

Examining the Characteristics of Eligible Burn Survivors Who Did Not Consent to Participate in a Longitudinal, National Database

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Introduction

- The Burn Model System (BMS) National Database is one of the largest prospective, longitudinal, multi-center research data repositories for burn survivors.
- It is important to understand the extent to which individuals who are often considered underserved are participating in long-term research studies.
- The purpose of this study was to assess the extent that consented participants of the BMS National Database are representative of the eligible population.

Methods

- Data for all BMS National Database eligible burn survivors from August 2005 to August 2019 were analyzed.
- Descriptive statistics compared demographic characteristics between participants who did and did not consent.
- Regression analyses examined the correlation between consent status and demographic characteristics, controlling for eligibility criteria and BMS site.

Results

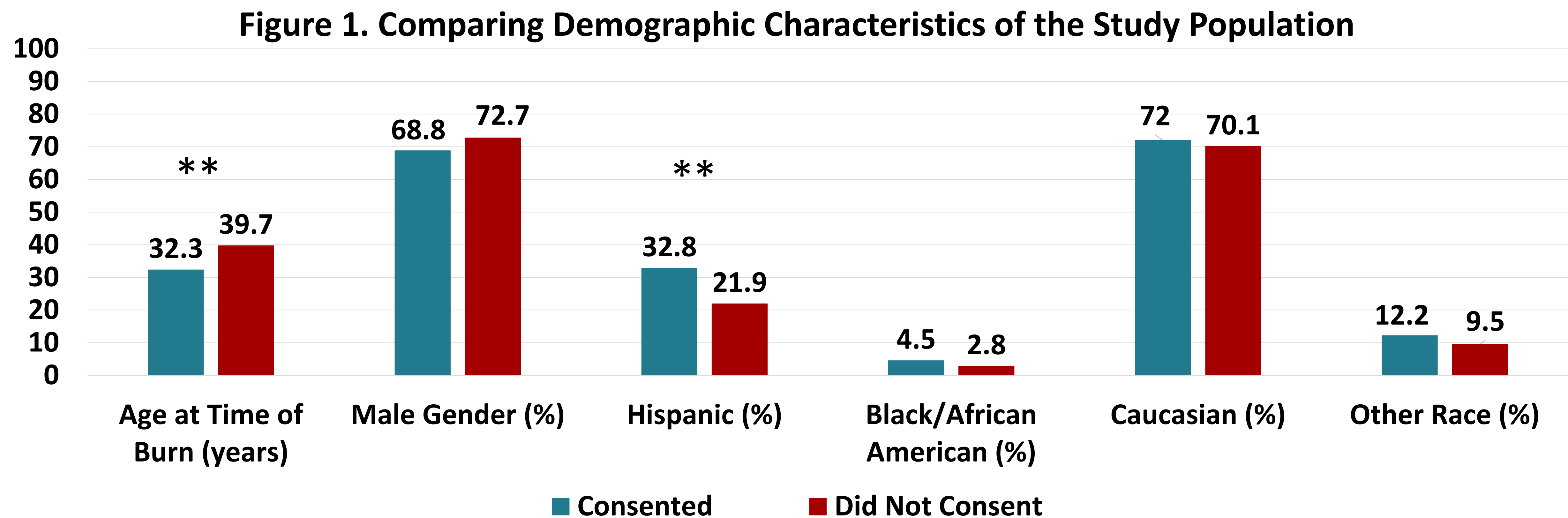
Table 1. Study Population by Eligibility Criteria[¥], percent (n)**

	Consented (n=2,607)	Did Not Consent (n=885)
10%+ TBSA, 65+ years	4.3 (111)	7.3 (65)
20% TBSA, 19-64 years	21.9 (571)	22.3 (197)
20% TBSA, 0-18 years	26.3 (686)	13.5 (119)
Electrical/High Voltage/Lightning	2.8 (72)	2.2 (19)
Hand/Face/Feet	44.8 (1,167)	54.8 (485)

[¥] eligible individuals must have also had autografting surgery for wound closure
******indicates statistically significant difference for all categories p<0.001

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Results



**indicates statistically significant difference using Bonferonni adjustment p<0.0083

Table 2. Logistic Regression Assessing Association between Consent Status and Demographic Characteristics

	Odds Ratio	p-value
19-39 years	0.431	0.118
40-59 years	0.475	0.166
60-79 years	0.246	0.01**
≥80 years	0.115	0.002**
Female	2.053	0.001**
Black/African American	0.533	0.01**
Hispanic/Latino	0.301	0.00**

Comparison groups: ≤18 years old; Male; White; non-Hispanic
******indicates statistically significant differences p<0.05

- In regression analyses, individuals under the age of 18 years old were 4 times as likely as those 60-79 years old and 9 times as likely as those over the age of 80 to consent.
- Female burn survivors were 2 times as likely to consent into the BMS National Database as males burn survivors.
- Burn survivors identifying as White were 2 times as likely as those identifying as Black/African American to consent.
- Those identifying as non-Hispanic/Latino were 3 times as likely to consent compared to Hispanic/Latino burn survivors.

Conclusions

- Underrepresentation of traditionally underserved populations in long-term outcomes research can have a significant impact on the generalizability of findings.
- Researchers are challenged to understand why certain populations of burn survivors are choosing not to participate in the BMS National Database and develop strategies to improve enrollment.