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BARRIERS TO HEALTHCARE ACCESS AND PATIENT OUTCOMES AFTER A HOSPITALIZATION FOR AN ACUTE CORONARY SYNDROME AND OTHER ACUTE CONDITIONS

A Dissertation Presented

By

NATHANIEL A. K. ERSKINE

Submitted to the Faculty of the
University of Massachusetts Graduate School of Biomedical Sciences, Worcester
in partial fulfillment of the requirements for the degree of

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CLINICAL AND POPULATION HEALTH RESEARCH

BARRIERS TO HEALTHCARE ACCESS AND PATIENT OUTCOMES AFTER A HOSPITALIZATION FOR AN ACUTE CORONARY SYNDROME AND OTHER ACUTE CONDITIONS

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This work was undertaken in the Graduate School of Biomedical Sciences

Clinical and Population Health Research Program

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ABSTRACT

Background: Guideline-concordant therapies for survivors of an acute coronary syndrome (ACS) hospitalization require healthcare access, something that millions of Americans lack.

Methods and Results: Using data from a prospective cohort study of over 2,000 survivors of a hospitalization for an ACS in central Massachusetts and Georgia from 2011 to 2013, the first two aims of this thesis sought to identify the post-discharge consequences for survival and health status of having: 1) financial barriers to healthcare, 2) no usual source of care, and 3) transportation barriers. We found that patients lacking a usual source of care and having a transportation barrier were more likely to have died within two years following hospital discharge compared to those without such barriers. Also, patients with financial barriers to healthcare were more likely to experience clinically meaningful declines in physical and mental health-related quality of life over the six months after hospital discharge. The third aim sought to better understand factors influencing the success of care transitions home after an unplanned hospitalization through a qualitative study of 22 patients. Participants described how adequate healthcare access, particularly having insurance and transportation to clinical appointments, facilitated the receipt of follow-up care and adherence to treatments.

Conclusions: Limitations in healthcare access may contribute to poorer survival, health-related quality of life, and survival. Additional research is needed to identify interventions to improve healthcare access and test whether improved access leads to better patient outcomes.

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LIST OF ABBREVIATIONS

ACA – Affordable Care Act
ACS – Acute Coronary Syndrome
CHD – Coronary Heart Disease
HRQOL – Health-Related Quality of Life
MCS – Mental Component Score
PCS – Physical Component Score
SF-36 – Short Form-36 Health Survey
TRACE-CORE – Transitions, Risks, and Action in Coronary Events - Center for Outcomes Research and Education

PREFACE

CHAPTER II of this dissertation is under preparation for publication as:

> Erskine, NA, et al. Barriers to healthcare access and long-term survival after hospital discharge for an acute coronary syndrome

CHAPTER III of this dissertation is under preparation for publication as:

> Erskine, NA, et al. Barriers to healthcare access and declines in health-related quality of life among hospital survivors of an acute coronary syndrome

CHAPTER IV of this dissertation has been accepted for publication as:

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CHAPTER I: INTRODUCTION

The acute coronary syndromes (ACS), consisting of acute myocardial infarction (AMI) and unstable angina (UA), continue to be a leading cause of morbidity and mortality in the US.[1] Patients who survive a hospitalization for an ACS are at an increased risk for complications that may result in a subsequent hospital admission or death.[2-4] Although this risk is substantial,[5] contemporary patients discharged from the hospital after an ACS have better chances of surviving and thriving than those in the past due, in part, to decades of progress in the understanding and treatment of coronary disease.[6,7]

Since the early twentieth century, treatment for an ACS has advanced from long-term bedrest to sophisticated reperfusion interventions and pharmacotherapies.[6] In the 1950s, the development of coronary angiography permitted physicians to identify the occlusive, atherosclerotic lesions precipitating an ACS.[6] This led to the development of techniques to restore coronary blood flow including coronary artery bypass grafting (1960s), thrombolytic therapy (1970s), balloon angioplasty (1970s), and intraluminal stenting (1980s).[6,8] Better understanding of cardiac physiology led to medical therapies to increase myocardial perfusion and reduce the oxygen demands of the heart. These treatments helped to further decrease in-hospital and post-discharge mortality after an ACS.[6] Cohort studies, such as the original and offspring Framingham Heart Studies, provided insights that would lead to the development of additional medical and lifestyle interventions to improve secondary prevention of coronary disease.[9,10] Never before have clinicians possessed so many effective means to treat patients with an ACS.

Delivering optimal therapy to patients both during and after a hospitalization for an ACS, however, is costly. Estimates of the average cost for a hospitalization for an ACS range from $9,000 to $64,000.[11] Pharmacotherapy for a patient's underlying coronary heart disease during the year after experiencing an ACS can average $3,000.[11] A full course of cardiac rehabilitation, which can greatly reduce the occurrence of cardiovascular disease-related mortality, can also cost thousands of dollars and impose substantial out-of-pocket costs on patients.[12,13] In addition to having means to pay for healthcare, patients may require additional resources such as having transportation to appointments and a usual source of care to coordinate treatment.[14,15] Successful treatment of an ACS and underlying heart disease may heavily depend on a patient's healthcare access.

What happens to patients with poor healthcare access following an ACS? Answering this requires a definition of healthcare access. The Institute of Medicine defines healthcare access as "the degree to which individuals and groups are able to obtain needed services from the medical care system."[16] Levesque and colleagues have more expansively defined it as "the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use healthcare services and to actually have the need for services fulfilled."[17] These definitions suggest that a wide range of factors affect access. A variety of frameworks describing healthcare access differ on the actual dimensions of healthcare access, particularly with regards to the degree to which healthcare access reflects characteristics of healthcare organizations as opposed to the population seeking these services.[17,18] In a contemporary systematic synthesis, Levesque and colleagues proposed a framework of healthcare access that incorporated most, if not all, of the elements of prior access models.[17] In their view, access arises from the interplay between healthcare providers (e.g., the supply aspect of healthcare) with characteristics of the consumer (i.e., the demand aspect of healthcare).[17] Healthcare access results from five aspects of providers: approachability, acceptability, availability/accommodation, affordability, and appropriateness; these provider aspects interact with consumer abilities to perceive the need for healthcare, to seek and reach healthcare, to pay for healthcare, and to engage with healthcare providers.[17] "Healthcare access" is facilitated by expansive and complex interactions between patients and healthcare-systems.

While the US has the highest per capita spending on healthcare in the world, contemporary national, state, and local survey data show that millions of persons in the US experience substantial deficits in healthcare access.[19] A complete elaboration of every such deficit falls beyond the scope of this thesis. We describe three healthcare access deficits relevant to patients with an ACS: having financial barriers to healthcare, lacking a usual source of care, and possessing transportation barriers to care. These barriers to healthcare access are examined in relation to various post-discharge outcomes among hospital survivors of an ACS.

Financial barriers to healthcare result from the mismatch between the cost of healthcare services with consumers' capacities to pay for those services.[20] Factors contributing to the expense of healthcare in the US include an underinvestment in preventative care, absence governmental price-controls, lack of integration, high administrative costs, financial compensation for services rather than outcomes, consolidation among health-care related entities, and delivery of unnecessary services.[21] Meanwhile, Americans have increasingly greater demands for healthcare partly due to the aging of the population and the higher prevalences of chronic diseases.[22] In 2014, an estimated 11.5% of Americans lacked insurance coverage and 5.3% could not get healthcare due to cost.[23] In general, Americans lacking insurance are more likely to utilize emergency services, not take medications prescribed by their physicians, and experience declines in their overall health status.[24]

Patients who have difficulty paying for care may experience unfavorable outcomes following a hospitalization for an ACS. Several cohort studies show that patients without insurance, and those who are underinsured, or report overall difficulty paying for care typically have worse long-term mortality after surviving an ACS than those with better financial resources.[20,25-28] They may experience worse health-related quality of life in the months following a hospitalization for an ACS than their peers with better access.[20,29,30] Despite these collective findings, there are limitations to their interpretation and generalizability, as they tend to be historical and failed to adjust for other barriers to healthcare, such as lacking transportation or a usual source of care. Professional society guidelines direct clinicians to evaluate patients' financial status and health insurance coverage when preparing for discharge during a hospitalization for an ACS.[31,32] However, there does not presently exist standardized, evidence-supported protocols for screening and addressing financial barriers to care in this population. This may be partly due to a lack of evidence about the role of financial barriers beyond just lacking insurance, as well as the lack of research performed as to how such barriers may influence changes in patient's health status over time. Further clarity on the role of financial barriers after an ACS may be necessary to develop effective interventions tailored to patients' ability to pay for care.

In addition to being able to pay for healthcare, patients typically require a usual source of care, "a place where an individual most often goes if he or she is sick or needs personal health advice, such as a doctor's office, clinic, or health center."[14] In general patient populations, a usual source of care can ensure that patients' receive appropriate healthcare.[33,34] In the US, patients without a usual source of care are at risk for receiving poor care,[35] having untreated hypertension or hypercholesterolemia,[36] and using emergency departments for ambulatory healthcare needs.[37,38] Moreover, a usual source of care is often necessary for directing patients to appropriate health resources in the complicated US healthcare system.[39] Even patients with insurance may be unable to receive care from specialists without referral from a usual source of care, typically a primary care provider.[40] National survey data, however, indicates that 12% of the U.S. non-institutionalized population did not have a usual source of care in 2014, with even higher proportions among African Americans and Hispanic populations.[23] Although low income and a lack of health insurance may predispose an individual to lack a usual source of care,[41] many persons without a usual source of care do possess health insurance.[41] Although some patients identify emergency departments (ED) as a usual source of care, EDs are generally not considered an acceptable usual source of care due to their high costs and prioritization of acute care.[34]

Current guidelines for treating patients with an ACS direct clinicians to arrange outpatient follow-up with a primary care provider, a typical usual source of care, following hospital discharge.[32] Since a usual source of care provider often has an established, longitudinal relationship with a patient, they may have the best capability to ensure that a patient best manages his or her medical condition, particularly in the setting of other comorbidities.[34] Their follow-up care may be particularly important given how common it is for patients to be discharged from the hospital with medication mistakes and pending studies.[42-44] There exists little data, however, on the consequences of lacking a usual source of care among patients discharged from the hospital after an acute coronary event. Among the 2,454 patients who survived a hospitalization for an AMI in 2003-2004 in the PREMIER study, those without a prior usual source of care had all-cause death rates at 6 and 12 months that were 3.0 and 1.9 times, respectively, greater than patients reporting a strong usual source of care.[14] Insights on the role of this under-studied, but highly prevalent, health access issue among survivors of an ACS may help inform more optimal management practices, particularly since healthcare organizations may have the ability to provide a usual source of care should one be lacking.

Another important component of access to healthcare is the ability to reach healthcare providers.[17] Few patients live within walking distance of their healthcare provider, or receive in-home or in-facility visits from providers; the vast majority of Americans typically travel via private automobiles to receive healthcare.[45] Not only can owning a vehicle be costly, but many Americans may lack the ability to drive due to disability or medical restrictions.[45] Hiring transportation may be prohibitively expensive, particularly if a clinic is far away and if patients require multiple visits over a short period of time. While many may use a social support network, including family and friends, to secure transportation,[45,46] an increasing number of Americans report social isolation and may not be able to obtain such help. While states and insurers may provide non-emergency transportation to certain populations, such services may be difficult to utilize and can be unreliable.[47]

To date there has been little study on the role of transportation access on patient-related outcomes after a hospitalization for an ACS, but circumstantial evidence suggests that a lack of transportation may lead to worse patient outcomes. Post-discharge outpatient care, including follow-up visits with primary care providers and cardiologists as well as cardiac rehabilitation, may lead to better treatment and patient adherence that could result in better health-related quality of life and lower mortality.[13,48,49] Survivors of an ACS underutilize both follow-up care and cardiac rehabilitation,[14,50] thereby foregoing its benefits, and the inability to obtain transportation may contribute to this underutilization.[15,50,51] Moreover, survivors of an ACS are at high risk of developing an acute complication or sequelae of their heart disease, such as a recurrent ACS, that would require prompt medical attention and hospitalization.[3,5] While most Americans have access to emergency medical transportation that will deliver them to an emergency room for evaluation regardless of their ability to pay,[52,53] many choose not to use it, even when appropriate due to concerns about costs and feelings that their symptoms may not warrant treatment.[54] A lack of transportation among survivors of an ACS could delay treatment seeking when one experiences acute complications and thereby worsen morbidity and mortality. However, the extent to which transportation barriers may influence overall health and survival over the months and years following a hospitalization for an ACS remains unknown. Since clinicians can readily screen for transportation barriers in their patient populations, and may be able to arrange for reliable transportation services, better study of the role of transportation barriers is particularly warranted given its role as a potentially modifiable risk factor.

In summary, advances over the past several decades in lifestyle interventions and medical treatments for both an ACS and underlying coronary heart disease have reduced morbidity and mortality. The current structure of the American healthcare system, however, makes the delivery of healthcare expensive and difficult. The millions of Americans who have suboptimal access to healthcare due to factors such as financial barriers, having no usual source of care, and inadequate transportation may have worse outcomes after surviving a hospitalization for an ACS. Both policymakers and clinicians face increasing pressure to address barriers to healthcare access as demand for healthcare services will continue to increase. Better understanding of how barriers to healthcare impact patient outcomes will be invaluable for both groups. Nevertheless, despite both the high incidence and costs associated with treatment for an ACS, there exists little data describing the role of healthcare access to the post-discharge outcomes of patients who survive a hospitalization for an ACS.

This thesis will address the substantial knowledge gap about the role of barriers to healthcare access on post-hospital outcomes of survivors of an ACS using data from the Transitions, Risks, and Actions in Coronary Events Center for Outcomes Research and Education (TRACE-CORE) longitudinal cohort study of more than 2,000 survivors of an ACS discharged from six hospitals in central Massachusetts and Georgia.[55,56] To better understand patients' perspectives on how barriers to healthcare may influence care transitions after an unplanned hospitalization, this thesis contains a qualitative study of 22 interviews with patients, including survivors of an ACS, from a PCORI-funded project to develop and validate a new measure of patient perceptions of the quality of transitions care from the hospital to outpatient setting. The discussion of this thesis will contextualize its findings in the ongoing national debate over healthcare policy. The specific aims of the thesis are:

Aim 1. Using data from the TRACE-CORE study, determine if patients with barriers to healthcare access at the time of hospitalization for an ACS have higher all-cause mortality within two years of discharge compared to patients with good healthcare access.

Aim 2: Using data from the TRACE-CORE study, determine if patients with barriers to healthcare access at the time of hospitalization for an ACS are more likely to experience clinically meaningful declines in health-related quality of life than their peers with better healthcare access during the six months after hospital discharge.

Aim 3: Through a qualitative study of patients with a recent unplanned hospitalization, examine patients' perceptions of how barriers to healthcare access, in conjunction with other factors within and outside of the medical system, influence the success of their transition to the outpatient setting.

CHAPTER II: BARRIERS TO HEALTHCARE ACCESS AND LONG-TERM SURVIVAL AFTER HOSPITAL DISCHARGE FOR AN ACUTE CORONARY SYNDROME

ABSTRACT

Background: Barriers to healthcare remain common in the US and may result in worse outcomes among hospital survivors of an acute coronary syndrome (ACS). We examined the relationship between barriers to healthcare and two-year post-discharge mortality among hospital survivors of an ACS.

Methods: Hospital survivors of an ACS were recruited from 6 medical centers in central Massachusetts and Georgia in 2011-2013. Participants reported whether they currently had a usual source of care as well as a financial or transportation barrier in the year prior to admission. Cox regression analyses calculated hazard ratios (HRs) for two-year all-cause mortality for the three individual healthcare barriers while adjusting for demographic, clinical, and psychosocial characteristics.

Results: The mean age of study participants (n=2,008) was 62 years, 33% were women, and 77% were non-Hispanic white. One third of patients reported a financial barrier, 17% lacked a usual source of care, and 12% had a transportation barrier. Five percent (n=100) died within two years after hospital discharge. Compared to their counterparts without barriers, those lacking a usual source of care and with barriers to transportation had significantly higher mortality (adjusted HRs 1.58, and 1.55, 95% CI: 1.15 to 2.09, respectively); while those having a financial barrier did not (adjusted HR 0.81, 95% CI: 0.49 to 1.33).

Conclusions: Hospital survivors of an ACS lacking a usual source of care and with barriers to transportation may be at higher risk for dying after an ACS; these patients may require more intensive follow-up.

INTRODUCTION

Guideline-concordant medical, physical, and behavioral therapies can reduce mortality among patients who survive a hospitalization for an acute coronary syndrome (ACS).[9,31,32] Utilizing these strategies requires both access to clinicians and means of financing healthcare. Survivors of an ACS may need costly pharmaceuticals and outpatient services in the year following hospital discharge, with total average costs ranging from $3,000 and $10,000.[11,57,58] National survey data, however, suggests that barriers to healthcare are common among Americans. In 2014, about 1 out of every 10 American adults reported lacking health insurance, a similar proportion lacked a usual source of medical care, and 1 out of 20 were unable to obtain needed care due to its cost.[23] Patients with poor healthcare access may receive suboptimal secondary prevention[14,15] and be at greater risk for poor outcomes.[24,59]

While current guidelines for the treatment of ACS advise clinicians to screen for barriers to healthcare, there lack definitive strategies to address deficits in healthcare access.[31,32] A limited number of studies have found an inconsistent relationship between different markers of poor access to healthcare, such as lacking a usual source of care or health insurance, with mortality following hospitalization for an acute myocardial infarction.[20,26,60,61] A consistent limitation of these prior studies, however, has been the focus on only one form of healthcare barrier without adjustment for other forms of barriers. A better understanding of how barriers to healthcare impact mortality following a hospitalization for an ACS could help guide the development of interventions to patients with worse access to care.

Using data from a prospective cohort of hospital survivors of an ACS,[55,56] we examined the association between financial barriers, no usual source of care, and transportation barriers to healthcare with two-year all-cause post-discharge mortality.

METHODS

Study Sample

This study uses data from the Transitions, Risks, and Actions in Coronary Events Center for Outcomes Research and Education (TRACE-CORE) study.[55,56] In brief, 2,174 adults hospitalized for an ACS were recruited from 3 community and tertiary medical centers in Worcester, Massachusetts, 2 hospitals in a managed care network in Atlanta, Georgia, and a tertiary care hospital in Macon, Georgia between April 2011 and May 2013. Eligible participants were

≥21 years of age and were discharged alive from participating medical centers. Exclusion criteria included having an ACS secondary to another acute medical event (e.g., surgery), delirium, pregnancy, and receipt of hospice or palliative care. Trained research assistants abstracted data from patient electronic medical records (EMRs) for the index hospitalization, performed computer-assisted interviews with participants during the index hospitalization or by telephone within 72 hours of discharge, and reviewed state vital records to assess mortality status at two years post-discharge. The institutional review boards at participating sites approved this study.

The analytic sample (n=2,008) for the current study consisted of patients with an adjudicated classification of their ACS type and the three measures of healthcare access. We performed multiple imputation by chained equations to estimate the values of potentially confounding covariates for the 204 (10.2%) participants with missing data.[62]

Measuring Barriers to Healthcare Access

Prior frameworks have identified factors ranging from individual patient attitudes to geography as determinants of healthcare access.[45] Using the Andersen Model of Access,[63,64] we chose to examine three enabling factors (logistical barriers to accessing care) identified in TRACE-CORE: financial barriers, no usual source of care, and transportation barriers.

Specific Barriers to Healthcare

For this study, we considered a financial barrier to healthcare as a lack of insurance coverage and/or self-reported difficulty affording healthcare. We determined insurance status according to EMR documentation. At baseline, interviewers asked participants “in the past twelve months, have you avoided obtaining any health care services because of the cost?” and/or “during the past 12 months, have you had any problems paying medical bills?”[20] We classified participants answering yes to either of these questions along with those lacking medical insurance as having a financial barrier.

To determine the presence of a usual source of care, interviewers asked participants “is there a place that you usually go to when you are sick or need advice about your health?” Interviewers asked participants responding “yes” to classify the place as a clinic or health center, doctor’s office or HMO, emergency room, or outpatient department.[23] We classified patients who reported no usual source of care and those who reported that their usual source of care was an emergency room as lacking a usual source of care.[23]

To assess transportation-related barriers to healthcare, interviewers asked patients “within the past 12 months, have you missed a medical appointment or been unable to obtain needed health care because of problems with your transportation?” and “overall, and in terms of transportation, how difficult is it for you to get to your health care appointments?” (no problem at all, not very, somewhat, moderately, or extremely difficult). We classified patients who reported missing an appointment in the prior year, or having moderate or extreme difficulty in getting to appointments, as having a transportation barrier.

Multiple Barriers to Healthcare

As a secondary analysis, we examined the relationship between 2-year all-cause post-discharge mortality with number of barriers to healthcare present. We lacked the statistical power to assess relationships between each potential combination of barriers with death. We instead categorized patients as having no barriers, 1 barrier, or 2 or more healthcare barriers.

All-Cause Mortality

Study coordinators reviewed state vital statistics records to ascertain patients' survival status within the first two years after hospital discharge for their index ACS event.

Potential Confounding Variables

We examined several sociodemographic, clinical, and psychosocial characteristics as potential confounders between healthcare barriers and 2-year total mortality.

Demographics

Age and sex were abstracted from EMRs. During the baseline interview, participants reported their race and ethnicity, household composition, employment status, and level of education. We assessed financial strain by asking patients "in general, how do your finances usually work out at the end of the month?" (some money left over, just enough to make ends meet, not enough to make ends meet).[20]

Clinical Characteristics

Trained reviewers abstracted data on participants' medical history and hospital course from hospital records. To confirm and classify patients' type of ACS as ST-segment elevation myocardial infarction (STEMI), non-STEMI (NSTEMI), or unstable angina (UA), two cardiologists reviewed ECG, cardiac biomarker, and cardiac catheterization data from medical records.[65,66] Patients reported their smoking status (current, former, or never) at baseline. We calculated Global Registry of Acute Coronary Events (GRACE) risk scores (2.0) for mortality using data on age, cardiac biomarkers, ST segment changes, systolic blood pressure, creatinine or history of renal dysfunction, Killip class, use of diuretics, and the development of cardiac arrest during the patient's index hospitalization.[67] GRACE 2.0 scores are scaled from 0 to 263, with higher scores indicating a higher probability of death; the GRACE model has demonstrated strong predictive discrimination of mortality for periods of 1 and 3 years after hospital admission for an ACS.[67] We divided GRACE risk scores into four categories after examining the distribution of deaths in our study population according to their GRACE risk score.

Psychosocial Characteristics

Patients were categorized as having low-health literacy if they reported having little or no confidence when they were asked how confident they were in filling out health forms by themselves.[68] To assess patient's cognitive status, participants completed the 11-item Telephone Interview for Cognitive Status (TICS, range 0 to 41); we classified patients as being unimpaired (≥ 33), ambiguous (26 to 32), or moderate to severely impaired (≤ 25).[69] We assessed depressive symptoms with the 9-item Patient Health Questionnaire (PHQ9, range 0 to 27) and designated participants as having no (≤ 4), mild (5 to 9), or moderate to severe (≥10) depressive symptoms.[70] We measured anxiety symptoms with the 7-item Generalized Anxiety Disorder questionnaire (GAD7, range 0 to 21) and designated participants as having no (≤ 4), mild (5 to 9), or moderate to severe (≥10) symptoms of anxiety.[71]

Statistical Analysis

We compared study participants' sociodemographic, clinical, and psychosocial characteristics according to the presence of individual barriers to healthcare access using chi-square goodness of fit tests for categorical variables, and unpaired t-tests for continuous variables.

To examine the association of healthcare barriers with all-cause mortality in the two years after hospital discharge, we calculated unadjusted and multivariable adjusted hazard ratios (HRs) with accompanying 95% confidence intervals (CIs) using adjusted and unadjusted Cox proportional hazard regression models.[72] We inspected Schoenfeld residuals and log-log plots[72] to confirm that the key exposure variables and additional covariates satisfied the proportional odds assumption.

We first examined the three specific barriers for care (e.g., financial barriers, lack of usual source of care, and transportation barriers) in the same regression model. Based on clinical judgement, we decided *apriori* to adjust for site, sex, race/ethnicity, GRACE risk score, and receipt of in-hospital reperfusion therapy as covariates. We included additional variables, including education, living situation, prior heart disease, prior peripheral vascular disease, chronic kidney disease, and depressive symptoms that we found changed the measure of association for one or more of the healthcare barriers with all-cause mortality by 10 percent or more. We did not include variables already accounted for in the GRACE risk score after preliminary analyses showed their incorporation did not improve model fit nor substantially change the main measures of association, with the exception of a history of chronic kidney disease. We used a clustered sandwich estimator to calculate the standard errors of coefficients to account for the potential lack of independence of outcomes of patients being treated at the same clinical site.[73] We present all of the calculated hazard ratios for all the variables in the adjusted models in the appendices.

We also constructed Cox proportional hazard regression models to examine the relationship between the number of healthcare barriers with all-cause mortality. We used the same set of adjustment variables for this analysis as described above.

RESULTS

Of the 2,174 TRACE-CORE study participants, we excluded those with missing information on type of ACS (n=53) and one or more of the health care barriers of interest (n=113) resulting in an analytic sample of 2,008. The sample mean age was 61.6 years (SD 11.3), 33.1% were women, and 76.7% were non-Hispanic white; 15.0%, 55.7%, and 29.3% were diagnosed with STEMI, NSTEMI, and UA, respectively.

One-third of participants (33.1%) reported a financial barrier, 17.1% lacked a usual source of care, and 11.9% reported a transportation barrier; 45.7% of participants had at least one of these three healthcare barriers (Table 2.1). Participants with each specific healthcare barrier were younger, on average, with smaller proportions reporting to be non-Hispanic white, a college graduate, living with a spouse, retired, or having no monthly financial strain compared to their counterparts who did not have the healthcare barrier of interest. Higher proportions of participants with each specific healthcare barrier were currently smoking and had a hospitalization of ≥ 3 days, but mean GRACE risk scores were lower than those without specific barriers. Low health literacy, mild to severely impaired cognitive status, moderately severe to severe symptoms of depression, and severe symptoms of anxiety were more prevalent among participants with specific barriers ($p < 0.05$ for all comparisons).

The crude all-cause mortality rates of the sample, both overall and according to the presence of specific barriers to healthcare, are presented in Table 2.2. After adjusting for several potentially confounding variables and other healthcare barriers, we identified statistically significant associations between higher rates of all-cause mortality with having no usual source of care (adjusted HR: 1.58, 95% CI: 1.24 to 2.01) and having a transportation barrier (adjusted HR 1.55, 95% CI: 1.15 to 2.09). We observed no significant associations between having a financial barrier with all-cause mortality in crude and multivariable adjusted models (Figure 2.1).

Figure 2.2 depicts a proportionate Venn graph showing the degree of overlap between barriers to healthcare together with crude all-cause mortality according to each possible combination of barriers. Overall, 1,090 patients (54.3%) had no barriers, 633 (31.5%) had 1 barrier, and 285 (14.2%) had 2 or more barriers with corresponding crude 2-year all-cause mortality rates of 4.9%, 4.4%, and 6.7%, respectively. After multivariable adjustment, patients with two or more healthcare barriers were 1.53 (95% CI: 1.03 to 2.27) times more likely to have died with two years after discharge than those without any healthcare barriers to care (Figure 2.3). We did not find a crude nor adjusted association between having only one barrier to healthcare with higher all-cause mortality.

DISCUSSION

In this prospective study of 2,008 survivors of an ACS almost one half reported barriers to healthcare access, including barriers related to affording care, having a usual source of care, and transportation. After adjusting for sociodemographic, clinical, and psychosocial characteristics, we found an association between barriers related to usual source of care and transportation with higher all-cause mortality over two years after hospital discharge. We did not identify an association between financial barriers to care and all-cause mortality, but those with two or more of these specific healthcare barriers were less likely to survive for two than those with no healthcare barriers. Having certain as well as more barriers to healthcare may be common among survivors of an ACS and impact long-term survival.

Prevalence of Healthcare Barriers

Our findings of a high prevalence of barriers to healthcare is consistent with results from regional and national studies of hospital survivors of an ACS. The Prospective Registry Evaluating Myocardial Infarction: Event and Recovery (PREMIER) study found that 18% of 2,498 participants reported avoiding healthcare due to costs in the year before hospitalization for an acute myocardial infarction (AMI) at 12 nationwide medical centers between 2003-04;[20] another analysis of PREMIER participants found that a similar proportion lacked a usual source of care.[14] A study of 4,908 patients hospitalized for AMI at three Maryland hospitals between 1993 and 2008 identified 16% of patients as being underinsured (i.e., lacking health coverage or having limited coverage).[25] A qualitative study of 14 patients with heart disease in Canada described how barriers to care, such as underinsurance and lack of transportation, can prevent patients from receiving optimal care by skipping follow-up appointments and taking their prescribed medications.[15] The high prevalence of barriers to care in the present study and others suggest the importance of assessing healthcare access among survivors of an ACS, especially since ongoing contact with the medical care system may be required to receive optimal secondary prevention therapies.[31,32]

Financial Barriers

We did not identify an association between financial barriers to healthcare access and utilization with increased all-cause mortality during the 2 years after hospital discharge for an ACS. This may result from these patients utilizing emergency services that do not require payment and/or still being able to obtain inexpensive generic medications.[34] In contrast, several studies have found positive associations of financial barriers to care with higher mortality among those with cardiovascular disease.[20,25,74] In the aforementioned study of patients hospitalized for an AMI at three Maryland hospitals, the risk of dying from all causes over a 14 year follow-up period was 30% higher among underinsured patients compared with well-insured patients.[25] Participants in the PREMIER study who reported avoiding medical care due to cost experienced all-cause mortality within a year of hospital discharge at a non-statistically significant rate 40% higher than for those without such a barrier.[20] Of note, a nationally representative cohort of 120,752 patients with pre-existing cardiovascular morbidity in Canada, which provides universal health coverage, found that patients reporting any financial barrier to healthcare (including medication costs and indirect costs of care) had an all-cause mortality rate approximately one quarter higher than those who had no financial barriers.[74]

Usual Source of Care

The presence of a usual source of medical care may confer benefits to patients and the healthcare system by leading to better health screens,[35,75] optimal chronic disease treatment,[36] and reducing the need for emergency care.[37,38] After accounting for financial barriers to care and transportation access, we found a positive association between lacking a usual source of care and higher all-cause mortality. An analysis of 2,454 survivors of an AMI in the PREMIER study found that those lacking a usual source of care experienced all-cause death rates at about double the rate of those with an established usual source of care during the year after hospital discharge.[14] Lacking a usual source of care might result in patients having greater difficulty establishing outpatient follow-up and, interfering with secondary prevention for their underlying coronary artery disease.

Transportation Barriers

There exists little data on the relationship between barriers to transportation and post-hospital outcomes after an ACS. We identified a higher risk of dying among those with, as compared to those without, transportation barriers. This may be a result of patients being unable to obtain adequate care for the secondary prevention of their heart disease due to transportation related concerns. A contemporary systematic review on the impact of transportation barriers in general patient populations suggests a lack of transportation is a leading cause of missed medical appointments and may prevent patients from obtaining prescription medications.[76] Despite requirements for many Medicare and Medicaid plans to offer transportation services to patients, many patient transportation services have poor reliability and include excessive wait times.[47] Now that mobile technology platforms are offering novel and less expensive ways to obtain transportation, healthcare systems may soon have better ways to assist patients with transportation barriers.[47] Further investigation is warranted to assess how ensuring adequate transportation access may improve both short and long-term clinical outcomes among patients discharged from the hospital after an ACS.

Quantity of Healthcare Barriers

Our secondary analyses suggest that patients with two or more specific barriers to healthcare may have a greater risk of dying following discharge from the hospital after an ACS. We recognize that these analyses presumed an equivalency of healthcare barriers, which has not been previously demonstrated to the best of our knowledge; however, we did not have sufficient power to examine the relationship of different combinations of barriers with all-cause death rates. Nevertheless, we believe it is important to recognize that theories of healthcare access suggest that any one of several barriers may prevent patients from obtaining healthcare;[17] just because a patient is free from one type of barrier does not mean that another barrier cannot prevent him or her from obtaining effective care. Indeed, efforts to evaluate and address the role of individual and absolute numbers of barriers to healthcare access and utilization will likely require multifactorial assessment.

Study Strengths and Limitations

The strengths of this multi-site prospective study include its large sample of patients with confirmed ACS. For several of our measures of healthcare access, we were able to pool the answers to related questions, reducing the risk of misclassification that could occur from using a single question to measure this construct. Nevertheless, we acknowledge several limitations. This study may lack generalizability in patient populations different than those at participating medical centers. As with all observational studies, despite the many potential confounders we adjusted for in our regression analyses, unmeasured confounding may have biased the associations observed. For instance, we could not account for the receipt of inpatient and post-discharge social services among those with barriers to care which may have attenuated the relationship between barriers to care and all-cause post-discharge mortality. Finally, since we only searched Massachusetts and Georgia death certificate records to confirm patient's vital status, we could have missed deaths that occurred in other states.

CONCLUSION

Hospital survivors of an ACS with barriers to a usual source of care and transportation exhibited higher all-cause mortality over two years following hospital discharge, suggesting that barriers to healthcare may contribute to poorer long-term health outcomes. Our findings suggest the need for clinicians to be aware of barriers to healthcare in devising patient’s treatment plans. Additional research to both confirm our findings in more generalizable populations, as well as determine ways for healthcare systems to best provide services for patients with barriers to care is warranted.

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Table 2.1: Baseline characteristics of survivors (n=2,008) of a hospitalization for an acute coronary, by presence of specific barriers to healthcare access

Characteristics	Full Sample (n = 2,008)	Financial Barrier (n = 665)	No Usual Source of Care (n = 343)	Transportation Barrier (n = 239)
Sociodemographic				
Age, mean, yrs (SD)	61.6 (11.3)	56.9 (10.2)	56.3 (11.6)	58.2 (10.9)
Female (%)	33.1	39.7	30.6	42.7
Non-Hispanic White (%)	76.7	68.4	64.0	59.8
Education (%)				
Less than high school	17.3	21.8	25.9	34.7
High school	29.7	35.0	36.4	28.5
Some college / post-high school	28.7	29.0	22.4	25.5
College graduate	24.2	14.1	15.2	11.3
Living Situation (%)				
With spouse	48.8	39.8	33.0	23.8
With family (non-spouse)	15.9	22.6	24.6	26.4
With non-family	13.5	14.5	17.8	17.2
Alone	21.9	23.2	24.6	32.6
Employment Status (%)				
Retired	39.0	24.4	20.2	30.4
Working	40.6	40.4	45.8	19.8
Unemployed	20.3	35.2	33.9	49.8
Finances at End of Month (%)				
Some left over	46.3	19.5	33.8	14.4
Just enough to make ends meet	34.4	40.3	34.7	36.4
Not enough to make ends meet	19.2	40.3	31.4	49.2
Clinical				
GRACE score, mean (SD)*	95.9 (28.5)	88.7 (26.4)	88.7 (28.2)	95.1 (27.6)
Prior Medical History (%)				
Arthritis	20.1	17.1	14.9	23.0
Cancer	11.8	9.2	8.7	10.9
Chronic lung disease	18.2	20.5	20.4	26.4
Chronic kidney disease	11.3	9.9	11.4	18.4
Diabetes	33.0	38.8	30.3	48.1
Heart disease	52.9	56.7	50.4	69.0
Heart failure	14.2	16.5	13.1	24.3
Hyperlipidemia	69.2	68.0	58.6	70.7
Hypertension	76.2	76.7	69.1	85.8
Peripheral vascular disease	9.9	9.6	9.3	18.4
Stroke/TIA	9.3	8.6	9.3	13.8
Smoking Status (%)				
Never smoked	30.4	25.6	23.0	19.2
Former smoker	46.1	40.6	35.6	43.9
Current smoker	23.5	33.8	41.4	36.8
ACS Type (%)				
STEMI	15.0	10.7	13.4	10.0
NSTEMI	55.7	59.2	58.0	56.9
UA	29.3	30.1	28.6	33.1
Reperfusion Therapy (%)				
PCI	65.8	66.5	62.4	61.9
CABG Surgery	13.2	11.4	13.7	12.6
No PCI nor CABG	21.0	22.1	23.9	25.5
In-hospital medications (%)				
ACEI / ARB	61.6	63.6	61.2	65.7
Aspirin	96.5	95.8	97.1	92.9
Beta-Blocker	90.2	90.1	93.6	92.5
Lipid lowering medication	89.7	89.5	92.4	90.4
Length of stay ≥ 3 Days (%)	52.1	54.6	58.0	63.2

Table 2.1 (continued)

Characteristics	Full Sample (n = 2,008)	Financial Barrier (n = 665)	No Usual Source of Care (n = 343)	Transportation Barrier (n = 239)
Psychosocial				
Health Literacy (%)				
High	63.7	58.2	58.0	46.4
Medium	17.8	18.9	18.3	25.5
Low	18.5	23.0	23.7	28.1
Cognitive Status (%)				
Normal	50.1	45.4	40.4	35.3
Ambiguous	42.8	45.4	47.6	48.7
Mildly or Severely Impaired	7.1	9.3	12.0	16.1
Depressive Symptoms (%)				
Absent	50.8	33.7	48.7	24.4
Minor	26.6	30.4	20.9	26.5
Moderate	13.4	18.0	15.2	23.1
Moderately Severe to Severe	9.1	17.9	15.2	26.1
Anxiety Symptoms (%)				
Absent	51.0	34.8	46.5	22.5
Mild	25.1	28.8	24.3	28.4
Moderate	12.6	16.2	12.3	22.9
Severe	11.3	20.3	17.0	26.3

Abbreviations: ACEI, angiotensin converting enzyme inhibitor; ACS, acute coronary syndrome; ARB, angiotensin II receptor blocker; GRACE, Global Registry of Acute Coronary Events; NSTEMI, non-ST-segment elevation myocardial infarction; STEMI, ST-segment elevation myocardial infarction, TIA, transient ischemic attack; UA, unstable angina

Missing data: cognitive status (n=41), depressive symptoms (n=44) employment status(n=20), finances at the end of month (n=36), GRACE risk score (n=39), health literacy (n=9), living situation (n=2), race/ethnicity (n=2)

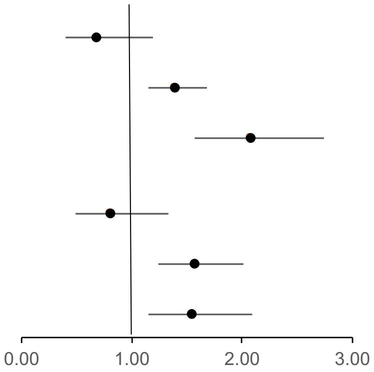
*GRACE risk scores (2.0) incorporate data on age, cardiac biomarkers, ST segment changes, systolic blood pressure, creatinine or history of renal dysfunction, Killip class or use of diuretics, development of cardiac arrest during the index hospitalization to calculate risk for mortality at 1 and 3 years after admission for an ACS. It is scored on a scale from 0 to 263, with higher scores indicating a higher probability of death.

Table 2.2: Crude all-cause mortality at 2-years after discharge for a hospitalization for an acute coronary syndrome and barriers to healthcare

	Overall	**Financial Barrier to Care**		**No Usual Source of Care**		**Transportation Barrier**	
	(n=2,008)	Yes (n=665)	No (n=1,343)	Yes (n = 343)	No (n = 1,665)	Yes (n=239)	No (n=1,769)
Mortality (%)	5.0	4.4	5.3	6.4	4.7	8.4	4.5

Figure 2.1: Barriers to healthcare and all-cause mortality at 2-years after discharge for a hospitalization for an acute coronary syndrome

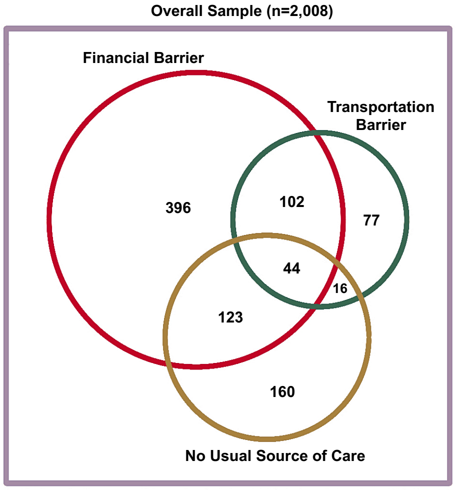
Model	Barrier	Hazard Ratio (95% CI)
Unadjusted	Financial Barrier	0.69 (0.40, 1.19)
	No Usual Source of Care	1.39 (1.15, 1.68)
	Transportation Barrier	2.08 (1.57, 2.74)
Adjusted	Financial Barrier	0.81 (0.49, 1.33)
	No Usual Source of Care	1.58 (1.24, 2.01)
	Transportation Barrier	1.55 (1.15, 2.09)



Adjusted for site, sex, race/ethnicity, GRACE risk score (incorporates data on age, cardiac biomarkers, ST segment changes, systolic blood pressure, creatinine or history of renal dysfunction, Killip class or use of diuretics, development of cardiac arrest during the index hospitalization), education, living situation, ACS treatment, prior heart disease, prior peripheral vascular disease, prior history of chronic kidney diseases, depressive symptoms

Figure 2.2: A) Proportional Venn diagram depicting extent of overlap between barriers to healthcare access. B) Prevalence of different combinations of barriers to healthcare access and all-cause mortality at 2-years after discharge

1A)

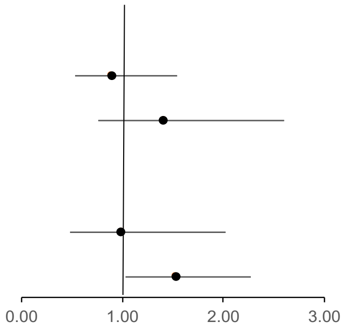


1B)

Barrier				
Financial	No Usual Source of Care	Transportation	Total (n=2,008, col %)	2-year mortality (row %)
No	No	No	54.3	5.3
Yes	No	No	19.7	3.8
No	Yes	No	8.0	4.4
No	No	Yes	3.8	11.7
Yes	No	Yes	5.1	3.9
Yes	Yes	No	6.1	8.1
No	Yes	Yes	0.8	12.5
Yes	Yes	Yes	2.2	11.4

Figure 2.3: Number of barriers to healthcare access and all-cause mortality at 2-years after discharge for a hospitalization for an acute coronary syndrome

Model	Barrier	Hazard Ratio (95% CI)
	No Barrier Present	Referent
Unadjusted	1 Barrier Present	0.90 (0.53, 1.54)
	2 or More Barriers Present	1.41 (0.76, 2.60)
	No Barrier Present	Referent
Adjusted	1 Barrier Present	0.99 (0.48, 2.02)
	2 or More Barriers Present	1.53 (1.03, 2.27)



Adjusted for site, sex, race/ethnicity, GRACE risk score (incorporates data on age, cardiac biomarkers, ST segment changes, systolic blood pressure, creatinine or history of renal dysfunction, Killip class or use of diuretics, development of cardiac arrest during the index hospitalization), education, living situation, ACS treatment, prior heart disease, prior peripheral vascular disease, prior history of chronic kidney diseases, depressive symptoms

CHAPTER III: BARRIERS TO HEALTHCARE ACCESS AND DECLINES IN HEALTH-RELATED QUALITY OF LIFE AMONG HOSPITAL SURVIVORS OF AN ACUTE CORONARY SYNDROME

ABSTRACT

Background: Little is known about how poor healthcare access may affect health-related quality of life (HRQOL) after an acute coronary syndrome (ACS).

Methods: In a cohort of hospital survivors of an ACS at six medical centers in Massachusetts and Georgia in 2011-2013, we categorized patients as having a financial barrier, no usual source of care, or a transportation barrier to healthcare. Using the SF36v2 physical and mental component summary scores, we examined clinically meaningful declines in generic physical and mental HRQOL scores between 1 and 6 months post-discharge. Using Poisson regression models, we calculated relative risks (RRs) for declines in HRQOL according to the presence of the individual and total number of healthcare barriers while adjusting for several sociodemographic, clinical, and psychosocial factors.

Results: Among the 1,053 survivors of an ACS, 29.0% had a financial barrier, 14.2% had no usual source of care, and 8.7% had a transportation barrier. Patients with a financial barrier had greater risks of experiencing clinically meaningful declines in generic physical (adjusted RR 1.38, 95% CI: 1.10,1.72) and mental (adjusted RR 1.37, 95% CI 1.08, 1.74) HRQOL than those without a financial barrier. Compared to those with no barriers to care, those with two or more barriers had a higher risk of experiencing declines in generic physical (adjusted RR 1.38, 95% CI: 1.09 to 1.75) and mental (adjusted RR 1.51, 95% CI: 1.18, 1.93) HRQOL.

Conclusions: Financial and multiple barriers to healthcare access may predict subsequent declines in generic HRQOL after a hospiutalization for an ACS.

INTRODUCTION

The majority of the 1.4 million American adults who annually survive a hospitalization for an acute coronary syndrome (ACS) avoid short-term readmission and death.[2,5] However, they tend to have worse health-related quality of life (HRQOL) than the general population,[77,78] and many experience subsequent declines in HRQOL after hospital discharge.[79] The American Heart Association recommends that clinicians monitor HRQOL, particularly since poor HRQOL is associated with adverse clinical events and can change clinical management.[80] Better knowledge about potential changes in HRQOL may be particularly useful for patients who are determining their long-term health goals,especially after being discharged from the hospital after an acute coronary event.[80]

We know little about the factors that affect HRQOL after an ACS,[80] particularly with regards to healthcare access.[81] Barriers to healthcare, including inadequate financial resources, lack of a usual source of care, and poor transportation access remain common in the U.S.[23,76] Such barriers may lead to poor uptake and adherence to secondary prevention therapies for coronary heart disease that could otherwise improve HRQOL.[82,83] Limited data suggest that patients with specific healthcare barriers may consistently have lower HRQOL over periods up to one year after a hospitalization for an ACS.[20,29] These studies did not, however, assess the relationship between barriers to healthcare and subsequent changes in HRQOL. Better understanding of the relationship between barriers to healthcare and subsequent changes in HRQOL may help identifty and treat patients at risk of health declines following an ACS.[84,85]

Using data from the Transitions, Risks, and Actions in Coronary Events Center for Outcomes Research and Education (TRACE-CORE) study of hospital survivors of an ACS,[55,56] we examined the association between financial barriers to healthcare, having no usual source of care, and transportation barriers to healthcare with clinically meaningful changes in HRQOL during the six months after hospital discharge.

METHODS

Source Study and Sample

In the prospective TRACE-CORE cohort study,[55,56] trained research assistants (RAs) recruited 2,174 adults who survived a hospitalization for ACS at 6 medical centers in central Massachusetts and Georgia between April 2011 and May 2013. Eligibility criteria included being 21 years of age or older, having a confirmed ACS,[65,66] and being discharged alive. Those with an ACS secondary to another acute medical event, delirium, pregnancy, or receiving hospice or palliative care were ineligible. After being informed of the risks and benefits of participation, patients provided written consent. Trained RAs abstracted data from electronic medical records and conducted an interview, either in-person during the index hospitalization or by telephone, within 72 hours of discharge. Patients participated in additional telephone interviews at 1, 3, 6, and 12 months after discharge. This study received approval from the institutional review boards at participating sites.

Participants with complete data on the specific barriers to healthcare, type of ACS, SF-36v2® Health Survey physical (PCS) and mental (MCS) component summary scores[86] and Seattle Angina Questionnaire Quality of Life (SAQ QOL)[87] at 1 and 6 months after discharge, and various potentially confounding factors, comprised the analytical sample.

Barriers to Healthcare

As exposures, we examined variables in the TRACE-CORE study that could act as enabling resources in the Andersen Model of Access.[63,64] These are factors that serve as logistical facilitators for accessing healthcare, namely having adequate financial resources, a usual source of care, and transportation for obtaining medical care.

Financial Barriers to Care

We defined financial barriers to healthcare as either difficulty affording care and/or a lack of insurance coverage at hospital discharge. Participants answered the following yes/no questions: “during the past 12 months, have you had any problems paying medical bills?" and "in the past twelve months, have you avoided obtaining any health care services because of the cost?"[20] We categorized patients responding affirmatively to either of these questions and/or lacking insurance as having a financial barrier to healthcare.

Lacking a Usual Source of Care

During the baseline interview, participants answered the question "is there a place that you usually go to when you are sick or need advice about your health?" Those responding yes received an additional prompt to classify this place as a clinic or health center, doctor's office or HMO, emergency room, or outpatient department.[23] Using the methodology of the National Health Interview Survey,[23] we classified patients responding no to the first question or listing an emergency room in the second question as having no usual source of care.

Transportation Barriers to Care

To assess the presence of transportation-related barriers to medical care, participants answered the following questions during the baseline interview: "overall, and in terms of transportation, how difficult is it for you to get to your health care appointments?" (no problem at all, not very, somewhat, moderately, or extremely difficult) and "within the past 12 months, have you missed a medical appointment or been unable to obtain needed health care because of problems with your transportation?" (yes, no). We classified patients who reported missing care or perceiving moderate to extreme difficulty in getting to appointments as having a transportation barrier.

Multiple Barriers to Healthcare

We examined the relationship between changes in HRQOL with the number of barriers to healthcare access. We lacked sufficient numbers to assess the relationships between each potential combination of barriers to healthcare access with changes in HRQOL. We instead categorized patients as having no barriers, 1 barrier, or 2 or more barriers to healthcare.

Changes in Health-Related Quality of Life

To assess generic HRQOL at 1 and 6 months after hospital discharge, participants completed the SF-36v2 Health Survey.[86] The SF-36v2 contains PCS and MCS scores that assess overall physical and mental health with higher scores indicating better HRQOL. The scales use norm-based scoring such that the U.S. general population has a mean of 50 (SD 10).[86]. Following recommendations from the instrument developer, we defined changes of ≥ 3.0 points as clinically meaningful decreases and increases in HRQOL.[88] Prior results support the reliability and validity of the SF-36v2® among patients with coronary heart disease.[89]

To assess disease-specific HRQOL, we used the 3-item quality of life subscale of the Seattle Angina Questionnaire (SAQ QOL),[87] an instrument developed for, as well as validated with, patients with coronary heart disease.[87] The SAQ QOL is scored from 0 to 100; higher scores indicate better HRQOL. Following expert consensus,[90] we defined changes of ≥ 16.0 points as clinically meaningful decreases and increases in HRQOL. Since both the SF-36v2 and

SAQ inquire about health status in the month prior to survey administration, we used the 1-month rather than baseline assessments of HRQOL.

Additional Variables

The RAs abstracted data on patient’s age and sex from hospital medical records. Patients self-described their race and ethnicity, education level, household composition, employment status, and smoking status during the baseline interview. Cardiologists classified patients’ type of ACS as either an ST-segment elevation myocardial infarction (STEMI), non-STEMI, or unstable angina according to abstracted ECG, cardiac biomarker, and cardiac catheterization data.[65,66] The RAs also abstracted data on patients’ pre-existing medical conditions and hospital treatment practices. We calculated Global Registry of Acute Coronary Events (GRACE) risk scores (2.0) using data on age, cardiac biomarkers, ST segment changes, systolic blood pressure, creatinine or history of renal dysfunction, Killip class or use of diuretics, and development of cardiac arrest during the index hospitalization.[67] GRACE 2.0 scores are scaled from 0 to 263, with higher scores indicating a higher probability of death.[67]

During the index hospitalization, RAs asked participants “how confident are you filling out medical forms by yourself?” on a 5-point Likert scale (not at all, a little bit, somewhat, quite a bit, or extremely confident);[68] we categorized those responding extremely/quite a bit, somewhat, and a little bit/not at all as having high, medium, and low health literacy, respectively. We assessed cognitive status using the Telephone Interview for Cognitive Status (TICS) at 1 month after hospital discharge.[69] Using cut-points from the instrument developer, we classified participants as having normal cognitive functioning, ambiguous functioning, or mild to severe cognitive impairment. At 1 month, patients completed the 6-item Patient Activation Measure, a measure of patients' knowledge, skills and confidence to manage their disease.[79,91] We assigned participants to 1 out of 4 possible levels of activation according to pre-specified cut-points from the instrument developer.[79,91]

Statistical Analysis

We examined the baseline sociodemographic, clinical, and psychosocial characteristics of participants according to the presence of a financial, usual source of care, and transportation-related barrier with the receipt of healthcare. We used chi-square goodness of fit tests and unpaired t-tests to compare differences in the distributions of categorical and continuous variables, respectively, among those with and without selected specific healthcare barriers. We examined differences in mean HRQOL scores between 1 month and 6 months after discharge using paired t-tests.

Using Poisson regression models with a sandwich error term,[92] we calculated relative risks (RR) and accompanying 95% confidence intervals (95% CIs) for experiencing a clinically meaningful decrease in HRQOL at 6 months according to the presence of individual healthcare barriers. We used this approach as the high prevalence of the outcome would violate the rare disease assumption in calculating odds ratios.[92] We first constructed a model that contained the three healthcare barriers together. We then adjusted the models for pre-specified sociodemographic (age, sex, race) and clinical factors (GRACE risk score and reperfusion therapy) as well as selected covariates if their inclusion changed beta coefficients (for the association between at least one barrier to access and changes in HRQOL) by ≥10%. Since preliminary analyses showed a strong association between initial HRQOL and subsequent changes in HRQOL scores, suggesting potential regression to the mean, we also adjusted for 1-month HRQOL scores.

To examine potential selection bias resulting from differential loss to follow-up, we also performed regression analyses using inverse probability weighting.[93] The weighted results were comparable to unweighted results (Appendix 3.1 and 3.2). Thus, we present unweighted results only.

RESULTS

Baseline Population Characteristics

The analytical sample consisted of 1,053 of the 2,174 original TRACE-CORE study participants. Compared to included participants, those excluded were younger and more likely to belong to a racial or ethnic minority, have less education, be unemployed, and have strained monthly finances (p<0.001 for all comparisons). Excluded participants were also more likely to have previously diagnosed heart failure, be a current smoker, not have undergone a percutaneous coronary intervention during their acute hospitalization, have an index length of hospital stay greater than 3 days, have worse health literacy, and have impaired cognition than included participants ($p<0.05$ for all comparisons). The prevalence of financial barriers to care (38.4% vs. 29.0%), lack of a usual source of care (19.3% vs 14.2%), and transportation barriers (14.4% vs. 8.7%) to care were significantly higher among excluded than included participants ($p<0.001$ for all comparisons).

In the analytical sample, 305 (29.0%) participants had a financial barrier, 149 (14.2%) lacked a usual source of care, and 92 (8.7%) had a transportation barrier to receiving healthcare. Participants with each barrier tended to be younger, female, of a racial or ethnic minority, unemployed, not living with a spouse, and have strained monthly finances than those without the specific barrier (Table 3.1, $p<0.05$ for all comparisons). The prevalences of chronic lung disease, current smoking status, and mildly to severely impaired cognitive status were higher among those with the specific barriers to healthcare access compared to those without ($p<0.05$ for all comparisons).

Physical HRQOL

Mean PCS scores increased by 1.6 points ($p<0.001$) between 1 and 6 months after hospital discharge, from 42.4 to 44.0 points, although 25.5% of participants experienced a clinically meaningful decrease in their generic physical HRQOL (i.e., ≥ 3 points). Patients with each specific healthcare barrier had significantly lower mean PCS scores at 1 and 6 months post-discharge compared to their counterparts without such barriers (Table 3.2, $p<0.001$ for all comparisons). Overall, 31.5% who reported a financial barrier to care, 22.0% who lacked a usual source of care, and 31.5% who had a transportation barrier to care experienced a clinically meaningful decline in their physical HRQOL. Patients with a financial barrier to care had a significantly higher risk of experiencing a clinically meaningful decrease in their physical HRQOL compared to those without a financial barrier (adjusted RR 1.38, 95% CI: 1.10 to 1.72), but not those lacking a usual source of care or having a transportation barrier (Table 2).

Mental HRQOL

Mean MCS scores of the sample increased by 1.7 points from 50.9 points at 1 month to 52.6 points at 6 months post-discharge ($p<0.001$), but 25% of patients experienced a clinically meaningful decline in MCS scores (i.e., ≥ 3 points). Mean MCS scores were significantly lower among participants with each kind of healthcare barrier compared to those without such barriers at 1 and 6 months post hospital discharge (Table 3.3, $p<0.001$ for all comparisons). Slightly less than one third of participants with a financial barrier, lack of a usual source of care, or transportation barrier experienced a clinical meaningful decline in their mental HRQOL. Patients with a financial barrier to healthcare had significantly higher risk (adjusted RR 1.37, 95% CI 1.08 to 1.74) of a meaningful decline in their mental HRQOL compared to those without a financial barrier to care between 1 and 6 months post-discharge.

Disease-Specific HRQOL

The mean disease-specific HRQOL scores of the sample increased by 4.7 points from 76.2 to 80.9 points between 1 and 6 months post-discharge ($p<0.001$). Overall, 12.7% of participants experienced a clinically meaningful decline in their disease specific HRQOL (i.e., ≥ 16 points) during the 6 months after hospital discharge (Table 3.4). Participants with each healthcare barrier had lower mean SAQ QOL scores than their counterparts without such a barrier at 1 and 6 months post hospital discharge (Table 3.3, $p<0.001$ for all comparisons). Participants with each form of healthcare barrier had a modest, non-significantly elevated risk of experiencing declines in disease-specific HRQOL over the six months after hospital discharge.

Number of Barriers to Healthcare

Overall, 54.5% of patients had no healthcare barriers, 12.4% had just one barrier, and 33.1% had two or more barriers. Table 3.5 shows that the prevalence of clinically meaningful declines in PCS and MCS scores increased with increasing number of barriers to healthcare (p trend < 0.01), but not for SAQ QOL scores. Patients with two or more healthcare barriers had a higher risk of experiencing declines in generic physical (adjusted RR 1.38, 95% CI: 1.09 to 1.75) and mental (adjusted RR 1.51, 95% CI: 1.18 to 1.93) HRQOL over six months compared to those without any healthcare barriers. After multivariable adjustment, the magnitude of the point estimates for the relative risks of experiencing clinically meaningful declines in PCS and MCS scores increased with the number of patient barriers to healthcare access (*p for* trend <0.01 for both comparisons). We did not identify higher risks of declines in disease-specific HRQOL in those with one, as well as two or more, healthcare barriers compared to those without any healthcare barriers.

DISCUSSION

This prospective observational study of more than 1,000 hospital survivors of an ACS found that about one quarter of participants experienced a clinically meaningful decline in their physical and mental HRQOL over the six months after hospital discharge, while about one-tenth experienced a decline in disease-specific HRQOL. Compared to patients without barriers to healthcare, patients with a financial barrier had higher risks of experiencing clinically meaningful declines in physical and mental HRQOL over this period, but not those lacking a usual source of care or having a transportation barrier. We found that those with two or more specific barriers to care also had higher risks of experiencing declines in physical and mental HRQOL compared to those with no barriers. To the best of our knowledge, these are the first results to identify an association between barriers to healthcare with subsequent declines in generic mental and physical HRQOL after an ACS. We did not identify any association with the individual and total number of barriers to healthcare access with increased risks of experiencing declines in disease-specific HRQOL.

Barriers to Healthcare Access and HRQOL Scores

A limited number of studies have examined the relationship between healthcare access and HRQOL at a pre-specified time following hospitalization for an ACS, but did not examine changes over time.[20,29] In a nationwide cohort study of 2,498 patients who survived their hospitalization for an acute myocardial infarction (AMI) between 2003-2004, those reporting avoiding healthcare due to costs reported lower mean generic physical and mental HRQOL, as well as SAQ HRQOL, at one year after discharge compared to those without such a barrier.[20] Similarly, a risk standardization model developed with a cohort of 4,340 survivors of AMI recruited from 24 nationwide hospitals between 2005-2008 also found an association with cost-related avoidance of healthcare with lower SAQ HRQOL scores at one year post-discharge.[29] We could not identify any prior studies that examined the relationship between lacking a usual source of care nor having a transportation barrier with HRQOL after an ACS. Our findings show that those with a financial barrier to care, who lacked a usual source of care, or with a transportation barrier tended to have lower generic and disease-specific HRQOL than their counterparts at 1 and 6 months following hospital discharge. Clinicians seeking to optimize the well-being of their patients may want to pay particular focus to those with barriers to care.

Changes in Physical HRQOL

Our results suggest that those with financial barriers to care may also be more likely to experience subsequent declines in physical HRQOL. Patients with difficulty affording healthcare may be less likely to receive follow-up care and effective therapies, such as cardiac rehabilitation, that would otherwise protect their physical health.[9] Alternatively, such patients may unnecessarily limit physical activities after their ACS because they lack reassurance about their safety from healthcare providers. Qualitative and survey studies suggest that survivors of an ACS restrict physical work, even when objective tests demonstrate excellent exercise capacity, due to fears of inciting a subsequent coronary event.[94,95] Given that exercise may have a protective effect against a recurent coronary event, financial barriers to healthcare could further adversely affect patient's long-term survival.[96]

Changes in Mental HRQOL

As with changes in generic physical HRQOL, participants reporting a financial barrier to healthcare were more likely to experience a subsequent decline in generic mental HRQOL compared to those without such a barrier. In general, survivors of an ACS have a high risk of developing depression,[97] the severity of which can be captured in the mental health subscale, and is correlated with overall MCS scores.[86] Patients with financial constraints on their healthcare may have difficulty accessing standard therapies for depression, including pharmacotherapy and cognitive-behavioral therapy, and/or be less adherent to these treatment modalities than patients without cost-related constraints.[97] Moreover, the constrained-financial resources themselves, rather than the lack of professional psychological services, could cause declines in mental HRQOL. Since secondary prevention treatment may impose substantial out-of-pocket costs on patients,[98,99] patients may have to make financial sacrifices, such as foregoing social activities, that would otherwise sustain their spirits, or skip treatment and worry about an increased risk of a recurrent coronary event.[15]

We were surprised to not find an association between lacking a usual source of care or having a transportation barrier with experiencing clinically meaningful declines in either physical or mental HRQOL. Conceivably, the same factors that cause a patient to have a financial barrier to healthcare could also lead someone to lack a usual source of care and have a transportation barrier. Our adjusting for financial barriers could mask an association between the other two factors with declines in HRQOL. Alternatively, historical data suggests that many patients lack a usual source of care due to having good health and/or perceiving no need to regularly see a doctor.[100,101] Our inability to find an association between lacking a usual source of care with declines in HRQOL could result from us not being able to distinguish patients who could not obtain such care from those who did not require a usual source of care. Alternatively, some patients with a transportation barrier at admission may have been able to receive transport help from social contacts or through arrangements by healthcare providers after discharge, thereby attenuating the association between transportation barriers with subsequent declines in HRQOL. Future studies should specify the exact reason for patients lacking a usual source of care and transportation for healthcare visits.

Changes in Disease-Specific HRQOL

In our data, individual and composite measures of barriers to healthcare did not predict declines in disease-specific HRQOL over the six months after hospital discharge with statistical significance. However, the positive point estimates for these relationships may suggest that this study was under powered. Alternatively, the three relevant items on the SAQ QOL measure ask patients to assess the impact of angina-like symptoms on their enjoyment of life, their satisfaction with their current state of anginal symptoms, and their overall concern about a subsequent coronary event.[87] Discrepancies between the generic physical and disease-specific HRQOL measures may be due to the latter's emphasis on symptoms of angina.

While the results of this study are insufficient to recommend particular interventions to optimize HRQOL after an ACS, it does leave open the possibility that actions to improve healthcare access may result in better HRQOL. A contemporary systematic review on interventions and changes in HRQOL after an AMI did not identify any studies that used improvements in healthcare access.[83] Some evidence suggests that improvements in HRQOL may result from improving healthcare access among the general population. An analysis of 20,745 individuals in the Portland, Oregon metropolitan area randomized to receive, or not, an invitation to apply for Medicaid in 2008 found that those offered to receive health coverage had greater generic mental HRQOL, on average, after two years compared with those who did not receive an offer to apply.[102] Similarly, the coverage gains through the 2006 Massachusetts healthcare reform and 2010 Affordable Care Act may have also led to gains in beneficiaries self-reported health.[84] As results from healthcare policy initiatives suggest that improvements in healthcare access may enhance HRQOL,[84] further research is warranted to more fully understand how enhancing healthcare access among survivors of an ACS may also improve their HRQOL and how providers might play a critical role in this process.

Study Strengths and Limitations

Strengths of this study include its large sample size and assessment of multiple barriers to healthcare as well as generic and disease-specific forms of HRQOL. In assessing clinically meaningful changes in HRQOL, we not only measured an outcome that matters to patients, but also permitted better identification of patients at risk of poorer outcomes than by examining mean changes in HRQOL. We acknowledge several limitations including the potential for selection bias due to fairly high loss to follow-up. Our study sample may not be representative of the national population of ACS survivors. Since this study did not assess changes in healthcare access over time, patients who experienced changes in their access following hospital discharge may have been misclassified. We also did not have insurance claims for participants describing their use of medications and clinician services in the time after hospital discharge that would better elucidate the potential mechanisms between barriers to healthcare and declines in HRQOL. Lastly, unmeasured confounders, such as the receipt of social services during and after hospitalization, changes in employment, or family related matters may have affected the relationship between barriers to healthcare access and changes in HRQOL.

Conclusion

In this study, survivors of an ACS who have difficulty affording healthcare are more likely to experience clinically meaningful declines in generic HRQOL than patients with better healthcare access. Given the high prevalence of barriers to healthcare in the U.S., additional research is warranted to finding the best approaches to improve healthcare access among patients with an ACS, and perhaps, consequentially, their health status through actions such as health policy changes and better referral of at-risk patients to support services.

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Table 3.1: Baseline characteristics of survivors of a hospitalization for an acute coronary syndrome according to presence of specific barriers to healthcare access

Characteristics	Full Sample (n = 1,053)	Financial Barrier (n = 305)	No Usual Source of Care (n = 149)	Transportation Barrier (n = 92)
Sociodemographic				
Age, mean, yrs (SD)	62.7 (10.8)	58.2 (9.9)	57.5 (11.1)	59.6 (10.0)
Female (%)	33.0	41.3	27.5	44.6
Non-Hispanic White (%)	80.3	68.9	63.8	63.0
Education (%)				
Less than high school	10.6	16.1	18.1	22.8
High school	29.5	35.7	40.9	29.3
Some college / post-high school	30.8	30.2	25.5	30.4
College graduate	29.1	18.0	15.4	17.4
Living Situation (%)				
With spouse	52.4	42.6	35.6	26.1
With family (non-spouse)	14.2	21.0	22.1	28.3
With non-family	13.3	14.1	18.8	19.6
Alone	20.0	22.3	23.5	26.1
Employment Status (%)				
Retired	42.5	26.9	20.8	32.6
Working	40.9	40.7	50.3	21.7
Unemployed	16.6	32.5	28.9	45.7
Finances at End of Month (%)				
Some left over	50.7	21.0	38.3	18.5
Just enough to make ends meet	34.1	43.0	34.9	41.3
Not enough to make ends meet	15.2	36.1	26.8	40.2
Clinical				
GRACE score, mean (SD)*	96.1 (26.5)	90.0 (25.4)	89.9 (25.8)	96.6 (27.0)
Prior Medical History (%)				
Arthritis	21.2	19.0	14.1	20.7
Cancer	12.2	11.5	11.4	13.0
Chronic lung disease	18.0	22.6	20.8	30.4
Chronic kidney disease	9.5	8.9	12.1	20.7
Diabetes	30.9	38.0	25.5	54.3
Heart disease	50.3	56.7	48.3	68.5
Heart failure	11.2	14.1	8.7	22.8
Hyperlipidemia	70.7	73.1	59.1	77.2
Hypertension	75.0	77.4	68.5	87.0
Peripheral vascular disease	9.6	9.2	9.4	17.4
Stroke/TIA	8.4	8.9	7.4	14.1
Smoking Status (%)				
Never smoked	31.1	26.9	20.8	18.5
Former smoker	49.1	42.3	43.0	45.7
Current smoker	19.8	30.8	36.2	35.9
ACS Type (%)				
STEMI	16.0	11.5	16.1	10.9
NSTEMI	54.9	58.4	55.7	57.6
UA	29.2	30.2	28.2	31.5
Reperfusion Therapy (%)				
PCI	69.2	68.9	61.1	69.6
CABG Surgery	12.9	10.5	16.8	13.0
No PCI nor CABG	17.9	20.7	22.1	17.4
Length of stay ≥ 3 Days (%)	49.4	50.5	55.0	57.6

(continued)

Table 3.1 (continued).

Characteristics	Full Sample (n = 1,053)	Financial Barrier (n = 305)	No Usual Source of Care (n = 149)	Transportation Barrier (n = 92)
Psychosocial				
Health Literacy (%)				
High	69.0	61.6	65.1	50.0
Medium	16.4	17.4	14.1	30.4
Low	14.5	21.0	20.8	19.6
Cognitive Status (%)				
Normal	67.1	59.3	54.4	43.5
Ambiguous	29.5	34.8	40.3	46.7
Mildly or Severely Impaired	3.3	5.9	5.4	9.8
Patient Activation (%)				
Level 1: Disengaged (lowest)	8.8	12.8	10.1	17.4
Level 2: Aware	40.7	40.7	41.6	43.5
Level 3: Taking Action	21.2	21.0	20.8	15.2
Level 4: Maintaining Behaviors	29.2	25.6	27.5	23.9

Abbreviations: ACS, acute coronary syndrome; NSTEMI, non-ST-segment elevation myocardial infarction; STEMI, ST-segment elevation myocardial infarction, TIA, transient ischemic attack; UA, unstable angina

*GRACE risk scores (2.0) incorporate data on age, cardiac biomarkers, ST segment changes, systolic blood pressure, creatinine or history of renal dysfunction, Killip class or use of diuretics, development of cardiac arrest during the index hospitalization to calculate risk for mortality in-hospital, with higher scores indicating a higher probability of death.

Table 3.2: Scores and clinically meaningful declines in generic physical health-related quality of life among survivors of an acute coronary syndrome between and 1 and 6 months after hospital discharge

	Financial Barrier to Care		No Usual Source of Care		Transportation Barrier	
	Yes (n = 305)	No (n = 748)	Yes (n = 149)	No (n = 904)	Yes (n = 92)	No (n = 961)
Mean SF36v2 PCS Scores						
1 Month Post Discharge (SD)	39.2 (10.8)	43.7 (9.9)	41.1 (10.5)	42.6 (10.3)	38.7 (10.0)	42.7 (10.3)
6 Month Post Discharge (SD)	40.0 (11.9)	45.7 (10.9)	42.9 (11.8)	44.2 (11.5)	38.6 (11.5)	44.5 (11.4)
Mean Change (SD)	0.8 (8.7)	2.0 (8.5)	1.8 (8.4)	1.6 (8.6)	-0.1 (8.0)	1.8 (8.6)
Experiencing Clinically Meaningful Decline (%)	31.5	23.0	22.2	26.0	31.5	24.9
Relative Risks Ratios (95% CI) for Clinically Meaningful Decline						
Adjusted for Barriers Only	1.36 (1.10, 1.70)	Referent	0.81 (0.59, 1.11)	Referent	1.17 (0.83, 1.63)	Referent
Fully Adjusted*	1.38 (1.10, 1.72)	Referent	0.87 (0.63, 1.22)	Referent	1.00 (0.72, 1.39)	Referent

Note: The SF36v2 PCS is scored on a scale of 0-100 with higher scores indicating better generic physical health-related quality of life. A clinically meaningful decrease was defined as a decline of ≥3.0 points between 1 and 6 months after hospital discharge.

*Adjusted for clinical site, age, sex, race/ethnicity, education, employment status, reperfusion therapy, GRACE risk score (incorporates data on age, cardiac biomarkers, ST segment changes, systolic blood pressure, creatinine or history of renal dysfunction, Killip class or use of diuretics, development of cardiac arrest during the index hospitalization), 1 month SF36v2 PCS score, 1 month SF36v2 MCS score

Table 3.3: Scores and clinically meaningful declines in generic mental health-related quality of life among survivors of an acute coronary syndrome between and 1 and 6 months

	Financial Barrier to Care		No Usual Source of Care		Transportation Barrier	
	Yes (n = 305)	No (n = 748)	Yes (n = 149)	No (n = 904)	Yes (n = 92)	No (n = 961)
Mean SF36v2 MCS Scores						
1 Month Post Discharge (SD)	47.4 (12.5)	52.3 (10.2)	47.6 (13.8)	51.4 (10.2)	44.3 (13.0)	51.5 (10.3)
6 Month Post Discharge (SD)	48.8 (12.4)	54.1 (9.8)	49.4 (14.0)	53.1 (10.5)	44.4 (13.4)	53.3 (10.8)
Mean Change (SD)	1.4 (10.6)	1.8 (9.2)	1.9 (11.2)	1.7 (9.4)	0.1 (10.8)	1.9 (9.5)
Experiencing Clinically Meaningful Decline (%)	30.8	22.1	28.2	24.0	32.6	23.8
Relative Risks Ratios (95% CI) for Clinically Meaningful Decline						
Adjusted for Barriers Only	1.35 (1.07, 1.69)	Referent	1.11 (0.84, 1.47)	Referent	1.23 (0.88, 1.71)	Referent
Fully Adjusted*	1.37 (1.08, 1.74)	Referent	1.12 (0.84, 1.49)	Referent	1.28 (0.91, 1.80)	Referent

Note: The SF36v2 MCS is scored on a scale of 0-100 with higher scores indicating better generic mental health-related quality of life. A clinically meaningful decrease was defined as a decline of ≥3.0 points between 1 and 6 months after hospital discharge.

*Adjusted for age, sex, race, clinical site, employment status, reperfusion therapy, 1 month SF36v2 MCS score

Table 3.4: Scores and clinically meaningful declines in disease-specific health-related quality of life among survivors of an acute coronary syndrome between and 1 and 6 months after hospital discharge

	Financial Barrier to Care		No Usual Source of Care		Transportation Barrier	
	Yes (n = 305)	No (n = 748)	Yes (n = 149)	No (n = 904)	Yes (n = 92)	No (n = 961)
Mean SAQ QOL Scores						
1 Month Post Discharge (SD)	68.0 (25.2)	79.5 (20.5)	69.3 (24.7)	77.3 (22.0)	64.5 (25.2)	77.3 (22.0)
6 Month Post Discharge (SD)	73.9 (24.0)	83.7 (18.4)	73.0 (27.2)	82.2 (19.1)	68.3 (27.4)	82.1 (19.5)
Mean Change (SD)	5.8 (20.9)	4.2 (19.3)	3.7 (21.3)	4.9 (19.5)	3.8 (24.4)	4.8 (19.3)
Experiencing Clinically Meaningful Decline (%)	14.1	12.2	17.5	12.0	16.3	12.4
Relative Risks Ratios (95% CI) for Clinically Meaningful Decline						
Adjusted for Barriers Only	1.09 (0.77, 1.55)	Referent	1.42 (0.96, 2.11)	Referent	1.22 (0.75, 2.03)	Referent
Fully Adjusted*	1.07 (0.75, 1.55)	Referent	1.22 (0.81, 1.82)	Referent	1.08 (0.66, 1.77)	Referent

Note: The Seattle Angina Questionnaire quality of life (SAQ QOL) questionnaire is scored on a scale of 0-100 with higher scores indicating better disease-specific health-related quality of life. A clinically meaningful decrease was defined as a decline of ≥16.0 points between 1 and 6 months after hospital discharge.

*Adjusted for age, sex, race, clinical site, education, living situation, reperfusion therapy, GRACE risk score (incorporates data on age, cardiac biomarkers, ST segment changes, systolic blood pressure, creatinine or history of renal dysfunction, Killip class or use of diuretics, development of cardiac arrest during the index hospitalization), 1-month SAQ QOL score, 1 month SF36v2 MCS score

Table 3.5: Clinically meaningful declines in health-related quality of life among survivors of an acute coronary syndrome between and 1 and 6 months after hospital discharge according of total number of barriers to healthcare access

	No Barriers (n = 630)	**1 Barrier** (n = 118)	**2 or More Barriers** (n = 305)
SF36v2 PCS Scores			
Experiencing Clinically Meaningful Decrease (%)	22.9	23.7	31.5
Relative Risks Ratios (95% CI) for Clinically Meaningful Decrease			
Unadjusted	Referent	1.04 (0.73, 1.48)	1.38 (1.11, 1.71)
Adjusted*	Referent	1.01 (0.70, 1.47)	1.38 (1.09, 1.75)
SF36v2 MCS Scores			
Experiencing Clinically Meaningful Decrease (%)	21.1	27.1	30.8
Relative Risks Ratios (95% CI) for Clinically Meaningful Decrease			
Unadjusted	Referent	1.28 (0.92, 1.76)	1.46 (1.17, 1.83)
Adjusted†	Referent	1.35 (0.97, 1.88)	1.51 (1.18, 1.93)
SAQ QOL Scores			
Experiencing Clinically Meaningful Decrease (%)	11.4	16.1	14.1
Relative Risks Ratios (95% CI) for Clinically Meaningful Decrease			
Unadjusted	Referent	1.41 (0.88, 2.25)	1.23 (0.87, 1.75)
Adjusted‡	Referent	1.06 (0.67, 1.70)	1.09 (0.74, 1.61)

Note: For the SF36v2 PCS and MCS, a clinically meaningful decrease was defined as a decline of ≥3.0 points between 1 and 6 months after hospital discharge. For the Seattle Angina Questionnaire quality of life (SAQ QOL) scale, a clinically meaningful decrease was defined as a decline of ≥16.0 points between 1 and 6 months after hospital discharge.

* Adjusted for clinical site, age, sex, race/ethnicity, education, employment status, reperfusion therapy, GRACE risk score, 1 month SF36v2 PCS score, 1 month SF36v2 MCS score

† Adjusted for age, sex, race, clinical site, employment status, reperfusion therapy, 1 month SF36v2 MCS score

‡ Adjusted for age, sex, race, clinical site, education, living situation, reperfusion therapy, GRACE risk score, 1-month SAQ QOL score, 1 month SF36v2 MCS score

CHAPTER IV: HOMEWARD BOUND: PATIENTS’ PERSPECTIVES ON CARE TRANSITIONS AFTER A HOSPITALIZATION

ABSTRACT

Background: Poor care transitions from the hospital to home (transitions) may lead to adverse patient outcomes. As reimbursement becomes increasingly linked to clinical and patient-centered outcomes, providers have strong incentives to better manage transitions. Patients may possess key insights to better assess and improve transitions.

Methods: In this qualitative study, we performed semi-structured concept elicitation interviews with patients experiencing a transition following an unplanned hospitalization in medical and surgical wards at a single academic medical center. Three analysts independently analyzed transcripts to identify themes within and outside the medical centers that influenced patients’ transition.

Results: Our analyses of interview transcripts of 22 patients identified four themes related to actions of discharging medical centers and five themes outside of the direct purview of the discharging hospital that influence transitions. In the medical center, participants generally described positive roles for quality patient-centered care, opportunities for patient participation, comprehensive discharge education, and coordination of medical services on their transitions. Outside of the medical center, participants reported that having caregiver support, social support, health literacy, adequate health insurance, and accessibility to healthcare and non-healthcare resources following hospital discharge assisted their transitions.

Conclusions: This qualitative study suggests that both actions of medical centers to engage and assist patients and a patient’s ability to utilize resources contributes to successful transitions. Future work on strategies to develop better patient-centered transitions, and their effect on patient outcomes is warranted.

INTRODUCTION

Care transitions home after an unplanned hospitalization require complex coordination among patients, caregivers, and multiple providers over a short period of time, and therefore presents multiple opportunities for harmful and costly errors.[42-44] One quarter of preventable 30-day readmissions may result from failures in the transition process such as inadequate patient education, outpatient follow-up, and medication reconciliation.[103] Trials have shown that interventions on care transition process, such as providing patient education, case management, and early follow up, can improve patient outcomes.[104,105] However, there is a lack consensus on optimal transition practices.[105,106]

Better understanding of patient perspectives may better inform interventions for transitions.[107] As patients may be the only common link between different providers in the fragmented US healthcare system,[108] their input may be essential for designing optimal transitional care. In this qualitative study, we sought to identify and describe patient views on key factors for transitions to the home after an unplanned hospitalization.

METHODS

This study uses data from an ongoing, PCORI-funded project to develop a new validated measure of patient perceptions of the quality of transitions. To identify pertinent domains, we interviewed 22 patients who were discharged directly home after an unplanned hospitalization for an acute surgical or medical condition at a 781-bed tertiary care hospital in central Massachusetts.

Materials

Drawing upon themes identified in the literature and prior studies of transitions, we developed a preliminary guide for semi-structured concept elicitation interviews for patients to identify and describe factors relevant to their transition from hospital to home. An iterative process of consultation from two clinicians with experience in transitional care, input from a multi-stakeholder advisory board of 2 clinicians, 1 nurse, 3 patients, and 1 healthcare administrator, and results of patient piloting testing, informed the development of the final guide. Starting with open-ended questions followed by specific, verbal probes, the guide directed patients to describe their overall transitions and factors influencing their transitions within and outside of the healthcare system.

Recruitment and Interviews

Eligible participants were 21 years or older, fluent in English, had an unplanned admission lasting two or more midnights (inpatient), and were discharged alive. Exclusion criteria included having a planned admission, a prior hospitalization within 90 days, observational status (less than two midnights), and/or cognitive impairment. Using purposive sampling,[109] providers identified potential participants treated in surgical and medical wards; study staff approached inpatients, and described the study along with potential benefits and risks. Participants who provided written consent participated in an audio-recorded in-person or telephone interview with one of two trained interviewers between 23 to 73 days after hospital discharge (median:33).

Study staff approached 75 out of 110 potentially eligible participants; 37 enrolled in the study. Between October 2015 and March 2016, study staff conducted 14 in-person interviews and 8 telephone interviews; interviewers were unable to schedule times to interview the other 15 enrollees. Interviews lasted 13 to 44 minutes (mean 23.2). Interview audio recordings were transcribed and imported into NVivo v.11.3.2 for coding and analysis (QSR International, Melbourne, Australia). The University of Massachusetts Medical School Institutional Review Board approved this study.

Analysis

Using triangulation,[110] transcripts were analyzed by three investigators from diverse academic backgrounds to minimize disciplinary and personal bias. Following grounded theory, an inductive approach,[111,112] each analyst reviewed transcripts to identify concepts, categories, and themes. Through a process of open coding, each team member independently generated nodes for newly identified themes.[113] To achieve consistency between coders, the team used a constant comparison method whereby they would meet to compare coding and memo descriptions of the interviews. Inter-coder agreement was evaluated, allowing a unified codebook, or taxonomy, to emerge.[114] The analysts reviewed the coding taxonomy, with any disagreements resolved by an independent adjudicator. We stopped after the 22nd interview as we had reached theoretical saturation.[115]

RESULTS

Among the 22 participants, ages ranged from 22 to 82 (median = 56.5), all but 4 were non-Hispanic and white, 13 were male; 18/22 had admissions to medical, rather than surgical, services (Table 4.1). We identified 23 separate concepts that were pertinent to the scope of this manuscript that we summarized into nine themes (Table 4.2) that are described with representative quotations in Tables 4.3 and 4.4.

Themes Related to the Discharging Medical Center

Care Quality: All participants reported that the perceived quality of their inpatient care influenced the success of their transition, particularly with regards to the length of hospital stay, information exchange, and provider-rapport. Participants reported the importance of being kept in the hospital for sufficient but not excessive periods of time. Some participants felt frustrated when break downs in coordination after successful treatment of their medical issue made their hospital stays unnecessarily lengthy. Others felt that they were discharged too soon after they received treatment for their health issues; they would have preferred longer stays in order to be more emotionally ready for discharge and have more monitoring by health professionals before returning home. When providers kept “the patient informed” about his or her in-hospital treatment and discharge planning, participants felt greater satisfaction, had more opportunities to “mentally prepare” for their transitions, and were better able to make arrangements with non-professional caregivers to ease the transition home. Optimal steps for communication included informing which provider(s) were primarily responsible for their care, ensuring providers took “their time to explain everything” and answer questions, and accommodating language barriers by speaking slowly, using interpretative services, and providing documentation in the patient’s native language. Seven participants described how confidence in their transition was enhanced through better rapport with providers, such as having providers demonstrate “concern” about their care and on “trying to get [patients] out of the hospital” as soon as possible.

Patient Participation: Participants described how being “involved in the discharge planning” was beneficial for their transitions (Table 2). Perceived benefits of patient participation included ensuring patients were physically and emotionally “ready to go home,” had special services set up before discharge, were able to follow the proposed discharge plan, and had adequate time to plan for their transition before discharge as well as to question providers about their post-hospital care.

Discharge Education: All participants reported receiving education about their transition, with varying levels of satisfaction. Participants learned about their diagnosis and hospital course, disease management, limitations to performing activities of daily living, symptoms requiring urgent evaluation, contacts for questions, follow up care, discharge medications, and potential adverse medication effects. Some participants reported receiving inadequate information about “how big a risk” they had for disease complications and about who to contact for medical advice after discharge. All participants reported receiving verbal and written discharge instructions, with one participant describing written instructions as a “confidence booster” during the transition. All participants reviewed their discharge instructions with a nurse; a few desired an opportunity to ask additional questions with a physician following this. Several participants reported difficulty comprehending verbal instructions due to perceived medication side effects and being “groggy” after a long hospital stay.

Coordination: All participants described either directly or potentially benefiting from inpatient providers coordinating services and outpatient care during transitions. Participant responses suggested a preference for having inpatient providers minimize the patients’ burden to organize healthcare after discharge. For instance, participants favorably described inpatient providers scheduling outpatient follow-up, obtaining transportation services, scheduling in-home services before discharge, and contacting outpatient pharmacies. Participants found in-home services, such as visiting nurses, to be valuable resources. Overall, participants benefited from outpatient follow-up care, describing these providers as “tighten[ing] up loose ends” and serving as “checks and balances to make sure everything is going well.” Participants saw poor coordination including lack of follow-up after discharge, outpatient care scheduled long after discharge, and improperly timing in-home services as failures in their transitions.

Themes Outside of the Discharging Medical Center

Caregiver Support: Overall, participants reported receiving assistance from a caregiver during their transition including a spouse or partner, child, sibling and/or parent (Table 3). Participants positively described caregiver involvement in the hospital to review and finalize the care plan and “asking questions,” particularly if patients were experiencing cognitive impairment. After discharge, participants reported a variety of help from caregivers in tasks such as interpreting and implementing the care plan, delivering “psychological support,” providing “help with medications,” driving for appointments and errands, and preparing meals. Five participants described how their caregiver helped carry out activities of daily living that they could not otherwise accomplish due to their medical condition.

Social Support: Interviewers queried participants on how social support beyond their caregivers might impact the care transition; participants described a positive role for social support including extended family, friends, and members of religious organizations (Table 3). Social support was noted to ease the stress of the transition. Participants reported that social networks were helpful for obtaining meals, transportation, and fulfilling errands. One participant noted that “community is a big thing in making sure you can get back to normal.”

Health Literacy: All 22 participants discussed benefits of written (“understand the paperwork”) and oral health literacy (“the ability to ask questions”) in their care transitions, mainly as a product of their formal education. Five participants described greater education as being an asset during in-hospital discharge education, particularly for comprehension and having productive conversations with providers. After hospital discharge, participants who at least had some college described having greater education as being beneficial for implementing the care plan, problem solving, and obtaining resources to better understand their disease. The five participants who received a high school diploma or less all denied that their education background affected their transition, although one also noted that “it’s a lot easier if you have a little bit more education to help understand what you should do.” Three participants with prior healthcare training described their educational background as an important asset in the transition.

Health Insurance: Twenty participants reported that health insurance had an important role both during and after their hospitalizations. Three participants reported concern that inadequate coverage may lead to premature discharge. In contrast, one patient described her insurer “blocking” her discharge because of its refusal to cover a medication. Eight participants reported that inadequate health insurance could prevent patients from executing the post-discharge treatment through financial barriers to obtaining medications, outpatient follow-up care, and in-home services. Four participants noted how sufficient health insurance coverage led to less stress during their transition. Two participants denied that their insurance coverage affected their transition; one patient reported that she “always had this insurance,” while another reported that “it shouldn’t [matter] unless you don’t have it.”

Accessibility: Participants described the importance of accessibility to healthcare and other resources for the transition as determined by their residential location and access to transportation. Participants noted that transportation was needed to obtain prescription medications, attend outpatient follow-ups, and acquire essentials such as groceries. Nine participants reported that a caregiver or friend supported their transition by “play[ing] chauffeur” when they could not drive. Participants described low socioeconomic status, lack of social support, and medication side effects as specific barriers to transportation. Nine participants (including 3 suburban, 2 rural, 2 urban residents) indicated that a “larger population [area] is better for more immediate support” stating that transitions may be more difficult in rural areas with little or no public transportation and further distance from social support pharmacies, hospitals, and stores. However, participants viewed home location only to be a problem if a patient lacked a source of transportation.

DISCUSSION

Our interviews with 22 patients with unplanned hospitalizations reveal that patients perceive factors within and beyond the direct control of the discharging hospital influenced their transitions. In general, patients viewed provider actions to deliver patient-centered care, invite patient participation, provide discharge education, and to coordinate services to be particularly beneficial for their transitions. Patients also found their transition to be facilitated by caregiver assistance, social support, greater education, adequate health-insurance, and accessibility to health resources.

Participants' experience suggests that medical centers can improve transitions by involving patients' in the discharge process while limiting their need to coordinate their own care following discharge. Better patient participation, comprehensive discharge education, and care coordination appear to be plausible strategies in addressing deficits found in quantitative studies of transitions. Poor patient education and follow-up care were identified as leading causes of preventable readmissions among 1,000 patients treated between 2012-2013 at 12 nationwide academic medical centers.[116] However, multiple barriers exist for improving transitions through the mechanisms reported by our study participants. Suboptimal patient participation in healthcare may result from low health-literacy, cognitive impairment, and inadequate provider time or inclination.[117] Inadequate discharge education may result from the lack of standardized processes to assess patients' informational needs.[118] Failures of coordination between inpatient and outpatient providers also result from the fragmentation of care, lack of financial resources, and inadequate training.[119] Lastly, absent financial compensation or incentives, healthcare systems may lack the resources to adopt transition interventions that patients value..[105,120,121]

Medical centers may encounter additional challenges in overcoming deficits in factors beyond their direct control. Many caregivers lack the training and emotional resilience for such roles; policymakers and clinicians have historically neglected to include and support caregivers.[122] Better transitions may results from engaging caregivers in the discharge process and through enhanced coordination of post-discharge services. The presence of additional social support besides the primary caregivers may reduce stress, promote better self-care behaviors, and be protective against hospital readmissions.[123,124] Providers have tested physical and virtual support groups to furnish additional social support to patients with chronic diseases, but the scalability of such interventions remain questionable.[123]

Participants also benefited from additional internal and external resources apart from those provided by the discharging medical center, including health-literacy, health insurance, and accessibility to healthcare resources. Participants described the utility of written and oral health literacy during and after hospital discharge. Systematic review and meta-analytic evidence suggests that patients with worse literacy may have worse treatment adherence and clinical outcomes.[125,126] This emphasizes the importance of assessing and accommodating patients' literacy levels,[127] particularly when a high proportion of discharge education materials may be unsuitable for some individuals.[128] A similar awareness about patients' ability to access healthcare resources based on their home location and availability of transportation may also benefit transitions; although government and commercial payers offer non-emergency medical transportation, many such services can be costly, and historically have been unreliable.[47] The influence of these factors in patient transitions suggests the difficulty of finding a "one-size" fits all approach towards transitions.

Our findings both overlap and extend upon themes identified as being influences on pertinent transitions in other qualitative studies. In conducting formative interviews for the development of the Care Transition with 49 elderly patients with a recent transition, Coleman and colleagues perceived adequate information transfer, patient and caregiver preparation, self-management support, and empowerment to assert preferences as elements of good transitions.[129] An ethnographic study of 24 enrollees of Kaiser Permanente also identified inclusion of caregivers, personal connection with providers, ability to implement health knowledge into self-care, and making advanced arrangements to fulfill needs as some of the key elements of transitions from the hospital to the outpatient setting.[130] A qualitative study of 40 patients who experienced transitions home with home health services, along with 35 caregivers and 15 home health clinicians, also described the importance of adequately educating patients and caregivers prior to discharge as well providing comprehensive discharge instructions for transitions.[131] Such themes overlap with our findings on the importance of quality of patient-centered care, discharge education, coordination, and caregiver support on transitions. Our results also provide additional emphasis on the need to consider patients' healthcare resources, accessibility, and health literacy in planning transitions.

We acknowledge several limitations. As with all qualitative research, we present exploratory findings that do not provide conclusive evidence of the influence of the described factors on care transitions. While our sample includes participants with diverse medical conditions, age, and education-levels the generalizability of our findings may be limited from our sampling English speakers at a single academic medical center in the northeastern US. We performed semi-structured interviews with prompts for many of the themes presented in our findings; this may have biased the participants towards considering certain items as influencing their care transitions.

CONCLUSIONS

This qualitative analysis of patients' experience transitioning home after an unplanned hospitalization suggests that both patients' individual circumstances and clinician actions influence the success of care transitions. Additional study of the role patient factors in care transitions, and ways in which hospital systems can address deficits in these factors, is warranted.

Table 4.1: Sociodemographic and clinical characteristics of qualitative interview participants (*n*=22) with an unplanned hospitalization

Characteristic	
Age, (y), median (Range)	56.5 (22 to 82)
< 50	5/22
50 – 59	7/22
60 – 69	6/22
70 or older	4/22
Female (n)	9/22
Non-Hispanic White (n)	18/22
Education*	
High School or Less	5/17
Some College	5/17
2-4 Years of College	4/17
Graduate Education	3/17
Primary Diagnosis (n)	
Cardiovascular	
Acute Coronary Syndrome	4
Angina, Stable	1
Dysrhythmia	2
Heart Failure	2
Pericarditis	1
Pulmonary	
Asthma Exacerbation	3
Pulmonary Embolism	1
Pulmonary Hypertension	1
Surgical	
Acute Limb Ischemia	1
Small Bowel Obstruction	1
Trauma	2
Other	
Migraine	1
Sepsis	2

*education data unavailable for 5 participants

Table 4.2: Concepts identified in qualitative interviews with patients (n=22) on care transitions, organized into 9 themes

Themes	**Concepts**
Related to the Discharging Medical Center	
Quality of Inpatient, Patient-Centered Care	Reason for Hospitalization Appropriate length of stay Communication with provider Languages spoken
Patient Participation	Patient involvement in discharge process
Discharge Education	Information given at discharge Understanding medication Receiving discharge information Additional discharge information requested
Coordination	Healthcare professional at home Helpfulness of discharger Logistics of discharge Outpatient clinical care post-discharge Post-discharge services
Outside of the Discharging Medical Center	
Caregiver Support	Caregiver involvement in discharge process Caregiver-provider communication
Social Support	Role of external social support
Health Literacy	Literacy impact Education impact
Health Insurance	Financial resources Insurance impact on transition
Accessibility	Geographical impact on transition Transportation and transition

Table 4.3: Themes and key quotations exemplifying patient perspectives on themes related to the discharging medical center as important for the care transition home after an unplanned hospitalization

Themes Outside the Discharging Medical Center Important to Care Transitions (number of participants citing this theme)	**Representative Quotations**
Quality of Inpatient, Patient-Centered Care (22/22)	"I think that keeping the patient informed as soon as the medical people have the info is the best time to do it. If that's the first day, then they can outline it. Or if not, they can say we're not sure about your discharge, we need to run these tests. If it's the next day and they say you'll be going home in a couple of nights, that's fine too." "[My doctor] and I hit it off and he's looked out for me and I respect him a lot for all of the things he did. He tells me I compliment him too much but he saved my life but he's just an incredibly warm man, very concerned about, in this case the heart and all of the functions that surround it.
Patient Participation (20/22)	"It's always good to be involved in this. It's good to have a lot of input on what the transition to home is going to be. It's good to be helpful and to tell the hospital what situations I am going to be in; like how my house is set up and whether I have to climb stairs so they know how to help me." "I liked that they asked me if I felt ready to go home. And liked that they told that if I didn't feel ready I didn't have to be rushed out. And I was like 'no I'm ready', you know."
Discharge Education (22/22)	"I think if you have any questions, they should answer them, which they did. I think they should give you some idea of how long it should take you to reach the point that you want to reach. And what to expect and what not to expect. In my case, my walking is not going to get any better." "I was given a list of medication and prescriptions and instructions on how to take them. I was given a list of things I should do, can't do, limitation, numbers to call in case I had any questions. I was told that if such and such happens to this degree you don't have to treat it as an emergency then call us the next day. If this happens to an extended degree, then call us right away. If it happens to you in a much larger degree then call 9-1-1….It was given to me by the nurse, the day of my discharge both verbally and on paper. She sat down on a chair next to me and asked me questions. … She was even able [to answer] simple questions like, if want coffee, should I have caffeinated or decaffeinated."

Table 4.3 (continued)

Coordination (22/22)	“They just made sure I had everything. They actually faxed over my prescriptions to, you know, the CVS for me. The nurse actually went above and beyond and you know, walked the list down the pharmacy here so they would be ready when I was leaving with my family member and they just didn’t accept my health insurance. So she came all the way back upstairs to give them to me instead of just leaving them down there. And then went above and beyond and asked to the nurse to fax them to my CVS. So that was very helpful, very helpful.” “The [Visiting Nurse Association] was sending nurses and I was on the Coumadin… But I am glad that they were available and were able to come see me.... The nurses did ask me those questions every time they came… they asked me a question if I had blood in my stool and I think so but the color of the stool was black and like tar and that’s what told them that I should go to the emergency and sure enough I was bleeding.” “Once I am discharged I am on my own. However, I never got any follow-up. That was very surprising to me. Because usually we go to urgent care and get some prescriptions and the next day they call to see how you are doing. We didn’t get any call for two weeks. There is some tension in there.”

Table 4.4: Themes and key quotations exemplifying patient perspectives on patient-centered factors related to the care transition home after an unplanned hospitalization

Themes Outside of the Discharging Medical Center Identified as Important to Care Transitions (number of participants citing this theme)	**Representative Quotations**
Caregiver Support (16/22)	“He was the advocate, he was the one asking questions and making sure that everything was lined up. I couldn’t move a whole bunch, so he was helping me get to the car, helping me get out of the car, um packing up all me stuff, making sure all of the follow up appointments were kind of ready and set up.” “I was not in my right mind. I read my discharge papers over and over and over, looking for, you know…I just couldn’t keep focus. So the fact that I had a family member there, who was like ‘no, this is why you were there, this is the medication…’ You know, just…I can’t imagine being alone in that process.” “My wife was there; she helped to drive me home, she provided food, she provided help when I couldn’t get up, she made sure I was taking my medications at the right time because I was in pain and couldn’t do too much. She did everything I needed.”
Social Support (21/22)	“You may have anxiety about leaving the hospital and [social support] can help with those kinds of feelings. When I first came home the hospital I was afraid to leave the house because I felt like I would have another heart attack and there would be no one there to help.” “Social support is very important because it kind of helps you forget what you are going through. I have a lot of support from church and my friends… I have people visiting me every day bringing me things like fruit and items. And I have people praying for me.”
Health Literacy (22/22)	“A lot of the stuff that was talked about was knowledge I knew from pharmacy and being a dentist. I certainly felt like I could discuss with them on a different playing field then a lot of people would be able to discuss as far the medications and the symptoms and the cause and effects. It was advantage to have some knowledge to know how things work. You sometimes have more knowledge than the doctors do.” “I don’t think I received any education [on asthma]. Again, because I do research and I’m a professor, I know how to get in to the NIH website and download all the studies and I can understand them when I read them, but how typical is that?”

Table 4.4 (continued)

Health Insurance (20/22)	“In my case I have good insurance. I don’t have to wait for bills to be paid and that’s a great privilege. If I had to pay thousands of dollars I would be very worried about it and I wouldn’t be able to focus on my recovery with all that worry.” “Some health insurance only covers so much and then you have to pay out of pocket for the rest. Which that could impact the way they do things. They could miss appointments. Anything that was important to their recovery, they may, um, you know not take it as seriously as they should.”
Accessibility (22/22)	“Access to transportation becomes a class issue. If can’t afford to buy to car then you don’t have access to this kind of transportation. If you don’t have money to take the bus or take a cab then this is an issue. This all has to do with your economic status in life. Your status on the economic ladder in life determines your type of transportation. If you don’t have a car, then how do you get to places?” “The first couple of weeks I wasn’t able to drive. So, if I didn’t have somebody here to be able to drive me. If you lived in an area that didn’t have access to public transportation, then that would impact your ability to have follow up care.” “I think [being in a] rural [area] would be a deficit because things are so much further away like hospitals, medicines, stores, support group, that sort of thing. I think that in circumstances a larger population is better for more immediate support.”

CHAPTER V: DISCUSSION AND CONCLUSIONS

This dissertation examined how barriers to healthcare access affect all-cause mortality and changes in health status following a hospitalization for an ACS. Using data from a contemporary cohort of over 2,000 hospital survivors of an ACS, the first study aim found that patients who either lacked a usual source of care or had a transportation barrier to healthcare experienced higher rates of two-year post-discharge all-cause mortality than those without such barriers. The second study aim examined clinically meaningful changes in generic and disease-specific HRQOL over six months post-discharge among approximately 1,100 members of the same study cohort. We found that those with a financial barrier to healthcare were more likely to experience clinically meaningful declines in generic physical and mental HRQOL than those without such a barrier. The final study aim described the perspectives of 22 patients with a recent unplanned hospitalization on factors affecting their transition home both within, and outside of, the healthcare system. In these interviews, patients described the importance of having adequate transportation and health insurance to receive follow-up care following discharge from the hospital, suggesting one potential mechanism by which poor access to healthcare could result in worse clinical outcomes following a hospitalization. The three study aims provide both qualitative and quantitative evidence that barriers to healthcare may lead to more difficult transitions from the hospital and adverse health consequences.

Financial Barriers to Care

Recent policy actions and trends in the health insurance market suggest that, in the short term, the prevalence of financial barriers to healthcare may increase. In 2010, the federal government passed the Affordable Care Act (ACA), a broad law intended to expand health insurance coverage, improve health outcomes, and reduce the rate of growth in overall, national healthcare expenditures.[1] Although a subsequent Supreme Court ruling and Congressional actions blocked full implementation of the ACA, by 2015 the proportion of Americans with health insurance coverage reached an all-time high, with much of this gain being directly attributed to provisions of the ACA.[2,3] Many, however, have vigorously sought repeal of the ACA due to a variety of concerns over the manner of its passage, concerns about its constitutionality, federal overreach, and cost, in addition to political opportunism.[4,5] In the summer of 2017 Congress almost passed legislation that would have effectively ended the ACA in its present form and reversed gains in health insurance coverage.[6] The current presidential administration has issued executive orders and performed administrative actions that could limit opportunities for enrollment through federal exchanges, force individuals out of the market due to premium increases, and provide cheaper plans that would provide potentially inadequate coverage.[7,8] Moreover, insurances premiums continue to rise faster than inflation, and increasing numbers of Americans have insurance plans with high-cost, out-of-pocket deductibles.[9,10] In light of potential reductions in insurance coverage and increasing financial burdens on healthcare consumers, providers should be aware of how financial barriers to healthcare may harm patient outcomes.

While this thesis does not explore how to fix financial barriers to healthcare, our results suggest that such barriers are common among survivors of an ACS and that addressing them may help prevent declines in HRQOL following hospital discharge. In our first study (Aim 1) we found that about a third of patients in a large, diverse sample of survivors of an ACS had a financial barrier to healthcare. Such high prevalence should encourage clinicians to regularly screen their patients for financial difficulties and consider the costs of treatment options for patients. While patients may be reluctant to disclose financial difficulties without prompting from a clinician, conversations about costs may help identify lower-cost treatment alternatives that patients would find easier to follow.[11,12]

Currently, patient HRQOL is rarely assessed.[13] Our findings also suggest that clinicians may want to pay closer attention to the physical and mental health status of patients with financial barriers to care, even though little is known about how to maintain or improve HRQOL among patients with heart disease.[13] Studies are needed to clarify the association between financial barriers to healthcare and declines in HRQOL following a hospitalization for an ACS, in particular to see if relieving financial barriers to healthcare can improve HRQOL. For instance, studies of the recent Medicaid expansion experiment in Oregon suggest that previously uninsured patients who were offered the opportunity to enroll in

Medicaid reported better overall HRQOL one year after randomization compared to those who did not receive an opportunity to enroll.[14] This thesis suggests the importance of developing better awareness about patients' financial barriers to healthcare and the potential impact of such a barrier on HRQOL.

Usual Source of Care

While there has been considerable recent national attention on financial barriers to healthcare in the US due to the debate over modifying the ACA, the country also faces a worsening shortage of primary care clinicians, the most common providers of a usual source of care.[15] Moreover, many individuals with no obvious barriers may not establish a usual source of care because they feel no immediate need.[16] To the best of our knowledge, only one other study has examined the consequences of lacking a usual source of care on all-cause mortality after surviving a hospitalization for an ACS.[17] Both that study and our work suggest that those lacking a usual source of care may have higher rates of long-term all-cause mortality. Future research could elucidate potential mechanisms that may be responsible for these observed associations, such as greater difficulty establishing outpatient follow-up after hospital discharge. Future studies should seek to better distinguish between patients who lacked a usual source of care due to personal preference from those who were simply unable to obtain one. If lack of a usual source of care does contribute to worse outcomes following a hospitalization for an ACS, policies and actions that increase the numbers of Americans with a usual source of care should help.

Transportation Barrier to Care

To the best of our knowledge, this is the first study to demonstrate that survivors of an ACS reporting a transportation-related healthcare barrier may have a heightened risk for long-term all-cause mortality following hospital discharge. However, we did not find that those with transportation barriers were more likely to experience declines in generic and disease-specific HRQOL than their peers with good transportation access. One potential explanation for this dichotomy may be the substantial loss-to-follow up in the HRQOL study aim resulting in selection bias for patients with having poor transportation but avoiding declines in HRQOL. Alternatively, patients with transportation barriers tended to have the lowest HRQOL compared to their peers; they may have been less likely to experience declines in HRQOL by having lower HRQOL at the start. Regardless, we believe that our results send an important message to clinicians about both the potential consequences on mortality due to a lack of transportation, as well as the potential for those with a transportation barrier to have, on average, a worse health status. Given the potential for transportation to be made increasingly accessible through smartphone-connected ride-sharing platforms, future studies could examine how eliminating transportation barriers could improve patient outcomes.

Healthcare Barriers and Patient Perspectives on Care Transitions

If indeed the above described barriers to healthcare contribute to mortality and/or HRQOL-related declines following a hospitalization for an ACS, one possibility is that they lead to worse transitions of care to the outpatient setting that ultimately lead to poorer overall outcomes. In examining the perceptions of medical and surgical patient who experienced a recent transition home after an unplanned hospitalization, we found that patients viewed a diverse array of factors within and outside of the healthcare as influencing the success of their transition. Notably, participants described how accessibility to healthcare services, particularly adequate transportation, was essential for obtaining follow-up care, prescriptions, and social support. Similarly having adequate insurance (that mitigated financial barriers to care) helped to ensure that patients would adhere to outpatient care as well as preventing the psychological distress of being unable to afford care. Thus, this third study suggests the mechanisms by which financial and transportation barriers to health care could influence clinical outcomes. While the third study aim did not specifically ask about having a usual source of care prior to their hospitalizations, several participants noted the importance of coordination between inpatient and outpatient providers, which should be easier for those with a usual source of care.

Future Directions

We can suggest several potential directions for future studies building on our findings that patients with specific barriers to healthcare access are more likely to experience adverse health outcomes following a hospitalization for an ACS. By studying patients hospitalized at select medical centers in Massachusetts and Georgia, our results may lack generalizability. Given substantial variations in healthcare access at both the state and community level,[18] future work in this field should incorporate a greater number of medical centers in geographically diverse locations. Such studies could also distinguish outcomes due to individual patient barriers versus the characteristics of clinical systems treating disadvantaged patients. It would be useful to identify and study clinical systems that have patients with better health outcomes despite barriers to healthcare access, in order to identify ways in which such barriers can be overcome.

In addition to incorporating a larger number of clinical sites, future studies would benefit from incorporating even more variables pertaining to healthcare access. As described in the introduction, healthcare access results from a complex interaction of healthcare and patient-centered factors, many of which we could not account for in the first two study aims.[19] For instance, we were unable to assess factors related to the approachability of healthcare systems, such as the availability for local primary care providers and cardiologists to provide timely follow-up care for patients or their willingness to accept particular forms of health insurance, such as Medicaid. An example of a patient-centered factor to be accounted for in future studies could be perceived need for healthcare following hospital discharge; effect estimates in this study may have been biased towards the null if patients who had good healthcare did not receive outpatient care after hospital discharge due to personal perceptions.

We also did not identify the particular mechanisms through which barriers to healthcare access could bring about worse health outcomes. Future studies could collect data on the consumption of healthcare resources following a hospitalization for an ACS, such as outpatient visits and emergency room, and prescription drug use. By combining such data with analytical methods such as mediation analysis, it may be possible to more precisely understand the causal pathways by which barriers to healthcare access influence patient outcomes following a hospitalization for an ACS.

Assuming that a relationship is established between barriers to healthcare access and poor outcomes after an ACS, clinicians will likely want to know how to screen for barriers to healthcare access and what interventions might help. While this thesis used a specific set of questions to determine healthcare access, these may not be the best way to assess healthcare access. Our third study suggests the utility of tools to assess 1) the healthcare access characteristics of a healthcare system, and 2) the individual healthcare access characteristics of a patient. It may be that some patients have healthcare access deficits that could more easily be handled by some systems than others.

CONCLUSIONS

Specific barriers to healthcare access may harm HRQOL-related outcomes and survival following a hospitalization for an ACS; patients also perceive adequate healthcare access as an important facilitator of care transitions home following discharge from the hospital. Future studies should explore the mechanisms by which barriers to access affect health, particularly by accounting for the multiple, complex patient-centered and healthcare system-oriented factors that constitute healthcare access. Such information could inform intervention studies to demonstrate the extent to which addressing healthcare barriers can improve patient outcomes. For the meantime, clinicians may be able to achieve better outcomes by screening for barriers to healthcare and accounting for them in their treatment plans. As policymakers debate the extent of the government’s role in healthcare financing and delivery, the public may particularly benefit from better understanding the adverse consequences of inadequate access to healthcare.

APPENDICES FOR CHAPTER II

Appendix 2.1: Fully adjusted model for assessing the relationship between individual barriers to healthcare access and all-cause mortality at 2-years after discharge for a hospitalization for an acute coronary syndrome

Variable	Meaning	Exp(b)	(95% CI)
1_probaffordcare	Financial barrier to healthcare access	.8067735	(0.4877355, 1.334501)
0_probaffordcare	No financial barrier to healthcare access	Referent	-
1_nousoc	Has no usual source of care	1.579893	(1.242683, 2.008606)
0_nousoc	Has usual source of care	Referent	-
1_reachingcare	Transportation barrier to healthcare	1.551654	(1.151812, 2.090299)
0_reaching care	No transportation barrier to healthcare	Referent	-
0_grace_risk_simpl	GRACE Risk Score <100	Referent	-
1_grace_risk_simpl	GRACE Risk Score >= 100 to <130	3.788572	(3.233139, 4.439425)
2_grace_risk_simpl	GRACE Risk Score >= 130 to <150	10.99798	(7.525892, 16.07193)
3_grace_risk_simpl	GRACE Risk Score >= 150	17.29312	(11.24443, 26.59556)
0_site_cat	Academic hospital – Worcester, Mass.	Referent	-
1_site_cat	Community hospital - Worcester, Mass.	0.2575456	(0.2451202, 0.2706008)
2_site_cat	Academic hospital – Macon, Georgia	2.042115	(1.700956, 2.451699)
3_site_cat	Community hospital, Atlanta, Georgia	3.170515	(2.823493, 3.560188)
1_female	Female	0.8429521	(0.4797331, 1.481174)
0_female	Male	Referent	-
1_race_whitehisp	Non-Hispanic white	1.333025	(0.8331162, 2.132902)
0_race_whitehisp	Not non-Hispanic white	Referent	-
0_acs_trt	Received percutaneous intervention	Referent	-
1_acs_trt	Received coronary artery bypass graft	0.3324538	(0.1024079, 1.079267)
1_acs_trt	Received medications only	1.099872	(0.8025591, 1.507326)
0_liv_sit	Lives with spouse	Referent	-
1_liv_sit	Lives with family	1.240019	(0.7540508, 2.039181)
2_liv_sit	Lives with non-family	1.482076	(1.306833, 1.680819)
3_liv_sit	Lives alone	1.116261	(0.8732555, 1.426889)
1_educ_simpl	Less than high school	Referent	-
2_educ_simpl	High school graduate	.8175456	(0.5321572, 1.255984)
3_educ_simpl	Post high school / some college	.8163778	(0.5429369, 1.227532)
4_educ_simpl	College graduate	.5401994	(0.2817703, 1.03565)
1_chd	Prior diagnosis of coronary heart disease	1.386727	(0.9685315, 1.985493)
0_chd	No prior diagnosis of coronary heart disease	Referent	-
1_ckd	Prior diagnosis of chronic kidney disease	1.39536	(1.18875, 1.63788)
0_ckd	No prior diagnosis of chronic kidney disease	Referent	-
1_pvd	Prior diagnosis of peripheral vascular disease	1.858307	(1.462165, 2.361774)
1_pvd	No prior diagnosis of peripheral vascular disease	Referent	-

Appendix 2.2: Fully adjusted model for assessing the relationship between individual barriers to healthcare access and all-cause mortality at 2-years after discharge for a hospitalization for an acute coronary syndrome

Variable	Meaning	Exp(b)	(95% CI)
0_numbar	No barriers to healthcare access	Referent	-
1_numbar	1 barrier to healthcare access	.9856506	(0.4818825, 2.016066)
2_numbar	2 or more barriers to healthcare access	1.533045	(1.033235, 2.274632)
0_grace_risk_simpl	GRACE Risk Score <100	Referent	-
1_grace_risk_simpl	GRACE Risk Score >= 100 to <130	3.785908	(3.283771,4.36483)
2_grace_risk_simpl	GRACE Risk Score >= 130 to <150	11.05089	(7.634646, 15.9958)
3_grace_risk_simpl	GRACE Risk Score >= 150	17.46634	(12.01679, 25.38725)
0_site_cat	Academic hospital – Worcester, Mass.	Referent	-
1_site_cat	Community hospital - Worcester, Mass.	.2508362	(0.2352974, 0.2674011)
2_site_cat	Academic hospital – Macon, Georgia	1.899153	(1.610459, 2.239598)
3_site_cat	Community hospital, Atlanta, Georgia	3.015871	(2.60538, 3.491037)
1_female	Female	.8184651	(0.4697366, 1.426087)
0_female	Male	Referent	-
1_race_whitehisp	Non-Hispanic white	1.263539	(0.8112837, 1.967906)
0_race_whitehisp	Not non-Hispanic white	Referent	-
0_acs_trt	Received percutaneous intervention	Referent	-
1_acs_trt	Received coronary artery bypass graft	.333648	(0.0951253, 1.170256)
1_acs_trt	Received medications only	1.097179	(0.8657838, 1.390419)
0_liv_sit	Lives with spouse	Referent	-
1_liv_sit	Lives with family	1.252108	(0.789981, 1.984571)
2_liv_sit	Lives with non-family	1.493128	(1.27254, 1.751954)
3_liv_sit	Lives alone	1.160262	(0.8835349, 1.523662)
1_educ_simpl	Less than high school	Referent	-
2_educ_simpl	High school graduate	.7890871	(0.5367954, 1.159955)
3_educ_simpl	Post high school / some college	.7938694	(0.5141213, 1.225837)
4_educ_simpl	College graduate	.5314696	(0.2664431, 1.060114)
1_chd	Prior diagnosis of coronary heart disease	1.383579	(0.9578369, 1.998557)
0_chd	No prior diagnosis of coronary heart disease	Referent	-
1_ckd	Prior diagnosis of chronic kidney disease	1.473686	(1.282154, 1.693829)
0_ckd	No prior diagnosis of chronic kidney disease	Referent	-
1_pvd	Prior diagnosis of peripheral vascular disease	1.890753	(1.435557, 2.490284)
1_pvd	No prior diagnosis of peripheral vascular disease	Referent	-

APPENDICES FOR CHAPTER III

Appendix 3.1: Comparisons of regression analyses for clinically meaningful declines in health-related quality of life and individual barriers to healthcare access among survivors of an acute coronary syndrome with and without inverse probability weighting

	Financial Barrier to Care		No Usual Source of Care		Transportation Barrier	
	Yes (n = 305)	No (n = 748)	Yes (n = 149)	No (n = 904)	Yes (n = 92)	No (n = 961)
Relative Risks Ratios (95% CI) for Clinically Meaningful Decrease						
SF36v2 PCS Scores						
Unweighted						
Adjusted for Barriers Only	1.36 (1.10, 1.70)	Referent	0.81 (0.59, 1.11)	Referent	1.17 (0.83, 1.63)	Referent
Fully Adjusted*	1.38 (1.10, 1.72)	Referent	0.87 (0.63, 1.22)	Referent	1.00 (0.72, 1.39)	Referent
Weighted						
Adjusted for Barriers Only	1.36 (1.08, 1.70)	Referent	0.85 (0.61, 1.18)	Referent	1.24 (0.88, 1.74)	Referent
Fully Adjusted*	1.43 (1.13, 1.80)	Referent	0.90 (0.65, 1.26)	Referent	1.03 (0.74, 1.43)	Referent
SF36v2 MCS Scores						
Unweighted						
Adjusted for Barriers Only	1.35 (1.07, 1.69)	Referent	1.11 (0.84, 1.47)	Referent	1.23 (0.88, 1.71)	Referent
Fully Adjusted†	1.37 (1.08, 1.74)	Referent	1.12 (0.84, 1.49)	Referent	1.28 (0.91, 1.80)	Referent
Weighted						
Adjusted for Barriers Only	1.34 (1.06, 1.69)	Referent	1.10 (0.82, 1.48)	Referent	1.20 (0.84, 1.70)	Referent
Fully Adjusted†	1.36 (1.07, 1.75)	Referent	1.12 (0.83, 1.51)	Referent	1.19 (0.83, 1.71)	Referent
SAQ QOL Scores						
Unweighted						
Adjusted for Barriers Only	1.09 (0.77, 1.55)	Referent	1.42 (0.96, 2.11)	Referent	1.22 (0.75, 2.03)	Referent
Fully Adjusted‡	1.07 (0.75, 1.55)	Referent	1.22 (0.81, 1.82)	Referent	1.08 (0.66, 1.77)	Referent
Weighted						
Adjusted for Barriers Only	1.01 (0.70, 1.46)	Referent	1.69 (1.14, 2.51)	Referent	1.31 (0.80, 2.17)	Referent
Fully Adjusted‡	1.04 (0.72, 1.52)	Referent	1.37 (0.92, 2.06)	Referent	1.13 (0.68, 1.87)	Referent

* Adjusted for clinical site, age, sex, race/ethnicity, education, employment status, reperfusion therapy, GRACE risk score, 1 month SF36v2 PCS score, 1 month SF36v2 MCS score

† Adjusted for age, sex, race, clinical site, employment status, reperfusion therapy, 1 month SF36v2 MCS score

‡ Adjusted for age, sex, race, clinical site, education, living situation, reperfusion therapy, GRACE risk score, 1-month SAQ QOL score, 1 month SF36v2 MCS score

Appendix 3.2: Comparisons of regression analyses for clinically meaningful declines in health-related quality of life and number of barriers to healthcare access among survivors of an acute coronary syndrome with and without inverse probability weighting

	No Barriers (n = 630)	**1 Barrier** (n = 118)	**2 or More Barriers** (n = 305)
Relative Risks Ratios (95% CI) for Clinically Meaningful Decrease			
SF36v2 PCS Scores			
Unweighted			
Unadjusted	Referent	1.04 (0.73, 1.48)	1.38 (1.11, 1.71)
Adjusted*	Referent	1.01 (0.70, 1.47)	1.38 (1.09, 1.75)
Weighted			
Unadjusted	Referent	1.07 (0.75, 1.55)	1.41 (1.13, 1.77)
Adjusted*	Referent	1.03 (0.70, 1.51)	1.44 (1.13, 1.84)
SF36v2 MCS Scores			
Unweighted			
Unadjusted	Referent	1.28 (0.92, 1.76)	1.46 (1.17, 1.83)
Adjusted†	Referent	1.35 (0.97, 1.88)	1.51 (1.18, 1.93)
Weighted			
Unadjusted	Referent	1.27 (0.90, 1.80)	1.47 (1.16, 1.86)
Adjusted†	Referent	1.30 (0.91, 1.87)	1.50 (1.17, 1.93)
SAQ QOL Scores			
Unweighted			
Unadjusted	Referent	1.41 (0.88, 2.25)	1.23 (0.87, 1.75)
Adjusted‡	Referent	1.06 (0.67, 1.70)	1.09 (0.74, 1.61)
Weighted			
Unadjusted	Referent	1.70 (1.06, 2.73)	1.27 (0.89, 1.83)
Adjusted‡	Referent	1.16 (0.74, 1.83)	1.10 (0.74, 1.65)

* Adjusted for clinical site, age, sex, race/ethnicity, education, employment status, reperfusion therapy, GRACE risk score, 1 month SF36v2 PCS score, 1 month SF36v2 MCS score

† Adjusted for age, sex, race, clinical site, employment status, reperfusion therapy, 1 month SF36v2 MCS score

‡ Adjusted for age, sex, race, clinical site, education, living situation, reperfusion therapy, GRACE risk score, 1-month SAQ QOL score, 1 month SF36v2 MCS score

Appendix 3.3: Full, multivariable-adjusted model for assessing the relationship between individual barriers to healthcare access and clinically meaningful declines in physical health-related quality of life over six months after discharge for a hospitalization for an acute coronary syndrome

Variable	**Meaning**	**Exp(b)**	**(95% CI)**
1_probaffordcare	Financial barrier to healthcare access	1.378837	(1.100711, 1.72724)
0_probaffordcare	No financial barrier to healthcare access	Referent	-
1_nousoc	Has no usual source of care	0.8736658	(0.6254936, 1.220303)
0_nousoc	Has usual source of care	Referent	-
1_reachingcare	Transportation barrier to healthcare	0.9993246	(0.7163315, 1.394117)
0_reaching care	No transportation barrier to healthcare	Referent	-
0_site_cat	Academic hospital – Worcester, Mass.	Referent	-
1_site_cat	Community hospital - Worcester, Mass.	1.238218	(0.916281, 1.673268)
2_site_cat	Academic hospital – Macon, Georgia	1.205765	(0.9468777, 1.535435)
3_site_cat	Community hospital, Atlanta, Georgia	0.9200461	(0.5122202, 1.65258)
0_age_cat2	59 years or less	Referent	-
1_age_cat2	60 to 64 years	0.8899943	(0.6266989, 1.263908)
2_age_cat2	65 to 69 years	0.6719675	(0.4587617, 0.9842589)
3_age_cat2	70 to 74 years	0.6342472	(0.4134595, 0.9729357)
4_age_cat2	75 to 79 years	0.7669496	(0.486417, 1.209275)
5_age_cat2	80 years and older	0.6685399	(0.3768082, 1.186136)
1_female	Female	0.9649633	(0.7761497, 1.199709)
0_female	Male	Referent	-
1_race_whitehisp	Non-Hispanic white	0.9983472	(0.7649599, 1.30294)
0_race_whitehisp	Not non-Hispanic white	Referent	-
0_employ_simpl2	Retired	Referent	-
1_employ_simpl2	Working	0.4215867	(0.3042832, 0.5841115)
2_employ_simpl2	Unemployed	0.7848118	(0.568958, 1.082557)
1_educ_simpl	Less than high school	Referent	-
2_educ_simpl	High school graduate	1.240019	(0.6685563, 1.236564)
3_educ_simpl	Post high school / some college	1.482076	(0.6571443, 1.226103)
4_educ_simpl	College graduate	1.116261	(0.5128056, 1.044036)
0_acs_trt	Received percutaneous intervention	Referent	-
1_acs_trt	Received coronary artery bypass graft	0.3709828	(0.2267615, 0.6069293)
1_acs_trt	Received medications only	0.9667711	(0.7449703, 1.254609)
grace_risk	+1 unit increase in GRACE risk score	1.007997	(1.002201, 1.013826)
pcs1	+1 unit increase in 1-month PCS score	1.034708	(1.022531, 1.047029)
mcs1	+1 unit increase in 1-month MCS score	0.9819731	(0.9733516, 0.990671)

Appendix 3.4: Full, multivariable-adjusted model for assessing the relationship between individual barriers to healthcare access and clinically meaningful declines in mental health-related quality of life over six months after discharge for a hospitalization for an acute coronary syndrome

Variable	Meaning	Exp(b)	(95% CI)
1_probaffordcare	Financial barrier to healthcare access	1.374199	(1.085889, 1.739057)
0_probaffordcare	No financial barrier to healthcare access	Referent	-
1_nousoc	Has no usual source of care	1.121421	(0.8436956, 1.490568)
0_nousoc	Has usual source of care	Referent	-
1_reachingcare	Transportation barrier to healthcare	1.280339	(0.9097538, 1.801881)
0_reaching care	No transportation barrier to healthcare	Referent	-
0_site_cat	Academic hospital – Worcester, Mass.	Referent	-
1_site_cat	Community hospital - Worcester, Mass.	1.533954	(1.138668, 2.066463)
2_site_cat	Academic hospital – Macon, Georgia	1.113063	(0.867543, 1.428067)
3_site_cat	Community hospital, Atlanta, Georgia	1.170904	(0.6870961, 1.995378)
0_age_cat2	59 years or less	Referent	-
1_age_cat2	60 to 64 years	0.8156995	(0.5923214, 1.123319)
2_age_cat2	65 to 69 years	1.013679	(0.7367626, 1.394675)
3_age_cat2	70 to 74 years	0.9252659	(0.6344435, 1.349398)
4_age_cat2	75 to 79 years	0.9185006	(0.5697216, 1.480799)
5_age_cat2	80 years and older	1.055797	(0.6164874, 1.808159)
1_female	Female	0.950185	(0.7487446, 1.20582)
0_female	Male	Referent	-
1_race_whitehisp	Non-Hispanic white	0.8774257	(0.6685857, 1.151499)
0_race_whitehisp	Not non-Hispanic white	Referent	-
0_employ_simpl2	Retired	Referent	-
1_employ_simpl2	Working	1.025094	(0.7638654, 1.375659)
2_employ_simpl2	Unemployed	1.746066	(1.260303, 2.419057)
0_acs_trt	Received percutaneous intervention	Referent	-
1_acs_trt	Received coronary artery bypass graft	0.937827	(0.6692346, 1.314217)
1_acs_trt	Received medications only	1.008047	(0.7632031, 1.331439)
mcs1	+1 unit increase in 1-month MCS score	1.045743	(1.032458, 1.059198)

Appendix 3.5: Full, multivariable-adjusted model for assessing the relationship between individual barriers to healthcare access and clinically meaningful declines in disease-specific health-related quality of life over six months after discharge for a hospitalization for an acute coronary syndrome

Variable	Meaning	Exp(b)	(95% CI)
1_probaffordcare	Financial barrier to healthcare access	1.070771	(0.7461753, 1.536571)
0_probaffordcare	No financial barrier to healthcare access	Referent	-
1_nousoc	Has no usual source of care	1.216192	(0.8116667, 1.822327)
0_nousoc	Has usual source of care	Referent	-
1_reachingcare	Transportation barrier to healthcare	1.079925	(0.6584914, 1.771077)
0_reaching care	No transportation barrier to healthcare	Referent	
0_site_cat	Academic hospital – Worcester, Mass.	Referent	-
1_site_cat	Community hospital - Worcester, Mass.	1.155978	(0.7125471, 1.875363)
2_site_cat	Academic hospital – Macon, Georgia	1.172866	(0.8068508, 1.704919)
3_site_cat	Community hospital, Atlanta, Georgia	0.9823956	(0.3697766, 2.609957)
0_age_cat2	59 years or less	Referent	-
1_age_cat2	60 to 64 years	0.7584606	(0.450193, 1.277813)
2_age_cat2	65 to 69 years	0.6027267	(0.3317696, 1.094975)
3_age_cat2	70 to 74 years	0.9656705	(0.54239, 1.719279)
4_age_cat2	75 to 79 years	1.051236	(0.526339, 2.099593)
5_age_cat2	80 years and older	1.045568	(0.4606631, 2.373126)
1_female	Female	0.9884023	(0.697647, 1.400334)
0_female	Male	Referent	-
0_race_whitehisp	Not non-Hispanic white	Referent	-
1_race_whitehisp	Non-Hispanic white	0.7318881	(0.4925264, 1.087577)
0_liv_sit	Lives with spouse	Referent	-
1_liv_sit	Lives with family	1.557629	(0.9918378, 2.446173)
2_liv_sit	Lives with non-family	1.754823	(1.124744, 2.737873)
3_liv_sit	Lives alone	1.433053	(0.9358127, 2.1945)
1_educ_simpl	Less than high school	Referent	-
2_educ_simpl	High school graduate	0.6982796	(0.4493237, 1.085174)
3_educ_simpl	Post high school / some college	0.5903039	(0.3667695, 0.9500755)
4_educ_simpl	College graduate	0.6579102	(0.3933127, 1.100513)
0_acs_trt	Received percutaneous intervention	Referent	-
1_acs_trt	Received coronary artery bypass graft	0.6767451	(0.389332, 1.176333)
1_acs_trt	Received medications only	1.058712	(0.6784421, 1.652124)
0_smoke	Non-smoker	Referent	-
1_smoke	Former smoker	1.28699	(0.8531865, 1.941362)
2_smoke	Current smoker	1.636896	(1.01178, 2.648233)
grace_risk	+1 unit increase in GRACE risk score	1.001355	(0.9920978, 1.010698)
saql1	+1 unit increase in 1-month SAQ QOL score	0.9696647	(0.9560534, .9834698)
mcs1	+1 unit increase in 1-month MCS score	1.028523	(1.019876, 1.037243

Appendix 3.6: Full, multivariable-adjusted model for assessing the relationship between number of barriers to healthcare access and clinically meaningful declines in physical health-related quality of life over six months after discharge for a hospitalization for an acute coronary syndrome

Variable	Meaning	Exp(b)	(95% CI)
0_numbar	No barriers	Referent	-
1_numbar	1 barrier	1.011338	(0.6956837, 1.470214)
2_numbar	2 or more barriers	1.382	(1.089038, 1.753773)
0_site_cat	Academic hospital – Worcester, Mass.	Referent	-
1_site_cat	Community hospital - Worcester, Mass.	1.254941	(0.9302359, 1.692988)
2_site_cat	Academic hospital – Macon, Georgia	1.212704	(0.9513728, 1.545821)
3_site_cat	Community hospital, Atlanta, Georgia	0.937311	(0.5236719, 1.677676)
0_age_cat2	59 years or less	Referent	-
1_age_cat2	60 to 64 years	0.9002778	(0.6356024, 1.275168)
2_age_cat2	65 to 69 years	0.6785938	(0.4636227, 0.9932421)
3_age_cat2	70 to 74 years	0.6420769	(0.4195335, 0.9826693)
4_age_cat2	75 to 79 years	0.7790289	(0.4939586, 1.228617)
5_age_cat2	80 years and older	0.6668483	(0.3762447, 1.181908)
1_female	Female	0.9726317	(0.782176, 1.209463)
0_female	Male	Referent	-
1_race_whitehisp	Non-Hispanic white	1.007552	(0.7712673, 1.316224)
0_race_whitehisp	Not non-Hispanic white	Referent	-
0_employ_simpl2	Retired	Referent	-
1_employ_simpl2	Working	0.4180692	(0.3016958, 0.5793315)
2_employ_simpl2	Unemployed	0.7790021	(0.5668385, 1.070577)
1_educ_simpl	Less than high school	Referent	-
2_educ_simpl	High school graduate	0.9117718	(0.6715024, 1.238012)
3_educ_simpl	Post high school / some college	0.9086419	(0.6651375, 1.241292)
4_educ_simpl	College graduate	0.7431636	(0.5211383, 1.05978)
0_acs_trt	Received percutaneous intervention	Referent	-
1_acs_trt	Received coronary artery bypass graft	0.3675486	(0.2246894, 0.6012389)
1_acs_trt	Received medications only	0.9613726	(0.740693, 1.247801)
grace_risk	+1 unit increase in GRACE risk score	1.008044	(1.002272, 1.01385)
pcs1	+1 unit increase in 1-month PCS score	1.035052	(1.022889, 1.04736)
mcs1	+1 unit increase in 1-month MCS score	0.9823695	(0.9737303, 0.9910854)

Appendix 3.7: Full, multivariable-adjusted model for assessing the relationship between number of barriers to healthcare access and clinically meaningful declines in mental health-related quality of life over six months after discharge for a hospitalization for an acute coronary syndrome

Variable	Meaning	Exp(b)	(95% CI)
0_numbar	No barriers	Referent	-
1_numbar	1 barrier	1.351852	(0.9698907, 1.884236)
2_numbar	2 or more barriers	1.510399	(1.180608, 1.932313)
0_site_cat	Academic hospital – Worcester, Mass.	Referent	-
1_site_cat	Community hospital - Worcester, Mass.	1.538755	(1.142964, 2.071604)
2_site_cat	Academic hospital – Macon, Georgia	1.11461	(0.8687304, 1.430081)
3_site_cat	Community hospital, Atlanta, Georgia	1.179623	(0.6962444, 1.998595)
0_age_cat2	59 years or less	Referent	-
1_age_cat2	60 to 64 years	0.8038264	(0.5843749, 1.105689)
2_age_cat2	65 to 69 years	1.017136	(0.7373085, 1.403165)
3_age_cat2	70 to 74 years	0.9513129	(0.6532811, 1.385309)
4_age_cat2	75 to 79 years	0.9298088	(0.5780703, 1.49557)
5_age_cat2	80 years and older	1.062801	(0.6204983, 1.820387)
1_female	Female	0.9457558	(0.7473751, 1.196794)
0_female	Male	Referent	-
0_race_whitehisp	Not non-Hispanic white	Referent	-
1_race_whitehisp	Non-Hispanic white	0.8760787	(0.6697, 1.146056)
0_employ_simpl2	Retired	Referent	-
1_employ_simpl2	Working	1.017426	(0.7595919, 1.362779)
2_employ_simpl2	Unemployed	1.781731	(1.289444, 2.461964)
0_acs_trt	Received percutaneous intervention	Referent	-
1_acs_trt	Received coronary artery bypass graft	0.9407935	(0.6714274, 1.318225)
1_acs_trt	Received medications only	0.9898801	(0.7484282, 1.309227)
mcs1	+1 unit increase in 1-month MCS score	1.045267	(1.032061, 1.058643)

Appendix 3.8: Full, multivariable-adjusted model for assessing the relationship between number of barriers to healthcare access and clinically meaningful declines in mental health-related quality of life over six months after discharge for a hospitalization for an acute coronary syndrome

Variable	Meaning	Exp(b)	(95% CI)
0_numbar	No barriers	Referent	-
1_numbar	1 barrier	1.063874	(0.6683424, 1.693485)
2_numbar	2 or more barriers	1.093767	(0.7443806, 1.607142)
0_site_cat	Academic hospital – Worcester, Mass.	Referent	-
1_site_cat	Community hospital - Worcester, Mass.	1.132788	(0.6883433, 1.8642)
2_site_cat	Academic hospital – Macon, Georgia	1.147093	(0.7800669, 1.686808)
3_site_cat	Community hospital, Atlanta, Georgia	0.939973	(0.3496723, 2.526792)
0_age_cat2	59 years or less	Referent	-
1_age_cat2	60 to 64 years	0.7461162	(0.4406044, 1.263467)
2_age_cat2	65 to 69 years	0.5974644	(0.3298012, 1.08236)
3_age_cat2	70 to 74 years	0.9472681	(0.5325906, 1.684816)
4_age_cat2	75 to 79 years	1.019932	(0.5076534, 2.049157)
5_age_cat2	80 years and older	1.032218	(0.4509289, 2.362843)
1_female	Female	0.9771188	(0.6902028, 1.383305)
0_female	Male	Referent	-
0_race_whitehisp	Not non-Hispanic white	Referent	-
1_race_whitehisp	Non-Hispanic white	0.7150626	(0.4803908, 1.064372)
0_liv_sit	Lives with spouse	Referent	-
1_liv_sit	Lives with family	1.577208	(1.006227, 2.472191)
2_liv_sit	Lives with non-family	1.760828	(1.125071, 2.75584)
3_liv_sit	Lives alone	1.438295	(0.9368821, 2.208061)
1_educ_simpl	Less than high school	Referent	-
2_educ_simpl	High school graduate	0.6896708	(0.4415009, 1.077338)
3_educ_simpl	Post high school / some college	0.5788523	(0.3577321, 0.9366504)
4_educ_simpl	College graduate	0.635258	(0.635258, 1.060499)
0_acs_trt	Received percutaneous intervention	Referent	-
1_acs_trt	Received coronary artery bypass graft	0.6887923	(0.3922292, 1.209586)
1_acs_trt	Received medications only	1.057779	(0.6760328, 1.655092)
0_smoke	Non-smoker	Referent	-
1_smoke	Former smoker	1.28699	(0.8488451, 1.936061)
2_smoke	Current smoker	1.636896	(1.012507, 2.648601)
grace_risk	+1 unit increase in GRACE risk score	1.00142	(0.9921814, 1.010744)
saql1	+1 unit increase in 1-month SAQ QOL score	1.028075	(1.01955, 1.036671)
mcs1	+1 unit increase in 1-month MCS score	0.9696356	(0.9558318, .9836388)

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