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Distrust of the Healthcare System in Ethnic Minority Populations and its Effect on Clinical Research Participation

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BACKGROUND

Over the past couple of years, there has been an increased interest in participation of members from minority populations, such as African Americans, Asians, and Hispanics, in clinical research trials¹. Women have also historically been less likely to participate in clinical trials than men, which some researchers attribute to fears regarding risks to the fetus². Thus, minority women have little to no representation in the clinical trials that are used to ensure the safety and efficacy of treatments for the general population.

A number of researchers studying the issue have determined that the lack of minority participation in clinical research is a result of not trusting the doctor, the entire healthcare system, or both⁴. The purpose of this study is to determine whether a lack of trust in the physician and possibly the entire system of healthcare is the root behind minority women's unwillingness to take part in clinical studies.

METHODS

A survey was developed by the research team that asked questions about whether and if the women had participated in clinical research, and which factors (e.g. money being offered, the patient's opinion of the doctor, family beliefs, pregnancy, religion, ethnicity) would encourage or discourage them. The survey was translated from English to Spanish and Chinese, and distributed to patients in these languages at several locations. This included CWM at the Lehigh Valley 17th Street Hospital, among others. Survey information was stored in a secure database, and the data was analyzed using statistical methods.

RESEARCH QUESTIONS

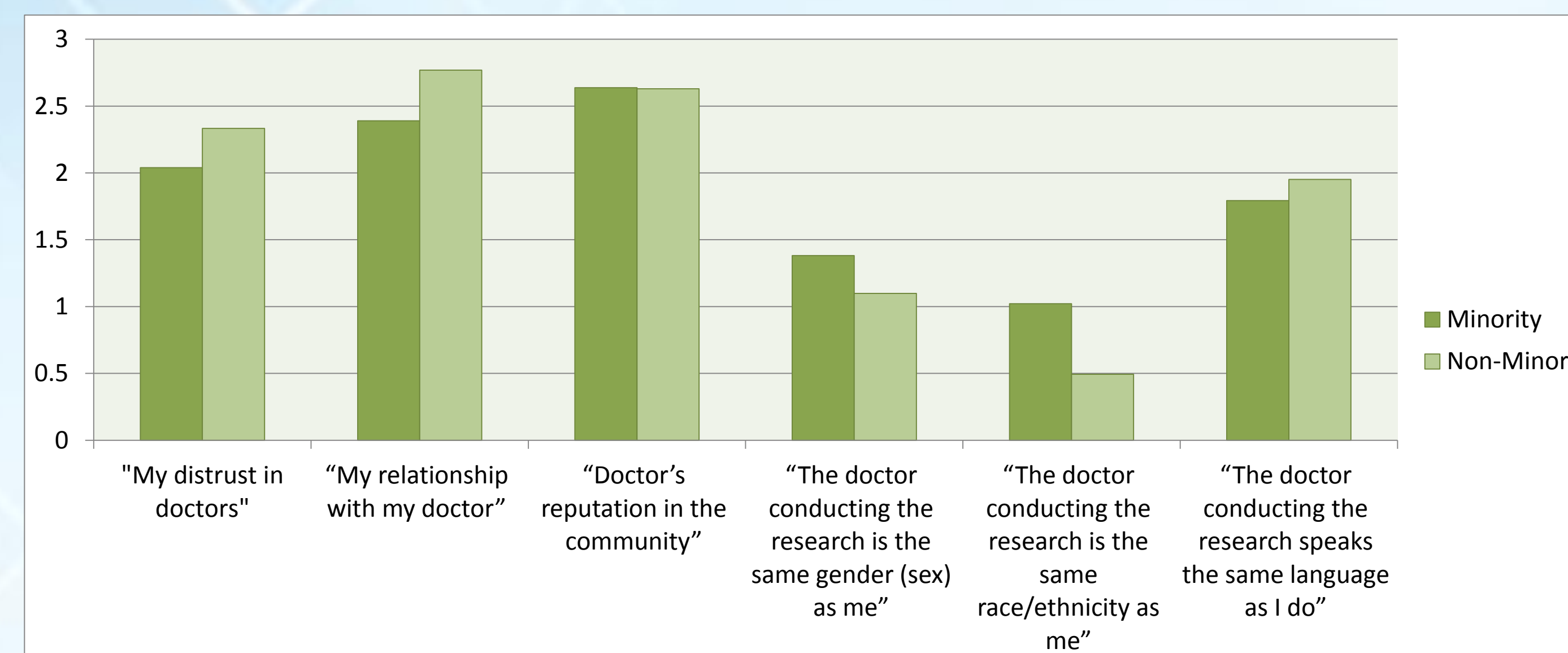
Are women who come from ethnic minorities less likely than non-minority women to participate in clinical research as a result of a lack of trust in the physician and system of healthcare?

Is there a general distrust of healthcare in society?

Even if the patient does not indicate "doctor distrust" is an issue, does his or her relationship with the doctor play a role?

RESULTS

FACTOR	P-VALUE
"My distrust in doctors"	0.055
"My relationship with my doctor"	0.008
"Doctor's reputation in the community"	0.479
"The doctor conducting the research is the same gender (sex) as me"	0.056
"The doctor conducting the research is the same race/ethnicity as me"	0.0002
"The doctor conducting the research speaks the same language as I do"	0.208



CONCLUSIONS

On a scale of 0-4, with 4 being the greatest barrier to participating in clinical research, there was no significant difference in the distrust in doctors between minority and non-minority women.

On a scale of 0-4, with 4 providing the most motivation to participate in clinical research, there was only a significant difference where the doctor was the same race/ethnicity as the patient. In this case, minority women indicated that this would be a greater motivator. Though distrust may not play a role, the finding that the doctor being the same race or ethnicity as the patient is a greater motivator for minority women is an important area of future research. In addition, the data being used was pilot data, meaning that no final conclusions can be drawn at this point.

FUTURE DIRECTIONS

- Determine how to incorporate all factors assessed in this study into one "distrust" rating rather than having to perform several different t-tests
- Repeat the analysis after obtaining data from several locations
- Possibly consider expanding the study to incorporate other factors such as socioeconomic status or education level

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