Distrust of the Healthcare System in Ethnic Minority Populations and its Effect on Clinical Research Participation
Nikita Mishra¹
Anita Kurt, PhD, RN²

¹Department of Emergency Medicine, Lehigh Valley Health Network
²Research Scholar Program Mentor

Abstract

Participation of less-represented groups in clinical research has recently gained a great deal of interest from organizations, as they have begun to recognize the importance of ensuring the safety of treatments and medications on a variety of people prior to use with the general population. One such group with the lowest amount of participation in clinical studies is minority women, as there are fewer minorities than non-minorities participating, and less women than men. One reason that has been suggested for why this occurs is that minorities are less trusting of doctors and the healthcare system. The purpose of this study in general was to determine the factors encouraging or discouraging women from clinical research, but the focus of this is on whether distrust is the root of the problem. This was accomplished by surveying women about this and other factors that may motivate their decisions to partake in clinical studies at a variety of locations, and performing statistical analyses after gathering the data. Though a concrete conclusion could not be reached, the data implicates that ethnic minorities may feel more comfortable with a doctor who is the same race/ethnicity, providing a basis for future study.

Introduction

Over the past couple of years, there has been an increased interest in participation of members from minority populations, such as African Americans, Asian Americans, and Hispanic Americans, in clinical research trials¹. The interest is largely a result of the growing population of ethnic “minorities” in the United States, and the inversely low amount of participation of these minority populations in trials testing new medications and treatments². Women have also historically been less likely to participate in clinical trials than men, which some researchers attribute to fears regarding risks to the fetus³. 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. This type of generalization can have disastrous consequences on these women, making their representation in clinical research of utmost importance. For instance, there are high numbers of Hispanic people suffering from chronic health conditions such as high blood pressure, diabetes, and cancer⁴. With adequate representation in testing for medications to treat these illnesses, this may not be the case. In order to alleviate the problem, it is important to first discover its source. 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. One scientist studying the issue explained that members of ethnic minorities are more likely than non-minorities to believe that their doctor does not have their best interests in mind when trying to enlist them in clinical research¹. Many concede that doctor distrust is not the only explanation, but it is an important issue that society needs to address. 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 populations’ unwillingness to take part in clinical studies.

The survey’s primary objective is to determine which factors encourage or discourage women from participating in clinical research, spanning a wide range of possible reasons such as risk to the fetus, possible side effects, etc. However, the focus of this study in particular is on whether there is a distrust of the healthcare system among minority women that discourages them from participating in clinical research. Associated factors include questions about whether the doctor’s reputation in the community or the patient’s relationship with the doctor makes a difference as to whether they would participate. These questions were addressed in the survey and analyzed for
differences between minorities and non-minority women as well. The hypothesis of this study is that minority women are less likely to participate in clinical research as a result of distrust of doctors and other elements of the healthcare system in general.

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 would motivate them to do so. The questions asked whether people would be more encouraged to participate if money were offered to them, and assessed other factors such as the patient’s relationship with the doctor, the doctor’s reputation in the community, family beliefs, religion, ethnicity, native language, and how well the research study is explained to them.

The survey was distributed by research scholars at several different locations in order to perform a multi-center study. These sites included the Center for Women’s Medicine (CWM) at the Lehigh Valley Health Network (LVHN) 17th Street Hospital, the Labor and Delivery (L&D) unit at the LVHN Cedar Crest Hospital, the Antenatal Testing Unit (ATU) at Saint Peters University Hospital, the Family Health Clinic at Saint Peters University Hospital, and other areas at Drexel University, Columbia University Medical Center, Virtua Hospital, and Christiana Care Hospital. Participants in the survey were female patients at any of these locations aged 18 or older. The survey was distributed in English, Spanish, and Chinese, with instructions provided to the patient in the language of the survey. These instructions included explaining that the survey is anonymous, that no contact information is required, and that the survey was voluntary. Data collection continued through eight weeks, with the goal of reaching the distribution of at least 500 surveys at all locations. Survey data from the Lehigh Valley Cedar 17th Street Hospital was added to a secure Excel database for each research scholar. Statistical tests were run on the data, depending on the factor that was the focus of the study.

Results and Discussion

The primary goal of the survey was to determine the motivating factors for women to participate in clinical research. Thus, the questions focused on asking patients whether they would be more likely to participate if offered money, which family member would motivate them the most, etc. Furthermore, participants were provided with the option to provide information such as the participants’ ethnicity, primary language, religious preference, occupation, and personal income, in order to assess which of these factors is associated with willingness to participate in clinical trials, and how they are associated as well. This study in particular focused on the role that distrust of the healthcare system plays in discouraging minority women from participating in clinical research, in comparison to non-minority women. One of the questions on the survey specifically asked how much of a barrier doctor distrust would play in discouraging the patient from partaking in clinical research, from a scale of 0 to 4, with 4 being the greatest barrier to participating in clinical research.

Based on prior research that people from ethnic minorities are less likely to participate in clinical research and that the least amount of information is available for minority women, I hypothesized that minority women would indicate that they are less likely to participate due to doctor distrust. In order to test this hypothesis, I performed a one-tailed t-test analyzing the values from 0 to 4 indicated by minority women and compared these numbers to those indicated by non-minority women on the survey.

The results of the t-test indicated that there is no significant difference in the amount of distrust of the healthcare system among minority women in comparison to non-minority women. The mean value for the non-minority population was 2.33 and the mean for the minority population was 2.04. This meant that the contrary information to the prior research was depicted through this study; that in fact the non-minority population seems to believe that distrust in doctors is a greater barrier to participation in clinical research than the minority population. Nevertheless, the results of the t-test comparing the two population means indicate that the difference between the answers provided by the minority and non-minority women is not statistically significant. The p-value obtained was 0.06, which is greater than the significance level α of 0.05. This meant there was not enough evidence to reject the null hypothesis, which was that minority women are less likely to participate in clinical research as a result of distrust in doctors.
Nevertheless, there were other factors considering the patient’s relationship with the doctor approaching them for participation that may be related to “doctor distrust” though the phrase was not stated in the question in the survey. For example, there are questions in the survey that ask about how much motivation there is to enter a clinical research study from the patient’s relationship with the doctor, the doctor’s reputation in the community, whether the doctor is the same gender or race/ethnicity as the patient, and whether the doctor speaks the same language as the patient. These factors can also contribute to how much the patient trusts the doctor, even if they do not ask outright about doctor distrust. I performed t-tests on the means for these five variables in order to see if there is a significant difference in how minorities versus non-minorities feel about these factors. Again using a significance level $\alpha$ of 0.05, the results of the t-tests indicated that minorities receive significantly less motivation than non-minorities to participate in a clinical research study ($p = 0.008 < 0.05$) as a result of the relationship with the doctor. The abilities of the doctor’s reputation in the community or the doctor speaking the same language did not differ in the amount of motivation it provided to minorities and non-minorities, but it appeared that the amount of motivation that the doctor being the same race/ethnicity as the patient was significantly more among minorities than in non-minorities ($p = 0.0002 < 0.05$). The data for each factor is summarized for comparison in Table 1 in the Appendix.

Returning to the original question of whether doctor distrust has a higher occurrence among minority women, and whether this is the reason why minority women are less likely to participate in clinical research, the results do not conclusively support the hypothesis that this is true. Although there was no significant difference in doctor distrust between minorities and non-minorities, it was notable that minorities appeared to be more motivated to participate in clinical research if the doctor was the same race/ethnicity as the patient. However, the doctor’s relationship with the patient appeared to not matter as much to patients.

Furthermore, the mean for “distrust in doctors” was 2 or greater, meaning that the “distrust in doctors” is at least somewhat of a barrier to participating in clinical research in the general population. More surveys are needed in order to reach a final conclusion on whether this is the case, which is why they are continuing to be distributed as several locations, since the data analyzed for this study only included Lehigh Valley Health Network 17th Street Hospital. Factors that may have interfered with the results include the possibility that the patients taking the surveys misunderstood or misinterpreted the questions in the surveys, although there is no other way around this other than providing proper instruction when distributing the surveys. In addition, the data being used was pilot data, meaning that no final conclusions can be drawn at this point, as the study is still continuing.

The results of the study indicate that although there was no significant difference in the amount of “doctor distrust” between minority and non-minority women that discourages them from participating in clinical research, it appeared that minority women were more motivated to participate if the doctor approaching them was of the same race/ethnicity as the patient than non-minority women. In addition to performing a separate analysis for each factor, it would be helpful to incorporate all factors assessed in this study into one “doctor distrust” rating. This is beneficial because it takes several aspects of distrust into account, since patients may have been deterred by the word “distrust” from answering honestly on the survey despite anonymity. Repeating the analysis of “doctor distrust” after data is obtained from every location because not only would there be a greater amount of data, but there would also be a wider range of it. The study could also be expanded to incorporate other factors such as socioeconomic status or education level that may be associated with distrust of doctors. Adequate representation of minority women in clinical trials is important in order to ensure that the treatments or medications being tested can safely be used on this underrepresented population as well. The findings of this study indicate that the problem may be alleviated by having medical professionals acquainted with the race/ethnicity of the patient approaching them for participation in clinical studies.

Acknowledgements

I would like to thank Dr. Anita Kurt for mentoring me with this project and provide me with this opportunity to perform clinical research in order to make an impact. In addition, I would like to thank Dr. Hubert Huang for organizing and directing the Research Scholar Program.
at LVHN, through which I was able to perform the research. I would like to acknowledge Samantha Myles, Matthew Meyers, Kylie Besz, Lauren Crawford, Meredith Kalberer, and Sandra Yin for collecting and entering data into the Excel database as well. Finally, thank you to Dr. Joseph Napolitano for supporting the Research Scholar Program.
References


### Table 1. Comparison of Factors Related to Doctor Distrust Influencing Participation in Clinical Research

<table>
<thead>
<tr>
<th>Factor</th>
<th>Mean for Non-Minority Women</th>
<th>Mean for Minority Women</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>“My distrust in doctors”&lt;sup&gt;a&lt;/sup&gt;</td>
<td>2.33</td>
<td>2.04</td>
<td>0.055</td>
</tr>
<tr>
<td>“My relationship with my doctor”&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2.77</td>
<td>2.39</td>
<td>0.008</td>
</tr>
<tr>
<td>“Doctor’s reputation in the community”&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2.63</td>
<td>2.64</td>
<td>0.479</td>
</tr>
<tr>
<td>“The doctor conducting the research is the same gender (sex) as me”&lt;sup&gt;b&lt;/sup&gt;</td>
<td>1.10</td>
<td>1.38</td>
<td>0.056</td>
</tr>
<tr>
<td>“The doctor conducting the research is the same race/ethnicity as me”&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0.49</td>
<td>1.02</td>
<td>0.0002</td>
</tr>
<tr>
<td>“The doctor conducting the research speaks the same language as I do”&lt;sup&gt;b&lt;/sup&gt;</td>
<td>1.95</td>
<td>1.79</td>
<td>0.208</td>
</tr>
</tbody>
</table>

<sup>a</sup> Patients who took the survey were asked to rate how much of a barrier her distrust in doctors was on a scale of 0-4, with 4 being the strongest barrier, to the decision to participate in a clinical research study.

<sup>b</sup> Patients who took the survey were asked to rate how strongly the factor would motivate them to partake in clinical research on a scale of 0-4, with 4 being the strongest motivating factor.