	161	10.4	59	11.2	102	10	
NH White	1073	69.6	372	70.9	701	69	
NH Black	203	13.2	55	10.5	148	14.6	
Multi/Other	104	6.7	39	7.4	65	6.4	
Insurance type							0.59
Private, no public	765	49.6	260	45.9	505	49.7	
Public	419	27.2	151	28.8	268	26.4	
Other/None	308	20	100	19.0	208	20.5	
Missing	49	3.2	14	2.7	35	3.4	
Presence of non-cardiac congenital anomalies							0.60
Yes	533	34.6	177	33.7	356	35	
No	1008	65.4	348	66.3	660	65	

	Total		**Severe CHD**		**Non-severe CHD**		
	***N* = 1541 (100%)**		***N* = 525 (34.1%)**		***N* = 1016 (65.9%)**		
Characteristic	***N***	**%**	***N***	**%**	***N***	**%**	**Chi-square *p*-value**
Ever married							0.21
Yes	397	25.8	125	23.8	272	26.8	
No	1144	74.2	400	76.2	744	73.2	
Education							0.50
≤ High school	572	37.1	201	38.3	371	36.5	
> High school	969	62.9	324	61.7	645	63.5	
Number of disabilities							0.03
0	934	60.6	299	57.0	635	62.5	
≥ 1	607	39.4	226	43.0	381	37.5	
Number of cardiac comorbidities							< .0001
0	1303	84.6	407	77.5	896	88.2	
≥ 1	193	12.5	99	18.9	94	9.3	
Missing	45	2.9	19	3.6	26	2.6	
Ever had heart failure							< .0001
Yes	69	4.5	48	9.1	21	2.1	
No	1427	92.6	458	87.2	969	95.4	
Missing	45	2.9	19	3.6	26	2.6	
Number of healthcare visits in past year							0.0008
0	274	17.8	69	13.1	205	20.2	
≥ 1	1260	81.8	450	85.7	810	79.7	
Missing	7	0.5	6	1.1	1	0.1	
Number of hospitalizations in past year							0.10
0	1353	87.8	451	85.9	902	88.8	
≥ 1	188	12.2	74	14.1	114	11.2	
Cardiology care in past 24 months							< .0001
Yes	726	47.1	396	75.4	330	32.5	
No	815	52.9	129	24.6	686	67.5	

	Total		Severe CHD		Non-severe CHD		
	N = 1541 (100%)		*N* = 525 (34.1%)		*N* = 1016 (65.9%)		
Characteristic	***N***	**%**	***N***	**%**	***N***	**%**	**Chi-square *p*-value**
Ever had a live birth							0.001
Yes	236	29.2	48	20.9	188	32.5	
No or never pregnant	572	70.8	182	79.1	390	67.5	
NA—Male respondent	708		286		422		
Missing	25		9		16		

AR Arkansas, *AZ* Arizona, *CH STRONG* Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG, *CHD* congenital heart defect, *DK/NS* Don’t know/Not sure, *GA* metropolitan Atlanta, GA, *NA* not applicable, *NH* non-Hispanic

Table 2

Associations between demographic and health characteristics and having an advanced care directive among young adults with congenital heart defects, CH STRONG, 2016–2019

Characteristic	Has an advanced care directive		cOR (95% CI)	aOR (95% CI)
	N	%		
CHD severity				
Severe	55	10.5	1.5 (1.1–2.2)	1.6 (1.1–2.3)
Non-severe	72	7.1	1.0	1.0
Age at survey completion (years)				
19–24	44	6.6	0.4 (0.3–0.7)	0.4 (0.3–0.7)
25–30	47	7.6	0.5 (0.3–0.8)	0.5 (0.3–0.8)
31–38	36	14.3	1.0	1.0
Site				
AR	45	7.7	0.7 (0.5–1.1)	0.7 (0.5–1.1)
AZ	33	6.8	0.6 (0.4–1.0)	0.7 (0.4–1.1)
GA	49	10.4	1.0	1.0
Sex				
Male	54	7.6	1.0	1.0
Female	73	8.8	1.2 (0.8–1.7)	1.2 (0.8–1.8)
Race/ethnicity				
Hispanic	13	8.1	1.2 (0.7–2.2)	0.9 (0.5–1.7)
NH White	102	9.5	1.0	1.0
NH Black	5	2.5	0.3 (0.1–0.8)	0.2 (0.1–0.6)
Multi/Other	7	6.7	0.8 (0.3–2.1)	0.7 (0.3–1.9)
Insurance type				
Private, no public	55	7.2	1.0	1.0
Public	55	13.1	2.0 (1.3–2.9)	1.7 (1.1–2.7)
Other/None	14	4.5	0.6 (0.3–1.1)	0.6 (0.3–1.2)
Presence of non-cardiac congenital anomalies				
Yes	59	11.1	1.7 (1.2–2.5)	1.9 (1.3–2.7)
No	68	6.7	1.0	1.0

Characteristic	Has an advanced care directive		cOR (95% CI)	aOR (95% CI)
	N	%		
Ever married				
Yes	37	9.3	1.2 (0.8–1.8)	1.1 (0.7–1.7)
No	90	7.9	1.0	1.0
Education [*]				
≤ High school	18	6.9	1.0 (0.6–1.8)	1.2 (0.7–2.1)
> High school	50	6.7	1.0	1.0
Number of disabilities				
0	61	6.5	1.0	1.0
≥ 1	66	10.9	1.7 (1.2–2.5)	1.5 (1.0–2.2)
Number of cardiac comorbidities [†]				
0	105	8.1	1.0	1.0
≥ 1	19	9.8	1.2 (0.7–2.1)	1.1 (0.6–1.8)
Ever had heart failure				
Yes	7	10.1	1.3 (0.6–2.8)	1.0 (0.4–2.3)
No	117	8.2	1.0	1.0
Number of healthcare visits in past year				
0	12	4.4	1.0	1.0
≥ 1	114	9.0	2.2 (1.2–4.0)	2.0 (1.1–3.8)
Number of hospitalizations in past year				
0	102	7.5	1.0	1.0
≥ 1	25	13.3	1.9 (1.2–3.0)	1.8 (1.1–2.8)
Cardiology care in past 24 months				
Yes	74	10.2	1.6 (1.1–2.4)	1.4 (1.0–2.2)
No	53	6.5	1.0	1.0
Ever had a live birth [‡]				
Yes	16	6.8	0.7 (0.4–1.2)	0.5 (0.3–1.0)
No or never pregnant	55	9.6	1.0	1.0

CH STRONG Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG; *CHD* congenital heart defect, *cOR* crude odds ratio, *aOR* adjusted odds ratio, adjusted for site, CHD severity, age, and presence of non-cardiac congenital anomalies, *CI* confidence interval, NH non-Hispanic

[*] Excluding $n = 533$ individuals with non-congenital cardiac anomalies

[†] Includes congestive heart failure, hypertension, stroke, myocardial infarction, and arrhythmia

[‡] Among females only