



Review

Low participation rates amongst Asian women: implications for research in reproductive medicine



V.S. Talaulikar^{a,*}, S. Hussain^a, A. Perera^b, I.T. Manyonda^a

^aSt. George's University of London, Cranmer Terrace, Tooting, London, UK

^bNottingham Medical School, Nottingham, UK

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ABSTRACT

The last two decades have witnessed tremendous advances in the field of reproductive medicine, especially assisted reproductive technology and stem cell research. As research continues in future, it is vital to ensure that individuals from all ethnic backgrounds are represented in the study populations so that the findings of the research can be generalised for the benefit of all. Many studies, however, have noted a trend of low participation rates amongst Asian women in reproductive research. Inequalities in the ethnicity of research participants can be a source of substantial bias, and have major ethical and scientific ramifications. Several factors such as educational status, fear of wrong-doing, communication barriers, and socio-cultural beliefs have been suggested to play a role. There is a need for further exploration of the factors influencing Asian women's decision to accept or decline participation in reproductive research and for development of effective targeted strategies for research recruitment with the aim of encouraging research participation as well as donation of cryopreserved embryos or other reproductive tissues.

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* Corresponding author at: Department of Obstetrics and Gynaecology, Division of Clinical Sciences, St. George's University of London, Cranmer Terrace, Tooting, London SW17 0RE, UK. Tel.: +44 208725 3695; fax: +44 208725 5958.

E-mail addresses: vtalauli@sgul.ac.uk, vtalauliker@gmail.com (V.S. Talaulikar).

1. Introduction

Medical research is aimed at understanding or treating a disease or health condition with the ultimate aim of improvement of human health or quality of life. The success of a research study is determined by the reliability and validity of its findings, and whether the results can be generalised to the target population under consideration. Thus it is the choice of correct sample size and

nature, or in other words the participation of representative patients or individuals, which is critical for good quality medical research.

One year ago we secured ethical approval for a research study on trophoblast–decidua interactions, which required collection of early pregnancy endometrial lining during the procedure of first trimester surgical termination of pregnancy (STOP). We provided patient information leaflets and consent forms to the women requesting first trimester STOP in the pregnancy advisory clinic. After making sure they had been allowed enough time for decision making, the specialist registrar in the clinic invited the women to take part in the research study and written consent was obtained if they wished to participate. The patient information leaflet was meticulously explained to the women and it was made clear that there would be no additional risk involved to them from the study and that no identifiable data would be used or recorded. It was made clear that whether they agreed to participate or not would not affect their care in any way. To avoid investigator bias, different specialist registrars with varying ethnic backgrounds across several clinics were asked to invite the participants for the research study.

Out of the 89 consecutive patients we attempted to consent in the STOP clinic for our study, we found the following results: (a) Caucasian women – 36 out of 40 consented (90%), (b) Asian women – 7 out of 27 consented (25.9%) and (c) Afro-Caribbean women – 18 out of 22 consented (81.8%). Intrigued by this trend, where almost 75% of the Asian women declined to participate in the study, we searched the literature to review the experiences of other research teams concerning this issue, and found similar reports from several groups across the developed world.

2. Are Asian women less likely to participate in reproductive research?

Although the number of studies is small and conflicting data do exist, most studies have reported low participation rates in reproductive research amongst Asian women [1–6]. A cross-sectional study from United States (US) involving 1049 women presenting for reproductive care found that Asians and Middle Eastern women were less likely than non-Hispanic Whites to express willingness to be contacted regarding research (odds ratio 0.44, 95% confidence interval 0.33; 0.57) [1]. Women born outside the US were less likely to consent to be contacted than those born in the US. In the United Kingdom (UK), a prospective study of 300 couples who underwent in vitro fertilisation (IVF) treatment showed that couples of ethnic minority origin were less willing to consent for research using their supernumerary embryos compared to Caucasians [2]. Of the 270 Caucasian couples, 151 (56%) consented whereas only 5 couples consented out of 17 (29%) in the Asian group. This difference was found to be statistically significant ($P < 0.05$). Interestingly, the five couples who did consent for research were second generation (born and raised in England). In another retrospective study of 400 consecutive patients undergoing IVF, compared with Europeans or Asians born in the US, Asians born outside the US were less likely to opt to donate excess embryos for research. Research donation was highly associated with interest in participation in clinical research [4]. Another analysis of the ethnicity profiles of six large multicentre, randomised, controlled trials conducted by the Northern and Yorkshire Clinical Trials and Research Unit revealed that people of South Asian ethnic origin seemed to be underrepresented [6]. South Asian (Indian, Pakistani, and Bangladeshi) people comprised only up to 1.7% (mean 0.6%) of total participants in the six trials.

3. What could be the reasons for low participation rates?

3.1. Socio-cultural and religious factors

In many Asian populations, religious and cultural concerns may preclude participation in research [7,8]. The disparity in participation rates between Asians born within the country of research and those born outside has led to suggestions that Asian immigrants may not feel a part of the Western society or culture and this could contribute to why they show less interest in research. Cultural values and traditions impact perceptions of the utilisation of tissue such as embryos or placental material in reproductive research. Some ethnic groups regard the placenta as a sacred object or spiritual companion of the baby, while embryos may often be viewed as children, and this may directly influence the decision not to participate [7,8]. Similarly, cultural taboos or religious restrictions on abortion could make couples feel uncomfortable with the process of termination of pregnancy and they would not want additional stress from consenting for a research study.

3.2. Lack of trust in doctors and fear of wrong-doing

Studies in African-American populations have revealed that distrust of the medical community is a prominent barrier to participation in clinical research [9,10]. It is possible that some Asian immigrants also carry fears of exploitation for the purpose of research and therefore decline to take part. They may worry that their clinical care may be compromised when associated with research. Such perceived risks of wrong-doing from physicians or researchers may stem from their experiences or knowledge about research in their home country. Some of the factors in their native countries which may negatively influence their attitude towards research are: lack of adequate communication between the patients and doctors due to overburdened health services, media publicity of medical malpractice cases, deficient consumer protection laws and non-existence of counselling and rehabilitative services.

3.3. Intimate nature of reproductive research and stress

Reproductive research deals with sensitive areas of a woman's life such as ability to conceive, sexuality, birth, abortion, family, children and reproductive career. The decisions associated with some of these life issues can be significantly stressful for the woman as well her partner in certain ethnic groups. Couples may experience difficulties in donating embryos or tissues to others for reproductive use, despite altruistic intentions to do so [4]. The need for confidentiality and concerns about modesty may also hinder participation in research studies.

3.4. Pressure from dominant partners

The dynamics of a couple's relationship in Asian culture may differ from that of Western culture. In some ethnic groups, a woman may not be able to make a decision on her own to participate in research without the permission of or discussion with her husband.

3.5. Level of education

Lack of medical knowledge about the research or tissue donation can negatively impact the decision to participate. Higher levels of education are associated with increased likelihood of donation for research [11]. The level of scientific knowledge may determine the woman's views on donation of tissues or embryos (recognition of scientific value may make it more likely that she

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