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## Race Matters: A Systematic Review of Racial/Ethnic Disparity in Society for Assisted Reproductive Technology (SART) Reported Outcomes

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## Abstract

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**Objective**—To systematically review the reporting of race/ethnicity in SART Clinic Outcome Reporting System (CORS) publications.

**Design**—Systematic review using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology of literature published in PUBMED on race/ethnicity that includes data from SART CORS.

**Setting**—Systematic review was performed on behalf of the ASRM Health Disparities Special Interest Group.

**Population**—IVF cycles reported to SART

**Exposure**—Race/ethnicity

**Main Outcome Measure**—Any outcomes reported in SART CORS

**Results**—Seven publications were identified that assessed racial/ethnic disparities in IVF outcomes using SART data. All reported a racial/ethnic disparity. However, over 35% of cycles were excluded from analysis because of missing race/ethnicity data.

**Conclusions**—Review of current publications of SART data suggests significant racial/ethnic disparities in IVF outcomes. However, the potential for selection bias limits confidence in these findings given that fewer than 65% of SART reported cycles include race/ethnicity. Our understanding of how race/ethnicity influences ART outcome could be greatly improved if information on race/ethnicity was available for all reported cycles.

## Keywords

race; ethnicity; disparity; in-vitro fertilization; SART

## Introduction

Racial and ethnic disparities in health outcomes are highly prevalent in the United States(1). Health disparities research in women's reproductive health is evolving, and disparities have emerged in many areas including pregnancy-related mortality, spontaneous abortion, preterm birth, and infertility. Issues related to cost of treatment, access to services, and variation in utilization by minority groups make infertility an area especially prone to disparity (2).

Social determinants of health play a large role in disparities, with some arguing that social factors are the predominant issue (3). Given that the small subset of infertile women who undergo assisted-reproductive technologies (ART) have higher education and incomes than the general population and greater access to medical care (4), a plausible conclusion is that racial/ethnic disparities do not impact ART patients. However, there are several factors that make ART prone to disparity. First, defined reasons for undergoing ART differ among racial/ethnic groups (2). Second, reproductive factors that may negatively affect fertility, such as uterine fibroids, are more prevalent in certain racial/ethnic groups (5–7). Third, response to treatment may differ among racial/ethnic groups (8–10).

Currently, our understanding of ART outcomes in this country relies heavily on Society for Assisted Reproductive Technology (SART) data. The public SART website shows that 123,200, 132,745, and 142,241 IVF cycles were reported by clinics in 2005, 2007, and 2009, respectively. For the same years, the live birth rates for women under 35 were 37.1, 39.9, and 41.4, respectively. This provides compelling evidence that IVF use and success are improving in this country. However, the ASRM Health Disparity Special Interest Group was concerned that data on race/ethnicity was not being universally reported to SART and that

research on racial disparity in ART could be affected by this lack of reporting. Therefore, we performed a systemic review of the literature using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology to identify research on IVF outcomes and race/ethnicity that used SART data in order to quantify the extent of race/ethnicity reporting in SART.

## Methods

### Search Strategy

A systematic review of PUBMED was conducted in September 2011. Independent extraction of articles by one author (MR) using predefined PUBMED Medical Subject Headings (MeSH) and terms was performed. MeSH and terms for the race/ethnicity exposure included were: minority groups, ethnic groups, African-Americans, Hispanic-Americans, American Native Continental Ancestry Group, Oceanic Ancestry Group, Black, Hispanic, Latino, Asian American, African American, Native American, Indian, Asian, and Pacific Islander. MeSH and terms used to limit the search to studies of ART included assisted reproduction, reproductive techniques, embryo transfer, in-vitro fertilization, IVF, intracytoplasmic sperm injections and ICSI; artificial insemination, gamete intrafallopian transfer, oocyte donation, oocyte retrieval, ovulation induction, zygote intrafallopian transfer, and assisted reproduction. Descriptive study MeSH and terms included those for epidemiologic, cross-sectional, cohort, retrospective, longitudinal, observational, comparative, or case-control studies. The search was limited to studies published in English. Quosa software was used to search the text of articles for mention of SART CORS data. Identified references were reviewed by one author (MW) and studies from single clinical centers and/or those limited to military populations were excluded as the focus of this review was on studies that analyzed SART CORS data.

Institutional Review Board approval was not obtained for this systematic review because it was determined that none was needed as all data used were abstracted from previously published studies and deidentified SART data.

## Results

The predefined search headings and terms generated 85 references in PUBMED. The Quosa search found the mention of SART CORS data in 22/85 references. Of these 22 references, 17 were excluded because they reported on single clinical centers only or were limited to military populations. The final sample comprised 7 references. All references reported a statistically significant racial/ethnic disparity in one or more SART reported reproductive outcomes (Table 1).

## Discussion

Our systematic review of the literature of studies using SART data and assessing racial/ethnic disparities suggests that significant racial/ethnic disparities exist in assisted reproduction outcomes in the United States (11–17). In the studies examined that reported rates of live births, Whites consistently had the highest rates of live births, followed by Hispanic and Asian women, while African-Americans had the lowest rate of life births following ART (11, 12, 14, 15, 17). Racial/ethnic disparity was also found for other SART CORS outcomes such as ovarian hyperstimulation syndrome and single embryo transfer.

However, we found that firm conclusions on disparity findings from SART data are not possible because of the lack of universal reporting of race/ethnicity by practices that submit their data to SART. In our systematic review of publications that used SART CORS data

from years ranging from 1999–2007, we found that over 35% of cycles could not be used for comparisons of racial/ethnic groups and reproductive outcomes because the data on race/ethnicity was indeterminate. This occurred even though, race/ethnicity has been a longstanding mandatory reporting field for SART (white, Asian, Hispanic, black, other, mixed, not asked, unknown, or refused) for each IVF cycle.

In SAR CORS, indeterminate race/ethnicity is defined as a report of “unknown, not asked, or refused” in the race/ethnicity field. Directly obtained SART CORS data reveals that in 2009, an indeterminate race/ethnicity for the patient and/or male partner/sperm donor was reported for 36.2% and 42.9% of SART CORS cycles, respectively. These percentages were comparable to the race/ethnicity field reporting rates for the years 2004–2008. In 2009, of the indeterminate entries, about 76% were “unknown,” 23% were “not asked” and less than 0.3% were “refused.” While the proportion of indeterminate race/ethnicity reporting appears to have remained somewhat steady over the past 5 years, within this subset, the proportion of “not asked” has increased from <3% to 23%.

As members of the ASRM Health Disparities Special Interest Group, our mission is “to identify disparities in access and outcomes of women of color seeking reproductive health services and to identify strategies to address these disparities and other reproductive problems in women of color”. Our main objective here is to emphasize the need for universal race/ethnicity reporting in SART and the need for this information to come directly from patients.

National consensus is that self-reporting of race/ethnicity is the gold-standard (18). SART requests this gold standard with explicit instructions: “Select each race/ethnicity of the female patient (a) whether or not she was the source of the oocytes used for this cycle and whether or not a gestational carrier was used. Race/Ethnicity should be ascertained by asking *“With which of the following racial/ethnic groups do you, the female patient, most closely identify?”* (Select ALL that apply) and with a similar question regarding the male partner/sperm donor. Universal collection of race/ethnicity through self-reporting as outlined by SART would generate data that would allow for more accurate comparisons of ART outcomes in racial/ethnic groups, ultimately enhancing our ability to eliminate racial/ethnic disparities in both ART access and outcomes.

In “Unequal Treatment: What Healthcare Providers Need to Know about Racial and Ethnic Disparities in Healthcare”(1), the Institute of Medicine (IOM) emphasized the critical need for improved data collection on race/ethnicity in order to understand and eliminate health disparities. The IOM acknowledged the challenges of standardized data collection of race/ethnicity: patient privacy concerns, costs of collection, and resistance from providers and patients. The field of reproductive medicine has already addressed many of these challenges. The SART reporting system for collecting information on ART outcomes is in place and is supported by providers and the public. We hope that by presenting the inadequacies of the current SART data on race/ethnicity, that we demonstrate a compelling argument for universal reporting of this important patient information. We hope that this will persuade those over-seeing the 8% of cycles where patients were “not asked” to identify their race/ethnicity to now ask. We also hope this will persuade those reporting “unknown” to ask their patients directly with which racial/ethnic group they most closely identify. Because, with adequate data in hand on race/ethnicity, we feel that we can best apply our efforts to ensure that all patients have an equal opportunity to achieve the family of their dreams.

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Table 1

Studies examining racial/ethnic disparities in SART CORS data 1999–2006

Authors	SART Data Years	SART cycles analyzed	Live Birth Race/Ethnic Disparity Reported	Other Major Race/Ethnic Disparity Reported
Seifer et al, DB (12)	1999–2000	80,309	Black (20.7) vs. White (28.4) <sup>d,*</sup>	
Fujimoto, VY et al (13)	2004–2006	139,027	Asian (81.6%), Hispanic(82.2%), or Black (75.0%) vs. White (83.7%) <sup>b,*</sup>	
Luke, B et al (14)	2004–2006	69,028	Not investigated	Elective single embryo transfer rate White (ref); Asian 1.52 (1.31–1.77) <sup>*</sup> ; Hispanic 0.67 (0.53–0.86) <sup>#</sup> ; Black 0.73 (0.57–0.92) <sup>#</sup> ; Unknown 1.32 (1.22–1.43) <sup>*</sup>
Seifer, DB et al (15)	1999–2000 2004–2006	190,562	Black, non-Hispanic (22.2%, 17.5%) vs. White (32.3%, 26.3%) <sup>c,d,*</sup>	
Baker, VL et al (16)	2004–2006	225,889	Asian (81.5%), Hispanic (82.1%), Black (75.1%), Other (82.8), Unknown 81.9% vs. White (83.7%) <sup>b,*</sup>	
Luke, B et al (17)	2004–2006	214,219	Not investigated	Development of Ovarian Hyperstimulation Syndrome White (ref); Asian 0.91 (0.75–1.10); Hispanic 0.79 (0.62–1.00); Black 1.88 (1.58–2.23) <sup>*</sup>
Luke, B et al (18)	2007	31,672	Asian (80.8%), Hispanic (79.8%), or Black (76.3%) vs. White (84.5%) <sup>b,*</sup>	

\* p<0.001

# p<0.01

<sup>a</sup>Rate per cycle started.

<sup>b</sup>Rate per pregnancy.

<sup>c</sup>Rate per cycle started, no prior ART.

<sup>d</sup>Rate per cycle started, prior ART.