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Race and ethnicity data in the cardiac arrest registry to enhance survival: Insights from medicare self-reported data

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Abstract

Background: For out-of-hospital cardiac arrest (OHCA), assignment of race/ethnicity data can be challenging. Validation of race/ethnicity in registry data with patients' self-reported race/ethnicity would provide insights regarding misclassification.

Methods: Using recently linked 2013–2019 Cardiac Arrest Registry to Enhance Survival (CARES) data with Medicare files, we examined the concordance of race/ethnicity in CARES with self-reported race/ethnicity in Medicare. Among patients with unknown race/ethnicity in CARES, race/ethnicity data from Medicare files were reported.

Results: Of 26,875 patients in the linked data, 5757 (21.4%) had unknown race/ethnicity in CARES. Of the remaining 21,118 patients, 14,284 (67.6%) were identified in CARES as non-Hispanic White, 4771 (22.6%) as non-Hispanic Black, 1213 (5.7%) as Hispanic, 760 (3.6%) as Asian or Pacific Islander, and 90 (0.4%) as American Indian or Alaskan Native. The concordance rate for race/ethnicity between CARES and Medicare was 93.4% for patients reported as non-Hispanic White in CARES, 89.1% for non-Hispanic Blacks, 74.6% for Hispanics, 69.6% for Asians and Pacific Islanders, and 37.8% for American Indian or Alaskan Natives. For the 5757 patients with unknown race/ethnicity in CARES, 3973 (69.0%) self-reported in Medicare as non-Hispanic White, 617 (10.7%) as non-Hispanic Black, 425 (7.4%) as Hispanic, 491 (8.5%) as

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CRediT authorship contribution statement

Paul S. Chan: Conceptualization, Methodology, Writing – original draft, Writing – review & editing, Supervision. **Robert Merritt:** Resources, Writing – review & editing, Supervision. **Anping Chang:** Formal analysis, Writing – review & editing. **Saket Girotra:** Writing – review & editing. **Pavitra Kotini-Shah:** Writing – review & editing. **Rabab Al-Araji:** Data curation, Writing – review & editing. **Bryan McNally:** Resources, Writing – review & editing, Supervision.

Asian or Pacific Islander, and 52 (0.9%) as American Indian or Alaskan Native. Race/ethnicity remained unknown in 199 (3.5%) of patients.

Conclusion: Race/ethnicity in CARES was highly concordant with self-reported race/ethnicity in Medicare, especially for non-Hispanic White and Black individuals. For patients with unknown race/ethnicity data in CARES, the vast majority were of White race.

Keywords

Race; Ethnicity; Concordance; Accuracy; Medicare

Introduction

Although out-of-hospital cardiac arrest (OHCA) is common and a major public health condition, it is the only cardiovascular condition in which over 70% of victims die before hospital arrival.¹ Determining the race and ethnicity of an OHCA victim in the field can be challenging, especially if the victim is unaccompanied by family members or acquaintances when emergency medical service (EMS) agency personnel arrive. This has raised questions regarding the accuracy of race and ethnicity data reported in large OHCA registries such as the Cardiac Arrest Registry to Enhance Survival (CARES), the largest OHCA registry in the U.S. This issue is further compounded by the fact that race/ethnicity is not reported by emergency medical service (EMS) agencies or is unknown for one in five patients in CARES. Thus, a better understanding of the accuracy of race and ethnicity data in CARES and the racial composition of those with missing data is critical as these registries can be a valuable resource to study racial and ethnic disparities in care and outcomes for OHCA.

Unlike CARES, race and ethnicity data in Medicare files are self-reported by patients or their families and may represent a ‘gold standard’ representation of patients’ race and ethnicity. In coordination with the Centers for Disease Control and Prevention, we recently linked data from CARES with Medicare files among patients who were 65 years or older. Leveraging this unique linkage, we examined the concordance of race and ethnicity data in CARES with Medicare data and investigated the racial and ethnic makeup of patients with unknown race/ethnicity data in CARES.

Methods

CARES is a prospective, multicenter registry of patients with OHCA in the U.S, with a catchment area of approximately 167 million residents. Its design has been previously described.² Briefly, all patients with a confirmed OHCA and initiation of resuscitation are identified by EMS agencies. Data are submitted using standardized international Utstein definitions to ensure uniformity in reporting. The study was approved by Saint Luke’s Hospital’s IRB, which waived the requirement for informed consent.

Based on prior work linking registries with Medicare files,^{3–5} we linked CARES patient-level data between 2013 and 2019 to Medicare files using 5 identifiers: patient age and sex, admission date, admitting hospital (identified using the hospital’s American Hospital Association number), and a qualifying *International Classification of Diseases*,

*Ninth Revision, Clinical Modification (ICD-9-CM) or Tenth Revision, Clinical Modification (ICD-10-CM) diagnosis or procedure code.*⁶ We selected Medicare records for the linkage if they included a primary or secondary diagnosis code for cardiac arrest, ventricular fibrillation, or ventricular flutter or a procedure code for cardiopulmonary resuscitation, defibrillation, or closed chest massage. To further maximize linkage, we additionally included diagnosis codes for acute respiratory failure and shock and a procedure code for cardioverter-defibrillator implantation. This cohort represents OHCA patients who survive to hospital admission, as a Medicare hospitalization record is generated on patients with an inpatient stay.

Within this linked cohort, for patients with identified race/ethnicity information in CARES, we assessed concordance of CARES-reported race/ethnicity data with self-reported race/ethnicity in Medicare. For patients with unknown race/ethnicity in CARES, we summarize their self-reported race/ethnicity from Medicare files to provide insights on these patients who have traditionally been excluded from race and ethnicity analyses in this national OHCA registry.

Results

During the period of 2013–2019, there were 56,425 patients with OHCA in CARES who were 65 years of age or older and survived to hospital admission. Of these, 26,875 (47.6%) were successfully linked to Medicare files and represent the analytical cohort for this study.

Among these 26,875 patients, 5757 (21.4%) were designated as having unknown race/ethnicity in CARES. Of the remaining 21,118 patients, 14,284 (67.6%) were identified in CARES as non-Hispanic White, 4771 (22.6%) as non-Hispanic Black, 1213 (5.7%) as Hispanic, 760 (3.6%) as Asian or Pacific Islander, and 90 (0.4%) as American Indian or Alaskan Native. Patients identified as non-Hispanic White in CARES self-reported as White in Medicare files 93.4% of the time. This concordance rate was 89.1% for those identified as non-Hispanic Black in CARES, 74.6% for Hispanics, 69.6% for Asians and Pacific Islanders, and 37.8% for American Indian or Alaskan Natives (Table 1). Overall, the concordance rate was 90.3% (19,060/21,118).

For the 5757 patients with unknown race/ethnicity in CARES, we examined self-reported race/ethnicity using Medicare data. We found that 3973 (69.0%) self-reported as non-Hispanic White in Medicare files, 617 (10.7%) as non-Hispanic Black, 425 (7.4%) as Hispanic, 491 (8.5%) as Asian or Pacific Islander, and 52 (0.9%) as American Indian or Alaskan Native, while 199 (3.5%) remained unknown.

Discussion

In a large national registry for OHCA, we found a 90% concordance of race and ethnicity data submitted by EMS agencies in CARES with self-reported race and ethnicity in Medicare files. Concordance rates were highest for those identified as non-Hispanic White (93.4%) or Black (89.1%) in CARES but was lower for individuals who were Hispanic, Asian and of other races/ethnicities.

Since the majority of studies on racial and ethnic disparities CARES have focused on comparisons of White vs Black patients, our findings provide reassurance that estimates from many of these studies are not threatened by major misclassification bias. Assignment of race and ethnicity by EMS personnel can be a challenging task in a cardiac arrest victim with no family member or acquaintance present, especially if the OHCA occurs in a diverse community. Moreover, as many U.S. residents are increasingly biracial or multiracial, homogeneous racial and ethnic categories may lead to misclassification and discordance with patients' self-reported data. Our analyses suggest that, as of 2019, EMS personnel were assigning race and ethnicity to OHCA victims with relatively high concordance to patients' self-reported data. However, the extent to which these concordance rates will continue as the U.S. becomes increasingly multiracial is unknown but deserves additional study.

Our study also provides important insights into CARES patients with unknown race and ethnicity data. The main reason for why patients have unknown race/ethnicity in CARES is because it is not a required variable and some EMS agencies have chosen to not report race/ethnicity data. Our findings generally support this, since 69% of patients with unknown race/ethnicity in CARES self-reported as non-Hispanic White in Medicare, similar to the overall proportion of non-Hispanic Whites in CARES (66.7%). However, among CARES patients with unknown race/ethnicity, we found a higher percentage of patients who self-reported as Hispanic and Asian as compared to patients with known race/ethnicity in CARES. It may be that some CARES patients have unknown race and ethnicity data in multiracial or diverse communities because of patient-level reasons (i.e., their race and ethnicity are difficult to assign by EMS personnel and are actually not known) rather than a system issue of EMS reporting. This issue may affect patients of Hispanic ethnicity or Asian race more but warrants additional investigation.

Our study findings should be interpreted in the context of the following limitations. First, our concordance analyses were limited to older patients who survived to hospital admission. However, while the median age of all CARES patients is 63–65 years of age, we do not expect concordance rates to differ substantially for younger patients in the registry, who represent slightly more than half of all OHCA victims in the registry. Moreover, data on race/ethnicity in CARES is assigned by EMS agency personnel and is not informed by hospital information on demographics. Therefore, restricting our CARES cohort to patients who survived to hospital admission is not expected to affect the concordance findings in this study. Second, our study was limited to CARES data; therefore, concordance rates for race and ethnicity may differ in other registries, especially those in other countries. Third, we were only able to link 48% of CARES patients to Medicare data. However, in the study design paper for this linkage, race and ethnicity data for patients linked and not linked to Medicare data were very similar.⁶ Finally, in instances where there was discordance in race and ethnicity between CARES and Medicare data, the assumption was that Medicare data is the gold standard. However, a recent study found that nursing home residents during their initial intake reported different race and ethnicity information as compared to their Medicare beneficiary information, with discordance rates of 1% for White residents, 4% for Black residents, 28% for Hispanic residents, 17% for Asian and Pacific Islander residents, and 46% for American Indian and Alaskan Native residents.⁷ These discordance rates were similar to the discordance rates we found between CARES and Medicare data in our study,

and it is possible that some of the discordance was due to inaccuracies in race and ethnicity data in Medicare beneficiary files, rather than those in CARES.

In summary, we found generally high concordance rates in race and ethnicity between the CARES registry and Medicare beneficiary files. For patients with unknown race and ethnicity data in CARES, the vast majority were of White race and suggest a system-related reason for missing data.

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Table 1 –

Concordance of Race/Ethnicity Data in CARES with Self-Reported Data in Medicare Files. Among the 021,118 patients with race and ethnicity data in the CARES registry, we examined the concordance of race/ethnicity data for 5 racial/ethnic groups with data from Medicare files. The overall concordance rate was 90.3% (19,060/21,118).

SELF-REPORTED RACE AND ETHNICITY IN MEDICARE DATA							
CARES Race/Ethnicity	Total	Non-Hispanic White	Non-Hispanic Black	Hispanic	Asian/PI	American Indian or AN	% Concordance with CARES
Non-Hispanic White	14,284	13,343	272	262	106	44	93.4%
Non-Hispanic Black	4771	398	4249	71	18	3	89.1%
Hispanic	1213	211	54	905	23	3	74.6%
Asian/PI	760	95	17	47	529	1	69.6%
American Indian/AN	90	23	18	4	4	34	37.8%

Abbreviations: AN, Alaskan Native; PI, Pacific Islander.