Attitudes and Perceptions of Research in Aging and Dementia in an Urban Minority Population

Judith Neugroschla, Margaret Sewellb,1, Angelica De La Fuentea,2, Mari Umpierrea, Xiaodong Looa and Mary Sanob

aAlzheimer’s Disease Research Center at the Icahn School of Medicine at Mount Sinai, New York, NY, USA
bJames J Peters VA Medical Center, Bronx, NY, USA

Handling Associate Editor: Jeff Burns

Accepted 23 March 2016

Abstract. In dementia trials, minority participation is low. We assessed attitudes toward research in a community based urban poor minority sample of elderly adults attending senior center talks using the 7-item Research Attitudes Questionnaire (RAQ). Presentations on cognitive aging were given at senior centers, and 123 attendees completed the RAQ-7. On trust and safety questions, a significant minority (42–48%) responded neutrally or negatively. Encouragingly, on questions concerning the importance of research, 72–81% answered positively. More work can be done to capitalize on these findings to engage and foster trust, and this can be a focus of outreach.

Keywords: Attitude, dementia, elderly, memory, minority, research

INTRODUCTION

Although there are a growing number of racial and ethnic minorities in the United States, they are underrepresented in research [1]. In dementia trials, overall minority participation is less than 5% [1]. Within fifty years, minorities will be disproportionately represented in the age groups most at risk for Alzheimer’s disease (AD) [2, 3]. Creating parity in research participation for minorities is important to allow generalizability of findings and equity in the provision of health care [1]. Identifying barriers to participation among minorities will allow for better recruitment and retention.

Barriers to clinical research participation among various minority groups include mistrust of the medical establishment and medical research, financial constraints relating to the competing demands of work, lack of information about research opportunities, as well as privacy [1, 4]. Compared to Caucasians, Latino participants are suspicious about research if they do not have a prior relationship with the researchers [5].

Although barriers can be significant for minorities, self-reported willingness to participate in research was comparable among minorities and Caucasians [6]. In one study concerning cancer research, only
48% of Latinos approached knew what a clinical trial was. However, after an explanation, 65% indicated they would consider participation [7].

The Alzheimer’s Disease Research Center at Mount Sinai (MSADRC) in New York City is in a diverse community that includes 55% Latinos and 33% African Americans. The percent of individuals living below the poverty level is very high. In an effort to increase the number of minorities enrolled at the MSADRC, outreach strategies such as community-based talks and screenings, home visits, as well as hiring coordinators with similar backgrounds have been implemented. These strategies have been successful in maintaining minority participation at over 25%. Anecdotal experience suggests that strong ongoing presence in the community coupled with sensitivity to community beliefs about aging, cognition, and research, are important to minority participation.

The Research Attitudes Questionnaire (RAQ) [8] has been used in predominantly Caucasian samples or research settings. The current project employed the RAQ in a novel setting of urban poor minority community elders. In order to decrease burden and increase likelihood of participation, we used the 7-item subset of the RAQ [9]. We examined how characteristics, such as age, years in the US, and education related to research attitudes. This project was undertaken to refine educational programming of the Outreach, Recruitment and Education Core of the MSADRC, in collaboration with the NY State service grant funded AD Assistance Center (ADAC).

METHODS

Eight presentations on cognitive aging (e.g., normal changes, symptoms of dementia, caregiver stress) were given over a six-month period at senior centers, in English and Spanish. The ADAC talks were part of local senior centers’ lecture series on health and lifestyle issues. Following the talks, attendees were asked to complete the questionnaire. The RAQ-7 was administered to 123 attendees. Data was collected anonymously; our IRB confirmed that approval was not required. Respondents were self-reported minorities. The questionnaire was translated into Spanish. Questions were rated on a 5-point Likert Scale (1 = Strongly disagree; 5 = Strongly agree), to assess attitudes toward research and research participation. T-tests were used to assess associations between research attitudes, and each of the following: Age (<70 versus ≥70), level of education (≤12 versus >12), if born outside mainland US, years in the US (≤30 versus >30), and language used for the questionnaire (English versus Spanish).

RESULTS

The sample consisted of 123 responders (65–85% of attendees): Mean age of 72.6 (± 8.9), 10.2 (± 4) years of education, and 66% born outside of the mainland US, representing 14 countries, with 43% from Puerto Rico. Thirty-two percent reported an 8th grade education or less. Of the demographic variables compared, the only significant differences were seen in those in the US for <30 years, who reported slightly more favorable responses on three items that reflected general hopefulness concerning the efficacy of research, and responsibility to participate. However only 17 of the 82 individuals born outside of the continental US had been in the country for <30 years. Only 4 had been in country for <10 years.

Mean scores suggested a mildly positive attitude toward research, with an aggregate mean of 3.7 (SD = 0.9). A positive response was defined as a 4 (“Agree”) or 5 (“Strongly agree”). Seventy-two percent chose a positive response on question 1 (“I have a positive view about medical research in general”) and 81% did on question 4 (“Society needs to devote more resources to medical research”) (Fig. 1).

In response to question 2: “Medical researchers can be trusted to protect the interest of people who take part in their research studies.”

Fig. 1. Positive, neutral, and negative responses by question. RAQ items: 1) I have a positive view about medical research in general. 2) Medical researchers can be trusted to protect the interest of people who take part in their research studies. 3) We all have some responsibility to help others by volunteering in research. 4) Society needs to devote more resources to medical research. 5) Participating in medical research is generally safe. 6) If I volunteer for medical research, I know my personal information will be kept private and confidential. 7) Medical research will find cures for many major diseases during my lifetime.
DISCUSSION

Research attitudes in a community-based minority urban population were explored. In our sample overall attitudes toward clinical research were positive. Surprisingly, 72% percent chose a positive response about medical research in general and 81% felt that society needs to devote more resources to medical research. However, a significant minority endorsed neutral or negative attitudes regarding perceived safety of research and trust of investigators. Our data is consistent with the literature that minorities are likely to distrust medical research [1].

In light of Jefferson et al. who used the RAQ in an observational cohort (78% white, mean of 16.2 years of education) who were participating in longitudinal research, we were interested in how their results compared to ours. The intent of their study was to understand barriers to enrolling in clinical trials [10]. On most questions, our group was markedly less positive than the well-educated, predominantly white participants enrolled in Jefferson’s sample. Depending on the question, 11–23% of our group endorsed frankly negative views particularly concerning safety (23%) and trust (18%). However, both cohorts were similar regarding allocation of resources for research and whether cures will be found (Fig. 2), indicating a generally favorable attitude toward research.

In our sample, respondents who had been in the US for <30 years had a statistically more favorable view of research in general than those who had been here for longer, but it is unclear whether this is a genuine cohort issue or related to sampling bias, as only 17 out of the 82 individuals born outside the continental US had been in the country for <30 years.

These results highlight that even in a community with generally positive attitudes toward research, mistrust and safety concerns persist and may be barriers to participation. Our data underscores the need to build trust through health communication strategies that encourage open dialogue.

In our ADRC, 44% of participants are minorities in contrast to the 2012 National Alzheimer’s Coordinating Center numbers (13.9% Black and 7.9% Hispanic). There may be overlap between these groups as one is coded as race and the other as ethnicity. To sustain this level of minority recruitment, we have identified successful strategies to engage and sustain minority participants in research. For example, we hire staff members of similar cultural background and work with community collaborators as outreach partners. We have established a community advisory board to facilitate the creation of culturally relevant programs and have developed long-standing relationships with community centers, where we give talks and memory screens. We have found that by having ongoing relationships, community centers do not feel that we are there to “take advantage” of their participants, and their trust of us extends to their members. By collaborating closely with the ADAC, the ADRC Satellite and Clinical Cores are able to offer research evaluations in participant’s homes, at senior centers, or at our center, depending on preference. The combination of familiarity and flexibility has promoted our minority recruitment. These approaches have also been explored by other researchers [11–13].

There are several limitations of our report. While all participants were either Latino or African American, we did not have a demographic item regarding specific breakdown of race/ethnicity. It is possible that our sample reflects a sampling bias of those particularly interested in research; however, the theme of the talks was not research but cognitive health/normal aging and approximately 75% of our attendees agreed to fill out the RAQ survey. Additionally, it is possible that our ongoing presence in the community and the general sense of trust and familiarity that our speakers engender increased the percentage of responders. Moreover, the familiarity and cultural and linguistic congruence with the speakers may have introduced a positive response bias.

Future research might include qualitative outreach methods such as community-based focus groups that
explore concerns around mistrust and safety. To isolate the variables of race, ethnicity, socioeconomic status, and current research participation, the RAQ could be used in a research setting with minority/non-minority participants across the spectrum of cognitive impairments, or with non-minority community-based individuals.

Historically, poor urban residents have not been comfortable with research or interested in participation. These results are encouraging because of the overall positive attitude toward research within the community, setting the stage for targeted interventions to address trust and safety within this positive framework.

ACKNOWLEDGMENTS

This work was supported by the Ichan School of Medicine, The Alzheimer’s Disease Research Center (ADRC: U01 P50 AG005138) and the New York State Alzheimer’s Disease Assistance Center at Mount Sinai (ADAC: C020360).

Authors’ disclosures available online (http://j-alz.com/manuscript-disclosures/15-1072r1).

REFERENCES


