Hospital Resource Utilization and Presence of Advance Directives at the End of Life for Adults with Congenital Heart Disease

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Abstract

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Objective: Overall healthcare resource utilization by adults with congenital heart disease has increased dramatically in the last two decades. No prior studies have examined utilization at the end of life. The objective of this study is to better understand the patterns and influences on the intensity of care at the end of life for adults with congenital heart disease.

Methods: We identified a sample of adults with congenital heart disease, cancer, or heart failure who died between January 2010 and December 2015. We used multivariate analysis to evaluate markers of resource utilization, location of death, and documentation of advance care planning among patients with congenital heart disease versus those with cancer and those with heart failure.

Results: Close to 40% of adults with congenital heart disease experienced inpatient and intensive care unit hospitalizations in the last 30 days of life; 64% died in the hospital. Compared to patients with cancer, patients with ACHD were more likely to have inpatient (adjusted risk ratio 1.57; 95% CI 1.12-2.18) and intensive care unit admissions in the

last 30 days of life (adjusted risk ratio 2.56; 95% CI 1.83, 3.61), more likely to die in the hospital (adjusted risk ratio 1.75; 95% CI 1.43, 2.13), and more likely to have documentation of advance care planning (adjusted risk ratio 1.46; 95% CI 1.09, 1.96). Compared to patients with HF, they were less likely to have an intensive care unit admission in the last 30 days of life (adjusted risk ratio 0.73; 95% CI 0.54, 0.99).

Conclusions: Adults with congenital heart disease have significant hospital resource utilization near the end of life, notable for more hospitalizations and a higher likelihood of death in the hospital compared to patients with cancer. This population represents an important opportunity for the application of palliative and supportive care.

Background:

Continued medical and surgical advances in recent decades have greatly increased survival past childhood for children with congenital heart disease, with the result that more than 1.5 million adults currently live with congenital heart disease in the United States.[1] Despite these advances and improved survival, adult congenital heart disease (ACHD) remains a life-limiting condition. Compared to the general population, those with moderate or more complex lesions have significantly shorter life expectancies.[2,3] Heart failure (HF), lethal arrhythmias, and damage to other organs are the leading causes of death for this group.[4-6] Adequate prognostication is difficult due to wide variations in potential disease course that are related to both the heterogeneity of this population and the fluctuating course of HF.[7,8]

Healthcare and hospital utilization by this growing group of patients with ACHD is of rising interest, as hospital admissions and their associated costs have increased dramatically in the past two decades.[9,10] However, no prior studies have examined resource utilization patterns for patients with ACHD specifically at the end of life. The time period near the end of life is associated with costs well beyond the day-to-day cost of care for patients with chronic illness and can be associated with unwanted or burdensome intensity of care.[11] In an effort to better understand the patterns of and influences on the intensity of care at the end of life for individuals with ACHD, we retrospectively studied patients with ACHD who died. For comparison, we examined resource utilization by patients who died with either cancer or HF who did not have ACHD. Our hypothesis was that patients with ACHD, as compared with these other groups, would have more intensive resource use, less documentation of advance care planning, and would be more likely to die in the hospital.

Methods

Sample: Using electronic health records (EHR) and death certificates, we identified adults (age 18 years and older) who died in Washington State between January 2010 and December 2015 and were affiliated with a single multi-hospital healthcare system in the Seattle area. Decedents were excluded if the death certificate indicated a cause of death due to "injury or poisoning emanating from an accident, suicide, homicide, or an undetermined source." Determination of healthcare system affiliation was adapted from the Dartmouth Atlas criteria, requiring at least one non-surgical inpatient visit at an affiliated hospital in the two years before death; or, at least two outpatient visits from the same site in the last 32 months of life, with at least one visit occurring during the last 24 months of life.[12] The sample was then limited to those who had a recorded diagnosis of at least one of three conditions: ACHD classified by ACC/AHA guidelines,[13] HF or non-hematologic cancer as defined in the Dartmouth Atlas based on International Classification of Disease (ICD) codes.[12] Patients with diagnosis codes for both cancer and HF were excluded. Patients with ACHD were limited to those with lesions of moderate or severe complexity, since these are more likely to limit longevity and play a causal role in death than simple lesions. Due to the poor accuracy of administrative codes to identify patients with ACHD, all subjects in this group were confirmed to have an ACHD lesion by manual EHR review.[14] Dual diagnosis of HF was not excluded in the ACHD group since HF is the leading cause of death for patients with ACHD.[15] The University of Washington Institutional Review Board approved the study.

Measures: Outcomes of interest occurring during the last 30 days of life were: 1) an inpatient admission and length of stay; 2) an intensive care unit (ICU) admission and length of stay; and 3) an Emergency Department visit that did not result in hospitalization. We also examined: 4) any 30-day hospital re-admission in the last 90 days of life and 5) location of death (hospital vs. non-hospital). Finally, because of the possible link between advance directives and utilization,[16] we examined documentation of advance care planning that included any of the following: health care directive, living will, designated power of attorney for healthcare, or

Physician Orders for Life-Sustaining Treatment (POLST) form. All outcome variables were obtained from the EHR with the exception of location of death, which was obtained from state death certificate data. If location of death was not available from death certificate data, it was obtained from the EHR. Decedents without a known site of death from either source were excluded.

Covariates: The following covariates were included: age at death, sex, race/ethnicity (White, Black, Asian/Pacific Islander, Hispanic, Other), educational attainment (some high school, high school degree, some college, bachelor's degree, master/doctorate), and marital status (married, not married). With the exception of sex, all covariates were obtained from death certificates.

Analyses: Patients with ACHD were compared separately to those with HF and those with cancer because there have been few studies of end-of-life care for patients with ACHD. With the exception of length of inpatient admission and length of ICU stay which were modeled as counts, all outcomes were binary. With the exception of age at death, which was numeric and continuous, all covariates were modeled as nominal categorical variables. Binary outcomes were evaluated with relative risk regression using Poisson regression with robust standard errors because the outcomes of interest were not rare events and odds ratios from logistic regression overestimate relative risks when outcomes are not rare.[17] Count outcomes (number of days of inpatient and ICU admissions in the last 30 days of life) were evaluated using linear regression, only among those patients who had an admission in the last 30 days of life. All analyses were adjusted for age, sex, race/ethnicity, educational attainment, and marital status. The proportion of patients with missing data were: race (11%), education (13%), marital status (12%), and location of death (9%). Missing data were imputed using multiple imputation by chained equations (StataCorp. 2017. Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC). Results were not materially different in analyses limited to patients with complete data (data not shown). Significance was set at $p < 0.05$.

Results

Sample demographics for all disease groups: 10,784 patients died with cancer, 3,809 died with HF, and 65 died with ACHD. Average age at death was highest in the group with HF (Table 1) and was about 10 years older than for those who died with cancer, and 25 years older than those with ACHD (71±15, 63±13, and 45±17, respectively). There were slightly more males than females in all groups (60%, 55%, and 52%). The sample was predominantly white (78%, 85%, and 89%). The majority of patients in all groups had either a high school degree or some college. Patients with HF and ACHD were more likely to be married, while those with cancer were more frequently single. More than 90% of patients in each group were insured.

Utilization patterns and differences: Almost 40% of patients with ACHD were hospitalized in the last 30 days of life, and nearly 40% had an ICU admission. Death occurred in the hospital for 64% of patients with ACHD. Forty-two percent had documentation of an advance directive prior to death.

Compared to patients with cancer, patients with ACHD were significantly more likely to have an inpatient admission (adjusted risk ratio (aRR) 1.57; 95% CI 1.12, 2.18) and an ICU admission in the last 30 days of life (aRR 2.57; 95% CI 1.83, 3.62; Table 2). They were also significantly more likely to die in the hospital (aRR 1.75; 95% CI 1.43, 2.13; Table 2), and were more likely to have documentation of advance care planning (aRR 1.46; 95% CI 1.09, 1.96). The findings for advance care planning were unchanged when we excluded designated power of attorney from the definition of advance care planning documentation. Other outcomes (Emergency Department visits, readmissions, and median length of stay in either the hospital or the ICU) did not differ significantly between groups.

Compared to patients with HF, patients with ACHD were significantly less likely to have an ICU admission in the last 30 days of life (aRR 0.73; 95% CI 0.54, 0.99; Table 3). Other outcomes (inpatient admissions, Emergency Department visits, median length of stay in either

the hospital or the ICU, readmissions, in-hospital death, and presence of advance care planning documentation) were not significantly different between groups.

Discussion

This study characterized resource utilization at the end of life for adults with congenital heart disease, finding that close to 40% experience inpatient hospitalizations and ICU admissions in the last 30 days of life. In addition, patients with ACHD are more likely to have an inpatient or ICU admission and die in the hospital compared to patients with cancer, and less likely to have an ICU admission than patients with HF. Hospice and palliative care models were initially developed for the care of patients with cancer. The implementation of such supportive measures has led to a decrease in the use of high intensity care at the end of life such as prolonged life support and hospitalization among patients with cancer, and patients have been able to die at home, if in line with their wishes.[18] Advance directives were also developed as tools to assist in this process of helping ensure that end-of-life care is in line with patients' wishes, and their completion is now relatively routine in cancer care.[19] Our findings suggest opportunities to improve these processes among patients with ACHD.

Palliative care principles have begun to expand to other diseases, including HF,[20] although the evidence base for their application is not as robust. The utility of palliative care for patients with ACHD is only now beginning to gain ground, and very little is known about how and when to begin palliative care or conversations about goals of care.[21] Our findings regarding fewer admissions and in-hospital deaths for patients with cancer as compared to patients with ACHD may reflect this failure to effectively implement palliative care approaches that are in place for cancer care. Uncertainty of prognosis for HF and ACHD is more of an issue than in cancer, which may also drive increased acute care resource utilization. The finding that patients with ACHD are less likely than those with HF to have an ICU admission may relate to lower candidacy for advanced heart failure therapies.

Interestingly, the prevalence of advance care planning documentation among patients with ACHD was much higher than what was suggested by Tobler and colleagues in 2011,[22] and significantly higher compared to patients with cancer in this study. Increased ACP documentation for patients with ACHD compared to cancer may reflect the fact that efforts surrounding documentation of advance care planning are often more concentrated in hospitalized patients compared to those in the outpatient setting.[23] It could also reflect guardianship or power of attorney appointments carried over from childhood or related to cognitive limitations, which are not uncommon in congenital disease. However, this relationship was unchanged when we excluded documentation of designated power of attorney from advance care planning documentation.

Studies have shown healthcare resource utilization in general by patients with ACHD (not limited to the end of life) to be substantial, which is not surprising given the potential for cardiovascular complications, noncardiovascular comorbidities, and the need for special care during physiologic events (such as pregnancy).[10] In one study, Mackie and colleagues reported higher hospitalization rates compared to the general population, with more than half of patients visiting the emergency room or hospitalized during the study period. They also showed higher utilization in those with severe lesions.[24] In a study of single ventricle patients compared to age-matched patients without CHD, single ventricle patients aged 30-45 years had longer lengths of stay for noncardiac conditions and they incurred higher costs for treatment.[25] In the surgical realm, Bhatt and colleagues and Kim and colleagues reported that ACHD admissions may disproportionately consume resources and are associated with longer lengths of stay and higher inpatient mortality.[26,27]

Our findings support the assertion that the population of adults with congenital heart disease is one with great potential for the application of palliative and supportive care. As patients in this group survive longer and develop increased cardiac and noncardiac complexity, resource utilization will likely continue to expand and, as with cancer[28,29] and to some extent

HF.[30,31] Symptom management and advance care planning, both key components of palliative care, may help address current gaps in care. Care that helps patients live fully despite illness should be integrated early in the care of all patients with ACHD, alongside life-prolonging interventions,[32] to help patients face challenges that arise with serious illness and at the end of life.

This is the first study to examine resource utilization at the end of life for patients with ACHD, and to put the findings in context by comparison to two well-characterized patient groups. A major potential limitation to this study is generalizability, because this investigation was done at a single center on a small sample of patients with ACHD that was predominantly white and insured. Care for patients in our sample whose end-of-life care was provided in hospitals outside the healthcare system under study may not have been fully captured. Given the relatively small number of patients with moderate or greater severity ACHD, there may also be important differences that we were not powered to detect. In addition, HF and cancer diagnoses were not manually reviewed for accuracy, and there is the possibility of misclassification by ICD coding. Finally, methods of documenting advance care planning may vary by disease category and future studies should examine this possibility.

In conclusion, we characterized resource utilization patterns at the end of life for patients with ACHD, and compared them to patients with cancer and HF. As hypothesized, patients with ACHD were more likely to receive inpatient and ICU care in the last 30 days of life and more likely to die in the hospital than patients with cancer, adjusting for age and other demographic characteristics. However, patients with ACHD were less likely to receive care in an ICU in the last 30 days of life than patients with heart failure, counter to our hypothesis. Patients with ACHD represent a population in which opportunities exist to improve palliative and supportive care. Multi-center involvement in research studies and registries is needed to identify larger numbers of patients with ACHD for future study.

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Table 1. Characteristics of patients* who died during 2010-2015 with diagnoses of ACHD, heart failure, or cancer

	ACHD Group n=65	Cancer Group n = 10,784	Heart Failure Group n=3,809
Age at death in years, mean±SD	45±17	63±13	71±15
Sex, n (%)			
Male	40 (61.5)	5971 (55.4)	2267 (59.5)
Female	25 (38.5)	4813 (44.6)	1542 (40.5)
Race, n (%)			
White	46 (88.5)	7966 (84.5)	2748 (78.3)
Black	1 (1.9)	424 (4.5)	303 (8.6)
Asian/Pacific	3 (5.8)	673 (7.1)	264 (7.5)
Islander	1 (1.9)	146 (1.6)	72 (2.1)
Hispanic	1 (1.9)	217 (2.3)	123 (3.5)
Other			
Education, n (%)			
Some High School	7 (14.0)	764 (8.2)	511 (15.0)
High School Degree	11 (22.0)	2898 (31.1)	1266 (37.1)
Some college	25 (50.0)	2732 (29.3)	884 (25.9)
Bachelor's Degree	4 (8.0)	1785 (19.1)	487 (14.3)
Master/Doctorate	3 (6.0)	1147 (12.3)	265 (7.8)
Marital Status, n (%)			
Married	30 (57.7)	3899 (42.6)	2081 (59.7)
Not Married	22 (42.3)	5483 (58.4)	1404 (40.3)
Insurance Status			
Insured	61 (93.9)	10506 (97.4)	3721 (97.7)
Not Insured	4 (6.2)	278 (2.6)	88 (2.3)

*Proportion with missing data: race (11%), education (13%), marital status (12%)

Table 2. Hospital resource use and advance directive documentation at end-of-life in adults with congenital heart disease compared to adults with cancer

Hospital utilization and advance directive documentation	**ACHD Group n=65**	**Cancer Group n=10,784**	**Adjusted RR* (95% CI)**
Any inpatient admission in last 30 days of life, %	38.5 (n=25)	19.2 (n=2,065)	**1.57 (1.12, 2.18)**
Any ICU admission in last 30 days of life, %	38.5 (n=25)	9.7 (n=1,041)	**2.57 (1.83, 3.61)**
Any ER visit in last 30 days of life, %	3.1	3.5	0.70 (0.18, 2.74)
Any 30-day readmission in the last 90 days of life, %	12.3	9.0	0.84 (0.44, 1.60)
In-hospital death, %	63.8	30.1	**1.75 (1.43, 2.13)**
Presence of documentation of advance care planning+, %	41.5	28.4	**1.46 (1.09, 1.96)**
Length of stay among patients with an admission in the last 30 days of life	**ACHD Group, median (IQR)**	**Cancer Group, median (IQR)**	**Adjusted* mean difference (95% CI)**
Inpatient days, median (IQR)	10 (6,15)	8 (5,14)	0.81 (-1.86, 3.48)
ICU days, median (IQR)	8 (5,11)	5 (4,10)	0.53 (-2.20, 3.26)

*Adjusted for age, sex, race, education, marital status

+Defined as presence of a living will, healthcare directive, healthcare power of attorney, or Physicians Order for Life-sustaining Treatments

Table 3. Hospital resource use and advance directive documentation at end-of-life in adults with congenital heart disease compared to adults with heart failure

Hospital utilization and advance directive documentation	**ACHD Group n=65**	**HF Group n=3,809**	**Adjusted RR* (95% CI)**
Any inpatient admission in last 30 days of life, %	38.5 (n=25)	37.9 (n=1,443)	0.74 (0.54, 1.01)
Any ICU admission in last 30 days of life, %	38.5 (n=25)	32.7 (n=1,245)	**0.73 (0.64, 0.99)**
Any ER visit in last 30 days of life, %	3.1	3.3	0.78 (0.19, 3.11)
Any 30-day readmission in the last 90 days of life, %	12.3	10.9	0.63 (0.32, 1.23)
In-hospital death, %	63.8	55.8	0.86 (0.71, 1.04)
Presence of documentation of advance care planning, %	41.5	36.3	1.21 (0.90, 1.64)
Length of stay among patients with an admission in the last 30 days of life	**ACHD Group, median (IQR)**	**HF Group, median (IQR)**	**Adjusted* mean difference (95% CI)**
Inpatient days, median (IQR)	10 (6,15)	9 (6,16)	-0.82 (-3.77, 2.12)
ICU days, median (IQR)	8 (5,11)	7 (4,13)	-2.27 (-5.05, 0.51)

* Adjusted for age, sex, race, education, marital status

+Defined as presence of a living will, healthcare directive, healthcare power of attorney, or Physicians Order for Life-sustaining Treatments