HHS Public Access

Author manuscript

Birth Defects Res A Clin Mol Teratol. Author manuscript; available in PMC 2017 February 01.

Published in final edited form as:

Birth Defects Res A Clin Mol Teratol. 2016 July ; 106(7): 580–586. doi:10.1002/bdra.23498.

Limitations, Depressive Symptoms, and Quality of Life among a Population-Based Sample of Young Adults with Congenital Heart Defects

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Abstract

Background—Little population-based data exist on limitations and health-related quality of life (HRQoL) in adults with congenital heart defects (CHD).

Methods—We used 2004 to 2012 Medical Expenditure Panel Survey data to identify a population-based sample of young adults ages 18 to 40 years reporting health symptoms or healthcare encounters in the previous year. Comparing adults reporting CHD to others, we examined the prevalence of cognitive, physical, and activity limitations, depressive symptoms, and physical and mental HRQoL. We used chi square tests to examine differences in demographic characteristics, logistic regression to generate adjusted prevalence ratios (aPR), and linear regression to examine HRQoL. Multivariable associations were adjusted for sex, age, race/ethnicity, and smoking status. All analyses were conducted in SUDAAN using weights to account for clustering within sampling units and nonresponse.

Results—Fifty-nine adults reported CHD (weighted prevalence=0.1%; representing 700,000 U.S. adults from 2004 to 2012 or, on average, 80,000 per year) and 54,011 did not. No demographic characteristics differed significantly by CHD status except health insurance; 31.5% of adults with CHD, compared with 11.0% without, reported public insurance (p=0.01). Compared with their counterparts, adults reporting CHD had a higher prevalence of cognitive (aPR=2.7, 95% confidence interval (CI): 1.0, 7.2), physical (aPR=4.0, 95% CI: 1.9, 8.2), and activity limitations (aPR=4.8, 95% CI: 2.6, 9.1), and poorer physical HRQoL (p=0.004). No differences were observed in depressive symptoms and mental HRQoL by CHD status.

Conclusion—Physical health and cognitive abilities of adults with CHD were compromised compared with adults without CHD.

Keywords

congenital heart defect; health-related quality of life; depression; cognition

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Introduction

Children with congenital heart defects (CHD), especially the more severe types and those requiring surgery, are more likely to experience developmental disabilities, poorer cognitive functioning (Karsdorp et al., 2007), and greater physical and activity limitations (Razzaghi et al., 2015) than children without CHD, resulting in the need for special education (Riehle-Colarusso et al., 2015) and occupational, physical, and speech therapies (Marino et al., 2012). With medical advances, at least 85% of children with CHD now survive to adulthood (Moons et al., 2010). However, the physical and cognitive limitations of adults with CHD are not well-understood. Depression is also a concern for individuals with CHD, although studies disagree on whether the prevalence of depression differs among individuals with and without CHD (Kovacs and Moons, 2014; Jackson et al., 2015). Systematic reviews and meta-analyses show that the majority of U.S.-based studies on limitations, health-related quality of life (HRQoL), and depressive symptoms among adults with CHD are based on convenience or clinical samples, with unknown generalizability to the general U.S. adult population with CHD (Fteropoulli et al., 2013; Jackson et al., 2015; Kahr et al., 2015). Therefore, to inform the healthcare needs of U.S. adults with CHD, we examined physical and cognitive limitations, depressive symptoms, and HRQoL among a population-based sample of U.S. adults ages 18 to 40 years with healthcare encounters for or symptoms attributed to CHD.

Materials and Methods

Using computer-assisted telephone interviewing, the Medical Expenditure Panel Survey (MEPS) surveys a subsample of participants in the National Health Interview Survey (NHIS), an annual population-based survey of adults (meps.ahrq.gov). When an adult is selected for MEPS, he/she is surveyed five times over 2 years and is asked about his/her own and his/her household members' demographic characteristics, income, employment, health insurance, health status, and medical care use and expenditures. At each contact, the household respondent is asked about his/her own and his/her family members' physical and mental health problems experienced since the previous interview (regardless of whether the person sought medical care for the condition). Those reported physical and mental health problems are subsequently translated into ICD-9-CM codes by MEPS survey staff. In addition, once a year, each household member 18 years and older completes a self-administered questionnaire on his/her physical and mental health, depressive symptoms, and HRQoL. When an individual cannot complete the self-administered questionnaire, a household member completes it for him/her. MEPS overall response rate varies over time; during the study period of the current analysis, the highest response rate was 63.1% in 2004 and the lowest was 53.5% in 2010. Each observation is associated with a weight, adjusted for nonresponse, to reflect the number of persons in the U.S. population represented by the participant.

For this analysis, we examined survey data collected from 2004 to 2012 to describe sociodemographic characteristics, cognitive, physical, and activity limitations, depressive symptoms, and HRQoL among adults ages 18 to 40 years with healthcare encounters for or symptoms of CHD and compared them with all other survey participants in this age group

who also reported healthcare encounters or symptoms due to conditions other than CHD. Adults over 40 years of age were excluded because many reported heart problems in this age category were assumed to be acquired rather than congenital. We compared adults with CHD (ICD-9-CM codes 745: bulbus cordis anomalies and anomalies of cardiac septal closure; 746: other congenital anomalies of heart; and 747: other congenital anomalies of circulatory system) to adults with at least one healthcare encounter or symptom, but no CHD reported. MEPS public use data provide only three-digit ICD-9-CM codes. A maximum of 2 years of data were collected for each individual included in MEPS. MEPS is designed so that each year of data is representative of the U.S. population for that year. For variables assessed more than once per year (e.g., marital status), we examined data from the first time point only.

Sociodemographic variables included age, sex, race/ethnicity, marital status, education, household income as a percentage of the federal poverty level (FPL), employment status, obesity (body mass index ≥30 kg/m^2), smoking status, and relationship to head of household (self/spouse or dependent/other). FPL was categorized according to U.S. Census Bureau categories as poor (incomes below the FPL), near poor (≥FPL to 125% FPL), low income (126–200% FPL), middle income (201–400% FPL), and high income (>400% FPL) (http://www.census.gov/hhes/www/poverty/data/threshld/index.html).

Cognitive limitations were defined as “confusion or memory loss, had problems making decisions, or required supervision for their own safety.” Physical limitations was defined as “difficulties walking, climbing stairs, grasping objects, reaching overhead, lifting, bending or stooping, or standing for long periods of time.” Activity limitations was defined as “limited in any way at work, in the house, or at school.” Depressive symptoms was a dichotomous measure (yes/no) based on a sum of ≥3 on the two-item Patient Health Questionnaire (PHQ-2), with a sensitivity of 82.9% and specificity of 90.0% for major depression (Kroenke et al., 2003). HRQoL was based on the 12-item short form (SF-12) survey that assesses separate components of physical health and mental health, resulting in a composite score with a range of 0 to 100; a lower score signifies poorer HRQoL (RAND/Quality Metric).

Age, sex, race/ethnicity, education, FPL, marital status, employment, obesity, smoking status, insurance status, and cognitive, physical, and activity limitations are based on the household respondent’s answers for the individuals in the sample. General health, depressive symptoms, and HRQoL were self-reported by most individuals.

Initially, we examined prevalence of sociodemographic and health characteristics, limitations, depressive symptoms, and HRQoL comparing those who did and did not report CHD. We examined differences in categorical variables using chi square tests and in continuous variables using t-tests. For all outcomes, we assessed differences by age group, sex, and inpatient hospitalization in the past year. Using the average marginal predictions approach to logistic regression (Bieler et al., 2010), we generated adjusted prevalence ratios for general health, cognitive, physical, and activity limitations, and depressive symptoms, with CHD status as the exposure of interest. We used linear regression to examine differences in summary scores for physical and mental health components of HRQoL. We

constructed separate models for each outcome of interest and included age, sex, race/ethnicity, and smoking status as potential confounders based on previous literature. We conducted all analyses using SUDAAN software to account for the complex sampling design, and used weights to produce unbiased prevalence estimates that account for clustering within sampling units, including family, multiple observations per person, and nonresponse. In sensitivity analyses, we also ran models in SAS without weights or accounting for sample design.

Results

Between 2004 and 2012, MEPS data were collected on 96,297 adults ages 18 to 40. Of these, 66,680 (69.2%) reported one or more healthcare encounters or symptoms and were eligible to complete the self-administered questionnaire. Of those, 62,553 (93.8%) completed the self-administered questionnaire and 54,070 (81.1% of eligible) had data on all variables of interest. Among this sample, 59 reported a healthcare encounter or symptom of CHD (weighted, this represents over 700,000 U.S. adults with CHD from 2004 to 2012, on average, 80,000 per year, or a "treated prevalence" of CHD of 0.1%) and 54,011 reported a healthcare encounter or symptom for a condition other than CHD. None of the adults reporting CHD also reported Down syndrome (ICD-9-CM code 748), nor did any report more than one three-digit ICD-9-CM code for CHD (e.g., both 745 and 746). Additionally, 15.3% of individuals with CHD and 7.5% of individuals without had a household proxy complete the self-administered questionnaire for them (chi square p-value = 0.04).

The majority (60.9%) of adults with CHD in our sample reported an ICD-9-CM code of 745 (Table 1). Point prevalence estimates for age group, race/ethnicity, education, and relationship to head of household varied by over 10 percentage points with CHD status; however, confidence intervals for the CHD group were wide and only one statistically significant difference in sociodemographic characteristics was found. Of individuals with CHD, 31.5% had public health insurance, compared with 11.0% of those without CHD (p = 0.01). A lower percentage of individuals with CHD, compared with those without CHD, were 34 to 40 years of age (19.7% and 32.4%), Hispanic or other race/ethnicity (9.2% and 22.8%), and the head of household or spouse (56.3% and 79.7%) (p >0.05 for all). Additionally, 36.9% of individuals with CHD, compared with 16.2% of those without, had <a high school education (p >0.05).

General health, physical, cognitive, and activity limitations, and physical HRQoL differed by CHD status, while depressive symptoms and mental HRQoL did not (Table 2). The majority of adults with and without CHD, respectively, reported excellent (13.4% and 23.2%) or very good (49.3% and 40.8%) health (p = 0.5). After adjusting for confounders, individuals with CHD were almost twice as likely to report fair or poor general health as individuals without CHD. In multivariable models, adults with CHD had 2.7 times the prevalence of cognitive limitations, 4.0 times the prevalence of physical limitations, and 4.8 times the prevalence of activity limitations as adults without CHD. Adults with CHD, compared with those without, were also more likely to report poorer physical HRQoL (p = 0.004). When running the same multivariable models without weights and not accounting for sampling design, point estimates were of the same magnitude and direction, but 95% CIs

were slightly more precise. Among adults with CHD, we found no difference in general health, limitations, or depressive symptoms by sex, age, ICD-9 code, or past-year hospitalization (chi-square *p*-value >0.05 for all).

Discussion

Within this population-based sample of U.S. adults aged 18 to 40 years, 0.1% (representing 700,000 U.S. adults from 2004 to 2012 or, on average, 80,000 per year) reported receiving care specifically for CHD or experiencing symptoms attributed to CHD in the year surveyed. Approximately a third of adults with CHD reported <a high school education, 30% reported having public insurance, and half were considered dependents in the household. After adjusting for confounders, adults with CHD were more likely to have fair or poor general health; cognitive and physical limitations; limitations affecting work, home, or school; and poorer physical HRQoL than adults without CHD. We found no differences in depressive symptoms or mental HRQoL by CHD status.

Our findings on general health, physical and cognitive limitations are similar to two recent systematic reviews which included 31 studies (Fteropoulli et al., 2013) and 5 studies (Tyagi et al., 2014) among adults with CHD. The majority of studies included in the first review found poorer self-perceived general health and poorer physical functioning among adults with CHD compared with the general adult population. The authors reported younger age, female gender, disease severity, and arrhythmias as risk factors for poorer physical HRQoL. In our analysis of young adults with CHD, we found no significant differences in physical limitations by age or sex, but power was limited. Unlike our analysis, which found a higher prevalence of limitations at work, home, or school, only a minority of studies included in the systematic review reported more disability in work and daily activities. The second systematic review on cognitive functioning reported that two out of four studies found lower intelligence quotient scores and a fifth study found impaired executive functioning in adults with CHD (Tyagi et al., 2014). The discrepancies between this study and ones included in the review may be due to differences in type and severity of CHD as well as age of adults and country where conducted.

Approximately 37% of adults with CHD had less than a high school education, although this estimate had wide confidence intervals and did not differ statistically from that among adults without CHD (16%). However, no meaningful differences in employment or FPL were seen by CHD status. Others have found lower educational attainment and employment rates among individuals with CHD compared with their counterparts (Kamphuis et al., 2002; Olsen et al., 2011). Additionally, studies among children have found a larger percentage of children with specific types of CHD and with surgical repair for CHD with adverse neurodevelopmental outcomes, lower academic achievement, and a greater need for special education services compared with children without CHD (Razzaghi et al., 2015; Riehle-Colarusso et al., 2015). Within MEPS data, we were unable to discern type of employment and, with 44% of adults with CHD living as a dependent in the household, the measure of FPL may reflect the individual’s parents’ income. Larger U.S. studies are needed to determine whether the differences in cognitive function seen in childhood have long-term financial and social implications in adulthood.

To our knowledge, this is one of the first U.S. population-based analyses of adults with healthcare encounters for or symptoms of CHD. We were able to examine key socioeconomic variables such as education, employment, and insurance status, in addition to cognitive, physical, and activity limitations, depressive symptoms, and HRQoL data that are typically unavailable in hospital, surgical, and administrative databases. However, this analysis is also subject to several limitations. First, health conditions, such as CHD, were reported by a household respondent who may be unaware of all symptoms experienced by individuals in his or her household.

Second, our results are generalizable only to individuals with healthcare encounters for or symptoms of CHD and may overestimate associations if generalized to the entire adult population with CHD. Our estimate of a treated prevalence of CHD of 0.1% is lower than the estimated prevalence of CHD in the general adult population (Hoffman et al., 2004; Marelli et al., 2007). This is likely due to under-reporting by the respondent, asymptomatic CHD that did not result in a healthcare encounter during the surveyed year, and CHD-related symptoms not attributed to CHD (e.g., shortness of breath or edema). Therefore, the adults reporting CHD in our analysis may have more severe CHD than the general U.S. population of adults with CHD because these data are limited to those with symptoms attributable to CHD and/or who sought healthcare for CHD.

Additionally, five-digit ICD-9-CM codes are not available in the MEPS public use data and may also be limited by the specificity of the self-report, precluding an assessment of associations by type of CHD. MEPS response rates are between 54% and 63% for the years included, although estimates are weighted for nonresponse and comparable to other national surveys. In addition, we excluded 6% of adults for not completing the self-administered questionnaire and another 12% for missing data. Lastly, because the sample size of individuals reporting healthcare encounters or symptoms of CHD was small ($n = 59$) our estimates are imprecise.

Overall, we found that young adults with healthcare encounters for or symptoms of CHD were almost two to four times more likely to report fair or poor general health; cognitive, physical, and activity limitations; and poorer physical HRQoL than adults without CHD. Novel methods of surveillance are needed to identify adult CHD survivors in the general population and understand their unique healthcare needs and outcomes. Information gained will help parents of children born with CHD plan for the future, current adults with CHD, along with their clinicians, make evidence-based decisions about their health, and policymakers ensure adequate resources are available for the growing population of adults with CHD.

Acknowledgments

The authors thank Ms. Karrie Finn, MPH, for replicating the statistical analysis. The findings and conclusions in this study are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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TABLE 1

Characteristics of Adults Ages 18–40 Years with and without Health Care Encounters for or Symptoms of Congenital Heart Defects (CHD),[a] Medical Expenditure Panel Survey, 2004 to 2012

	Healthcare encounters for or symptoms of CHD		
	Yes *N* = 59 Weighted %, 95% CI	**No[b] *N* = 54,619 Weighted %, 95% CI**	***p*-Value[c]**
ICD-9-CM code			
745	60.6 (37.1, 80.1)	n/a	
746	17.9 (8.0, 35.2)		
747	21.5 (8.5, 44.7)		
Sex			0.79
Female	50.9 (26.6, 74.7)	54.5 (53.9, 55.1)	
Male	49.1 (25.3, 73.4)	45.5 (44.9, 46.1)	
Age (years)			0.41
18–25	37.3 (19.2, 59.9)	31.4 (30.6, 32.1)	
26–33	43.0 (26.2, 61.5)	36.3 (35.5, 37.1)	
34–40	19.7 (7.8, 41.5)	32.4 (31.6, 33.1)	
Race/ethnicity			0.08
Hispanic/other	9.2 (3.5, 22.2)	22.8 (21.5, 24.1)	
Black, non-Hispanic	9.9 (4.4, 20.7)	11.4 (10.6, 12.3)	
White, non-Hispanic	80.9 (68.3, 89.3)	65.9 (64.5, 67.2)	
Marital status			0.98
Married	42.8 (21.6, 67.0)	42.3 (41.4, 43.3)	
Unmarried	57.2 (33.0, 78.4)	57.7 (56.7, 58.6)	
Education (years)			0.29
<12	36.9 (14.7, 66.5)	16.2 (15.5, 16.8)	
12	20.7 (9.0, 40.9)	43.3 (42.4, 44.2)	
>12	37.2 (17.9, 61.6)	34.9 (33.8, 36.0)	
Missing	5.2 (1.5, 17.1)	5.7 (5.4, 6.0)	
Federal poverty level			0.71
Poor/near poor	13.2 (7.1, 23.3)	17.9 (17.2, 18.6)	
Low	13.6 (7.4, 23.7)	13.5 (13.0, 14.0)	
Middle	33.6 (17.3, 55.0)	33.2 (32.5, 33.9)	
High	39.6 (24.2, 57.5)	35.4 (34.4, 36.4)	
Employment status			0.54
Employed/fulltime student[d]	78.1 (66.7, 86.4)	81.2 (80.6, 81.7)	
Unemployed	21.9 (13.6, 33.3)	18.8 (18.3, 19.4)	
Smoking			0.29
Yes	14.1 (5.5, 31.4)	21.7 (21.0, 22.5)	
No	86.0 (68.6, 94.5)	78.3 (77.5, 79.0)	

	Healthcare encounters for or symptoms of CHD		
	Yes *N* = 59 Weighted %, 95% CI	**No[b] *N* = 54,619 Weighted %, 95% CI**	***p*-Value[c]**
Obese (BMI ≥30 kg/m^2)			0.47
Yes	20.1 (9.0, 39.1)	26.1 (25.4, 26.8)	
No	79.9 (61.0, 91.0)	73.9 (73.2, 74.6)	
Insurance status			0.01
Private	65.4 (35.0, 86.9)	72.0 (71.1, 72.9)	
Public	31.5 (10.9, 63.3)	11.0 (10.4, 11.6)	
Uninsured	3.1 (0.5, 16.0)	17.0 (16.4, 17.7)	
Relationship to head of household			0.19
Self/spouse	56.3 (29.8, 79.7)	79.7 (78.9, 80.4)	
Other	43.7 (20.4, 70.2)	20.3 (19.6, 21.1)	

[a] Defined as ICD-9-CM codes 745, 746, 747; a condition is reported if the individual received care for it or it "bothered" the person in the past year. All variables based on the household respondent report.

[b] Among individuals with ≥1 healthcare encounters or symptomatic health conditions other than CHD.

[c] Chi square *p*-value for categorical variables; t-test *p*-value for means.

[d] Fulltime student status assessed for individuals ages 18–23 years.

BMI, body mass index; CHD, congenital heart defect; CI, confidence interval; ICD-9-CM, The International Classification of Diseases, Ninth Revision, Clinical Modification.

TABLE 2

Quality of Life and Depressive Symptoms among Adults Ages 18–40 Years with and without Healthcare Encounters for or Symptoms of Congenital Heart Defects (CHD),[a] Medical Expenditure Panel Survey, 2004 to 2012

	Healthcare encounters for or symptoms of CHD						
	Yes *N* = 59	**No[b] *N* = 49,439**					
	Weighted %, 95% CI	**Weighted %, 95% CI**	***p*-Value[c]**	**PR**	**95% CI**	**aPR[d]**	**95% CI**
Self-reported general health[e]							
Excellent	13.4 (5.0, 31.3)	23.2 (22.5, 23.9)					
Very good	49.3 (33.0, 65.8)	40.8 (40.1, 41.5)					
Good	24.7 (15.4, 37.1)	28.0 (27.4, 28.7)					
Fair	7.4 (3.3, 15.8)	7.0 (6.7, 7.3)					
Poor	5.2 (1.1, 22.1)	1.1 (1.0, 1.2)					
Poor or Fair[f]			0.5	1.6	0.7, 3.6	1.9	1.0, 3.9
Cognitive limitations[g]	5.5 (2.0, 14.5)	2.4 (2.2, 2.6)	0.3	2.3	0.9, 6.3	2.7	1.0, 7.2
Physical limitations[h]	16.0 (8.3, 28.9)	4.5 (4.2, 4.8)	0.08	3.5	1.9, 6.7	4.0	1.9, 8.2
Activity limitations[i]	16.8 (8.6, 30.1)	3.9 (3.7, 4.2)	0.05	4.3	2.3, 8.1	4.8	2.6, 9.1
Depressive symptoms[j]	6.2 (1.9, 18.1)	8.3 (8.0, 8.7)	0.6	0.7	0.2, 2.3	0.9	0.3, 2.6
	Mean (se)	Mean (se)		Beta coefficient	*p*-value	Beta coefficient	*p*-value
Physical HRQoL[k]	48.8 (1.7)	53.2 (0.06)	0.01	−4.4	0.01	−5.0	0.004
Mental HRQoL[k]	51.6 (1.7)	50.0 (0.06)	0.3	1.7	0.3	1.3	0.4

[a] Defined as ICD-9-CM codes 745, 746, 747.

[b] Among individuals with ≥1 healthcare encounter or health condition other than CHD.

[c] Chi square *p*-value for categorical variables; t-test *p*-value for means.

[d] Adjusted for sex, age, race/ethnicity, and smoking status.

[e] For the adjusted model, general health dichotomized as poor or fair compared to excellent, very good, or good.

[f] Compared to excellent, very good, or good.

[g] Reported by household respondent and defined as confusion or memory loss, has problems making decisions, or requires supervision for their safety.

[h] Reported by household respondent and defined as difficulties walking, climbing stairs, grasping objects, reaching overhead, lifting, bending or stooping, or standing for long periods of time.

[i] Reported by household respondent and defined as any limitation in work, housework, or school.

[j] Based on a score of ≥3 on the self-reported 2-item Patient Health Questionnaire.

[k] Composite score of the self-reported Short Form-12.

aPR, adjusted prevalence ratio; CI, confidence interval; HRQoL, health-related quality of life; SE, standard error.

Birth Defects Res A Clin Mol Teratol. Author manuscript; available in PMC 2017 February 01.