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Changes in Hospitalization Patterns Among Patients With Congenital Heart Disease During the Transition From Adolescence to Adulthood

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Objectives This study was designed to evaluate hospitalization patterns of congenital heart disease (CHD) patients surrounding the transition from adolescence to adulthood.

Background Few population data exist on hospitalizations among adolescent and adult CHD patients.

Methods Patients ages 12 to 44 years with CHD were selected from the 2000 to 2003 California hospital discharge database. Patient demographics, hospitalization patterns, emergency department (ED) admissions, CHD complexity, and insurance patterns were described. Data were analyzed in 3-year age increments and compared between patients over and under age 21. Predictors of admission via the ED were determined using multivariate regression analysis.

Results There were 9,017 hospitalizations at 368 hospitals. For patients ages 12 to 20 years, 12 hospitals accounted for 70% of hospitalizations; for patients ages 21 to 44 years, 25 hospitals accounted for only 44.8% of cases. Regarding insurance, 53% of admissions were private, 44% public, and <4% were self-pay. Sixty-five percent of patients had complex CHD and 19% had a cardiac procedure during hospitalization. The proportion of patients admitted via the ED nearly doubled surrounding the transition to adulthood. The positive predictors of admission via the ED included public insurance, self-pay, and age >17 years, whereas having a procedure and being female decreased the likelihood.

Conclusions Congenital heart disease hospitalizations occur at a wide variety of hospitals and disperse as patients enter adulthood. Those without private insurance and >17 years old are at higher risk of being admitted via the ED. These findings require further investigation to examine access to care and possible disparities, as they are important for future healthcare planning. (J Am Coll Cardiol 2007;49:875–82) © 2007 by the American College of Cardiology Foundation

Tremendous improvements in diagnosing and treating congenital heart disease (CHD) are changing patient demographics in the U.S. Currently, 85% to 90% of children born with CHD will survive to adulthood. Estimates suggest that between 650,000 and 1.3 million adults with CHD now live in the U.S. The incidence of CHD in live births in the U.S. has been relatively stable; however, as survival improves, the number of adults with CHD should continue growing at 5% per year (1–3). Nevertheless, information about the adult CHD population, its basic demographics, or detailed outcomes remains scarce. The existing domestic data come, instead, from estimated birth and survival rates and from the databases of a few major centers that do not capture the majority of U.S. patients (3). The rest of the available data on adults with CHD represent countries with national healthcare systems or regionalized services, including Finland, the United Kingdom, and the Netherlands (3–5).

Although many resources have been dedicated to the care of U.S. children with CHD, the dearth of adult information reflects the scant attention devoted to CHD survivors

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Abbreviations and Acronyms

CHD = congenital heart disease

ED = emergency department

ICD-9-CM = International Classification of Diseases-Ninth Revision-Clinical Modification

OSHPD = Office of Statewide Health Planning and Development

transitioning from adolescence to adulthood. However, children with CHD and their parents have clear concerns, including keeping medical insurance and finding an adult physician with appropriate specialized training in pediatric illnesses (6,7). The difficulty in finding a physician is especially important, as it is estimated that at least one-half of adult CHD patients will require care by a physician specializing in CHD, and recent evidence suggests that there are not enough physicians with this training to care for the increasing number of patients (2,8). These studies suggest that between 19 and 23 years of age (depending on the state), many of these youth will lose public or parental insurance and will struggle to obtain comprehensive health insurance (9,10).

Without national databases, the domestic population of adolescents and adults with CHD remains undescribed. Outside of a few major U.S. centers, the medical outcomes, maintenance of insurance, location of care, and types of physicians providing care remain unknown. Thus, neither policymakers nor providers know how changes during the transition from adolescence to adulthood may affect medical care and services.

Because care for CHD patients in the U.S. is not formally regionalized, we hypothesized that adolescents and adults with CHD would be admitted to a variety of different hospitals for both general admission and CHD procedures. Next, we suggested that the care of inpatients under 21 years would be more centralized than for the group that is 21 years and older. And finally, we proposed a shift in admission patterns as patients entered the difficult transition ages of 18 to 23 years. During that transition, we expected an increasing proportion of admissions via the emergency department (ED). This type of shift might result from changes in disease patterns, insurance sources, or access to care. We examined this issue further within the CHD population by evaluating demographic variables as risk factors for admission via the ED. We expected that those who were over 21 years, those with more complex disease, and those without private insurance would be more commonly admitted via the ED.

Methods

Data sources and study population. The California Office of Statewide Health Planning and Development (OSHPD) provided the hospital discharge dataset for years 2000 to 2003 after approval from the human subjects protection committee. The OSHPD data contain International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) primary and secondary diagnosis and procedure codes assigned by California hospitals to each individual hospital discharge. Fields are provided for up to 24 principal and secondary diagnoses and 20 procedures. The database lists routine demographic and administrative information such as age, gender, race, ethnicity, admission hospital, admission source, and primary payment source. The unit of analysis is each hospitalization of patients, ages 12 to 44 years, who were identified in OSHPD with a primary or secondary ICD-9-CM code for CHD. Pregnancy-related hospitalizations, which made up approximately 10% of CHD hospitalizations and approximately 6% of non-CHD hospitalizations, were excluded. This population of patients has characteristics that would, if not excluded, affect the hypothesis testing. All other admissions for CHD patients in the 12-to-44 year age range were included. For this study, the general population comparison group consisted of a non-pregnant, non-CHD California OSHPD dataset for patients ages 12 to 44 years in the year 2000.

Variables. The main outcome variable is admission source, specifically admission via the ED or admission from a non-emergent source, such as home or physician office. Another evaluated variable was age, grouped into 3-year aggregates. This range was based at age 12, which is often considered the beginning of adolescence. By age 12, most CHD patients have completed primary surgical repair or palliation and may be developing sequelae of their disease or entering a phase of maintenance therapy. In order to minimize confounding effects from the onset of adult diseases that may affect hospitalizations, insurance status, or the miscoding of acquired aortic or mitral valve disease as CHD lesions, we bounded the sample limit at age 44 years.

Complexity of CHD took 2 categories: complex and non-complex CHD. Complex CHD was defined by the presence of ICD-9-CM codes for lesions outlined as moderate or complex CHD in published data (1). Although CHD is a broad category of heart disease, patients with these more complex diagnoses are thought to require care by adult CHD specialists (1,2). The complex CHD group also included any CHD patients with an ICD-9-CM code for cyanosis or pulmonary hypertension. All others were considered non-complex CHD.

Admission with a cardiac-related principal procedure, such as catheterization, congenital heart surgery, electrophysiologic study, radiofrequency ablation, or pacemaker was an additional independent variable. Hospitalizations for these procedures are typically elective and often do not require admission via the ED.

Primary insurance source was divided into 3 categories: 1) public (i.e., Medicaid, Medicare, other government, county indigent); 2) private (i.e., fee-for-service, health maintenance organization, preferred provider organization); and 3) self-pay/uninsured. Secondary insurance sources are not included in the database. The "other government" group

includes California Children's Services, which provides primary insurance coverage for CHD children <21 years old if no other coverage is available. The Medi-Cal (California Medicaid) group includes those in both Medi-Cal fee-for-service and Medi-Cal managed care coverage. In a second regression analysis, the public insurance category was also evaluated with separate categories for Medi-Cal, Medicare, and other public.

Other variables for description included race, ethnicity, and gender. Race was divided into white, black, Asian, and other race. Ethnicity was identified as Hispanic or non-Hispanic.

Statistical methods. Descriptive statistics were used to characterize the variables identified both in aggregate and by year for CHD hospitalizations. The CHD hospitalizations were then stratified based on 21 years of age as the threshold for transition into adulthood. This is the age when California Children's Services expires and, depending on the policies of different hospitals, often when patients can no longer be admitted to children's hospitals or pediatric wards.

Categorical outcome and independent variables as a group and over the time period 2000 to 2003 were examined with chi-square analysis and chi-square test for trend. The variables included gender, insurance status, admission pattern by source, and proportion with complex CHD.

Multivariate logistic regression on predictors for admission via the ED was performed. Independent variables included age category, primary insurance source, complex CHD or not, race, ethnicity, gender, and having a cardiac principal procedure. The regression was performed a second time including a variable for interaction of complex CHD and insurance status, as the complexity of CHD was thought to potentially influence the ability to obtain private insurance.

Results

Demographics and insurance sources for hospitalizations. The results of the aggregate 2000 to 2003 descriptive statistics are shown in Table 1. Just under 50% of the hospitalizations were women, more than 70% were white, and about 27% were Hispanic. Sixty-five percent of the CHD hospitalizations were for patients with complex CHD, and 19% had a cardiac-related principal procedure during their admission. Regarding insurance status, 52% of the hospitalizations had private insurance as a primary payment source, 44% were publicly insured, and a much smaller percentage (3.5%) was self-pay/uninsured.

For the years 2000 to 2003, there was a gradually increasing number of annual CHD hospitalizations. The hospitalizations also increased in relation to the total California hospitalizations in this age range (from 0.14% to 0.15%) over the 4-year span. There were no significant differences in insurance type or proportion of complex CHD from 2000 to 2003. However, there were statistically significant trends of increasing proportion of admissions via the ED ($p = 0.009$) and decreasing proportion of female hospitalizations ($p = 0.01$) (Table 2).

Table 1 Demographics for CHD Hospitalizations Aggregated 2000 to 2003

Variable Category	Frequency (%)
Age category (yrs)	
12–14	1,408 (15.6%)
15–17	1,137 (12.6%)
18–20	797 (8.8%)
21–23	567 (6.3%)
24–26	595 (6.6%)
27–29	625 (6.9%)
30–32	622 (6.9%)
33–35	716 (7.9%)
36–38	829 (9.2%)
39–41	834 (9.2%)
42–44	887 (9.8%)
Gender	
Female	4,295 (47.6%)
Male	4,722 (52.4%)
Race	
White	6,324 (70.1%)
Black	715 (7.9%)
Asian	666 (7.4%)
Other	1,311 (14.5%)
Ethnicity	
Non-Hispanic	6,550 (72.6%)
Hispanic	2,467 (27.4%)
Insurance source	
Private	4,703 (52.2%)
Public	3,998 (44.3%)
Uninsured/self-pay	315 (3.5%)
ED as admission source	
ED	3,390 (37.6%)
Non-ED	5,627 (62.4%)
Complex CHD	
Non-complex CHD	3,140 (34.8%)
Complex CHD	5,877 (65.2%)
Procedure	
No cardiac procedure	7,311 (81.1%)
Cardiac procedure	1,706 (18.9%)

CHD = congenital heart disease; ED = emergency department.

There was a decrease in the absolute number of CHD hospitalizations per age group from age category 12 to 14 years until age category 21 to 23 years. The number of hospitalizations per age group then remained relatively even until age category 33 to 35 years, when the number began to slowly increase again (Fig. 1).

Distribution of hospitalizations by age. In the years 2000 to 2003, there were 9,017 non–pregnancy-related hospitalizations for CHD patients ages 12 to 44 years in 368 hospitals in California. Among these 9,017 hospitalizations, 846 (9.4%) included a congenital heart operation. These operations were performed at 70 different hospitals.

Table 2 Comparisons of Selected Independent Variables by Year

Year	2000	2001	2002	2003	Total	Chi-Square*
Hospitalizations	2,144	2,199	2,271	2,403	9,017	
Admit via ED						
No	1,379	1,390	1,393	1,465	5,627	
Yes	765 (35.7%)	809 (36.7%)	878 (38.7%)	938 (39%)	3,390 (37.6%)	Chi-square = 6.8; p = 0.009
Gender						
Male	1,087	1,134	1,202	1,299	4,722	
Female	1,057 (49.3%)	1,065 (48.4%)	1,069 (47.1%)	1,104 (45.9%)	4,295 (47.6%)	Chi-square = 5.95; p = 0.01
Insurance						
Private	1,159 (54.1%)	1,142 (51.9%)	1,152 (50.7%)	1,250 (52%)	4,703 (52.2%)	
Public	920 (42.9%)	982 (44.6%)	1,038 (45.7%)	1,058 (44%)	3,998 (44.3%)	
Self-pay	64 (3%)	75 (3.4%)	81 (3.6%)	95 (4%)	315 (3.5%)	Chi-square = 2.3; p = 0.13
Complex CHD						
No	742	749	775	874	3,140	
Yes	1,402 (65.4%)	1,450 (65.9%)	1,496 (65.9%)	1,529 (63.6%)	5,877 (65.2%)	Chi-square = 1.55; p = 0.21

*Chi-square is test for trend.
Abbreviations as in Table 1.

For comparison, we divided the hospitalizations at age 21 years. For patients ages 12 to 20, there were 3,342 discharges from 239 hospitals. Only 12 hospitals averaged ≥12 discharges per year (1 per month). These hospitals, however, accounted for 70% of the discharges in this age group. For hospitalizations associated with congenital heart surgery in 12- to 20-year-olds, there were 362 discharges from 31 hospitals. Only 7 hospitals performed the vast majority (71%) of surgical hospitalizations. The remaining CHD procedures were in hospitals averaging <5 CHD surgical hospitalizations per year (Table 3).

For those patients ages 21 to 44 years, there were 5,675 discharges from 346 hospitals. Of these, 25 hospitals averaged more than 12 discharges per year. These 25 hospitals accounted for only 44.8% of the total number of discharges.

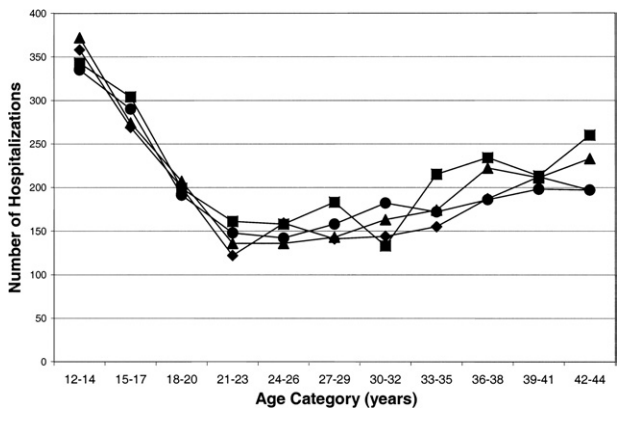

Figure 1 Total Hospitalizations of CHD Patients by Year and Age Category

Diamonds = 2000; **circles** = 2001; **triangles** = 2002; **squares** = 2003.
CHD = congenital heart disease.

For discharges associated with congenital heart operations in this same age range, there were 484 discharges from 67 different hospitals. The 4 hospitals with the greatest number of CHD surgical hospitalizations accounted for only 41.5% of the surgical admissions. The majority (58.5%) of the CHD surgical hospitalizations were at hospitals that averaged <5 CHD operations per year (Table 3).

Admission source. Admissions from the ED made up more than 37% of the total number of hospitalizations. When the CHD hospitalizations were analyzed by age, there was an increase in the proportion of admissions from the ED starting after age 17 years and continuing through ages 21 to 23 years. This trend then stabilized before showing a slight increase for age groups 39 to 41 years and 42 to 44 years (Fig. 2). Similar trends of increasing proportion of admissions via the ED between ages 17 and 23 years were also found when the CHD group was separated into publicly and privately insured. Comparison of the absolute volume of admissions by age category showed that the increase in proportion of admissions via the ED was driven by a decrease in the number of non-ED admissions. The number of admissions via the ED remained stable from ages 12 to 32 years and increased slightly at the 33- to 35-year age category (Fig. 3). In short, though there is a decrease in the number of hospitalizations in the late teen and young adult years, those who require admission more frequently enter the hospital via the ED. This is in direct contrast to the non-CHD California hospital discharges in this age group (Fig. 4).

Multivariate analysis. In the multivariate logistic regression analysis, significant factors associated with admission via the ED included public insurance, uninsured/self-pay, age categories older than 15 to 17 years, having a cardiac principal procedure, and female gender. Having public insurance or being uninsured increased the odds of admission via the ED by factors of 2.3 and 4.6, respectively, over

Table 3 Comparison of Hospitalizations by Age: 12 to 20 Years and 21 to 44 Years (Aggregate 2000 to 2003)

	12–20 yrs	21–44 yrs
Total hospitalizations (n = 9,017)	3,342 (37%)	5,675 (63%)
Total number of hospitals (n = 368)	239	346
Hospitals with ≥12 CHD hospitalizations/yr	12	25
% of total hospitalizations	70%	44.8%
Hospitals with <12 CHD hospitalizations/yr	227	321
% of total hospitalizations	30%	55.2%
Total CHD surgical hospitalizations (n = 846)	362 (42.8%)	484 (57.2%)
Hospitals with ≥5 CHD operations/yr	7	4
% of total hospitalizations	71%	41.5%
Hospitals with <5 CHD operations/yr	24	63
% of total hospitalizations	29%	59.5%

CHD = congenital heart disease.

those with private insurance. In a second regression model separating publicly insured into Medicare, Medi-Cal, and other public, odds of admission through the ED were similar to the first model for all 3 (odds ratios of 2.6, 2.7, and 1.8 respectively). All of the age categories over age 17 years showed higher likelihood of admission via the ED compared with those in the ages 12 to 14 category. Patients who had a principal cardiac procedure during hospitalization were only about 25% as likely to come through the ED as those who did not have these procedures. Women were 20% less likely to be admitted through the ED than were men (Table 4). There was no significant effect of the interaction of complex CHD with insurance. As operationalized, CHD complexity does not contribute to the observed difference in admission source between hospitalizations associated with public and private insurance.

Discussion

From 2000 to 2003 in California there were, on average, 2,250 non–pregnancy-related hospitalizations of persons ages 12 to 44 years with CHD per year. Inpatient hospitalizations of patients with CHD increased slightly each year during this period. There is also a small but statistically significant increase in the proportion of admissions via the ED trending over the 4-year period. The increased total hospitalizations over the different years may reflect both general population growth and a larger number of survivors, with both simple and complex CHD, using services.

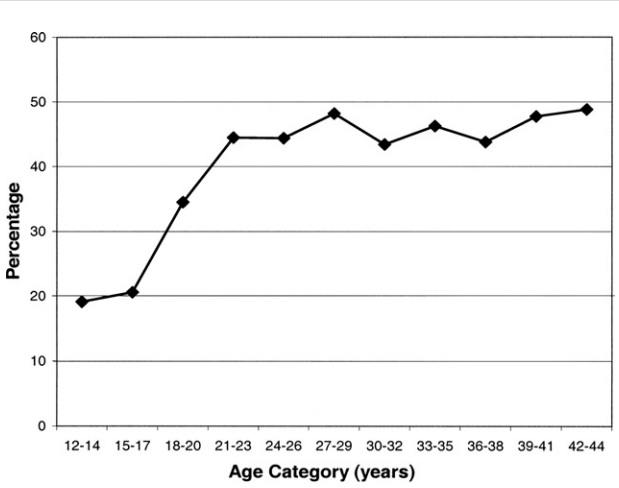

Figure 2 Percentage of Admissions Via the ED for CHD Patients by Age Category, 2000 to 2003

CHD = congenital heart disease; ED = emergency department.

The CHD hospitalizations occurred at a wide distribution of hospitals across the state. Approximately 9% of hospitalizations had congenital cardiac surgery as the principal procedure, and these were performed at a variety of hospitals, many of which averaged fewer than 5 CHD procedures per year. When the group was divided at age 21 years, often the age when patients can no longer be admitted to a children's hospital or a pediatric ward, the older patients had a greater diversity in the number of hospitals for admission and for surgery. In the under-21 age group, more than 70% of surgical procedures and hospitalizations were at the hospitals performing most of the admissions and pro-

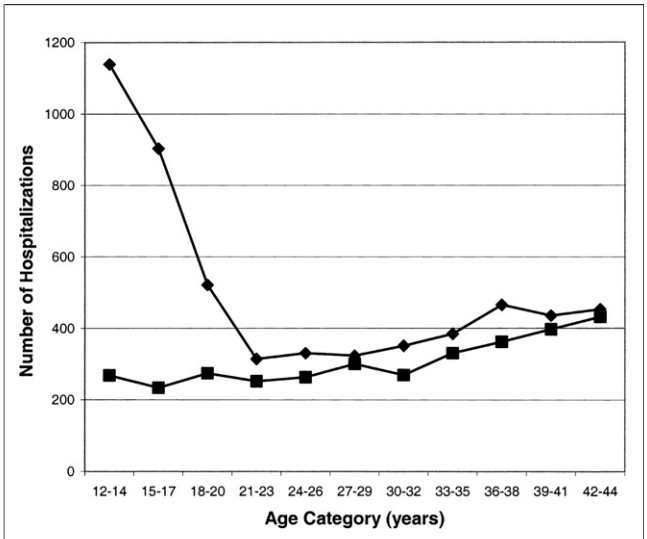

Figure 3 Total Hospitalizations From ED and Non-ED Sources for CHD Patients by Age Category, 2000 to 2003

Squares = ED admits; **circles** = non-ED admits. Abbreviations as in Figure 2.

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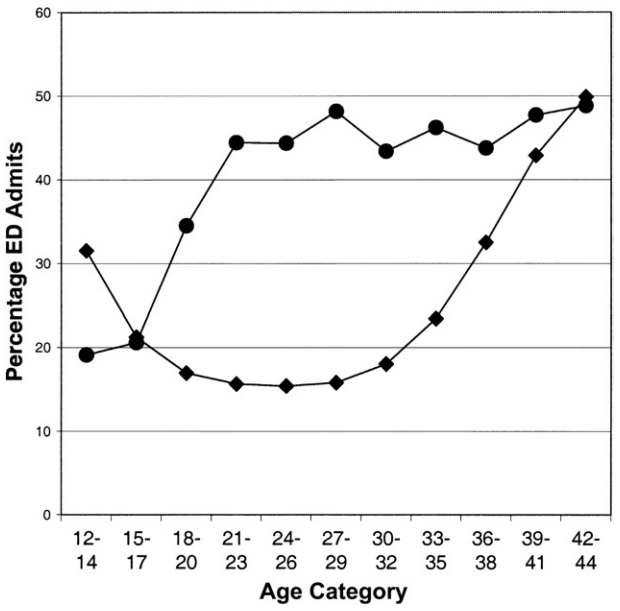

Figure 4 Percentage of Admissions Via the ED for CHD and Non-CHD Patients by Age Category, Year 2000

All years (2000 to 2003) showed similar patterns for proportion of admissions via the ED by age. **Diamonds** = percent ED admits for non-CHD in year 2000 all; **circles** = percent ED admits for CHD in 2000. Abbreviations as in Figure 2.

cedures. In the older age group, the more experienced facilities accounted for <45% of procedures and hospitalizations. This may be due to a form of regionalization of CHD care in the pediatric age group, where there are relatively few pediatric cardiologists and pediatric tertiary care hospitals compared with the number of adult physicians and facilities for general cardiology. It is probable that because of the small number of CHD specialists for adults, CHD patients end up diversifying to the larger number of general adult cardiologists and hospitals. Adults with CHD seem to be receiving care at hospitals with less CHD experience than their pediatric counterparts; the effects that this may have on clinical outcomes are unclear and, unfortunately, could not be addressed in this study. These effects may be especially important regarding congenital heart surgical procedures, as it has been shown that patients having surgery at higher volume CHD centers have better outcomes (11,12).

For admissions via the ED, the proportion is twice as high for those ages 21 to 23 years compared with those ages 15 to 17 years. The reason for this shift during the transition age period is unknown but might be explained by the natural history of CHD, adulthood barriers to care, different care patterns among adult cardiology providers, or individual insurance changes for these patients with CHD. Each factor might drive patients to seek care via the ED when care is required or delay preventive services until such a time as the patients require ED admission. Interestingly, the trend stands in direct opposition to the trend of ED admissions for all non-pregnant, non-CHD hospitalizations in California in the same age ranges.

The actual number of ED admissions does not greatly increase with age; instead, a decline in non-ED admissions with age causes the proportion of ED admissions for CHD patients to increase upon entering adulthood. Possible explanations include a natural history of a "good period of health" from the twenties to early thirties requiring fewer overall admissions. It also may reflect parental attention to preventive services, or surveillance procedures being performed in the years before ages 18 to 21 years, when the child is normally expected to leave home for school/work or to lose parental or governmental insurance. Another possibility is that adults with CHD may have an increase in urgent medical issues with age, even with good outpatient services. This might include certain types of CHD that have an increase in arrhythmia risk with time after a surgical repair. With this administrative dataset, we are unable to assess timing or appropriateness of admissions and procedures. In either case, although there are, overall, fewer

Table 4 Multivariate Logistic Regression Analysis for Predictors of Admission Via the ED

Variables	Odds Ratio	Confidence Interval	p Value
Insurance source			
Private insurance	Reference		
Public insurance	2.32	1.97–2.73	<0.001
Self-pay	4.61	3.34–6.37	<0.001
CHD complexity			
Noncomplex CHD	Reference		
Complex CHD	1.11	0.97–1.28	0.131
Cardiac procedure			
Without procedure	Reference		
With procedure	0.25	0.19–0.33	<0.001
Age group (yrs)			
12–14	Reference		
15–17	1.14	0.82–1.59	0.425
18–20	2.2	1.59–3.04	<0.001
21–23	3.46	2.53–4.76	<0.001
24–26	3.25	2.3–4.58	<0.001
27–29	4.11	2.89–5.84	<0.001
30–32	3.48	2.47–4.89	<0.001
33–35	3.87	2.7–5.54	<0.001
36–38	3.65	2.63–5.06	<0.001
39–41	4.49	3.2–6.29	<0.001
42–44	4.91	3.53–6.84	<0.001
Gender			
Male	Reference		
Female	0.8	0.72–0.89	<0.001
Race/ethnicity			
White	Reference		
Hispanic	1.11	0.92–1.34	0.26
Black	1.17	0.93–1.47	0.18
Asian	0.88	0.68–1.14	0.33
Other	0.97	0.73–1.28	0.82

The odds ratio for the reference group of each variable is 1.
Abbreviations as in Table 1.

hospitalizations of patients in their twenties and thirties, those who require inpatient care are more frequently admitted via the ED than either the younger CHD adolescents or the general population.

The significant positive predictors of admission via the ED in the regression analysis were age category older than 15 to 17 years, public insurance, and self-pay/uninsured. Conversely, having a cardiac principal procedure and being female decreased the likelihood of ED admission. The different effect of age over 17 years is consistent with the contention that as patients enter adulthood they encounter changes in care patterns, disease patterns, or barriers to care. As most cardiac procedures for CHD are typically scheduled, it is logical that these would less commonly be ED admissions. The gender effect is unexpected and has an uncertain etiology, although this result has some consistency with the results of surveying the general population (13).

The results regarding insurance may question the suggestion that adult CHD patients have difficulty obtaining private insurance (9). The majority of CHD hospitalizations in this dataset had a private insurance source (53%). It is critical to note, however, that these data do not reflect the ability to access specialty care with private insurance, the insurance status of outpatients with CHD, or the status of those not receiving cardiology care. The general hospitalized population ages 12 to 44 years in the year 2000 had a slightly lower percentage of privately insured hospitalizations (50%). It is not surprising that those without insurance and those with public insurance had higher odds of using the ED relative to those with private insurance, because those without private insurance may have reduced access to a usual source of care or routine preventive services.

Although one might expect that patients with complex disease would be admitted via the ED more commonly, in fact, disease complexity was not significant. Greater CHD complexity did not explain the differences between publicly and privately insured. It may be that even though all moderate and complex CHD patients are thought to require care by a CHD specialist, this group remains fairly diverse in diagnoses and severity of clinical status. Another problem is that patients with complex CHD may have different and opposite care patterns as adults. For example, some may be able to maintain a regular source of care and probably have fewer admissions via the ED, whereas others may be more likely to use the ED, even with good follow-up care, owing to a higher risk of acute events with complex disease. Although diagnostic codes are an available marker for type of CHD, this complexity measure may not be completely accurate as a proxy for actual CHD severity.

Study limitations. The study has various limitations. First, it reflects only information regarding inpatients with CHD in California. Most comparisons are performed within the inpatient CHD population, as only limited information is available for comparisons with the general inpatient population. The information does not necessarily reflect the entire population of California adults with CHD, as it is likely that most adult CHD patients do not require inpatient care and use either outpatient services or do not use medical services. Second, insurance status may not reflect national distribution, as California has a larger proportion of patients insured by health maintenance organizations than most other states. Moreover, Medicaid regulations differ by state. Also, although there is an ethnically and socioeconomically diverse population in California, these data might not reflect other states or the U.S. population in general.

As with most administrative data, this study is limited by the comprehensiveness and quality of the database. The only way to identify patients with CHD is via a diagnostic code; if patients are admitted and the CHD is not coded, they will not be captured in the dataset. Thus, the study may underestimate the utilization of services by CHD patients, particularly for those admitted with noncardiac diagnoses or those coded more generically as "arrhythmia" or "congestive heart failure." There is also no possibility of measuring the appropriateness of services performed, only that the hospitalizations and procedures occurred. Finally, the data are limited to the variables collected by the hospital and do not include other variables that may affect admission via the ED or insurance type such as income, level of education, or marital status.

Conclusions

This study reveals considerable differences in hospitalization patterns of CHD inpatients in California surrounding the ages of transition from adolescence to adulthood. As patients reach the age of 21 years and older, the locations of hospitalizations and surgical procedures are greatly diversified to hospitals with fewer CHD hospitalizations and likely less CHD experience. The admission source pattern also changes during the transition to adulthood, with a decreasing number of nonemergent admissions and an increasing proportion of admissions via the ED. Patients without private insurance and older age groups are at higher risk of being admitted via the ED, whereas women are less likely. The findings of this study provide an impetus for further investigation into clinical outcomes, use of services, and potential healthcare disparities, which will be important in determining future provider workforce allocations and sites of care for the rapidly growing adult CHD population.

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REFERENCES

1. Warnes CA, Liberthson R, et al. The 32nd Bethesda Conference Task Force 1: the changing profile of congenital heart disease in adult life. J Am Coll Cardiol 2001;37:1171–5.

JACC Vol. 49, No. 8, 2007
February 27, 2007:875–82

2. Hoffman JI, Kaplan S, Liberthson RR. Prevalence of congenital heart disease. Am Heart J 2004;147:425–39.
3. Niwa K, Perloff JK, Webb GD, et al. Survey of specialized tertiary care facilities for adults with congenital heart disease. Int J Cardiol 2004;96:211–6.
4. Engelfriet P, Boersma E, Oechslin E, et al. The spectrum of adult congenital heart disease in Europe: morbidity and mortality in a 5 year follow-up period. The Euro Heart Survey on adult congenital heart disease. Eur Heart J 2005;26:2325–33.
5. Nieminen H, et al. Long-term results of pediatric cardiac surgery in Finland: education, employment, marital status, and parenthood. Pediatrics 2003;112:1345–50.
6. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. Pediatrics 2005;115:1562–8.
7. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. Pediatrics 2005;115:112–20.
8. Gurvitz MZ, Chang RK, Ramos FJ, Allada V, Child JS, Klitzner TS. Variations in adult congenital heart disease training in adult and pediatric cardiology fellowship programs. J Am Coll Cardiol 2005;46:893–8.
9. White PH. Access to health care: health insurance considerations for young adults with special health care needs/disabilities. Pediatrics 2002;110:1328–35.
10. Muhll I, Cumming G, Gatzoulis M. Risky business: insuring adults with congenital heart disease. Eur Heart J 2003;24:1595–600.
11. Jenkins KJ, Newburger JW, Lock JE, et al. In-hospital mortality for surgical repair of congenital heart defects: preliminary observations of variation by hospital caseload. Pediatrics 1995;95:323–30.
12. Hannan EL, Racz M, Kavey RE, Quaegebeur JM, Williams R. Pediatric cardiac surgery: the effect of hospital and surgeon volume on in-hospital mortality. Pediatrics 1998;101:963–9.
13. Schappert SM, Burt CW. Ambulatory care visits to physician offices, hospital outpatient departments, and emergency departments: United States, 2001–02. Vital Health Stat 13 2006;159:1–66.