

Original Article

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Abstract

Introduction: Adults with congenital heart disease (CHD) face a unique set of medical, psychological, and social challenges, and access to specialised adult congenital heart disease care has been associated with improved outcomes. Rural adults with CHD may represent a uniquely disadvantaged group given additional challenges when accessing specialised care. The aim of this study was to investigate the challenges faced by adults with CHD in accessing outpatient cardiac care, with a specific focus on understanding differences between urban- and rural-dwelling patients. **Methods:** This cross-sectional, survey-based study took place in the adult congenital heart disease clinic at an urban academic medical center. Additional medical information was abstracted in a retrospective manner from the electronic health record. In addition to descriptive statistics, t-tests and Chi-square tests were performed to investigate differences between urban and rural dwelling patients. **Results:** A total of 100 patients participated in the study (mean age 40 ± 13 years, 60% female, 18% rural dwelling). Across the total sample, the median driving distance to clinic was 20 miles (interquartile range 12–77); it was 15 miles for urban dwellers and 77 miles for rural dwelling patients ($p < 0.001$). The most commonly identified barriers to cardiac clinic visits were financial losses related to taking time off from work (39%), distance of clinic from home (33%), and weather (33%). Compared to urban dwelling patients, on average those who were rural dwelling had a lower level of education ($p = 0.04$), more difficulty paying insurance premiums ($p < 0.001$) and copays ($p = 0.005$), and were more likely to identify the distance from clinic ($p = 0.05$) and having to go into the city ($p = 0.02$) as barriers to clinic appointments. **Conclusions:** The financial impact and distance to clinic were the most commonly identified barriers to outpatient cardiac care in this cohort of adults with CHD. These barriers, along with difficulty paying insurance premiums, are more common in rural dwelling patients. Initiatives such as telemedicine visits or providing financial subsidies for travel and treatment could help to expand specialty adult congenital heart disease care and better serve this growing patient population.

Adults with congenital heart disease (CHD) are a rapidly growing population with a unique set of medical and psychosocial challenges leading to high utilisation of resources.^{1–3} Referral to specialised adult congenital heart disease care is independently associated with mortality reduction,⁴ and patient adherence to scheduled adult congenital heart disease outpatient clinic visits is associated with better survival.⁵ In light of these findings, guidelines recommend adult congenital heart disease specialist consultation for most adults with CHD.⁶

Despite this, adults with CHD face significant challenges in accessing specialised care. Nearly half of the United States population lives greater than 1 hour away from an adult congenital heart disease center. Those who live more than 6 hours away face additional challenges, including higher rates of uninsurance, a higher burden of poverty, and a lower average education level.⁷ Rural dwelling patients are further burdened by lack of transportation options and limited healthcare provider availability.^{8,9} Rural adults with CHD may represent a uniquely disadvantaged group given the distance they need to travel for care, as well as the nationwide shortage and variation in adult congenital heart disease physician availability.¹⁰

The aim of this study was to investigate the challenges faced by adults with CHD in accessing outpatient cardiac care, with a specific focus on understanding differences between urban- and rural-dwelling patients. Understanding barriers to specialised care has important implications for developing systems of healthcare delivery to expand access to this growing yet underserved patient population.

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Methods

This cross-sectional, survey based study took place in the adult congenital heart disease clinic at an academic medical center, Oregon Health and Science University, in an urban area of Portland, Oregon. All participants were asked to complete surveys at the time of clinic visit. All study surveys were completed on an iPad, using REDCap hosted at Oregon Health and Science University. Complete survey questions are available in an online supplement.

Medical information was abstracted in a retrospective manner from the electronic health record. Home location was determined by the home zip code provided in the electronic medical record. Rural dwelling status was defined as either of the following criteria: census areas with population <2500 people or residence in a rural county as defined by the Oregon Office of Management and Budget.¹¹

Study survey

Survey questions were designed by an interdisciplinary team consisting of adult congenital heart disease cardiologists, researchers, and psychologists.

Demographic questions asked about marital status, education level, employment, annual income, race, and ethnicity. Questions about access to care asked participants about the frequency of receiving medical care, having a primary care provider, and their perceived importance of seeing an adult congenital heart disease specialist. Transportation questions addressed the means of transport to clinic appointments and asked participants to rate the difficulty of traveling to cardiology clinic, primary care appointments, and to the pharmacy. Insurance questions asked about type of insurance coverage, monthly premiums and copays, and total out of pocket costs. In addition, participants were asked to rate specific barriers to care on a scale from 1 (not a barrier) to 5 (significant barrier), including taking time off from work, loss of income related to needing to take time off from work, distance of clinic from home, lack of childcare, the weather, the stress of thinking about their heart or coming into the city, and the timing of clinic visits.

Quality of life was measured using the linear analog scale, which consists of a vertical line ranging from 0 ("worst imaginable quality of life") to 100 ("best imaginable quality of life").

Statistical analyses

Data were analysed using descriptive statistics (counts and percentages). Student t-tests were used to compare means, and Pearson Chi-square tests were used to compare groups defined by dwelling status, education level, and income level. Wilcoxon rank-sum tests were used to calculate the median driving distances to care. All statistical analyses were completed using Stata/IC software version 15 for Windows (StataCorp, College Station, TX).

The study was approved by the Institutional Review Board at Oregon Health and Science University. Informed consent was obtained from all participants.

Results

Demographics, access to care, and transportation

A total of 100 patients participated in the study. The mean age was 40.3 ± 13.2 years, and 60% of the patients were female and 93% Caucasian (Table 1). The most common lesion complexity was

moderate (63%), 27% had a lesion of great complexity, and 10% had a simple lesion. Over half were in adult congenital heart disease physiologic stage A or B (55%), and New York Heart Association (NYHA) functional class I (60%). The majority of the patients had a primary care provider (87%), but 29% had a previous gap in cardiac care of >3 years, with the longest care gap being 14.5 ± 2.9 years.

A total of 18% of were categorised as rural dwelling. The median driving distance to clinic for the entire cohort was 20 miles (interquartile range 12–77 miles); it was 15 miles (interquartile range 10–43) for urban dwellers and significantly longer (77 miles, interquartile range 63–121) for rural dwelling patients ($p < 0.01$). 13% had considered moving for better cardiac care and 8% had actually moved.

Most participants (68%) reported that they were working outside of the home either full-time or part-time, 58% were married or living with a partner, and 52% had less than a college level education. As compared to patients with a college degree or beyond, those with a lower level of education travelled farther to clinic (41 versus 15 miles, $p = 0.006$), were more likely to be rural dwelling (53.1 versus 22.2%, $p = 0.018$), less likely to be partnered or married (48.1 versus 70.2%, $p = 0.026$), and less likely to be employed (53.8 versus 83%, $p = 0.002$). 52% of the patients had an annual household income of less than \$50,000, which falls below the poverty level in Oregon. Those who had an annual household income of less than \$50,000 were younger as compared to those with a higher annual income (35.1 versus 45.8 years, $p < 0.001$), were less likely to be partnered or married (32.7 versus 87%, $p < 0.001$), and less likely to be employed (59.2 versus 78.3%, $p = 0.05$).

Health insurance

Most patients (65%) had commercial insurance, with a median monthly insurance premium of \$170 (interquartile range \$60–\$760). There was no difference in the type of insurance coverage based on rural or urban dwelling status; however, those with an education level below a college degree and an annual income level of less than \$50,000 were more likely to have government-sponsored insurance (50.0 versus 25.5%, $p = 0.012$ for education level; 59.2 versus 13.0%, $p < 0.001$ for income level).

Quality of life

The mean quality of life score for the cohort was 74 ± 18 ; this was significantly lower for those with an income level below \$50,000 (linear analog scale = 68 versus 80, $p = 0.003$). There was no statistically significant difference between the quality of life of rural dwelling patients as compared to urban dwellers (linear analog scale = 74 versus 73, $p = 0.9$), or between those with a college education or beyond as compared to those with a lower education attainment (76 versus 71, $p = 0.234$).

Barriers to clinic attendance

The most commonly identified barriers to attending cardiology office visits were loss of income when taking time off work (39%), distance of clinic from home (33%), and the weather (33%) (Table 2). 23% expressed that not wanting to think about their heart was also a barrier to follow-up. Finding a ride to clinic, finding childcare, and finding an available appointment time were not perceived as significant barriers. As compared to urban dwellers, those residing in rural areas were more likely to cite distance to

Table 1. Demographics, all patients.

Demographics, N = 100	Mean ± SD, or N (%)
Age, years	40.3 ± 13.2
Female gender, N (%)	60 (60)
CHD lesion complexity, N (%)	
Great complexity	27 (27)
Moderate complexity	63 (63)
Simple	10 (10)
AHA physiologic stage, N (%)	
Stage A or B	53 (55)
Stage C or D	44 (45)
Clinical history, N (%)	
Cyanosis	7 (7)
PHTN/Eisenmenger	9 (9)
Arrhythmia	39 (39)
Heart failure	25 (25)
Sudden cardiac death	2 (2.6)
≥Moderate ventricular dysfunction (LV or RV)	14 (14)
NYHA functional class	
Class I or II	89 (89)
Class III or IV	11 (11)
Driving distance to OHSU, median in miles (IQR)	20.0 (12.0, 76.8)
Rural dwelling, N (%)	18 (18)
Highest level of school, N (%)	
Less than college degree	52 (53)
College degree or beyond	47 (47)
Marital status, N (%)	
Married or living with a partner	58 (58)
Other	42 (42)
Work type	
Working (full or part time)	67 (68)
Not working (disabled, retired, student)	32 (32)
Household income, \$	
<50,000	49 (52)
≥50,000	46 (48)
Home situation, N (%)	
Rent	56 (58)
Own	41 (42)
Insurance type, N (%)	
Commercial insurance	64 (65)
Medicaid or medicare	34 (34)
Monthly insurance premium, \$ median(IQR)	170 (60, 760)
Have a primary care provider, N (%)	87 (87)
Previous gap in cardiac care ≥ 3 years, N (%)	29 (29)
Longest gap in cardiac care, years	14.5 ± 2.9

(Continued)

Table 1. (Continued)

Demographics, N = 100	Mean ± SD, or N (%)
Have ever moved for better cardiac care, N (%)	
No	79 (79)
Yes, and I actually moved	8 (8)
Yes, but I did not move	13 (13)
Quality of life score, mean ± SD	73.6 (18.2)

AHA, American Heart Association; CHD, congenital heart disease; IQR, interquartile range; NYHA, New York Heart Association; OHSU, Oregon Health and Science University; PHTN, pulmonary hypertension.

Table 2. Barriers to care, all patients

Barrier	N (%)
Don't get paid if don't go to work	38 (38)
Clinic is too far from my home	33 (33)
The weather makes it hard	33 (33)
I don't like thinking about my heart	23 (23)
I don't like going into the city	18 (18)
Difficulty paying copays	15 (16)
Difficulty paying for medications	15 (16)
Difficulty affording insurance copays	13 (13)
Overall difficulty getting to OHSU cardiology	11 (11)
Clinic appointments are stressful	9 (9)
Difficult to take time off work	7 (7)
Difficulty getting the money to get to clinic	6 (6)
Difficulty finding childcare	3 (3)
Clinic appointments are not at a time that work for me	3 (3)
Difficulty finding someone to drive me to clinic	1 (1)

OHSU, Oregon Health and Science University.

care (61 versus 27%, $p = 0.005$) and not liking to go into the city (39 versus 15%, $p = 0.02$) as important barriers. Rural dwellers also had more difficulty paying monthly insurance premiums (44 versus 5%, $p < 0.001$) and copays (39 versus 10%, $p = 0.002$). Those with a lower level of education were more likely to cite distance to care (42 versus 23%, $p = 0.046$), loss of income when taking time off work (48 versus 28%, $p = 0.04$), and bad weather (46 versus 19%, $p = 0.004$) as significant barriers, as compared to those with a college degree or beyond. The loss of income related to needing to take time off work was also significantly more burdensome to those with an annual income level of less than \$50,000 (51% versus 22%, $p = 0.003$). The most commonly identified barriers across subgroups are presented in Figure 1.

Discussion

Our study examined the characteristics and barriers to accessing specialised congenital cardiac care of adults with CHD in Oregon. We found that the most common barriers to care are loss of compensation from taking time off work to attend a visit and physical distance to clinic location. In particular, rural dwelling

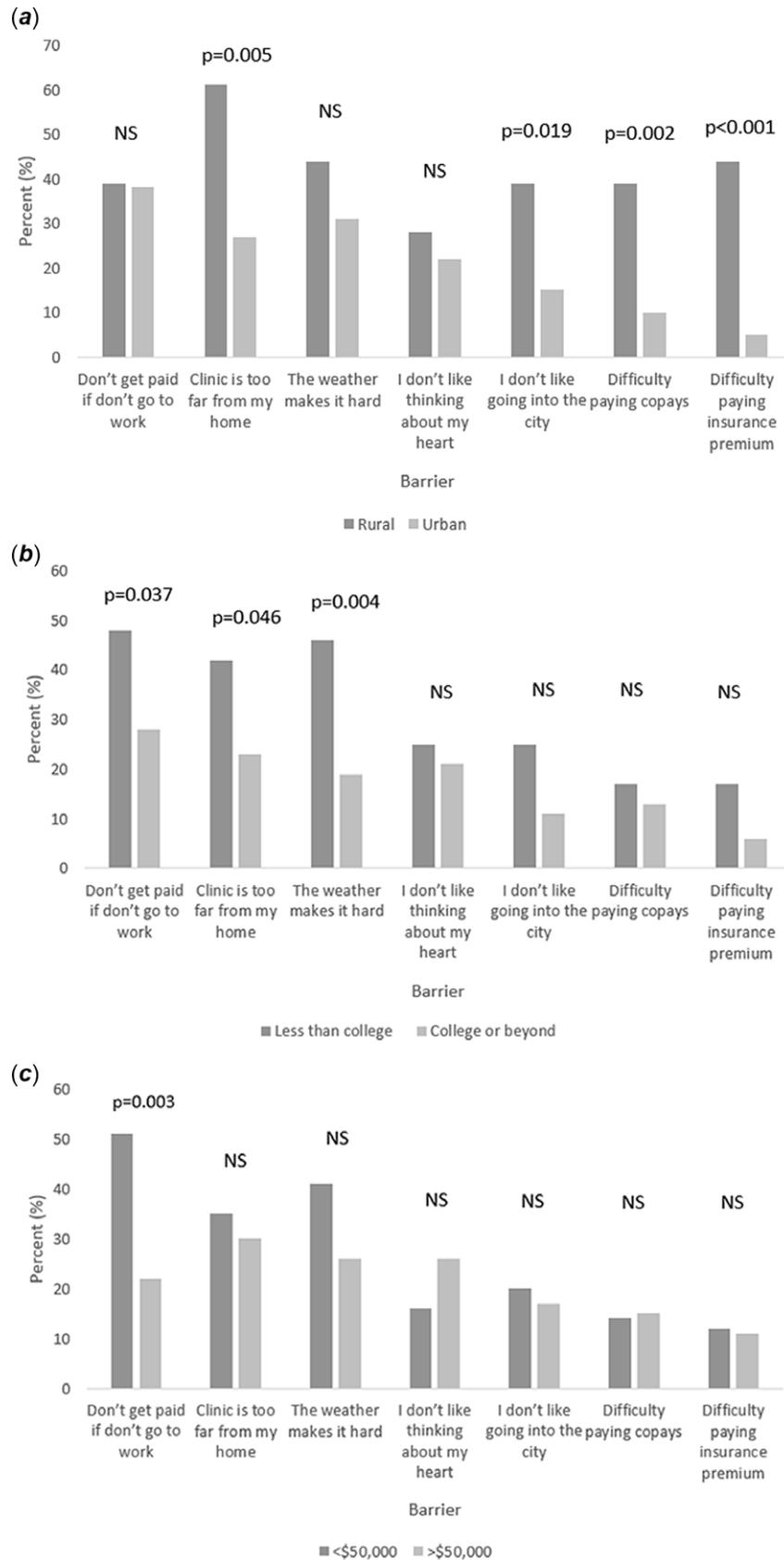


Figure 1. (a) Barriers to care based on dwelling status (rural versus urban). (b) Barriers to care based on education level. (c) Barriers to care based on annual household income.

patients are significantly more likely to find the distance to clinic to be an important barrier.

The impact of distance to adult congenital heart disease care on access to care has been recently examined by our group, using an administrative dataset which showed that adults with CHD who live further away from specialised care are less likely to access adult congenital heart disease-specific care.¹² Distance to clinic has been identified as a predictor of gaps in adult congenital heart disease care,¹³ most notably in states in the Western United States. Interestingly, distance to care was not found to be a significant predictor of clinic attendance in a non-United States-based population, suggesting that regional factors may play an important role.⁵ In Oregon, a significant proportion of the population lives in rural areas which are geographically remote to the state's only accredited adult congenital heart disease center.

Rural-urban health disparities are widening over time in the United States. Cardiovascular disease outcomes and mortality are associated with home location, with rural individuals comprising a higher risk group for adverse outcomes.¹⁴ Patients residing in rural areas are less likely to receive evidence-based care for heart failure,^{15,16} as well as timely high-quality care for myocardial infarction,¹⁷ for instance. In adults with CHD, specialised adult congenital heart disease care and patient adherence to scheduled adult congenital heart disease clinic visits have been shown to be associated with better survival.^{4,5} Because most adult congenital heart disease centers are located in urban areas, understanding and addressing the barriers rural patients face when accessing care is of utmost importance, and may impact patient outcomes. Telehealth services have great potential in addressing the geographic barriers patients face; however, some rural and lower income communities also face challenges with access to these virtual technologies (e.g., lack of broadband access),¹⁸ and this is not an ideal solution for all patients. Historically, satellite clinics have been a common solution, especially in pediatric cardiology, but the nationwide shortage of adult congenital heart disease cardiologists¹⁰ makes this challenging to achieve at scale. In addition, neither of these solutions to geographic barriers would fully address the barriers identified by patients in this study, including the loss of income related to taking time off work. This would require either flexible clinic scheduling (e.g., with after hours or weekend appointments) or employer-specific level in efforts to institute a paid time off policy.

Although Oregon has an overall lower percentage of uninsured patients as compared to many other states,¹⁹ it does have high rates of disparities in educational attainment and income level.²⁰ This is reflected in our study, in which rural dwelling patients were more likely to have a lower education level and more difficulty affording monthly insurance premiums and copays. We found differences in educational attainment to have an important association with barriers to care: those with less than a college degree were more likely to cite loss of compensation when taking time off to attend a clinic visit as a significant barrier, as compared to those with a college degree or beyond. Similarly, distance to clinic and bad weather were more significant barriers for those who achieved a lesser degree of education. Not surprisingly, the loss of income related to taking time off work was also the most commonly cited barrier and statistically significantly more likely in patients with an annual income level of less than \$50,000. Therefore, in addition to addressing geographic barriers to expand access to care for adults with CHD, developing programs that address the socio-economic challenges patients face and narrow the gap in disparities is of great

importance. Providing financial assistance for travel costs and lodging, as well as coordinating clinic visits and tests is an important first step.

The main limitations of the study include its small sample size and the fact that this study was performed on individuals who had successfully made it to clinic. Therefore, it is possible that a significant number of patients who might face further challenges with access to care are not captured in the study. The study was completed before the widespread availability of telemedicine and virtual visits brought on by the COVID-19 pandemic, and it is thus possible that the findings and conclusion would be different during pandemic conditions.

Conclusions

Loss of compensation from taking time off from work to attend a visit and distance to clinic were the most commonly identified barriers to outpatient cardiac care in this cohort of adults with CHD. These barriers, along with difficulty paying insurance premiums, are more common in rural dwelling patients. Initiatives such as telemedicine visits or providing financial subsidies for travel and treatment could help to expand specialty adult congenital heart disease care and better serve this growing patient population. Efforts should focus on optimizing systems of care to allow specialised care of all adults with CHD, irrespective of geographic location, and to narrow the gap of disparities that is present.

Supplementary material. To view supplementary material for this article, please visit <https://doi.org/10.1017/S1047951121002766>.

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Conflicts of interest. None.

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