HHS Public Access

Author manuscript

Circ Cardiovasc Qual Outcomes. Author manuscript; available in PMC 2022 September 12.

Published in final edited form as:

Circ Cardiovasc Qual Outcomes. 2020 July ; 13(7): e006231. doi:10.1161/CIRCOUTCOMES.119.006231.

Rates and Predictors of Patient Underreporting of Hospitalizations During Follow-Up After Acute Myocardial Infarction

César Caraballo, MD[*,1], **Rohan Khera, MD**[*,2], **Philip G Jones, MS**[3], **Carole Decker, RN PhD**[3], **Wade Schulz, MD PhD**[2,4], **John A Spertus, MD MPH**[3,5], **Harlan M Krumholz, MD SM**[1,6,7]

[1]Center for Outcomes Research and Evaluation, Yale-New Haven Health, New Haven, CT

[2]Division of Cardiology, University of Texas Southwestern Medical Center, Dallas, TX

[3]Saint Luke's Mid America Heart Institute, Kansas City, MO

[4]Department of Laboratory Medicine. Yale School of Medicine, New Haven, CT

[5]Division of Cardiology, Department of Internal Medicine, University of Missouri-Kansas City, Kansas City, MO

[6]Section of Cardiovascular Medicine, Department of Internal Medicine, Yale School of Medicine, New Haven, CT

[7]Department of Health Policy and Management, Yale School of Public Health, New Haven, CT

Abstract

Background: Many clinical investigations depend on participant self-report as a principal method of identifying health care events. If self-report is used as the trigger to collect and adjudicate medical records, any event that is not reported by the patient will be missed by the investigators, reducing the power of the study and misrepresenting the risk of its participants. We sought to determine the rates and predictors of underreporting hospitalization events during

Corresponding Author: Dr. Harlan M. Krumholz, 1 Church St., Suite 200, New Haven, CT 06510, Phone: 203-764-5885. Fax: 203-764-5653. harlan.krumholz@yale.edu.

*Drs. Caraballo and Khera contributed equally to this study as co-lead authors

DISCLOSURES: **Dr. Krumholz** works under contract with the Centers for Medicare & Medicaid Services to support quality measurement programs; was a recipient of a research grant, through Yale, from Medtronic and the U.S. Food and Drug Administration to develop methods for post-market surveillance of medical devices; was a recipient of a research grant with Medtronic and is the recipient of a research grant from Johnson & Johnson, through Yale University, to support clinical trial data sharing; was a recipient of a research agreement, through Yale University, from the Shenzhen Center for Health Information for work to advance intelligent disease prevention and health promotion; collaborates with the National Center for Cardiovascular Diseases in Beijing; receives payment from the Arnold & Porter Law Firm for work related to the Sanofi clopidogrel litigation, from the Ben C. Martin Law Firm for work related to the Cook IVC filter litigation, and from the Siegfried and Jensen Law Firm for work related to Vioxx litigation; chairs a Cardiac Scientific Advisory Board for UnitedHealth; was a participant/participant representative of the IBM Watson Health Life Sciences Board; is a member of the Advisory Board for Element Science, the Advisory Board for Facebook, and the Physician Advisory Board for Aetna; and is the founder of HugoHealth, a personal health information platform, and co-founder of Refactor Health, an enterprise healthcare AI-augmented data management company. **Dr. Schulz** was an investigator for a research agreement, through Yale University, from the Shenzhen Center for Health Information for work to advance intelligent disease prevention and health promotion; collaborates with the National Center for Cardiovascular Diseases in Beijing; is a technical consultant to HugoHealth, a personal health information platform, and co-founder of Refactor Health, an AI-augmented data management platform for healthcare; is a consultant for Interpace Diagnostics Group, a molecular diagnostics company. **Drs. Caraballo**, **Khera**, **Decker**, **Spertus**, and **Mr. Jones** have no potential conflicts of interest to disclose.

the follow-up period of a prospective study of patients hospitalized with an acute myocardial infarction (AMI).

Methods and Results: The Translational Research Investigating Underlying disparities in acute Myocardial infarction Patients' Health status (TRIUMPH) registry, a longitudinal multicenter cohort study of people with AMI in the US, queried patients for hospitalization events during interviews at 1, 6 and 12 months. To validate these self-reports, medical records for all events at every hospital where the patient reported receiving care were acquired for adjudication, not just those for the reported events. Of the 4340 participants in TRIUMPH, 1209 (28%) reported at least one hospitalization. After medical records abstraction and adjudication, we identified 1086 hospitalizations from 639 participants (60.2 ±12 years of age, 38.2% women). Of these hospitalizations, 346 (31.9%) were underreported by the participants. Rates of underreporting ranged from 22.5% to 55.6% based on different patient characteristics. The odds of underreporting were highest for those not currently working (adjusted odds ratio [aOR] 1.66; 95% CI, 1.04 – 2.63), lowest for those married (aOR 0.50; 95% CI, 0.33 – 0.76), and increased the longer the elapsed time between the admission and the patient's follow-up interview (aOR per month of 1.16; 95% CI, 1.08 – 1.24). There was substantial within-individual variation on the accuracy of reporting.

Conclusions: Hospitalizations after AMI are commonly underreported in interviews and should not be used alone to determine event rates in clinical studies.

BACKGROUND

Many clinical investigations depend on participant self-report as a principal method of identifying health care events.[1–15] These investigations include longitudinal clinical cohorts, randomized controlled trials and observational studies where self-report initiates the process of outcome ascertainment. However, several studies have shown that, when compared to medical records, self-reported events are often inaccurate, with overreporting and underreporting.[16–26] Confirming the occurrence of self-reported events through formal adjudication of medical records can counter overreporting (false positives). Underreporting, however, cannot be addressed in a similar manner. If self-report is used as the trigger to collect and adjudicate medical records, any event that is not reported by the participant will be missed by the investigators.

A recent study[22] showed that after an acute myocardial infarction (AMI) patients are often in error when reporting subsequent hospitalizations. However, it is unknown if this finding is particular to that study or is generalizable. Also, there has been little attention to how rates of underreporting vary by patient characteristics, event type, or timing from the event to the interview. This information is important because if underreporting is largely concentrated in specific subgroups, then targeted strategies might be employed to better balance costs and yield in designing follow-up strategies. However, if underreporting is a problem across all subgroups of patients, then there is a need for a more comprehensive re-design of outcomes ascertainment.[27–29]

To better understand the rates and predictors of underreporting hospitalizations, we evaluated the experience of the TRIUMPH study (Translational Research Investigating

Underlying Disparities in Acute Myocardial Infarction Patients' Health Status), a large, National Institutes of Health-funded, multicenter U.S. observational cohort study of people hospitalized with an AMI. In this study, a centralized follow-up team interviewed participants at 1, 6, and 12 months after hospital discharge. We calculated the rates of unreported hospitalizations by comparing self-reported events with a detailed review of medical records from recruitment sites and any hospital that the patient had reported receiving care. Additionally, we sought to identify participant characteristics that were associated with underreporting. Since overreporting compromises the efficiency of clinical investigations that use formal adjudication of events, but not its validity, the objective of this study was not to evaluate the overall self-report accuracy to focus on the rates and predictors of underreporting.

METHODS

Study Design

Between April 2005 and December 2008, the TRIUMPH study enrolled 4340 participants hospitalized with AMI at 24 US centers. The TRIUMPH investigators published their methods.[30] In brief, patients were eligible if they were ≥18 years of age, had an elevated troponin or creatinine kinase-MB blood test during the initial 24 hours of admission, and presented with other evidence supporting the diagnosis of AMI (e.g., 20 minutes of ischemic symptoms or electrocardiographic ST changes).[30] Patients who did not present to the enrolling institution were eligible only if they were transferred within the first 24 hours of presentation. Patients who developed elevated cardiac enzymes as a complication of elective coronary revascularization were excluded along with those with overt dementia, who had already participated in the study, were unable to communicate in English or Spanish, had hearing impairment precluding telephone contact for interview, were discharged or died before contact with the study coordinator, were prisoners, or were living on hospice care. The data that support the findings of this study are available from coauthor JAS (spertusj@umkc.edu) upon reasonable request. The institutional review board at each institution approved the study, and participants gave informed consent.

Study Sample

Of the 4340 participants, 3632 completed at least one follow-up assessment, at which they were asked to report any rehospitalizations since their index event. We included those participants that had any hospitalization confirmed after reviewing the requested medical records (n=639).

Data Collection

Trained personnel collected baseline hospitalization data by medical chart abstraction and standardized in-person interviews administered within the first 72 hours of the index AMI admission. Patients were interviewed at 1, 6, and 12 months after their index AMI hospitalization, and during the interviews were asked to report all hospitalizations since their last contact, including the hospital name, date, reason and if it was planned or emergent. One month after the last scheduled contact (12 months after index event), we contacted the TRIUMPH enrollment hospital and any other hospital where the participant

had reported care and requested all hospitalization records since enrollment (not just the reported hospitalizations). We requested medical records from the TRIUMPH enrollment site even if the patient did not report any event, while we requested medical records from non-TRIUMPH sites if the participant reported an event in that location. The Coordinating Center abstracted the received charts and a medical records coder and two registered nurses classified them by type of event (including hospitalization, emergency department visit, office visit) and the reason for the event (cardiovascular/bleeding events–including AMI, heart failure, revascularization procedures, or any bleeding– versus all other events). The possible or definite cardiovascular/bleeding events records were sent to two cardiologists for independent adjudication, who confirmed whether a hospitalization occurred, and identified the reason for admission and the urgency of the hospitalization (planned versus emergent). If there was disagreement, a third senior cardiologist adjudicated the record. If disagreement persisted, up to 5 cardiologists independently reviewed the charts until a majority was obtained. Non-cardiovascular/non-bleeding events were recorded, but their type, status, and reason for admission were not adjudicated by cardiologists. A brief overview of the outline of the study process is included in Figure 1. The adjudicating physicians also collected information on cardiac catheterization procedures, angiographic results, and in-hospital events.

Statistical Analysis

We first conducted descriptive analyses of our study sample. Categorical variables were described as proportions, and continuous variables as means and standard deviations as well as medians and interquartile ranges. We then described rates of unreported events, which were defined as the proportion of hospitalization events extracted from the medical records over the course of patient follow-up that were not reported by participants. Further analyses were conducted at both patient and event levels. At the patient level, we defined underreporting as failure by the patient to report at least one hospitalization event identified through medical records. Chi-square or Fisher's exact test was used to assess for differences in rates of underreporting by participants' baseline characteristics, including variables from their index hospitalization. At the event-level, we examined hospitalization characteristics associated with failure to report individual hospitalization events, including admission status and reason, and patient recall time (the elapsed time in months from the admission to the patient's follow-up interview). These analyses employed generalized estimating equations with an exchangeable working correlation structure to account for clustering of repeated admission events within patients. To identify independent factors associated with underreporting, we constructed a hierarchical logistic regression model including patient factors, patient recall time in months, and random effects for patient and site. Adjusted odds ratios (aORs) are presented with their respective 95% confidence intervals (95% CI). In addition, we used the predictions from the model to partition the total variation in underreporting into the percentages attributable to site, observed patient factors (i.e., the R-square associated with the predictor variables), unobserved patient factors (the variance of the patient random effect), and residual within-patient variation. Individual covariate missing rates were <5% and we used single-value mean/mode imputation to include all patients in the final analysis. All analyses were conducted using SAS 9.4 (SAS Institute Inc., Cary,

NC) and R version 3.5.2.[31] The study was reviewed and approved by the Yale University's Institutional Review Board.

RESULTS

Charts abstraction and overall underreporting rate

In total, 1209 participants reported 2016 hospitalizations (Figure 2). Of these, we excluded 320 events from our analysis because the patient did not consent to release their medical records, and we excluded an additional 107 events due to inability or failure to request records (e.g., administrative error, or the patient could not recall the name of hospital). Thus, we requested the medical records for 1589 admissions from 251 hospitals.

Among the hospital records requested, we identified 1320 encounters (we did not receive information on 269 reported events despite multiple requests to the hospitals). Of these, we determined that 580 (43.9%) were not a hospital admission but represented visits to an emergency department, outpatient care center, polysomnography, or no identified encounter (overreported events). Trained study coordinators confirmed 740 self-reported hospitalizations (accurate self-reports). Importantly, the total number of hospitalizations rose to 1086 because, from the hospital records received, we identified an additional 346 hospitalizations not reported by patients, representing an overall underreport rate of 31.9% (346/1086).

Overall Characteristics of the Population and Hospitalizations

The total 1086 hospitalizations were from 639 participants with at least one hospitalization event confirmed with medical records, representing our study sample. The average age was 60.2 years (SD, 12 years), 38.2% were women and 29.6% were non-Caucasian. The characteristics of study participants are included in Table 1. From these participants, median (interquartile range [IQR]) number of self-reported hospitalizations was 1 (1–1), ranging from 1 to 5, whereas median (IQR) number of confirmed hospitalizations was 1 (1–2), ranging from 1 to 14 (Supplemental Figure S1). The relationship between the frequency of confirmed hospitalizations and patient-reported hospitalizations are shown in Figure 3. Cardiovascular or bleeding event was the cause of 777 (71.5%) of the hospitalizations. Heart failure was the reason for admission in 166 (15.3%) of the cases, percutaneous coronary intervention (PCI) in 164 (15.1%), and AMI in 75 (6.9%). The status in 655 (60.3%) hospitalizations was emergent.

Compared to those excluded due to failure to obtain medical records or no hospitalization event confirmed (n = 601), our study sample had a higher mean age (60.2 ±12 years vs 58.8 ±11.8 years, P = 0.034), were less likely to report difficulty getting care (10.3% vs 16.8%, P < 0.001), and were less likely to have a full time job (32.0% vs 37.7%, P =0.018 for the overall work status variable) (Supplementary Table S1).

Rates of Underreporting Hospitalizations by Patient Characteristics

Rates of underreporting a hospitalization event across patients based on their characteristics are shown in Figure 4. Underreporting was more frequent among individuals who were

black/African American (40.0% vs 28.7% among white/Caucasian and 36.4% among other races, P = 0.03), unmarried (40.7% vs 22.6% among married, P < 0.001), lived alone (39.9% vs 28.8% among those who did not, P = 0.008), were not currently working (37.7% vs 22.5% among those with part time work and 24.1% among those who work full time, P < 0.001) or had a history of heart failure (46.6% vs 29.9% with no history of heart failure, P = 0.003). Those in the highest ZIP median income quartile had a lower underreporting rate (22.6%) than those in the other quartiles (33.8%, 34.6%, and 35.4%, for those in the first, second, and third quartile, respectively) (P = 0.046). By discharge disposition, underreporting was less frequent among those discharged to home (30.4%) than among those discharged to nursing home (42.9%) or to other facilities (52.6%) (P = 0.043). No differences were found among other characteristics, including sex, age category, education level, or depression at the index hospitalization.

Rates of Underreporting Hospitalizations by Time from Event to Interview

The rate of unreported hospitalizations was the lowest (23.3% [73/313]) when the event was less than 1 month from the interview, with a stepwise increase by length of the recall period thereafter: 29.9% (105/351) when between 1 month and 3 months, 35.2% (118/335) when between 3 months and 6 months, 57.4% (35/61) when between 6 months and 9 months, and 57.7% (15/26) when between 9 and 12 months (p<0.001).

Rates of Underreporting Hospitalizations by Event Characteristics

When clustering by patient, no differences were found in the distribution of reported and unreported hospitalizations by status or reason for admission. Planned admissions were not reported in 21.3% of the cases, compared to 32.1% of the emergent events (P value = 0.31). The proportion of underreported events by reason for admission was 28.7% of those for PCI (vs 32.4% for any other reason, P=0.36), 30.7% of those due to MI (vs 31.9% for any other reason, P=0.58), and 42.2% of those due to heart failure (vs 30.0% for any other reason, P=0.96).

Predictors of Underreporting

In the multivariable regression analysis, the variable associated with the highest odds of underreporting hospitalizations was not currently working (aOR 1.66; 95% CI, 1.04 – 2.63). On the other hand, married participants had the lowest odds of underreporting (aOR 0.50; 95% CI, 0.33 – 0.76). Recall time (the duration between the hospitalization event and the patient's follow-up interview) was also strongly predictive, with odds of underreporting increasing by a factor of 1.16 (95% CI 1.08 – 1.24) per each additional month elapsed. No significant differences were observed in the aORs by sex, age, race, insurance, ZIP median income, and other predictors shown in Figure 5. Of the total variation in reporting across all hospitalization events, 0.5% was attributable to site, 11.1% was attributable to observed patient factors in the model, 14.6% was attributable to unobserved differences between patients, and the remaining 73.9% was attributable to within-patient variation.

DISCUSSION

This study establishes that for people who have just suffered an AMI, self-report of hospitalizations is often in error. Nearly 1 in 3 hospitalization events were underreported, both overall and by any cardiovascular reasons for admission, reaching nearly 1 in 2 when the admission was due to heart failure. While there were differences in underreporting rates by patient characteristics, they were consistently high and increased progressively as the time between the event and the interview increased. This performance occurred despite people being contacted 3 times within the one-year period and having consented to report their events. Furthermore, approximately three quarters of the variability in reporting occurred between different hospitalization events for the same patient, suggesting a high degree of inconsistency in patients' abilities to recall all their hospitalization events. Overall, our findings suggest that a better general strategy for capturing incident events is needed in cardiovascular research, rather than focusing on certain subgroups that might be at higher risk of underreporting.

This study extends the prior literature in several ways. First, we demonstrate that the study from TRANSLATE-ACS (Treatment with ADP Receptor Inhibitors: Longitudinal Assessment of Treatment Patterns and Events after Acute Coronary Syndrome) findings of underreporting are generalizable across another study of AMI. In TRANSLATE-ACS, patients with an ACS were treated with percutaneous coronary intervention and adenosine diphosphate receptor inhibitor therapy. In this group, medical bills verified 59% of patient-reported hospitalization events, and found that 33% of hospitalizations recorded in the billing data were underreport by patients.[22] Our results were consistent with this, despite having a broader population of patients with AMI (not limited to those who received percutaneous coronary intervention), and a different search strategy for the incident events on other hospitals rather than the recruiting one. In addition, our study also adds by showing that high rates of underreporting are not restricted to specific subgroups, that there is substantial within-individual variation in their ability to recall an event accurately, and underscoring the importance of recall time. This is important and consistent with studies of other diagnoses[17, 21, 32, 33] and raises concern regarding studies that depend on self-report.

Our study also provides a strong methodological approach to investigate this issue. Many of the prior studies were limited by sparse interviews, no or single-adjudication of the events, using bill codes instead of medical records, or analyzing overall agreement of patient-reported outcomes rather than focusing on underreports. In this study, we address those shortcomings by contacting the participants at least 3 times for in-person visits (or phone interviews if not possible) during follow-up, which also made it possible to analyze the influence of recall period, having multiple cardiologist as adjudicators of the medical records, and describing the scope of underreporting rather than disagreement in general. We also tested what characteristics were most strongly associated with underreporting.

There are several key insights from our investigation of predictors of underreporting. Most importantly, rates of underreporting were high for all groups. We did not identify a group with an underreporting rate lower than 20%. Another notable finding is that the time between the event and the interview was strongly associated with underreporting, which is

expected and supports the validity of our findings. What is striking, however, is that even events that occurred with a month of the interview were often (almost 1 in 4) underreported. Moreover, sociocultural characteristics of patients including unemployment and marital status were more strongly predictive of underreporting events, as opposed to demographic characteristics of age and sex, which we did not find to be associated with underreporting of hospitalization events.

Our findings have several implications for research. Many studies, including clinical trials, use self-report to ascertain events. They employ adjudication to eliminate false positive findings but rely on self-report to identify the events. Our findings suggest that any study that only uses self-report as a means to initiate the cascade of event ascertainment will underestimate the total events. Although this underreporting may not bias the study, it will reduce power and misrepresent the risk of the participants. Given our study and others, self-report alone should not be used to ascertain hospitalizations, especially in, but not restricted to, studies that use long intervals between contact with patients. Furthermore, our study also highlights that similar evaluations in the clinical setting are important as clinical care decisions frequently relies on patient's self-reported diagnosis and events that cannot be immediately complemented with available medical records. For example, an inaccurate self-report might potentially lead to misdiagnosis, repeated testing, or delayed treatments.

Our study establishes the need for additional strategies to ensure that all events are captured. In an age of electronic health records and payor databases, it may be even better to develop more comprehensive ways of assessing these events in the future, rather than depending on self-report as the trigger event for collecting hospitalization outcomes. Many studies are already employing such strategies, often as a means to avoid the costs of patient interviews, but there may be a more important aspect to a digital strategy. Certain strategies leveraging technology have already been tested and implemented. These include the use of smartphone geofencing to detect when a participant is hospitalized,[34] leveraging common format data from electronic health records to capture endpoints as in ADAPTABLE (Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-Term Effectiveness, clinicaltrials.gov identifier NCT02697916),[35] or a combination of several digital sources including activity monitors, pharmacies, wearable devices, among others.[36] Furthermore, a diverse population of patients have shown interest in embracing similar digital strategies into their care,[37] signaling their potential accessibility across sociodemographic subgroups that could also be leveraged for research.

The study has several limitations. We only had access to hospitalizations at TRIUMPH enrolling sites and hospitals where the participant indicated that they had received acute care. Thus, the results in this study represent the lower bound of the actual underreporting rate. Also, we could not assess whether the additional hospitalizations identified represent the entire set of hospitalizations for that individual at that institution during the study period. Also, the study was conducted in a real-world setting and 16% of the patients did not consent to have their medical records requested. Nevertheless, this study was conducted by experienced investigators with highly-trained staff, and with a commitment to acquire as much follow-up information on hospitalizations as was possible. Finally, TRIUMPH was

conducted over a decade ago. Nevertheless, there is no reason to believe that the current performance of self-report would be different.

In conclusion, self-report of hospital events after AMI are unreliable, with high rates of underreporting hospitalizations, which can undermine the power of clinical investigations and treatment decisions based on patient-reported hospitalization events during clinical encounters. These results underscore the importance of leveraging better approaches to ascertain outcomes in longitudinal studies, while also verifying self-reported data.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGMENTS:

We thank Drs. Shiwani Mahajan, Karthik Murugiah, Sumeet Pawar, Yuan Lu, and Ms. Daisy Massey for their useful suggestions and discussions on this manuscript.

SOURCE OF FUNDING:

The TRIUMPH study was funded in part by a grant from NIH-NHLBI, #P50-HL077113).

REFERENCES

1. Montone RA, Niccoli G, Fracassi F, Russo M, Gurgoglione F, Camma G, Lanza GA, Crea F. Patients with acute myocardial infarction and non-obstructive coronary arteries: safety and prognostic relevance of invasive coronary provocative tests. Eur Heart J 2018;39:91–98. [PubMed: 29228159]
2. Stienen S, Salah K, Moons AH, Bakx AL, van Pol P, Kortz RAM, Ferreira JP, Marques I, Schroeder-Tanka JM, Keijer JT, Bayes-Genis A, Tijssen JGP, Pinto YM, Kok WE. NT-proBNP (N-Terminal pro-B-Type Natriuretic Peptide)-Guided Therapy in Acute Decompensated Heart Failure: PRIMA II Randomized Controlled Trial (Can NT-ProBNP-Guided Therapy During Hospital Admission for Acute Decompensated Heart Failure Reduce Mortality and Readmissions?). Circulation 2018;137:1671–1683. [PubMed: 29242350]
3. Franzone A, Pilgrim T, Arnold N, Heg D, Langhammer B, Piccolo R, Roost E, Praz F, Raber L, Valgimigli M, Wenaweser P, Juni P, Carrel T, Windecker S, Stortecky S. Rates and predictors of hospital readmission after transcatheter aortic valve implantation. Eur Heart J 2017;38:2211–2217. [PubMed: 28430920]
4. Hess CN, Kaltenbach LA, Doll JA, Cohen DJ, Peterson ED, Wang TY. Race and Sex Differences in Post-Myocardial Infarction Angina Frequency and Risk of 1-Year Unplanned Rehospitalization. Circulation 2017;135:532–543. [PubMed: 28153990]
5. Hess CN, Wang TY, McCoy LA, Messenger JC, Effron MB, Zettler ME, Henry TD, Peterson ED, Fonarow GC. Unplanned Inpatient and Observation Rehospitalizations After Acute Myocardial Infarction: Insights From the Treatment With Adenosine Diphosphate Receptor Inhibitors: Longitudinal Assessment of Treatment Patterns and Events After Acute Coronary Syndrome (TRANSLATE-ACS) Study. Circulation 2016;133:493–501. [PubMed: 26680241]
6. Murphy PB, Rehal S, Arbane G, Bourke S, Calverley PMA, Crook AM, Dowson L, Duffy N, Gibson GJ, Hughes PD, Hurst JR, Lewis KE, Mukherjee R, Nickol A, Oscroft N, Patout M, Pepperell J, Smith I, Stradling JR, Wedzicha JA, Polkey MI, Elliott MW, Hart N. Effect of Home Noninvasive Ventilation With Oxygen Therapy vs Oxygen Therapy Alone on Hospital Readmission or Death After an Acute COPD Exacerbation: A Randomized Clinical Trial. JAMA 2017;317:2177–2186. [PubMed: 28528348]
7. Wallentin L, Lindhagen L, Arnstrom E, Husted S, Janzon M, Johnsen SP, Kontny F, Kempf T, Levin LA, Lindahl B, Stridsberg M, Stahle E, Venge P, Wollert KC, Swahn E, Lagerqvist B. Early invasive

versus non-invasive treatment in patients with non-ST-elevation acute coronary syndrome (FRISC-II): 15 year follow-up of a prospective, randomised, multicentre study. Lancet 2016;388:1903–1911. [PubMed: 27585757]

8. Margulies KB, Hernandez AF, Redfield MM, Givertz MM, Oliveira GH, Cole R, Mann DL, Whellan DJ, Kiernan MS, Felker GM, McNulty SE, Anstrom KJ, Shah MR, Braunwald E, Cappola TP. Effects of Liraglutide on Clinical Stability Among Patients With Advanced Heart Failure and Reduced Ejection Fraction: A Randomized Clinical Trial. JAMA 2016;316:500–8. [PubMed: 27483064]
9. Michler RE, Smith PK, Parides MK, Ailawadi G, Thourani V, Moskowitz AJ, Acker MA, Hung JW, Chang HL, Perrault LP, Gillinov AM, Argenziano M, Bagiella E, Overbey JR, Moquete EG, Gupta LN, Miller MA, Taddei-Peters WC, Jeffries N, Weisel RD, Rose EA, Gammie JS, DeRose JJ Jr, Puskas JD, Dagenais F, Burks SG, El-Hamamsy I, Milano CA, Atluri P, Voisine P, O'Gara PT, Gelijns AC. Two-Year Outcomes of Surgical Treatment of Moderate Ischemic Mitral Regurgitation. N Engl J Med 2016;374:1932–41. [PubMed: 27040451]
10. Page MG, Boyd K, Ware MA. Examination of the Course of Low Back Pain Intensity Based on Baseline Predictors and Health Care Utilization Among Patients Treated in Multidisciplinary Pain Clinics: A Quebec Pain Registry Study. Pain Med 2019;20:564–573. [PubMed: 30690515]
11. Zheng L, Hu R, Dong Z, Hao Y. Comparing the needs and utilization of health services between urban residents and rural-to-urban migrants in China from 2012 to 2016. BMC Health Serv Res 2018;18:717. [PubMed: 30223803]
12. McNeil JJ, Wolfe R, Woods RL, Tonkin AM, Donnan GA, Nelson MR, Reid CM, Lockery JE, Kirpach B, Storey E, Shah RC, Williamson JD, Margolis KL, Ernst ME, Abhayaratna WP, Stocks N, Fitzgerald SM, Orchard SG, Trevaks RE, Beilin LJ, Johnston CI, Ryan J, Radziszewska B, Jelinek M, Malik M, Eaton CB, Brauer D, Cloud G, Wood EM, Mahady SE, Satterfield S, Grimm R, Murray AM. Effect of Aspirin on Cardiovascular Events and Bleeding in the Healthy Elderly. N Engl J Med 2018;379:1509–1518. [PubMed: 30221597]
13. Xaplanteris P, Fournier S, Pijls NHJ, Fearon WF, Barbato E, Tonino PAL, Engstrom T, Kaab S, Dambrink JH, Rioufol G, Toth GG, Piroth Z, Witt N, Frobert O, Kala P, Linke A, Jagic N, Mates M, Mavromatis K, Samady H, Irimpen A, Oldroyd K, Campo G, Rothenbuhler M, Juni P, De Bruyne B. Five-Year Outcomes with PCI Guided by Fractional Flow Reserve. N Engl J Med 2018;379:250–259. [PubMed: 29785878]
14. Huang SS, Singh R, McKinnell JA, Park S, Gombosev A, Eells SJ, Gillen DL, Kim D, Rashid S, Macias-Gil R, Bolaris MA, Tjoa T, Cao C, Hong SS, Lequieu J, Cui E, Chang J, He J, Evans K, Peterson E, Simpson G, Robinson P, Choi C, Bailey CC Jr., Leo JD, Amin A, Goldmann D, Jernigan JA, Platt R, Septimus E, Weinstein RA, Hayden MK, Miller LG. Decolonization to Reduce Postdischarge Infection Risk among MRSA Carriers. N Engl J Med 2019;380:638–650. [PubMed: 30763195]
15. Velazquez EJ, Morrow DA, DeVore AD, Duffy CI, Ambrosy AP, McCague K, Rocha R, Braunwald E. Angiotensin-Neprilysin Inhibition in Acute Decompensated Heart Failure. N Engl J Med 2019;380:539–548. [PubMed: 30415601]
16. Bergmann MM, Byers T, Freedman DS, Mokdad A. Validity of self-reported diagnoses leading to hospitalization: a comparison of self-reports with hospital records in a prospective study of American adults. Am J Epidemiol 1998;147:969–77. [PubMed: 9596475]
17. Bolland MJ, Barber A, Doughty RN, Grey A, Gamble G, Reid IR. Differences between self-reported and verified adverse cardiovascular events in a randomised clinical trial. BMJ Open 2013;3.
18. Eliassen BM, Melhus M, Tell GS, Borch KB, Braaten T, Broderstad AR, Graff-Iversen S. Validity of self-reported myocardial infarction and stroke in regions with Sami and Norwegian populations: the SAMINOR 1 Survey and the CVDNOR project. BMJ Open 2016;6:e012717.
19. Lofters A, Vahabi M, Glazier RH. The validity of self-reported cancer screening history and the role of social disadvantage in Ontario, Canada. BMC Public Health 2015;15:28. [PubMed: 25630218]
20. Machon M, Arriola L, Larranaga N, Amiano P, Moreno-Iribas C, Agudo A, Ardanaz E, Barricarte A, Buckland G, Chirlaque MD, Gavrila D, Huerta JM, Martinez C, Molina E, Navarro C, Quiros JR, Rodriguez L, Sanchez MJ, Gonzalez CA, Dorronsoro M. Validity of self-reported prevalent

cases of stroke and acute myocardial infarction in the Spanish cohort of the EPIC study. J Epidemiol Community Health 2013;67:71–5. [PubMed: 22577182]

21. Yasaitis LC, Berkman LF, Chandra A. Comparison of self-reported and Medicare claims-identified acute myocardial infarction. Circulation 2015;131:1477–1485. [PubMed: 25747935]
22. Krishnamoorthy A, Peterson ED, Knight JD, Anstrom KJ, Effron MB, Zettler ME, Davidson-Ray L, Baker BA, McCollam PL, Mark DB, Wang TY. How Reliable are Patient-Reported Rehospitalizations? Implications for the Design of Future Practical Clinical Studies. J Am Heart Assoc 2016;5:e002695. [PubMed: 26811163]
23. Ho PJ, Tan CS, Shawon SR, Eriksson M, Lim LY, Miao H, Png E, Chia KS, Hartman M, Ludvigsson JF, Czene K, Hall P, Li J. Comparison of self-reported and register-based hospital medical data on comorbidities in women. Sci Rep 2019;9:3527. [PubMed: 30837593]
24. Camplain R, Kucharska-Newton A, Loehr L, Keyserling TC, Layton JB, Wruck L, Folsom AR, Bertoni AG, Heiss G. Accuracy of Self-Reported Heart Failure. The Atherosclerosis Risk in Communities (ARIC) Study. J Card Fail 2017;23:802–808. [PubMed: 28893677]
25. Ritter PL, Stewart AL, Kaymaz H, Sobel DS, Block DA, Lorig KR. Self-reports of health care utilization compared to provider records. J Clin Epidemiol 2001;54:136–141. [PubMed: 11166528]
26. Bhandari A, Wagner T. Self-reported utilization of health care services: improving measurement and accuracy. Med Care Res Rev 2006;63:217–235. [PubMed: 16595412]
27. Cowie MR, Blomster JI, Curtis LH, Duclaux S, Ford I, Fritz F, Goldman S, Janmohamed S, Kreuzer J, Leenay M, Michel A, Ong S, Pell JP, Southworth MR, Stough WG, Thoenes M, Zannad F, Zalewski A. Electronic health records to facilitate clinical research. Clin Res Cardiol 2017;106:1–9.
28. Raman SR, Curtis LH, Temple R, Andersson T, Ezekowitz J, Ford I, James S, Marsolo K, Mirhaji P, Rocca M, Rothman RL, Sethuraman B, Stockbridge N, Terry S, Wasserman SM, Peterson ED, Hernandez AF. Leveraging electronic health records for clinical research. Am Heart J 2018;202:13–19. [PubMed: 29802975]
29. Mc Cord KA, Ewald H, Ladanie A, Briel M, Speich B, Bucher HC, Hemkens LG. Current use and costs of electronic health records for clinical trial research: a descriptive study. CMAJ Open 2019;7:E23–e32.
30. Arnold SV, Chan PS, Jones PG, Decker C, Buchanan DM, Krumholz HM, Ho PM, Spertus JA, Cardiovascular Outcomes Research C. Translational Research Investigating Underlying Disparities in Acute Myocardial Infarction Patients' Health Status (TRIUMPH): design and rationale of a prospective multicenter registry. Circ Cardiovasc Qual Outcomes 2011;4:467–76. [PubMed: 21772003]
31. R Core Team. R: A language and environment for statistical computing R Foundation for Statistical Computing, Vienna, Austria. 2018. Accessed on January 4, 2020. Available from: https://www.R-project.org/.
32. Seidl H, Meisinger C, Kirchberger I, Burkhardt K, Kuch B, Holle R. Validity of self-reported hospital admissions in clinical trials depends on recall period length and individual characteristics. J Eval Clin Pract 2016;22:446–54. [PubMed: 26711475]
33. St Clair P, Gaudette E, Zhao H, Tysinger B, Seyedin R, Goldman DP. Using Self-reports or Claims to Assess Disease Prevalence: It's Complicated. Med Care 2017;55:782–788. [PubMed: 28617703]
34. Nguyen KT, Olgin JE, Pletcher MJ, Ng M, Kaye L, Moturu S, Gladstone RA, Malladi C, Fann AH, Maguire C, Bettencourt L, Christensen MA, Marcus GM. Smartphone-Based Geofencing to Ascertain Hospitalizations. Circ Cardiovasc Qual Outcomes 2017;10:e003326. [PubMed: 28325751]
35. Aspirin Dosing: A Patient-Centric Trial Assessing Benefits and Long-term Effectiveness (ADAPTABLE) Study Protocol Accessed on January 4, 2020. Available from: https://theaspirinstudy.org/wp-content/uploads/2018/07/ADAPTABLE-V3-Revised-Protocol_Clean_12.18.17_Final.pdf.
36. Dhruva SS, Ross JS, Akar JG, Caldwell B, Childers K, Chow W, Ciaccio L, Coplan P, Dong J, Dykhoff HJ, Johnston S, Kellogg T, Long C, Noseworthy PA, Roberts K, Saha A, Yoo A, Shah

ND. Aggregating Multiple Real-World Data Sources using a Patient-Centered Health Data Sharing Platform: an 8-week Cohort Study among Patients Undergoing Bariatric Surgery or Catheter Ablation of Atrial Fibrillation. medRxiv 2019:19010348.

37. Liu P, Astudillo K, Velez D, Kelley L, Cobbs-Lomax D, Spatz E. Use of mobile health apps in low-income populations: a prospective study of facilitators and barriers. medRxiv 2019:2019.12.22.19015636.

What is Known?

- Clinical investigations often rely on self-report as the main method to identify incident events, but it is often inaccurate when compared with medical records.
- Whereas overreported events can be mitigated with adjudication of medical records, underreported events will be missed by the investigators and pose a threat to the study.
- There has been little attention to how rates of underreporting vary by patient characteristics, event type, or timing from the event to the interview.

What the Study Adds?

- Self-reported hospitalization events after a myocardial infarction are often in error, with nearly one third not being reported, and—while there are differences in rates of underreported events by patient characteristics or event type—across all subgroups the rates are high, increasing progressively as time between the time of event and the interview increased.
- This evidence provides impetus to the need for better ascertainment methods beyond self-report.

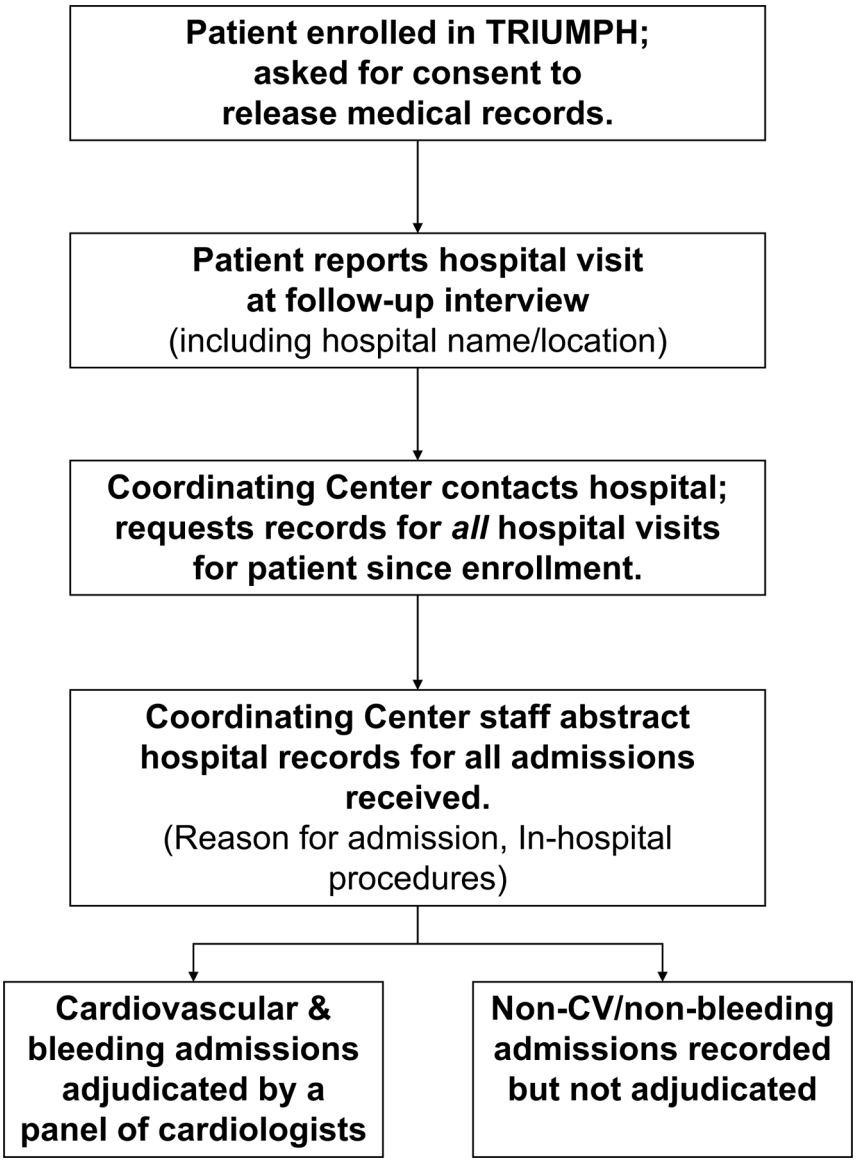

Figure 1.
Overview of study methodology
Abbreviations: CV, cardiovascular.

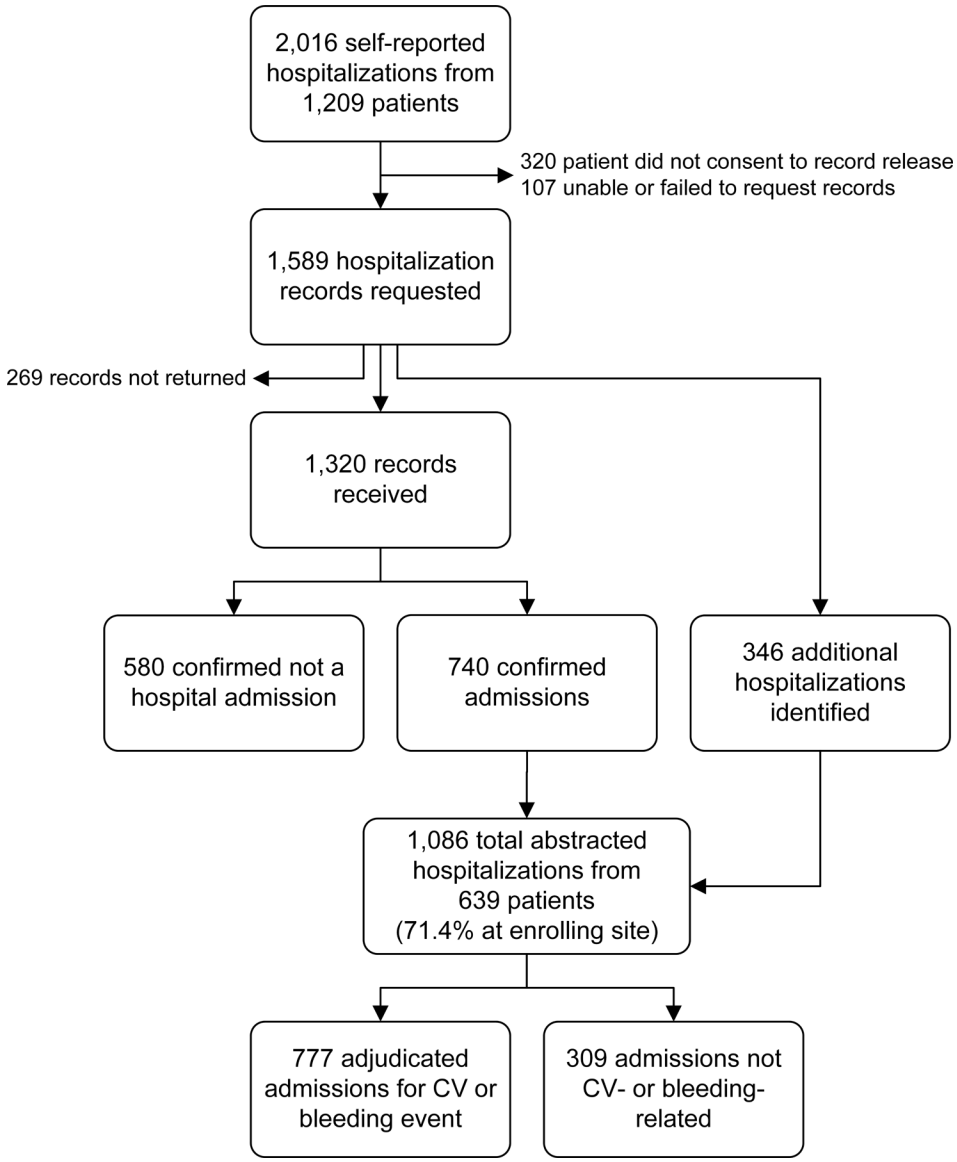

Figure 2.

Number of hospitalization records request, received and adjudicated to be hospitalization events.

Abbreviations: CV, cardiovascular.

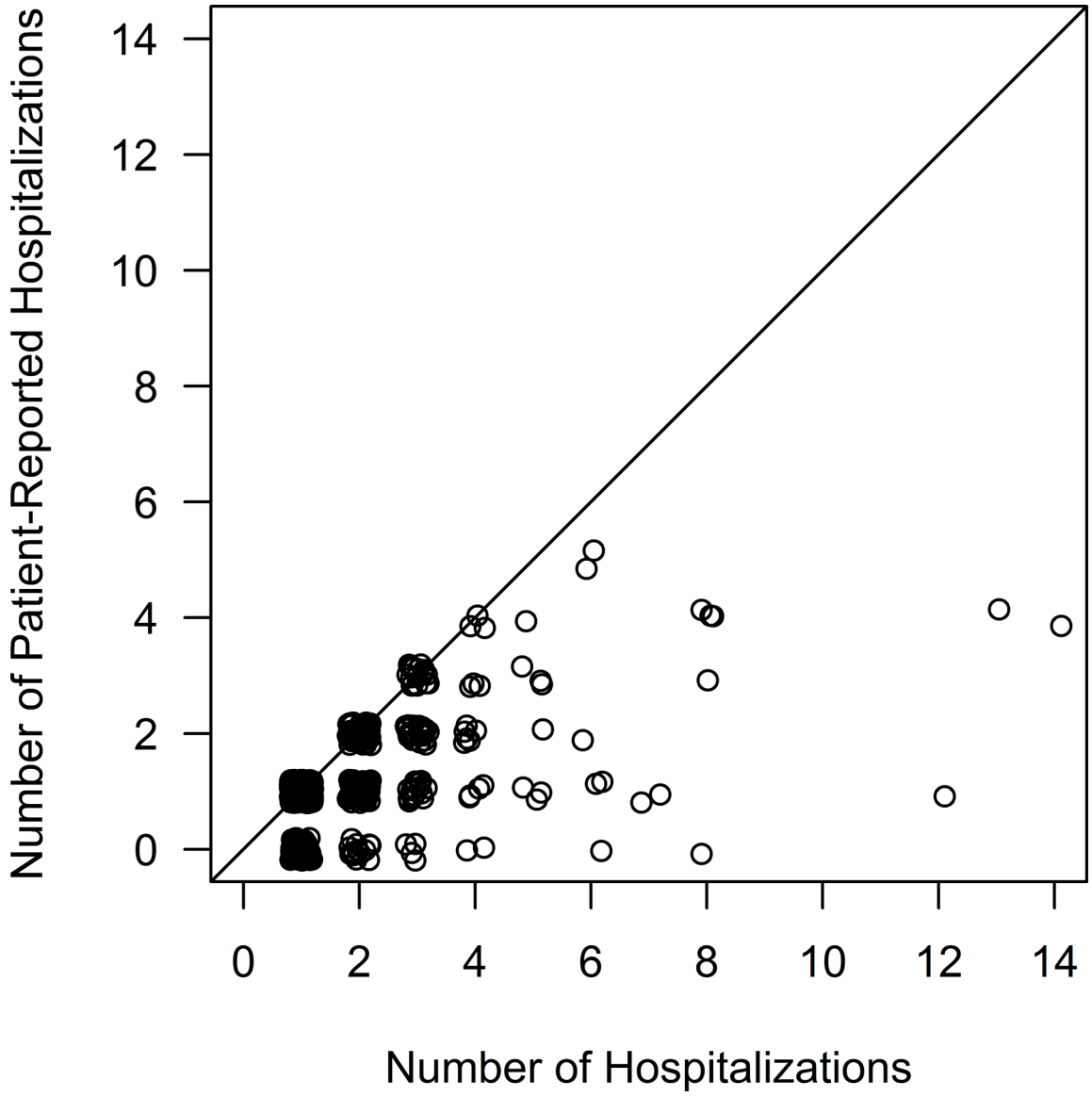

Figure 3.
Relationship Between Number of Confirmed Hospitalization Events and Number of Patient-Reported Events

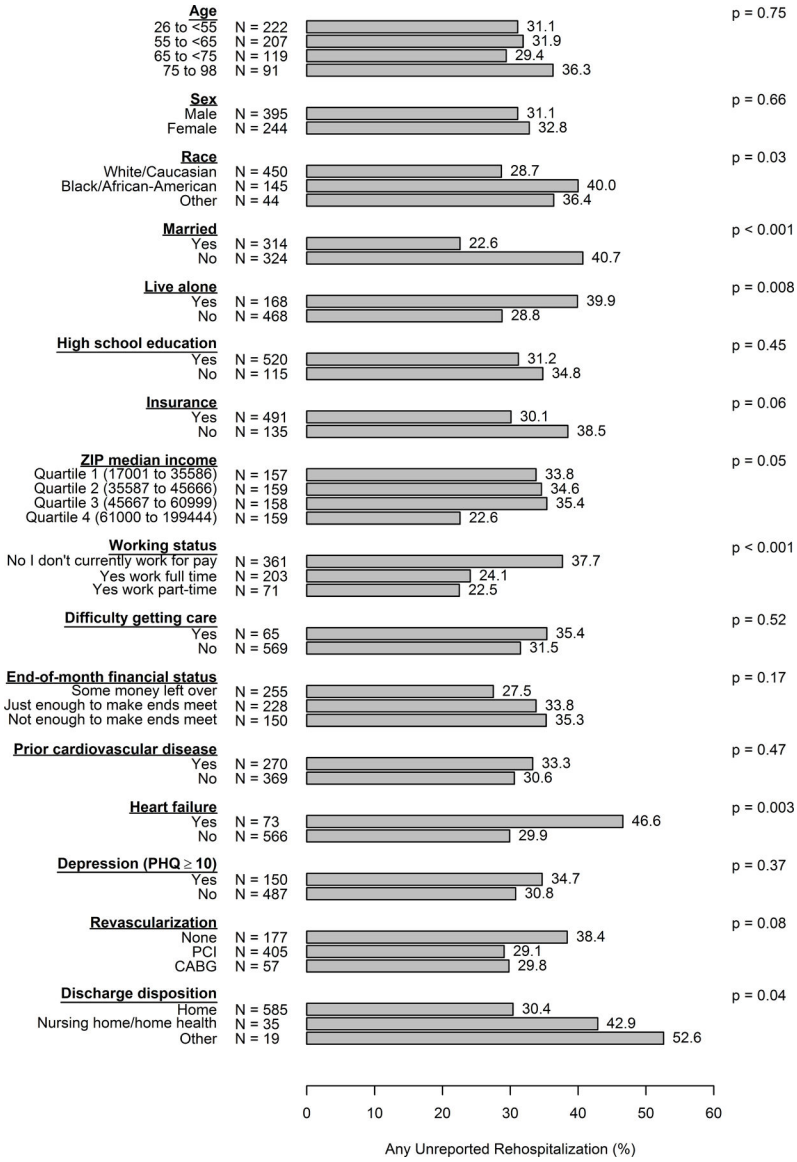

Figure 4.

Proportion of Patients with Any Unreported Rehospitalization by Baseline Characteristics Abbreviations: PHQ, Patient Health Questionnaire; PCI, percutaneous coronary intervention; CABG, coronary artery bypass grafting.

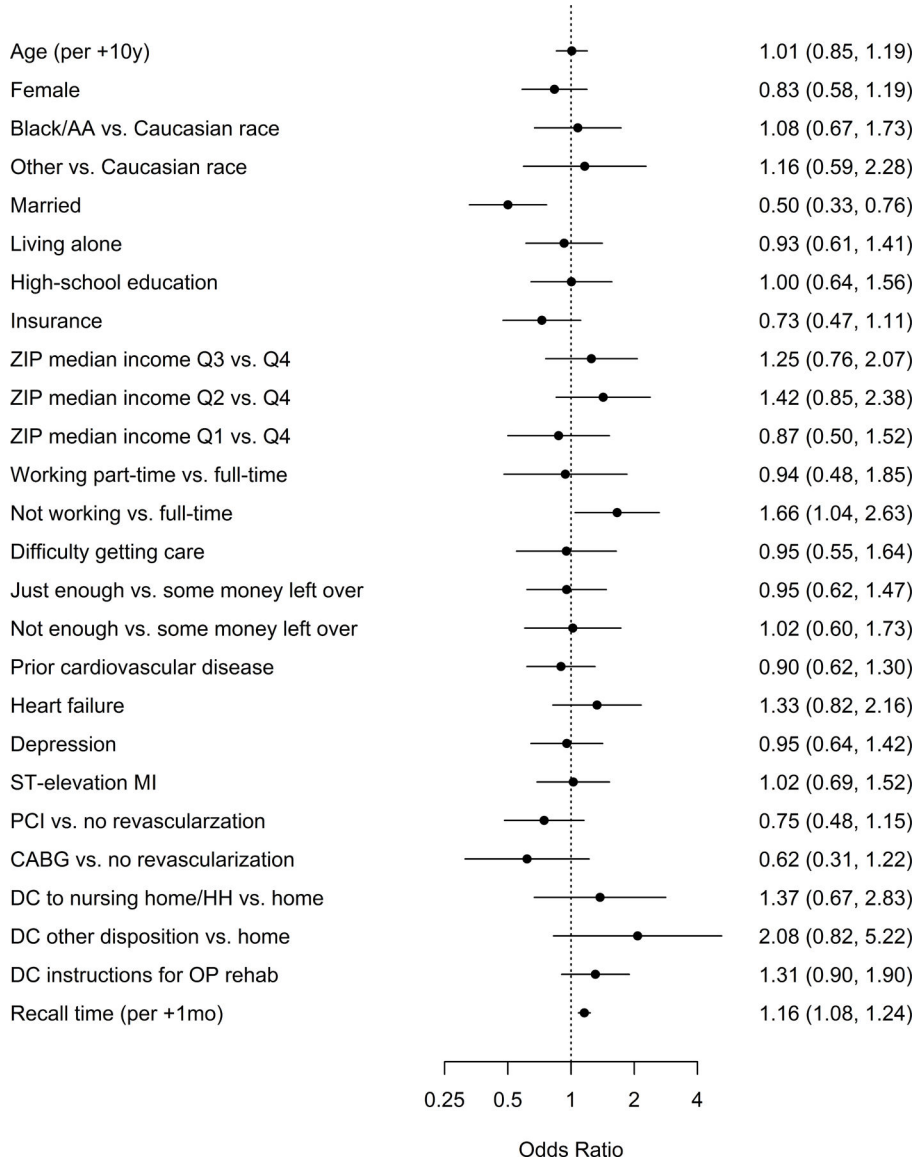

Figure 5.

Adjusted Odds Ratios of Underreporting Hospitalization Events by Patients Characteristics

Abbreviations: AA, African American; Q1, quartile 1; Q2, quartile 2; Q3, quartile 3; Q4, quartile 4; MI, myocardial infarction; PCI, percutaneous coronary intervention; CABG, coronary artery bypass grafting; DC, discharge; HH, home health; OP Rehab, outpatient rehabilitation.

Table 1.

Patients Baseline Characteristics

Characteristic	Total n = 639
Age (years)	60.2 ± 12.0
Sex **Male** **Female**	395 (61.8%) 244 (38.2%)
Race **White/Caucasian** **Black/African-American** **Other**	450 (70.4%) 145 (22.7%) 44 (6.9%)
Married **Missing**	314 (49.2%) 1
Live alone **Missing**	168 (26.4%) 3
High school education **Missing**	520 (81.9%) 4
Insurance **Missing**	491 (78.4%) 13
ZIP median income (Median (IQR)) **Missing**	45667.0 (35587.0, 61000.0) 6
Working status **No, I don't currently work for pay** **Yes, work full time** **Yes, work part-time** **Missing**	 361 (56.9%) 203 (32.0%) 71 (11.2%) 4
Difficulty getting care **Missing**	65 (10.3%) 5
End-of-month financial status **Some money left over** **Just enough to make ends meet** **Not enough to make ends meet** **Missing**	 255 (40.3%) 228 (36.0%) 150 (23.7%) 6
Prior cardiovascular disease	270 (42.3%)
Heart failure	73 (11.4%)
Depression (PHQ>=10) **Missing**	150 (23.5%) 2
Revascularization **None** **PCI** **CABG**	177 (27.7%) 405 (63.4%) 57 (8.9%)

Characteristic	Total n = 639
Discharge disposition	
Home	585 (91.5%)
Nursing home/home health	35 (5.5%)
Other	19 (3.0%)

Abbreviations: IQR, interquartile range; PHQ, Patient Health Questionnaire; PCI, percutaneous coronary intervention; CABG, coronary artery bypass grafting