ORIGINAL ARTICLE

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Hospital resource utilization and presence of advance directives at the end of life for adults with congenital heart disease

Jill M. Steiner MD[1] [iD] | James N. Kirkpatrick MD[1] | Susan R. Heckbert MD, PhD[2] |
James Sibley BS[3] | James A. Fausto MD[3] | Ruth A. Engelberg PhD[3] |
J. Randall Curtis MD, MPH[3]

[1]Division of Cardiology, School of Medicine, University of Washington, Seattle, Washington

[2]Department of Epidemiology, School of Public Health, University of Washington, Seattle, Washington

[3]Cambia Palliative Care Center of Excellence, University of Washington, Seattle, Washington

Correspondence
Jill M. Steiner, Division of Cardiology, School of Medicine, University of Washington, 1959 NE Pacific St., HSB AA522, Box 356422, Seattle, WA 98196.
Email: jills8@uw.edu

Abstract

Objective: Overall health care resource utilization by adults with congenital heart disease has increased dramatically in the past two decades, yet little is known about utilization patterns at the end of life. The objective of this study is to better understand the patterns and influences on end-of-life care intensity for adults with congenital heart disease.

Methods: We identified a sample of adults with congenital heart disease (n = 65), cancer (n = 10 784), or heart failure (n = 3809) who died between January 2010 and December 2015, cared for in one multi-hospital health care system. 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: Approximately 40% of adults with congenital heart disease experienced inpatient and intensive care unit (ICU) hospitalizations in the last 30 days of life; 64% died in the hospital. Compared to patients with cancer, patients with adult congenital heart disease (ACHD) were more likely to have inpatient (adjusted risk ratio 1.57; 95% CI 1.12-2.18) and ICU 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 heart failure (HF), patients with ACHD were less likely to have an ICU 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 compared to patients with cancer, notable for more hospitalizations and a higher likelihood of death in the hospital. This population represents an important opportunity for the application of palliative and supportive care.

KEYWORDS
adult congenital heart disease, advance care planning, palliative care, resource utilization

1 | 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]

Health care 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, information is limited regarding 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 and less documentation of advance care planning, and would be more likely to die in the hospital.

2 | METHODS

2.1 | 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 health care system in the Seattle area.[12] 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 health care system affiliation was adapted from the Dartmouth Atlas criteria, requiring at least one nonsurgical 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.[13] 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,[14] HF or non-hematologic cancer as defined in the Dartmouth

Atlas based on International Classification of Disease (ICD) codes.[13] 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.[15] Dual diagnosis of HF was not excluded in the ACHD group since HF is a leading cause of death for patients with ACHD.[16] The University of Washington Institutional Review Board approved the study.

2.2 | 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 readmission in the last 90 days of life and (5) location of death (hospital vs nonhospital). Finally, because of the possible link between advance directives and utilization,[17] we examined documentation of advance care planning that included any of the following: health care directive, living will, designated power of attorney for health care, 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.

2.3 | 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). All covariates were obtained from death certificates, with the exception of sex, which was obtained from the EHR.

2.4 | 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. All covariates were modeled as nominal categorical variables with the exception of age at death, which was numeric and continuous. 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

TABLE 1 Characteristics of patients[a] 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 = 3809
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 Islander	3 (5.8)	673 (7.1)	264 (7.5)
Hispanic	1 (1.9)	146 (1.6)	72 (2.1)
Other	1 (1.9)	217 (2.3)	123 (3.5)
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)

[a]Proportion with missing data: race (11%), education (13%), marital status (12%).

relative risks when outcomes are not rare.[18] 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, Texas: StataCorp LLC). Results were not materially different in analyses limited to patients with complete data (data not shown). Significance was set at $P < .05$.

3 | RESULTS

3.1 | Sample demographics for all disease groups

Ten thousand seven hundred eighty-four patients died with cancer, 3809 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

62%). 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.

3.2 | 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 per cent had documentation of an advance care planning document in the EHR 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; Table 2) and an ICU admission in the last 30 days of life (aRR 2.57; 95% CI 1.83-3.62). They were also significantly more likely to die in the hospital (aRR 1.75; 95% CI 1.43-2.13), and were more likely to have documentation of advance care planning (aRR 1.46; 95% CI 1.09-1.96). The differences for advance care planning were similar when we excluded designated power of attorney from the definition of advance care planning documentation. Other outcomes (Emergency Department visits,

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[a] (95% CI)
Any inpatient admission in last 30 d of life, %	38.5 (n = 25)	19.2 (n = 2,065)	**1.57 (1.12, 2.18)**
Any ICU admission in last 30 d of life, %	38.5 (n = 25)	9.7 (n = 1,041)	**2.57 (1.83, 3.61)**
Any ER visit in last 30 d of life, %	3.1	3.5	0.70 (0.18, 2.74)
Any 30-day readmission in the last 90 d 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,[b] %	41.5	28.4	**1.46 (1.09, 1.96)**
Length of stay among patients with an admission in the last 30 d of life	**ACHD group, median (IQR)**	**Cancer group, median (IQR)**	**Adjusted[a] 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)

[a]Adjusted for age, sex, race, education, marital status.
[b]Defined as presence of a living will, health care directive, health care power of attorney, or Physicians Order for Life-sustaining Treatments.

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.

4 | 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 more patients have been able to die at home, if in line with their wishes.[19] 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.[20] Our findings suggest opportunities to improve these processes among patients with ACHD.

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[a] (95% CI)
Any inpatient admission in last 30 d of life, %	38.5 (n = 25)	37.9 (n = 1,443)	0.74 (0.54, 1.01)
Any ICU admission in last 30 d of life, %	38.5 (n = 25)	32.7 (n = 1,245)	**0.73 (0.64, 0.99)**
Any ER visit in last 30 d of life, %	3.1	3.3	0.78 (0.19, 3.11)
Any 30-d readmission in the last 90 d 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,[b] %	41.5	36.3	1.21 (0.90, 1.64)
Length of stay among patients with an admission in the last 30 d of life	**ACHD group, median (IQR)**	**HF group, median (IQR)**	**Adjusted[a] 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)

[a]Adjusted for age, sex, race, education, marital status.
[b]Defined as presence of a living will, health care directive, health care power of attorney, or Physicians Order for Life-sustaining Treatments.

Palliative care principles have begun to expand to other diseases, including HF,[21] although the evidence base for their application is not as robust as for cancer. 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.[22] Our findings regarding fewer admissions and in-hospital deaths for patients with cancer as compared to patients with ACHD may reflect a limitation in the implementation of palliative care approaches for ACHD by comparison to cancer. 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. In addition, acute or decompensated HF, which often leads to ICU admission, accounts for less than half of ACHD deaths.[16] Patients with ACHD who die suddenly, such as from arrhythmia or hemorrhage, may not have the opportunity for an ICU stay.

Interestingly, the prevalence of advance care planning documentation among patients with ACHD was much higher than what was found by Tobler and colleagues in 2011,[23] and significantly higher when compared to patients with cancer in our study. This finding could represent a heightened awareness of the importance of advance care planning at our institution. However, it seems more likely that this finding reflects the fact that efforts surrounding documentation of advance care planning are often more concentrated in hospitalized patients compared to those in the outpatient setting.[24] This high proportion could also reflect guardianship or power of attorney appointments carried over from childhood or related to cognitive limitations, which are common in congenital disease. However, this relationship was unchanged when we excluded documentation of designated power of attorney from advance care planning documentation. The proportion of patients with ACHD who have advance care planning discussions, and what these discussions actually entail, likely varies widely based on differences in cultural norms and resource availability, and this topic deserves more study.

Studies have shown health care resource utilization in general by patients with ACHD throughout the lifespan 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.[25] In a study of patients with single ventricles compared to age-matched patients without CHD, patients with single ventricles aged 30-45 years had longer lengths of stay for noncardiac conditions and they incurred higher costs for treatment.[26] 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.[27,28] In one study of patients with ACHD who died in the hospital, 67% died in the ICU, with 44% mechanically ventilated and 15% undergoing renal replacement therapy at the time of death.[23]

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, as with cancer[29,30] and to some extent HF.[31,32] Symptom management and advance care planning, both key components of palliative care, may help address current gaps in care. Palliative care that helps patients live fully despite illness should be integrated early in the care of all patients with ACHD, alongside life-prolonging interventions,[33] to help patients face challenges that arise with serious illness and at the end of life.

This is the first study to compare hospital resource utilization patterns for patients with ACHD to other patient groups and adds to the literature on health care utilization at the end of life for this group. 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. Data regarding other medical and social history that may have allowed for finer interpretation of results (such as prior transplant assessment, presence of other organ disease, circumstances surrounding death, or whether patients had children) were not included in this dataset, and future studies should consider examination of these factors. Care for patients in our sample whose end-of-life care was provided in hospitals outside the health care 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. Multicenter involvement in research studies and registries is needed to identify larger numbers of patients with ACHD for future study.

CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

Jill M. Steiner, MD: Concept/Design, Data analysis/interpretation, Drafting of article, Revision and approval of the article

James N. Kirkpatrick, MD: Concept/Design, Revision and approval of the article

Susan R. Heckbert, MD, PhD: Concept/Design, Data analysis/interpretation, Revision and approval of the article

James Sibley: Data acquisition, Revision and approval of the article.

James A. Fausto, MD: Revision and approval of the article

Ruth A. Engelberg, PhD: Concept/Design, Revision and approval of the article

J. Randall Curtis, MD, MPH: Concept/Design, Funding secured by, Revision and approval of the article

ORCID

Jill M. Steiner 🆔 http://orcid.org/0000-0002-1333-6836

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