ORIGINAL RESEARCH

Access and Outcomes Among Hypertrophic Cardiomyopathy Patients in a Large Integrated Health System

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***Background*—**Hypertrophic cardiomyopathy (HCM) is the most common inherited cardiomyopathy. Current guidelines endorse management in expert centers, but patient socioeconomic status can affect access to specialty care. The effect of socioeconomic status and specialty care access on HCM outcomes has not been examined.

***Methods and Results*—**We conducted a retrospective cohort study that examined outcomes among HCM patients receiving care in the Yale New Haven Health System between June 2011 and December 2017. Patients were assigned to lower or higher socioeconomic status groups (LSES/HSES) based on medical insurance provider and to receivers of specialty care (SC) at Yale's Inherited Cardiomyopathy clinic or general cardiology care (GC). The primary outcome was all-cause death, and the secondary outcome was all-cause hospitalization. We identified 953 HCM patients; 820 (86%) were HSES and 133 (14%) were LSES. Forty-three (4.5%) patients died from cardiac and noncardiac causes. LSES patients within the general cardiology care cohort had significantly higher all-cause mortality compared with HSES patients (adjusted hazard ratio, [95% CI]=10.06 [4.38–23.09]; $P<0.001$). This was not noted in the specialty care cohort (adjusted hazard ratio, [95% CI]=2.87 [0.56–14.73]; $P=0.21$). The moderator effect of specialty care on mortality difference between LSES versus HSES, however, did not reach statistical significance (hazard ratio, 0.29 [0.05–1.77]; $P=0.18$). Specialist care was associated with increased hospitalization (adjusted hazard ratio, [95% CI]=3.28 [1.11–9.73]; $P=0.03$ for LSES; 2.19 [1.40–3.40]; $P=0.001$ for HSES).

***Conclusions*—**Socioeconomically vulnerable HCM patients had higher mortality when not referred to specialty care. Further study is needed to understand the underlying causes. **(*J Am Heart Assoc*. 2020;9:e014095. DOI: 10.1161/JAHA.119.014095.)**

Key Words: hypertrophic cardiomyopathy • socioeconomic disadvantage • health outcomes • cardiomyopathy specialty care

Hypertrophic cardiomyopathy (HCM) is the most common inherited cardiomyopathy, affecting >600 000 people in the United States alone.[1] It is morphologically characterized by left ventricular hypertrophy in the absence of increased afterload, and pathologically characterized by myocyte hypertrophy and disarray, as well as interstitial fibrosis and abnormal myocardial fiber twitch and relaxation times.[2] Clinically, the disease causes heart failure (HF), atrial fibrillation, and sudden cardiac death, with age-adjusted mortality of 1.5 to 3.0 times that of the general population.[3]

Prognosis is affected by several risk factors, including age of symptom onset, genotypic status, family history of sudden death, and pathological features (wall thickness, fibrosis).[3] Current society guidelines emphasize the importance of team-based comprehensive specialty care (SC) for optimal treatment of HCM.[4] Recent work has demonstrated differences in resource utilization between specialty and nonspecialty centers.[5] Socioeconomic status (SES) is known to be an important driver of healthcare access, outcomes, and resource utilization[6–8] and may also critically influence access to SC.[9] The combined effect of team-based SC access and SES on HCM outcomes has not been previously examined.

The Yale New Haven Health System (YNHHS) is a large multihospital medical system in southern New England serving ≈1.5 million patients. We compared outcomes for HCM patients of different socioeconomic background, receiving care in either a team-based specialty HCM care center or followed by general cardiologists. The purpose of this study

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Clinical Perspective

What Is New?

- Socioeconomically disadvantaged patients with hypertrophic cardiomyopathy had increased mortality when not involved in care at a specialty center.
- Specialty care of hypertrophic cardiomyopathy patients leads to more-consistent guideline-directed testing and treatments.

What Are the Clinical Implications?

- Patients with hypertrophic cardiomyopathy should be considered for referral to specialty care, especially among those who are socioeconomically disadvantaged.
- Further study of specialty care should be undertaken to better assess for the drivers of patient benefit and evaluate for improved implementation strategies.

was to observationally assess for differences in outcomes and guideline adherence.

Methods

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Study Design and Sample

This was a retrospective cohort study that included all patients with a diagnosis of HCM receiving care in the YNHHS anytime between June 2011 and December 2017. This included patients cared for by the Yale Inherited Cardiomyopathy program, the only specialty HCM care program in the state of Connecticut. This program offers a team-based holistic approach to diagnosis, risk stratification, and treatment of HCM patients, including psychosocial support from a dedicated social worker.

Eligible patients were identified by querying the YNHHS' electronic medical record (EMR) system (Epic Systems Corp., Verona, WI). Inclusion criteria was age ≥18 years, the keywords "hypertrophic cardiomyopathy" (including any variations such as "hypertrophic obstructive cardiomyopathy" or "apical variant hypertrophic cardiomyopathy") or nonstandard/disused HCM diagnostic nomenclature ("idiopathic hypertrophic subaortic stenosis") on the patient's medical problem list as captured on EMR, and at least 1 documented cardiology visit in the YNHHS. Exclusion criteria were the existence of diagnostic confounders for HCM (uncontrolled hypertension, moderate or severe aortic stenosis, subaortic membrane, cardiac amyloid, myopathy, or storage disease).

EMR query captured demographics (eg, age, sex, race/ethnicity, and health insurance), medical history, surgeries, cardiology visits, and HCM-related medical resource utilization (echocardiography, cardiac magnetic resonance imaging [MRI], Holter monitoring, and cardiopulmonary exercise tests). Eligible subjects were designated to 1 of 2 groups, using their medical insurance as a proxy for income/SES. Patients with Medicaid/no insurance were designated to the lower socioeconomic group (LSES), whereas patients with any other insurance were designated to the higher socioeconomic group (HSES). In addition, patients were categorized depending on having access to SC or being cared for by general cardiology practitioners alone (GC). Access to SC was defined as at least 1 visit to Yale's Inherited Cardiomyopathy program.

The primary outcome of the study was death from all causes. Morbidity was examined by tracking hospitalizations for any cause after the first visit to a cardiology practice. For patients who met the primary outcome, we conducted a detailed chart review to determine cause of death.

Statistical Analyses

We describe patient characteristics as mean and SD for continuous variables and as frequency and percent for categorical variables. Student *t* tests, chi-square tests, or Fisher's exact tests were used to compare characteristics and clinical outcomes between groups, as appropriate. A Cox proportional hazards model was built to examine the effect of SES on all-cause mortality and hospitalization. Models were adjusted for potential confounders, including age, sex, and race, and comorbidities, including coronary artery disease, diabetes mellitus, and hypertension. Patients were followed until death or the last day of follow-up in our study (December 31, 2017). The moderation effect of SC was determined by including an interaction term between socioeconomic group and SC/GC in the model. All analyses were performed using SAS software (version 9.4; SAS Institute Inc, Cary, NC), with 2-sided statistical tests and an alpha of 0.05. The study protocol was approved by the Yale Institutional Review Board and granted a waiver for informed consent.

Results

Study Cohort Characteristics

A total of 1062 patients within the YNHHS were identified with the diagnosis of HCM. One hundred nine patients were excluded either because they received cardiology care outside the YNHHS (EMR failing to capture at least 1 in-system

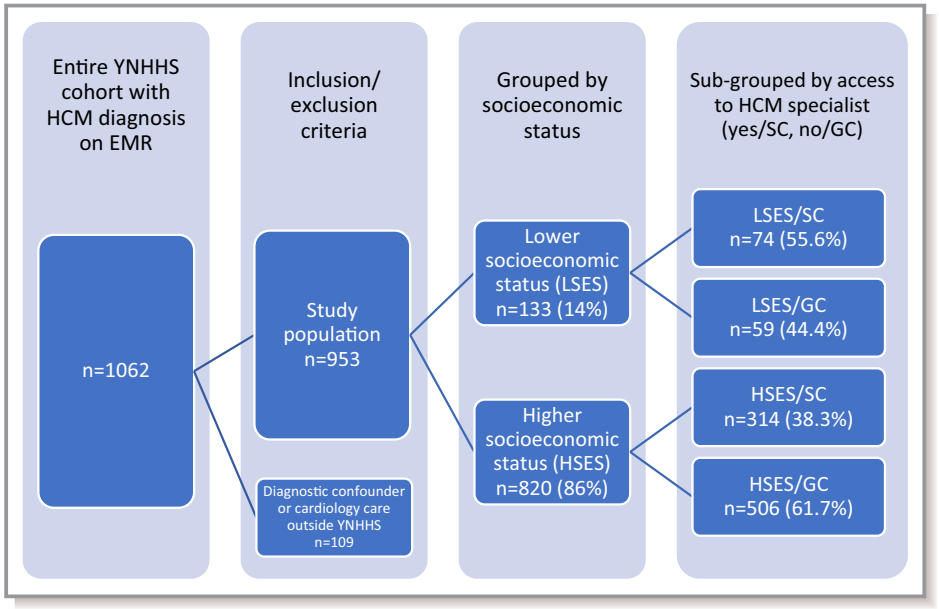

Figure 1. Breakdown of enrolled subjects. EMR indicates electronic medical record; GC, general cardiology care; HCM, hypertrophic cardiomyopathy; HSES indicates high socioeconomic status; LSES, low socioeconomic status; SC, specialty care; YNHHS, Yale New Haven Health System.

cardiology clinic visit) or were identified as also having a possible diagnostic confounder for HCM, leaving 953 subjects available for analysis (Figure 1). Mean age was 58.6±18.6 years. Fifty-eight percent were males, with 75% being white, 12% black, 1% Asian, and 12% of other/unknown race. Age-related comorbidities were common, with 12% of study patients having a history of coronary artery disease, 14% of diabetes mellitus, and 55% of hypertension (Table 1).

Table 1. Characteristics of Hypertrophic Cardiomyopathy Populations: Patient Groups by Socioeconomic Status and Access to Specialty Care

	Higher Socioeconomic Status (HSES)			Lower Socioeconomic Status (LSES)			*P* Value (between totals)
	SC	GC	Total	SC	GC	Total	
n (%)	314 (38)	506 (62)	820	74 (56)	59 (44)	133	
Age, y (SD)	54.67 (15.6)	65.2 (17.3)	61.1 (17.4)*	45.7 (15.5)	40.2 (21.0)	43.3 (18.3)	<0.001*
Sex, n (%)							
Male	199 (63)	273 (54)	472 (58)*	49 (66)	33 (45)	82 (62)	<0.37*
Female	115 (37)	223 (46)	348 (42)*	25 (34)	26 (55)	51 (38)	
Race, n (%)							
White	251 (80)	392 (77)	643 (78)	38 (51)	29 (49)	67 (50)	<0.001*
Black	31 (10)	48 (10)	79 (10)	20 (27)	16 (27)	36 (28)	
Asian	3 (1)	5 (1)	8 (1)	2 (3)	1 (2)	3 (2)	
Other/unknown	29 (9)	61 (12)	90 (11)	14 (19)	13 (22)	27 (20)	
Comorbidities, n (%)							
CAD	33 (11)	75 (15)	108 (13)	3 (4)	3 (5)	6 (5)	0.004*
DM	31 (10)	87 (17)	118 (14)*	11 (15)	6 (10)	17 (13)	0.62
Hypertension	159 (51)	313 (62)	472 (56)*	34 (46)	25 (42)	59 (44)	0.005*

CAD indicates coronary artery disease; DM, diabetes mellitus; GC, general cardiology care; SC, specialty care.
*Denotes statistically significant differences ($P<0.05$) between SC and GC within HSES and LSES groups.

Regarding SES, 133 patients (14%) had either Medicaid as their medical insurance or were uninsured and were thus assigned to the LSES group, whereas the rest (n=820; 86%) were assigned to the HSES group. Seventy-four LSES patients (55.6%) and 314 HSES patients (38.3%) received care at the specialty center (SC). The remaining 59 (44.4%) LSES and 506 (61.7%) HSES patients received GC care only.

Primary Outcome (All-Cause Mortality)

During the follow-up period (mean 3.6±1.8 years), 43 (4.5%) patients died from cardiac and noncardiac causes (Table 2). Specifically, LSES patients within the GC cohort had significantly higher all-cause mortality compared with HSES patients after adjustment for age, sex, race, and comorbidities (adjusted hazard ratio, 10.06 [4.38–23.09]; $P<0.001$; Table 3 and Figure 2A). This difference in mortality between LSES and HSES was not noted in the SC cohort (adjusted hazard ratio=2.87 [0.56–14.73]; $P=0.21$; Table 3 and Figure 2B). The moderator effect of SC on the mortality difference of LSES versus HSES, however, did not reach statistical significance (adjusted hazard ratio, 0.29 [0.05–1.77]; $P=0.18$), suggesting that, in our cohort, access to SC alone was not the only driver of better outcomes for LSES patients.

Table 2. Characteristics of Hypertrophic Cardiomyopathy Patients Who Died During the Study Period

	LSES		HSES	
	Specialist Care	General Cardiology	Specialist Care	General Cardiology
Total deaths, %	2 (3%)	8 (14%)	6 (2%)	27 (5%)
Primary cardiac death, %	1 (50%)	4 (50%)	2 (33%)	5 (19%)
Sepsis/infection, %	0	1 (12%)	1 (17%)	3 (11%)
Cancer, %	0	1 (12%)	0	2 (7%)
Stroke, %	0	1 (12%)	0	3 (11%)
Unknown, %	1 (50%)	1 (12%)	3 (50%)	14 (52%)
Average age at death, y (SD)	69 (1)	53 (19)	73 (9)	73 (16)
Ethnicity, %				
White	2 (100%)	8 (100%)	4 (67%)	24 (89%)
Black	0	0	0 (0%)	1 (4%)
Other	0	0	2 (33%)	2 (7%)
Male sex, %	1 (50%)	5 (63%)	3 (50%)	9 (33%)
Atrial fibrillation, %	1 (50%)	5 (63%)	3 (50%)	12 (44%)

HSES indicates high socioeconomic status; LSES, low socioeconomic status.

Table 3. Cox Regression Adjusting For Age, Sex, Race, Diabetes Mellitus, and Coronary Artery Disease to Examine Moderation of Specialist Care on the Effect of Socioeconomic Status on Mortality

	HR (95% CI)	*P* Value
Specialist care cohort		
LSES	2.87 (0.56–14.73)	0.21
HSES	1.00	
General cardiology cohort		
LSES	10.06 (4.38–23.09)	<0.001*
HSES	1.00	
Interaction (moderation), HRR	0.29 (0.05–1.77)	0.18
Age, y	1.06 (2.81–2.97)	<0.001*
Male	0.79 (1.51–4.60)	0.49
Race		
Black (vs white)	0.16 (1.02–3.24)	0.071
Other (vs white)	0.40 (1.10–5.57)	0.22
Unknown (vs white)	1.19 (1.32–156.65)	0.81
DM	2.30 (3.05–116.28)	0.024*
CAD	1.51 (2.02–25.53)	0.29

CAD indicates coronary artery disease; DM, diabetes mellitus; HR, hazard ratio; HRR, Hazard Ratio's Ratio; HSES, high socioeconomic status; LSES, low socioeconomic status.
*Reached statistical significance.

Causes of Death

For deceased patients with documented causes of death, cardiovascular death (sudden cardiac death or fatal HF) was most frequent in all groups regardless of SES or access to SC. Notably, the LSES/GC subgroup had a substantially lower average age at death of 53 years, compared with all other groups, which had an average age of death between 69 and 73 years (Table 2).

Hospitalizations and Resource Utilization

During follow-up, 112 HCM patients were hospitalized for any cause. Time-to-event analysis showed significantly higher risk for hospitalization during follow-up for both LSES and HSES patients receiving SC (adjusted hazard ratio, 3.28 [1.11–9.73], $P=0.03$ for LSES; 2.19 (1.40–3.40), $P=0.001$ for HSES; Table 4). The moderator effect of SC on rate of hospitalization of LSES versus HSES, however, was not significant, again suggesting other factors at play.

When focusing on the most common hospitalization causes for HCM patients (atrial fibrillation, syncope, and HF), there was no difference between LSES/HSES groups for atrial fibrillation or syncope (1.5% versus 2.8% and 2.3% versus 0.7%, respectively), but LSES patients were more likely

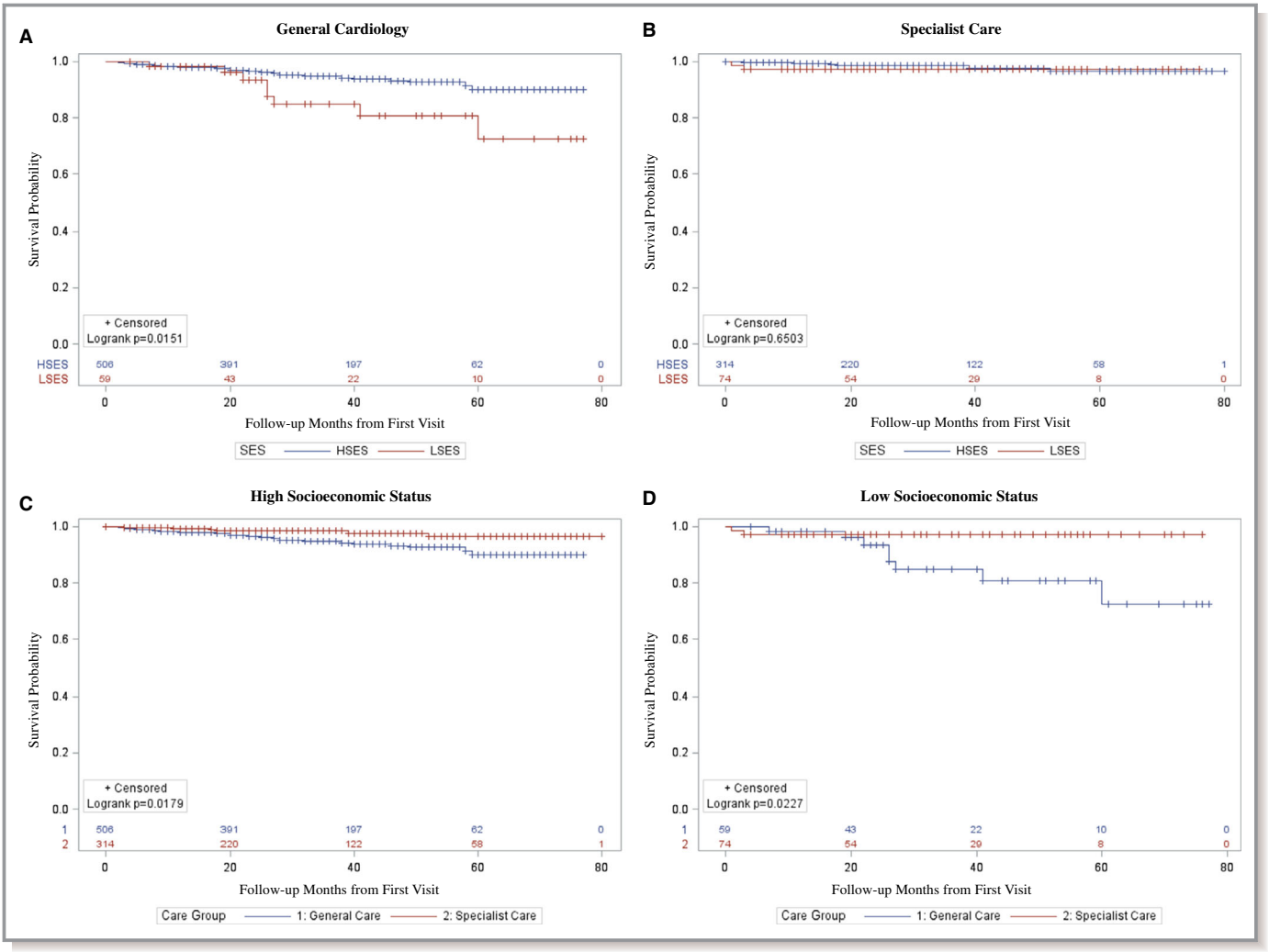

Figure 2. Kaplan–Meier curve showing unadjusted mortality differences between subgroups (LSES, HSES, SC, and GC). **A**, Survival among all HCM patients within general cardiology care comparing survival of those within HSES and LSES. **B**, Survival among all HCM patients within specialty care comparing survival of those within HSES and LSES. GC indicates general cardiology care; HCM, hypertrophic cardiomyopathy; SES, socioeconomic status; HSES, high socioeconomic status; LSES, low socioeconomic status; SC, specialty care.

to be hospitalized for HF (4.5% versus 0.9%; $P<0.001$). Thirteen patients were hospitalized with HF, of whom 12 were in the SC subgroup. A focused chart review of HF hospitalizations showed that, regardless of SES, most HF exacerbations requiring admission occurred while already under SC (in 8 of the 13 patients). Notably, of the 5 patients with HF hospitalizations while under GC care, 4 were subsequently referred to the HCM center (within a short period of time) and thus became part of the SC cohort in our study.

Clinic visits and resource utilization data are presented in Figure 3. LSES patients had fewer clinic visits and were more likely to undergo septal reduction therapy, specifically myectomy, compared with HSES patients (6.36±6.61 versus 7.71±8.62 for visits, 9 [6.8%] versus 26 [3.2%] for myectomies) without significant differences in alcohol septal ablation. There were no significant differences between LSES and HSES patient groups regarding ECGs, echo, Holter, cardiac MRI, cardiopulmonary stress tests, and implantable cardiac defibrillators.

Advanced testing and interventions were not associated with SES, but rather with access to SC. Septal reduction therapies (myectomy and alcohol ablation) and cardiopulmonary stress tests for both LSES and HSES patients were almost exclusively performed at group S (41 septal reduction therapies and 62 cardiopulmonary exercise tests in SC patients versus 4 and 0, respectively, in GC). Furthermore, SC patients (in both LSES and HSES groups) were more likely to have cardiac MRIs (for LSES: 38 [51.4%] versus 13 [22.0%]; $P<0.001$; for HSES: 198 [63.1%] versus 59 [11.7%]; $P<0.001$). An exception in similar findings for patients of different SES status was observed for implantable cardiac defibrillator implantation. Implantation was more frequent for HSES

Table 4. Both LSES and HSES Patients Were at Higher Risk of Being Hospitalized If They Received Specialty Care

	HR (95% CI)	*P* Value
LSES		
Specialist care	3.28 (1.11–9.73)	0.032*
General cardiology	1	
HSES		
Specialist care	2.19 (1.40–3.40)	0.001*
General cardiology	1	
Interaction (moderation), HRR	1.50 (0.47–4.85)	0.50
Age, y	1.02 (2.73–2.79)	0.014*
Male	0.66 (1.56–2.68)	0.042
Race		
Black (vs white)	0.99 (1.69–6.54)	0.98
Other (vs white)	1.38 (1.89–19.47)	0.41
Unknown (vs white)	1.12 (1.36–55.15)	0.87
Ethnicity		
Hispanic (vs non-Hispanic)	1.16 (1.68–13.71)	0.71
Unknown (vs non-Hispanic)	0.12 (1.02–2.10)	0.023*
DM	1.08 (1.86–6.48)	0.79
CAD	1.75 (2.82–19.38)	0.036*

CAD indicates coronary artery disease; DM, diabetes mellitus; HR, hazard ratio; HRR, Hazard Ratio's Ratio; HSES, high socioeconomic status; LSES, low socioeconomic status.
*Reached statistical significance.

patients in the SC versus GC groups (48 [15.3%] versus 33 [6.5%]; $P<0.001$), whereas no difference was found for LSES patients (7 [9.5%] versus 5 [8.5%]; $P=0.68$).

Discussion

We found that HCM patients with a background of lower SES suffered higher all-cause mortality compared with patients with a higher SES when treated exclusively in general cardiology clinics. We did not find a similar mortality difference for patients referred to a specialized HCM care team, with comparable survival rate between different SES. These differences in mortality could not be explained by differences in age, sex, race, or comorbidities of referred patients.

Outcome Disparities

Differences in outcomes associated with SES is an almost universal finding in medical care.[6–8,10,11] Specifically, worse outcomes have been persistently observed for those with lower SES. We found this also to be the case for LSES HCM patients without access to SC, although in our cohort the moderation effect of specialist care on mortality did not reach statistical significance. Regardless of effect size, SC influence on outcomes is likely to be driven, at least in part, by a team-based approach to care. In this approach, care of HCM patients does not rest on the shoulders of a single physician, who may or may not have experience in HCM, but more closely resembles the Heart Team paradigm promoted by society guidelines in other areas of cardiovascular medicine.[12–14] Supporting this, we and others have found substantive differences in resource utilization for HCM patients prereferral and postreferral to an expert center,[5] as well as between expert and nonexpert centers overall.[15] Case review by an "HCM team," that consists of an in-house network of clinical cardiologists, electrophysiologists, cardiac surgeons, genetic counselors, and social workers, is the care model most often used by centers specializing in HCM. These common program features may address some of the drivers of the poorer outcomes observed among LSES populations described in literature, including reduced access to care, lower medical compliance, and a higher prevalence of cardiovascular risk factors and other comorbidities.[7,8,10,16]

Our study assigned patients to SC for any single referral visit to that clinic. Surprisingly, a great proportion of LSES patients (55.6%) were referred for SC than HSES patients (38.3%). We also noted that among HCM patients experiencing hospitalization, many referrals to SC occurred immediately following the hospitalization event, and most of the hospitalizations occurred in the LSES group. It is possible that LSES patients were sicker or more likely to have a sentinel event that prompted referral to SC. Given that more-substantial barriers to access are typically noted among LSES patient populations, it may be that there is a lack of perceived need for specialist care in stable patients, especially if incentive structures make referral of some patients (HSES) less attractive. A larger sample size and longer duration of follow-up, potentially in the setting of a prospective longitudinal study, are needed to further explore these issues.

Care Strategies and Compliance With Guidelines

Current society HCM guidelines propose routine annual clinic visits with transthoracic echo and/or 24-hour ECG monitoring every 1 to 2 years, along with cardiac MRI, stress echo, and/or cardiopulmonary exercise tests at first contact.[4] In our study, access to specialty care influenced availability and frequency of guideline directed clinical testing and procedures. Although patients in both the SC and GC groups where, on average, within the recommended time frame for clinic visits and transthoracic echocardiogram exams, SC group patients were more likely to undergo cardiac MRI, stress echo, or cardiopulmonary exercise tests. In addition, the majority of hospitalizations and implantable cardiac defibrillator

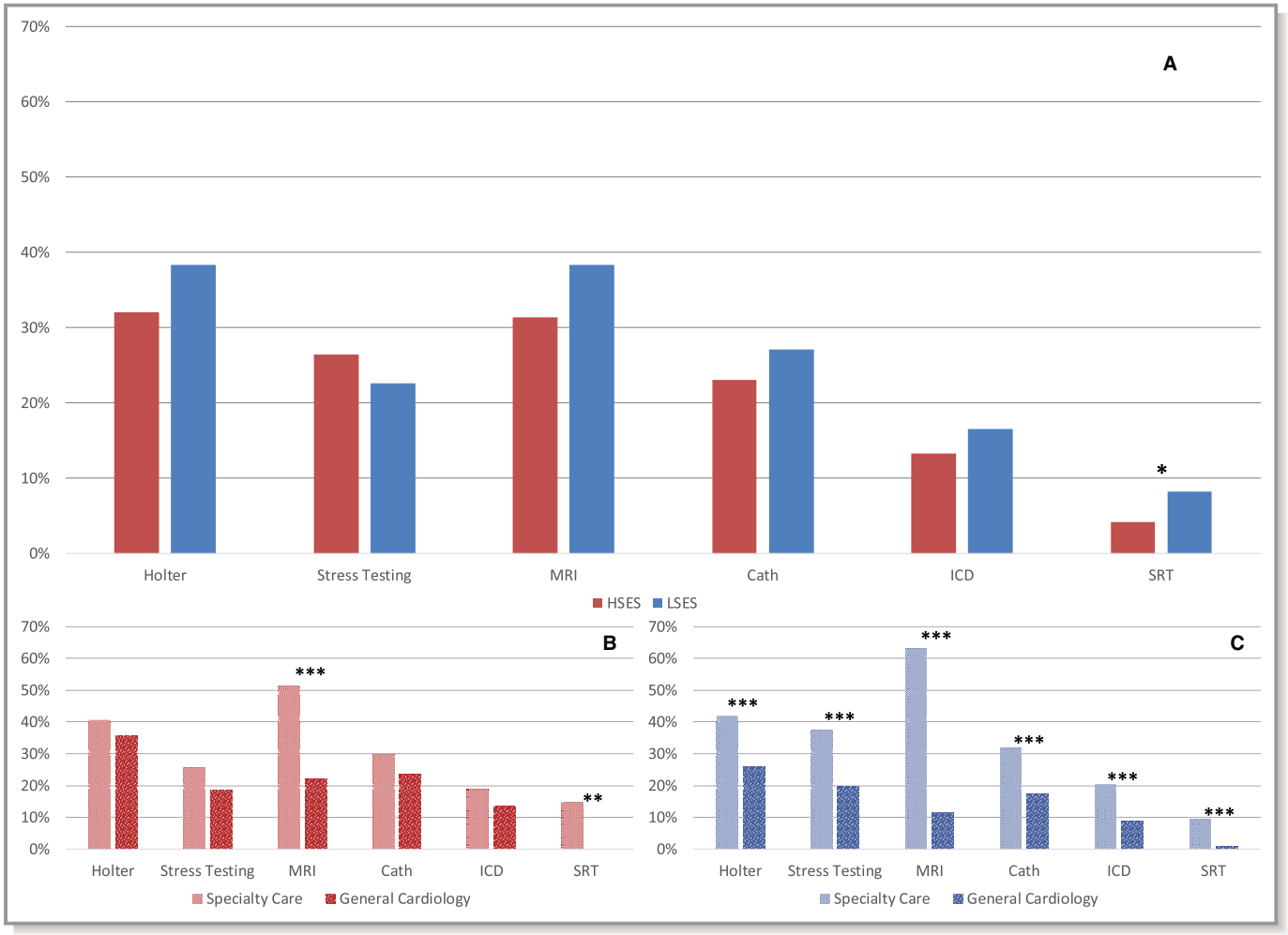

Figure 3. Comparison of guideline recommended testing for hypertrophic cardiomyopathy (HCM) comparing high and low socioeconomic groups as well as specialty care and general cardiology subgroups. **A**, Comparison of HSES and LSES groups. **B**, Comparison of HCM patients with LSES between specialty care and general cardiology subgroups. **C**, Comparison of HCM patients with HSES between specialty care and general cardiology subgroups. *P<0.05; **P<0.01; ***P<0.001. Septal reduction therapy includes alcohol ablation procedures and myectomies. Cath indicates cardiac catheterization; HSES, high socioeconomic status; ICD, implantable cardiac defibrillator; LSES, low socioeconomic status; MRI, magnetic resonance imaging; SRT, septal reduction therapy.

implantations, and the vast majority of septal reduction procedures, took place in SC group patients (Figure 3).

with Medicare as their primary insurance transitioned from Medicaid or none.

Limitations of the Study

This single-health-system retrospective review took advantage of the concurrent implementation of a broad-based, system-wide EMR and the development of a highly structured disease specialty program embedded within that system. Although this allowed for identification and comparison between separate treatment groups within a single health system, the study was limited by the length and breadth of EMR data and the retrospective nature of the review. Additionally, it remains possible that some older patients

Conclusions

We found that socioeconomically vulnerable HCM patients had higher mortality when not involved in SC. Additionally, SC provided more-consistent guideline-driven testing and treatment strategies. Although a causative link cannot be established, our findings do suggest that team-based, guideline-driven care may be particularly important for at-risk populations with implications for healthcare policy. Given the cost of SC derived from multiprovider involvement and aggressive testing and treatment strategies, further study would be

useful to assess the drivers of benefit and interrogate implementation strategies supporting broader access.

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Disclosures

None.

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