



Exploring willingness of elder Chinese in Houston to participate in clinical research



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ABSTRACT

Background and objectives: Inadequate minority participation in clinical research can threaten the applicability and strength of scientific findings. Previous research suggests that trial participation rates are lowest among Asian Americans, compared to other groups. This study explored barriers to clinical research participation among elder Chinese living in Houston, Texas. Additionally we administered the Trust in Medical Researchers Scale (TIMRS), used previously in researching trust in medical researchers as related to research participation.

Design: In this mixed methods study, a semi-structured interview, including the TIMRS were administered to 30 adults of Chinese ancestry aged 50 years or older recruited from a Chinese community center. Interviews were conducted in English, Mandarin and Cantonese and independently coded and analyzed using thematic content analysis. TIMRS scores were calculated for participants.

Results: Participants were 70% female, 70% were 60 or older, all were foreign born and on average lived in the US for 21.8 years. Participants perceived risks to research participation and preferred language concordant research staff. Interviewees were more willing to participate if they perceived personal and community health-related benefits. The overall TIMRS score was 23.9 (± 5.0), lower than the overall TIMRS for Whites in a previous study ($P < 0.001$).

Conclusions: The barriers and facilitators to research participation confirmed previous research among Asians. Our participant TIMRS scores were consistent with decreased levels of trust observed in the original TIMRS study for African Americans as compared and lower than Whites. Employing strategies that utilize language concordant staff who build trust with participants may aid in recruiting elder Chinese, especially if the research is personally relevant to those being recruited.

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1. Introduction

Underrepresentation of racially and ethnically diverse groups in medical research is an ongoing problem [1–4]. Participant diversity in medical research allows researchers to generalize their findings

more broadly and to analyze responses to experimental interventions received by different racial and ethnic groups [5–9]. When participants lack diversity, researchers are limited in their ability to draw scientifically rigorous conclusions about the efficacy of experimental interventions. The U.S. Census Bureau projects that the proportion of the population over age 65 will continue to increase and the population in general will continue to increase in diversity [10]. With Medicare bearing the health care costs for most of those over age 65, interventions to maintain or improve the health of this population are increasingly important. The proportion of elder Asians in the US is also expected to increase [11].

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Asian Americans are disproportionately affected by several debilitating diseases including chronic hepatitis B, HIV/AIDS, and tuberculosis [12]. Currently, Asian Americans experience higher rates of morbidity and mortality from liver and stomach cancer when compared to non-Hispanic whites [13]. Despite the disease burden, clinical trial participation rates among Asians were reported to be lowest compared to other racial and ethnic minorities [14,15].

In general, medical researchers often confront challenges when recruiting minority participants, especially elder adults [16]. Numerous studies have reported barriers to enrollment including lack of participant trust [17–20], ineligibility due to comorbid conditions [21,22], and lack of information about clinical study opportunities [23]. We reviewed the extant research examining barriers and facilitators for minority participation. The majority of studies have focused on barriers among African Americans relative to other racial and ethnic groups [3,4,24,25].

The literature gives some insight as to why there is low participation and suggests that Asian have similar barriers to trial participation as other ethnic groups such as fear of side effects from experimental treatments [26], limited knowledge about clinical research [27–29], language barriers [27,30,31], and mistrust [28]. A 2005 study reported that, compared to non-Asians, elder Asian immigrants were more influenced to participate in research by children, landlords, physicians and the media [32]. Personal gain [31], involving the patient's family in the decision making process [27], and receiving a recommendation to participate by trusted relatives or family physicians [27] have all been identified as possible motivators for research participation among Asians. Few studies take the Asian population's heterogeneity in to account [33] or characterize facilitators and barriers exclusively for the Chinese population, the largest Asian subgroup in the U.S. [28,29].

We explored the patient perspective on willingness to participate in medical research among a sub-group of elder Chinese living in Houston, TX. We addressed the patient perspective via in-depth interviews supplemented by a psychometrically validated self-report scale. The present study is the first to administer the Trust in Medical Researchers Scale (TIMRS) in this population. This validated scale has examined mistrust in medical researchers in African American and White community residents [20]. The scale measures the impact of researcher honesty and participant deception, two key domains in researchers mistrust. Since much of the body of evidence exploring mistrust in minority populations is overwhelmingly qualitative in nature we wanted to supplement our qualitative study with a scale to quantify trust in medical researchers in the elder Chinese population.

2. Methods

2.1. Design

This study applied a mixed methods approach (in-depth interviews and a quantitative scale). A qualitative research approach was selected as a useful framework for studying patients' beliefs and willingness to participate in medical research [34]. Qualitative research explores research participation from the participant perspective and generates theories to be tested further in more traditional study designs. Qualitative research cannot determine causal relationships [35]. The qualitative analyses of the in-depth interviews were supplemented with quantitative data from the TIMRS.

2.2. Participant recruitment

Participant recruitment was facilitated by an established

relationship between the University of Texas Health Science Center at Houston (UTHealth) and the Houston (TX) Chinese Community Center, which provides a variety of services ranging from childcare to senior services. Community center staff were familiar with regular visitors to the center so they recruited a purposive sample of 30 participants based on the study eligibility criteria, i.e., of Chinese ancestry and aged 50 years or older. Sample size was determined based on qualitative research employing semi-structured in-depth interviews to achieve saturation of themes [36] and develop theories for future testing. The participants were specifically recruited from programs oriented towards the elder population such as the Adult Day Program and the Senior Companionship Program. This age group was selected to gain more information about this Asian group's willingness to participate in research evaluating treatments.

2.3. Study instruments

The research project received approval through the UT Health Committee for Protection of Human Subjects (HSC-SPH-11-0608). The interview guide was developed in English based on previous research that studied knowledge and awareness about the goals of medical research; trust of health care providers and the health care system; and attitudes toward volunteering in research [20,37–39]. The interview guide included three open-ended questions about the participant's knowledge and awareness of medical research. The remaining five questions asked the participant to rate on a 10-point scale their willingness to participate in a hypothetical clinical trial within the next three months where 10 represented very likely and 0 represented not at all likely. Specifically, we asked whether compensation, free transportation, flexible clinic hours, Asian study staff, native language, or translation services increased their willingness to participate. We also administered the TIMRS to participants [20] a validated scale measuring trust in medical researchers. Items on TIMRS can be separated into two subscales: participant deception (items 1–6) and researcher honesty (items 7–12). Participant deception items relate to the participant's beliefs about being deceived or misled by medical researchers. The researcher honesty subscale relates to participant's beliefs about the honesty of the researchers in explaining aspects of clinical trial participation. The TIMRS scores and subscale scores range from 0 to 48 with higher scores indicating a greater level of trust in medical researchers. A Chinese graduate student translated the interview guide and the TIMRS into Chinese. A different Chinese student, unfamiliar with the project, back translated the instruments into English. We did not find discrepancies between the forward and back translations. The interview guide and TIMRS also underwent brief cognitive pretesting prior to use and no problems were noted [40].

2.4. Procedures

The Chinese graduate student that translated the interview guide also conducted interviews in Mandarin. A second Chinese graduate student was hired to conduct interviews in Cantonese. Two non-Chinese students and a non-Chinese study coordinator conducted the English interviews. All interviewers were trained in qualitative interview methods by an experienced qualitative researcher. Participants were read a consent form and provided verbal consent prior to the beginning of the study. The 20–30-min, in-person interviews were conducted in a private room at the community center.

The TIMRS was administered after the qualitative questions. Participants were read each question aloud and asked to point to a card indicating their response. The scale items were answered on a

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