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ORIGINAL ARTICLE

Too little too late? Communication with patients with congenital heart disease about challenges of adult life

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Abstract

Objective: To investigate the experiences and communication preferences of adult patients with congenital heart disease (CHD) in the domains of employment, insurance, and family planning.

Design: Patients ≥ 18 years of age completed a questionnaire about experiences and communication preferences regarding employment, health insurance, and family planning.

Results: Of 152 patients (median age = 33 years, 50% female, 35% with CHD of great complexity), one in four reported work-related problems due to CHD and a quarter also recalled a previous gap in health insurance. Of females, 29% experienced an unplanned pregnancy. The median importance of discussion ratings (on a 0-10 scale) were 3.5 (employment), 6.0 (insurance), and 8.0 (family planning). Few patients recalled discussions about employment (19%) or health insurance (20%). Over half recalled discussions about family planning, although males were less likely to have had these discussions than females (24% vs 86%, $P < .001$). Across the three domains, patients identified 16-18 years as the most appropriate age to initiate discussion, although for patients who recalled discussions, they typically occurred between 20 and 25 years.

Conclusions: Adults with CHD commonly face employment, health insurance, and family planning challenges. However, discussions about these matters occur with less frequency than recommended and at older ages than patients would prefer. Communication about such issues should be incorporated into a comprehensive educational curriculum for adolescents during the process of transition to adult care.

KEYWORDS
adult congenital heart disease, communication, employment, family planning, health insurance

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Lisa X. Deng and Lacey P. Gleason contributed equally to this manuscript.

1 | INTRODUCTION

Due to advances in medical and surgical treatment of congenital heart disease (CHD), there are now more adults than children living with CHD.[1] While great progress has been achieved in increasing life expectancy, the field is shifting from an emphasis on survival to a dual focus on quantity and quality of life. As patients reach adulthood, they may face potential challenges including employment, acquisition and maintenance of health insurance, and family planning. The 2018 American College of Cardiology/American Heart Association Guidelines for the Management of Adults with CHD recommend addressing insurance barriers and issues of contraception, pregnancy, and sexual health.[2]

Previous studies indicate that adults with CHD often feel different from their peers and face physical limitations and other challenges of growing up.[3] Adults with CHD have historically had more difficulty obtaining insurance than healthy peers and are at a substantial socioeconomic disadvantage due to lower education and higher unemployment rates.[4,5] Family planning issues are increasingly important as almost all individuals with CHD reach reproductive age. However, current counseling practices on pregnancy and contraception are often inadequate.[6-8]

The aims of this study were to (1) describe both experienced and perceived challenges in the domains of employment, health insurance, and family planning; (2) investigate how important the discussion of these issues is to patients, and (3) determine patient preferences regarding the timing of such discussions with health care providers.

2 | METHODS

2.1 | Study population

In this prospective cross-sectional study, consecutive patients aged ≥ 18 years with a documented history of CHD were recruited from an adult CHD clinic at a tertiary care center in the United States. Patients with known developmental disorders and/or those who lacked proficiency in English were excluded. Study procedures included completion of a questionnaire and medical record review. Disease complexity was designated as simple, moderate, or great according to guidelines.[2] If patients had more than one CHD lesion, they were categorized according to the lesion of highest severity. Study data were collected and managed using REDCap electronic data capture tools.[9] The study was approved by the Institutional Review Board and written informed consent was obtained from all patients.

2.2 | Study measures

An interdisciplinary research team developed the study questionnaire, based upon their collective clinical and research experiences, and drawing from other studies.[8,10] In addition to background information (eg, educational attainment), patients were presented with a series of questions regarding experiences and challenges in the areas of employment, health insurance, and family planning.

2.2.1 | Employment

Current employment status included the following options: full-time employment, part-time employment, caring for home or family, not currently working, unemployed and seeking work, disability, retired, or student. Patients were asked whether they had experienced difficulties related to employment, specifically whether CHD had impacted their choice of work pursued or had led to work-related problems (eg, missing work due to illness). They were also asked whether they believed they were more or less likely to encounter problems in finding and keeping a job compared to people without CHD.

2.2.2 | Health insurance

Health insurance providers included the following options: employer-based, self-purchased, spouse or parents' insurance plan, Medicare, or Medicaid. Patients were asked whether they had experienced the following challenges: difficulty obtaining health insurance because of CHD, lapse in coverage during the previous 5 years, and difficulty paying medical bills over the past year. They were asked to rate their current health insurance coverage (response options: excellent, very good, good, fair, poor, unknown), and report how the Patient Protection and Affordable Care Act (ACA), introduced in 2010, had or would affect their coverage (response options: better, worse, about the same, unknown). Finally, they were asked whether they thought they were more or less likely to have problems obtaining and keeping health insurance compared to people without CHD.

2.2.3 | Family planning

Sexual history was queried including whether the patient had ever had sexual intercourse and if so, from what age. Women were asked whether they had ever been pregnant and if so, whether it was planned. Women were asked if they were ever counseled against pregnancy, if they had ever postponed or avoided pregnancy based on advice from a health care provider, and whether they thought they were more or less likely to have heart problems during pregnancy compared to women without CHD. All patients were asked whether they believed they were more or less likely to have a child with CHD.

2.2.4 | Communication preferences

The following preferences were ascertained for the three topics (employment, health insurance, family planning) in terms of *importance* of each topic and the *appropriate age* when these topics should be broached: Patients were asked to rate the importance of discussing the topic with their health care provider on a scale ranging from 0 ("not important at all") to 10 ("extremely important"); scores ≥ 7 were categorized as being of high importance. Patients were also asked whether (and if so, at what age) they had discussed these issues with a provider. In addition, they were asked what they thought was the appropriate age for a health care provider to start discussing these issues with a patient with CHD.

2.3 | Statistical analysis

Descriptive statistics were performed. Normally distributed continuous variables are summarized as mean and standard deviation while skewed continuous variables are summarized as median and interquartile range (IQR). Categorical variables are reported as counts and percentages. Statistical analysis was performed using chi-square and Mann-Whitney *U* tests. Survey responses were compared by three factors: age, sex, and CHD complexity. Age was examined as a bivariate variable, with 26 years of age chosen because this is the cut-off for parental health insurance coverage in the United States. All statistical tests were two-tailed, and *P* values of < .05 were considered statistically significant; given the exploratory nature of this study, we did not adjust the p-value for multiple tests. The data were analyzed using SPSS version 22 software (IBM Corp., Armonk, NY, USA).

3 | RESULTS

3.1 | Participants

A total of 321 patients were approached to participate in the study and 165 (51%) consented to participate, of whom 152 met all inclusion criteria and completed the study survey. Time and scheduling limitations were most often cited among nonparticipants. Patient characteristics are summarized in Table 1.

3.2 | Employment

Most patients (79%) were employed or students at the time of survey completion. One in five patients recalled employment challenges, which were often attributed to their CHD (Table 2). Individuals with CHD of great complexity were more likely than those with simple or moderate complexity to report work-related problems due to CHD (36% vs 18%, *P* = .018) and that CHD had impacted their career choices (30% vs 16%, *P* = .045). Reported employment challenges did not differ by age or sex.

Patients provided a median score of 3.5 (IQR 1-6) for the importance of discussing employment with health care providers; 25% (37/150) believed these conversations were highly important (score ≥ 7). Patient importance ratings did not differ by age, sex, or CHD complexity.

Overall, 19% (28/151) recalled previous discussions about employment with health care providers, which occurred at a median age of 23 years (IQR 17-28). Patients identified 17 years as the most appropriate age for initiating employment discussions (Figure 1) and 81% (17/21) of those who recalled previous discussions wished for communication to have occurred earlier.

3.3 | Health insurance

As this study was conducted in a setting in which health insurance or self-payment is required to obtain care, almost all patients (99%) reported having health insurance. However, 22% of patients recalled a lapse of insurance at some point during the previous 5 years (Table 2). Those with coverage lapse were more likely to report work-related problems due to CHD (39% vs 20%, *P* = .024). Age, sex, and CHD complexity were not significantly associated with lapse in health insurance.

Eighty-four percent (128/152) considered their insurance to be good, very good, or excellent, 14% (22/152) reported their insurance was fair or poor, and 1% (2/152) did not know. When patients were asked how health care reforms implemented as part of the ACA had or would impact their insurance coverage, 11% (17/151) considered this a positive change, 21% (32/151) thought that their coverage was or would be worse, 30% (45/151) thought their coverage was or would be the same, and 38% (57/151) did not know.

Patients provided a median rating of 6 (IQR 4-8, *n* = 151) for the importance of health insurance discussions, with 46% (70/151) rating these discussions as highly important (score ≥ 7). Those with simple or moderate disease complexity rated the importance of these discussions higher than those with great disease complexity (median score 7 vs 5, *P* = .036). Age and sex were not associated with patient importance ratings.

Overall, 20% (30/152) of patients recalled prior discussions about health insurance and for those, the median age at which these discussions first took place was 25 years (IQR 20-35). Patients (*n* = 122) identified 18 years as the most appropriate age to initiate discussions about health insurance and 88% (23/25) of those who recalled previous discussions would have preferred initial communication to occur earlier (Figure 1).

3.4 | Family planning

Ninety percent (135/150) had been sexually active, with first intercourse occurring at a median age of 18 years (IQR 16-20). Approximately one-third (41/126) reported first intercourse at age 16 years or younger. Among female patients, 29% (22/76) had previously experienced an unplanned pregnancy and almost one-third (22/75) postponed or avoided pregnancy based on counseling from a health care provider. Among all patients, 41% (62/151) had children (although the question did not specify whether children were biological). Thirty-six percent (54/148) did not believe they were more likely to have a child with CHD, and this belief was not associated with age, sex, or CHD complexity.

In regard to family planning discussions, patients provided an importance rating of 8 (IQR 5-10, *n* = 148), with 65% (96/148) characterizing these discussions as highly important (score ≥ 7). Women reported higher ratings than men, although both considered these discussions as highly important (median score 9 vs 7, *P* < .001). Age and CHD complexity were not associated with importance ratings for family planning discussion.

TABLE 1 Demographic and clinical characteristics of study sample ($N = 152$)

	N (%)
Age (years)[a]	33 (19-67)
Female	76 (50)
White	126 (83)
Partnered	60 (40)
Have children (*n* = 151)	62 (41)
Congenital heart disease lesion	
Tetralogy of Fallot	30 (20)
Transposition of the great arteries	25 (16)
Bicuspid aortic valve disease	13 (9)
Aortic coarctation	13 (9)
Ventricular septal defect	10 (7)
Double-outlet ventricle	10 (7)
Partial anomalous pulmonary venous return	8 (5)
Pulmonary stenosis	7 (5)
Atrioventricular canal defect	6 (4)
Pulmonary atresia	5 (3)
Other	25 (16)
Congenital heart disease complexity	
Simple	25 (16)
Moderate	74 (49)
Great	53 (35)
Highest level of education	
Less than high school	0 (0)
High school or GED diploma	52 (34)
Vocational or technical diploma	10 (7)
Associate's degree	13 (9)
College or university degree	40 (26)
Graduate or professional degree	37 (24)
Employment status[b]	
Full-time	93 (61)
Part-time	17 (11)
Caring for home/family	4 (3)
Not working	18 (12)
Unemployed and looking for work	4 (3)
Unable to work due to illness or disability	16 (11)
Retired	2 (1)
Student	10 (7)
Other	4 (3)
Health insurance provider[b]	
Employer	64 (42)
Spouse/parent	55 (36)
Medicare	15 (10)
Medicaid	12 (8)
Self-purchased	11 (7)
No health insurance	2 (1)

Abbreviation: GED, general equivalency diploma.

[a] Median (range).

[b] Patients were asked to select all that applied.

Overall, 53% (80/150) of patients recalled previous family planning discussions with their health care providers. Fewer men than women recalled having had these discussions (24% vs 86%, $P < .001$). The median age at which these discussions were initiated was 20 years (IQR 16-25, $n = 62$). Eight-four percent (52/62) of patients who had these discussions would have preferred for the initial discussion to have occurred sooner than it did (Figure 1), with both men and women identifying 16 years as the preferred age.

4 | DISCUSSION

Our study investigated CHD patients' experiences and preferences for provider-patient communication on three topics of adult life. We learned that employment and insurance challenges were common yet not frequently discussed with providers. Second, males and females both value opportunities to discuss family planning. Third, discussions, when they occur, tend to happen in young adulthood although patients prefer them to be initiated during adolescence.

4.1 | Employment and insurance challenges are common in American patients

Even within a sample that was predominantly employed and had health insurance coverage, challenges in these domains were common. This is consistent with previous studies that have shown that compared to healthy peers, adults with CHD have lower employment rates.[11,12] As expected, patients with CHD of great complexity were disproportionately susceptible to employment difficulties.[13,14] Proposed explanations for this association include physical limitations that preclude regular employment as well as lower educational attainment due to increased school absences and/or neurocognitive deficits.[15] Patients with complex CHD should be considered a vulnerable population when it comes to employment and warrant concerted clinical attention. While employment discussions received the lowest importance rating of the three topics, providers should still provide tailored guidance, such as helping patients identify employment options that are consistent with their current and future physical functioning.

Approximately one in five patients lacked health insurance at some point during the previous 5 years. As expected, insurance difficulties were associated with employment difficulties and

TABLE 2 Experiences and challenges related to employment, health insurance, and family planning

	Total *n* (%)
Employment	
Had a history of work-related problems due to CHD (*n* = 151)	37 (25%)
Reported that health had impacted their career choice (*n* = 151)	32 (21%)
Believed they were more likely to have difficulties finding and keeping a job than individuals without CHD (*n* = 149)	37 (25%)
Health insurance	
Had been uninsured in the previous 5 years (*n* = 152)	33 (22%)
Reported difficulty paying medical bills in the previous year (*n* = 152)	30 (20%)
Experienced difficulty obtaining health insurance due to health history (*n* = 152)	27 (18%)
Believed they were more likely to have difficulty obtaining and maintaining health insurance than individuals without CHD (*n* = 150)	84 (56%)
Family planning	
Recalled being told not to get pregnant by health care provider (*n* = 75, women only)	27 (36%)
Had postponed or avoided pregnancy based on advice of a health care provider (*n* = 75, women only)	22 (29%)
Had at least one unplanned pregnancy (*n* = 75, women only)	22 (29%)
Believed they were more likely to have a child who also has a heart problem (*n* = 146)	94 (64%)
Believed they were more likely to have a heart problem during pregnancy than women without CHD (*n* = 75, women only)	64 (85%)

Abbreviation: CHD, congenital heart disease.

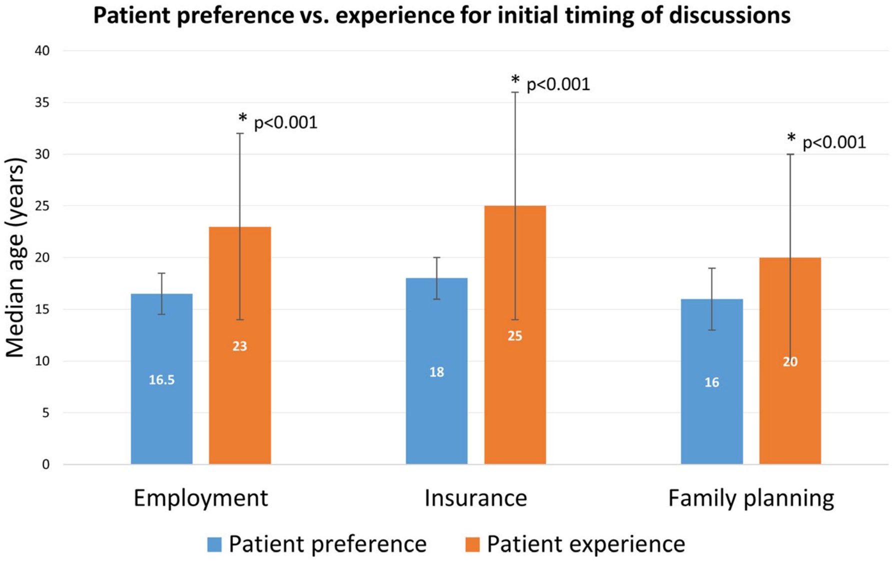

FIGURE 1 Patient preference vs experience for initial timing of discussions on employment, insurance, and family planning. Bars represent interquartile range

concerningly, lapse of care predicts adverse cardiac outcomes among adults with CHD.[16] Historically, patients with CHD have faced difficulties obtaining insurance.[4,17] Our study was conducted around the time of the implementation of the ACA, which has since been shown to result in similar coverage rates for those with CHD compared to patients without CHD.[18] However, it is anticipated that any changes to provisions on preexisting conditions would detrimentally impact access for this population.

It was surprising and unknown why patients with CHD of great complexity reported less interest in insurance discussions than those with milder defects. Despite this unexpected finding, we advocate for screening for insurance difficulties and referral to social work when appropriate. Discussions about employment and insurance should occur concurrently and emphasize that benefits may be as important as salary when it comes to a chronic condition that requires uninterrupted health insurance.

4.2 | Family planning should not be restricted to females

In our study, the majority of individuals (90%) had been sexually active and there was a high rate (29%) of unplanned pregnancy among women.

Many patients (36%) did not know that their offspring would be more likely to have CHD, similar to a recent Canadian study.[8] Furthermore, although family planning discussions were identified by patients as the most important topic of the three, only half recalled such prior discussions with providers. Our findings are consistent with previous studies that documented low rates of family planning counseling among women and lack or inappropriate use of contraception.[6-8,19,20]

There were notable differences in family planning discussions based on sex. Our study uniquely included an equal number of men and women, whereas most studies have focused predominately on women.[6-8] We found that like females, most males rated family planning discussions as highly important and wanted discussions to be initiated as early as females. Despite this high valuation, men were far less likely to have recalled family planning discussions with their health care providers. Thus, our study demonstrates an unmet need among men and suggests that balanced family planning counseling should be provided to *both* men and women with CHD. Information should be provided about contraception options, risks to the patient and offspring, and sexual health, and ideally as part of a formal patient education curriculum.[2,21]

4.3 | Discussions should be introduced during the process of transition from pediatric to adult care

As reported above, despite published recommendations, discussions about employment (19%), health insurance (20%), and family planning (53%) do not appear to routinely occur. Furthermore, even when patients did recall discussions, they typically took place several years later than patients would prefer. On average, communication about employment and health insurance was initiated 6-7 years later than preferred. Although family planning discussions occurred relatively closer to the preferred age (20 vs 16 years), of great concern is that they were typically initiated 2 years after the average age of first sexual encounter.

Across the three topics, patients identified 16-18 years as the ideal age for health care providers to initiate discussions—in other words during the transition period from pediatric to adult care. These crucial topics of adult life should be incorporated into a comprehensive transition curriculum involving a multidisciplinary team (eg, social workers), to prepare young patients to navigate their lives with a chronic illness.[22-24] "Education checklists" may be created in patient charts and reviewed on a scheduled basis or with changes in patient's education, career, health status, interest in starting a family, etc[25,26] Peer support groups and informational seminars for patients and families around these topics can also be offered.[22]

4.4 | Limitations

Some factors may affect the generalizability of these results including the single center design, sample of patients already engaged with specialized CHD care, and a predominantly white, well-educated, and insured study population. However, if anything, we would predict that insurance difficulties might be more common in those not currently receiving specialized CHD care. Patients with developmental disorders were not included in this study, which would also presumably predict study outcomes (primarily employment). Furthermore, communication experiences were assessed through self-report measures and thus we are able to describe communication that was recalled by patients, not necessarily actually provided. The development of the questionnaire did not include patients, however future mixed methods research could investigate how to best incorporate the patient voice in planning patient-centered research projects and education initiatives. Last, there was a surprisingly low participation rate mostly due to time constraints. However, there was no negative feedback from those who declined to enroll to suggest there was a sampling bias as result.

5 | CONCLUSIONS

Although challenges related to employment, health insurance, and family planning are common among adults with CHD, few patients recall discussing these issues with their health care providers. Patients consider these discussions important and would prefer for them to be initiated during adolescence. With significant improvements in medical outcomes of adults with CHD, we must expand our focus to help patients optimize quality of life. Clinicians should provide early, individualized counseling on crucial issues of adult life to enable patients with CHD to live as full and independent lives as possible.

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CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest with the contents of this article.

AUTHOR CONTRIBUTIONS

Concept/Design: Deng, Khan, Drajpuch, Fuller, Mascio, Partington, Tobin, Kovacs, Kim

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