Barrier to Pneumococcal and Influenza Vaccinations in Black Elderly Communities: Mistrust

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Objectives: To understand the role of trust of medical institutions in the decision by elderly black Americans to receive pneumococcal and influenza vaccinations.

Design: Cross-sectional, qualitative study, using semistructured in-depth interviews.

Participants: Twenty black Americans age ≥65 years from two different socioeconomic groups.

Results: Six main themes were identified: prevention, vaccine-caused illnesses, vaccines as irrelevant to health, experience with healthcare, self-advocacy and attitudes toward childhood vaccinations. The majority of vaccinated participants viewed vaccines as a preventive measure, while the unvaccinated group viewed vaccines as irrelevant to their health. In addition, the majority of the participants in the unvaccinated group believed vaccines caused illness. Mistrust of medical institutions or the knowledge of the historical medical injustices was not a significant influence in participant's willingness to be vaccinated against pneumococcal or influenza disease.

Conclusion: Mistrust of medical institutions was not a key concern affecting willingness to be vaccinated in this black community of elderly adults. Participant's willingness to be vaccinated was largely influenced by prior positive or negative experiences with healthcare systems.

Key words: vaccinations ■ health disparities ■ qualitative study ■ elderly health ■ African Americans ■ mistrust

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Pneumococcal and influenza infections cause significant morbidity and mortality.[4,5] Roughly 36,000 people ≥65 years of age die annually from influenza in the United States, and 20,000 are hospitalized with invasive pneumococcal disease resulting in 6,000–7,000 deaths.[1] African Americans are at higher risk for death from influenza and invasive pneumococcal disease but are less likely to be immunized against either than whites.[2,24,27]

Rates of vaccinations have steadily increased over time, but disparities persist.[3] In 2004, pneumococcal vaccination rates were 61.3%, 39.2% and 34.4%, respectively, for whites, blacks and Hispanics, while influenza vaccination rates were 71.5%, 50.5% and 56.6%, respectively. These disparities are not explained by sociodemographic or other conventional risk factors for nonvaccination.[1,6,7,13,32,34,35]

Given these findings of disparities in vaccination rates, we sought to better understand and describe the sociocultural factors and concerns that influence a group of elderly black Americans' willingness to be vaccinated against pneumococcal and influenza disease. Understanding these concerns may help healthcare providers better ascertain the cultural context on which their patients base some of their medical decisions.

METHODS

Design

The research subjects review board at the University of Rochester (NY) approved the study. Recruitment of subjects for the study occurred at two senior adult residential facilities, two community health centers and one black church. Each facility was chosen in order to allow for a socioeconomically diverse sample of participants. We used educational level as a proxy for SES. Sampling was purposive rather than random to ensure the widest variation in experiences and beliefs. Snowball sampling technique was used for additional recruitment. Twenty in-depth, semistructured interviews were conducted between April 2004 and January 2005 by the first

author, an African-American physician. No compensation was offered to the participants. Interview sequencing was based on participant availability. The average interview duration was 45 minutes. Interviews were tape-recorded with concomitant notes taken. Tapes were professionally transcribed.

Setting

The study occurred in Rochester, a metropolitan city with a population of 1.1 million. Thirteen percent of the population is aged ≥65 years. Nine percent of those ≥65 years live below the poverty level. According to the 2000 U.S. Census of Population, 39% of the population in the city of Rochester is African-American.[38]

Participants

All participants gave verbal consent for the interview. Self-report of vaccine status against pneumococcal and/or influenza disease was used to define vaccinated group versus unvaccinated group. The number of interviews was based on a target sampling frame of 20 or until saturation (redundancy of themes) occurred.

Data Analysis

The primary analysis involved content analysis in which the data were maintained in its textual form and coded into analytical categories. In order to address the issue of internal validity or credibility, a triangulation method for data analysis was used. Using a constant comparison approach and multiple coding among independent analysts, each author identified codes that were cycled among authors for discussion. The construction of matrices bases on themes and demographic characteristics of the participants allowed the analytic team to identify patterns between themes and demographics. The analysis and discussions ended when saturation was reached. Consensus regarding themes and patterns was reached among analysts.

RESULTS

Sociodemographic characteristics of the sample are shown in Table 1. There were 14 women and six men in the sample. Groups were categorized into 11 vaccinated and nine unvaccinated participants. Educational level was divided into low and high educational level. High educational level was defined as those participants with a high-school diploma and/or some college and above. Low educational level consisted of participants with less than a high-school diploma. Table 2 identifies six key questions that lead the in-depth interviews. The analysis yielded six recurring themes: 1) prevention, 2) vaccines caused illness, 3) vaccines as irrelevant to health, 4) experiences with healthcare, 5) self-advocacy, and 6) attitudes toward childhood vaccinations.

Prevention

Many of the participants in the vaccinated group were vaccinated because they saw the vaccines as a preventive measure in maintaining their health. Specifically, several vaccinated participants recognized their age as a risk factor for infection.

I believe when you get a certain age now, every little bit helps. You know. And you have to have something [vaccination] to ward off whatever is going around. We've got so many different things that I know I have my shots when required every year. I don't miss a one.

—80-year-old female, 10th-grade level, vaccinated

In the beginning, there was kind of a prelude to, you know, what the flu shot [was]. She'd explain to me what it was, and I think you know you certainly at an age where you need to take it but there's none of that kind of discussion when I take it now ... It's just an automatic kind of thing. She'll say, 'It's time for your flu shot,' you know, and then the nurse will come in and give it to me.

—65-year-old female, graduate level, vaccinated

One vaccinated participant was also motivated by a need to protect a loved one from becoming ill. She clearly understood the influenza and pneumococcal vaccine would not prevent her from contracting the disease. She understood the vaccines would help to lessen the affects of a similar strain.

Well, my belief is that it [vaccine] ... may not necessarily prevent it [disease] but that if we should get the strain, it would be milder than had we not had the shot. At our age, and particularly with my husband's asthmatic problem, it's very important to us to have some measure of defense built up in

Table 1. Characteristics of participants

Category	Number of Participants by Category	
	Vaccinated	Unvaccinated
Women	9	5
Men	2	4
Median age (years)	71.5	74.0
Low educational level[1]	3	5
High educational level[2]	8	4
Total	11	9

1: Participants with less than a high-school diploma; 2: Participants with a high-school diploma and/or some college and above

the system. And so we try to get the flu shot or the pneumococcal vaccine early in the fall before ... the viruses all have had so much time to permeate the whole society.

—72-year-old female, college educated, vaccinated

Vaccines Cause Illness

A majority of the participants in the unvaccinated group felt the influenza vaccine made them sick and/or caused influenza. Several subjects speculated that the main reason why black Americans do not get their vaccines is due to the belief that the vaccines cause some type of illness instead of preventing illness.

I never cared about flu shots and when I did get [one], when I have gotten flu shots, I've gotten very sick ... Took one last year and got sick as a dog. I got a cold, couldn't shake the cold, couldn't do nothing, and finally it just faded away ... I don't think they're good. I think—I take that back. I think they're good for some people. I think some people they're not good for ... like me. You know, I think they just don't agree with me. And as long as I didn't take them I was fine.

—65-year-old female, high-school educated, unvaccinated

Vaccines as Irrelevant to Health

Many participants in the unvaccinated group did not believe influenza and pneumococcal vaccines were relevant to their health and would not improve their own health. This example illustrates how one participant felt the vaccines were irrelevant to her health (perceived healthy) but relevant to her husband's health (perceived unhealthy).

I think they are good if you really need it. You know, some people, I think, take it and they are sick. They do it in the cold season ... I've never taken it, and I am still doing okay. I don't think you should take it ... My husband—he has to take it. He takes a pneumonia shot too, because he has a lot of sickness and things. He's not that healthy.

—70-year-old female, high-school educated, unvaccinated

Table 2. Six key questions for the in-depth interviews

What do you think about flu shot or pneumococcal shots in adults?
What do you think about shots for children?
Why might black folks choose not to get their flu shot or pneumococcal shot?
Do you trust your physician?
Do you trust medical institutions?
Have you heard of the Tuskegee Syphilis Experiment?

Experience with Healthcare (Personal or Historical)

Most participants reported healthcare experiences that shaped their attitudes toward the healthcare system. Unvaccinated participants specified their own reasons for not receiving vaccinations. There was one particular participant who still had negative memories of his vaccination experiences as a child in the segregated South. As a result, his childhood experience affected his perceptions of vaccinations and the healthcare system.

I remember when I was a boy in the South, we had to take shots for everything right until the fifth grade. And the nurse down there treated you like you were an animal. They did not care. They were not sensitive. They would just jab you in your arm like you were an animal. That's how they treated us, you see. So I don't want any shots. I still have those memories.

—70-year-old male, college educated, unvaccinated

On the other hand, several vaccinated participants who had similar negative experiences in the segregated South and in Rochester were able to overcome the effects of the negative memories from the healthcare system.

[W]ell, I have decided to get them primarily because my husband has been working in the medical field. We had friends who were doctors, medical doctors and nurses, who have also influenced my thinking and helped me to understand the importance of preventive medicine. However, I do remember that there were lots and lots of times when I did not trust; I didn't feel comfortable with being experimented on.

—72-year-old female, college educated, vaccinated

My mother died in the color ... wing at the hospital in Bradenton, FL, back in the early '50s ... [W]hen she died, we certainly believed [she died] because of neglect, systemic neglect. First of all, I mean the room that they were in ... the ward was no bigger than here to here. Crammed full of people, there were people even in the hall because they couldn't go into the other section. So for a long time there was this mistrust in my family around doctors ... But my father died in a nursing home. That's another—that's another whole chapter. Because, of course, we

were not people who trusted, you know, our loved ones to nursing homes. And I think our trust was rebuilt in the process of my father who actually, here was a case where my father lived longer because he was in a convalescent home. So I think ... that was ... the genesis of us beginning to see that [the] system wasn't [t]he same, you know, and then of course ... we were ... adults at the time having to use health systems. I know ... it's possible for yourself to feel a level of comfort and trust with your doctor.

—65-year-old female, graduate level, vaccinated

Self-Advocacy

For many participants, the historical medical injustices or personal experiences served as a catalyst for self-advocacy. Most of the participants who reported healthcare self-advocacy were also advocates in civic issues. One unvaccinated participant, a community activist in New York City, embodied advocacy that transcended her own personal health advocacy and informed all aspects of her life.

Yes, I kept a diary. I read an article just before I had my operation in the New York Daily News, *where Ann Landers wrote an article answering someone's question about what would seniors expect to do once they got to the age of retiring and what was the government going to do. And she had said when you go to a doctor if you don't understand you have to ask questions, and when you ask questions if you don't understand you find literature that will give you some idea on what you want to know ... And then if you don't understand this, you make notes or you keep a diary and then you ask the doctor the meaning of what is and what is not supposed to be done. I have done that.*

—81-year-old female, college educated, unvaccinated

For a few, the Tuskegee Syphilis Study demonstrated what could happen if a person does not take an active role in their health and healthcare. One participant viewed the Tuskegee Syphilis study as a tragic example that has positively shaped her self-advocacy:

It's [Tuskegee Syphilis Study] part of my memory to the extent that it makes me question how long and what's going to happen, you know. And I want to be sure they're telling me the truth. Not just placating me. Because sometimes I think that people are given answers that they don't really understand and they haven't been given enough, you know, detail to understand just what could happen, and if this happens then what we can do. That's the part of the Tuskegee experiment that I didn't, that I don't like and don't trust ... when ... [my husband] had his problem with prostate and the doctors, we asked all kinds of questions, what do you recommend? What is best? What will happen if? So they are accustomed to us asking."

—72-year-old female, college educated

Attitudes toward Childhood Vaccinations

All of the participants supported vaccinations for children, even though some refused vaccinations against influenza and pneumococcal disease for themselves.

I believe in them. All my kids was vaccinated ... kids, they don't know enough ... specially like catching colds and flus, they don't know enough about taking care of themselves,. I think kids are exposed to more, especially the ones that go to school and the nursery, I think they're exposed more than adults.

—74-year-old female, less-than-high-school educated, unvaccinated

Mistrust of Institutions

Most participants trusted their physicians. A few participants (three out of 20, two unvaccinated and one vaccinated) acknowledged mistrust of medical institutions due to historical abuses that occurred to black Americans or due to medical mistakes by institutions.

Historical Medical Injustices or Medical Mistakes

I heard you go into a hospital and they [doctors] sew instruments inside of you and chop off the wrong leg. And when they're giving you treatment, they could be giving you something else ... institutions can do what they want and not answer to no one. They can treat you like a [guinea] pig and no one would know. I don't trust institutions because they're the ones who get research dollars to conduct these experiments, and they can do anything for the sake of research.

—70-year-old male, college educated, unvaccinated

Acts of Racism (Historical or Personal)

The issue of racism reported by a few participants illustrates how social trust can influence interpersonal trust. Once again, the primary example of racist historical abuse against African Americans was the Tuskegee Syphilis Study.

It [Tuskegee Syphilis Study] made me feel that it was black folks and so forth, and I still believe they

[institutions] are doing that now with black folks. We have a tendency to some degree to use blacks as guinea pigs and so forth. Our society is still doing that... [Racism] is not necessarily just limited to the medical profession, but you see it otherwise in your daily living. Look at the jails, etc., whatever. Look at the law enforcers, so forth and so on. Most of the laws so forth and so on, and, for example, is to protect white folks from blacks. If you was black you were the scourge of the earth...

—70-year-old male, college educated, unvaccinated

Mistrust of Physicians

A few of the participants did not trust physicians because of a general lack of confidence in physicians or conflicting priorities (i.e., commitment to research versus patients). The example below illustrates how trust operated differently depending whom or what it was directed toward.

I trust medical institutions as far as the medical part [is] concerned but some of the individuals performing some of these things I don't trust ... Many of them are more research oriented in the sense that they were there to perform a job, disregarding the individual['s] rights. When I say that, I mean, some doctors, they stay in research for the benefit of some of the pharmaceutical companies. And their livelihood is basically on the ... findings.

—78-year-old male, college educated, vaccinated

DISCUSSION

Despite both members of the vaccinated and unvaccinated groups reporting mistrust of medical institutions, it did not seem to be a concern for following recommendations for vaccinations. For most participants, trust or lack of trust in medical institutions depended on which entity, i.e., clinic or hospital, trust was directed. On the other hand, the majority of the participants (18 out of 20) trusted their physician. Previous experiences with healthcare systems were described as a key factor shaping and influencing decisions for vaccinations.

Many of the elderly black Americans in the vaccinated group perceived vaccinations as a preventive health measure for their current medical condition (or family member) or age category. As similarly demonstrated in focus groups commissioned by the National Immunization Program,[15] the vaccinated participants understood, due to their age, extra precautions would be needed to protect their health. These participants felt that the vaccinations were relevant to wellness and willingly complied with their doctors' recommendations for influenza and pneumococcal vaccinations.

In contrast to the vaccinated group, the unvaccinated group did not perceive vaccinations as a preventive measure or a wellness component. Interestingly, even though the majority of the unvaccinated participants trusted their physician, this did not translate into more willingness to be vaccinated against pneumococcal or influenza disease. Consistent with previous studies,[14] the majority of the participants refused their doctors' recommendations for vaccination due to their previous negative experience from the vaccines or their belief that the vaccine for influenza caused illness. Some of the participants felt the vaccines would not make a difference in their current state of health, and the influenza vaccine would exacerbate their health. Furthermore, a few participants did not believe the vaccinations were relevant to maintaining their health either because they did not view themselves as vulnerable to illness or they did not believe vaccines were necessary for wellness. Interestingly, the participants in the unvaccinated group viewed children as more vulnerable than themselves in contracting an illness. Moreover, several of the participants saw immunizations as an integral and relevant component of total wellness of children's health and development, even though it was seen as irrelevant to their own wellness.

A majority of the participants migrated from the South as children and had personally experienced or had relatives who experienced legal segregation in the South within medical institutions. Even though experiences differed among participants and within groups, most were able to overcome their memory of sanctioned segregation and its consequences. In this study, social trust, described as the attitudes that exist towards an organization or collective body, affected the participant's perception of medical institutions. In a previous study by LaVeist et al.,[33] participants' beliefs and perceptions of racism within medical institutions affected their trust of medical institutions. However, in our study, most participants overcame mistrust of medical institutions and racism. Many regarded racist acts as case-specific institutional or individual events that should be examined separately from medical care given by other individuals or institutions. Only a few participants offered the Tuskegee Syphilis Study as an example of historical medical injustices, and this was not associated with an unwillingness to be vaccinated. This finding was consistent with the Green et al.[25] study that demonstrated that the Tuskegee Syphilis Study did not have a negative impact on the participation in clinical trials. Interestingly, participants felt that the historical medical abuses and historical experiences with medical institutions or society reinforced the importance of self-advocacy.

Limitations

The findings of this study were subject to several limitations. The findings of the study represent the views of the elder participants from Rochester. The views expressed might have differed if the interviews were conducted in a different region or state. Given the

use of in-depth interviews and sample size, the findings are limited in generalizability. The majority of the participants were women (14 women versus six men). This study occurred after the 2004 influenza vaccine shortage following the contamination of some British vaccine with *Serratia*. This may have had a negative effect on participants' willingness to be vaccinated. In our study, only one participant expressed a concern of vaccine contents. There may have been response bias due to the interviewer being a physician. Different responses may have occurred if a nonmedical individual conducted the interviews. Furthermore, the responses from the participants could have been limited due to unconscious effects of trust or mistrust of the interviewer.

Implications

This qualitative study suggests that disparities in health and health outcomes are multifactorial. Mistrust of medical institutions was not described as a key concern for receipt of the vaccines. However, previous experiences with medical institutions were important in shaping views and decisions among participants to comply with vaccine recommendations. More qualitative research is needed to further explore how previous experiences or the collective memory of experiences affect current decision-making, which may lead to disparities in health and health outcomes.

CONCLUSION

The qualitative study gives a voice to the beliefs, perceptions and attitudes of black elderly Americans toward medical systems. Previous studies[8-10,17,25] have mentioned that mistrust of physicians and medical institutions may be a factor in patients' willingness to participate in medical care. Our study demonstrates that mistrust is not a key reason patients refuse vaccinations. Instead, previous interactions between patients and healthcare systems coupled with certain sociocultural forces seem to affect willingness to comply with recommendations for vaccinations. Although mistrust of medical institutions was not a barrier to receipt of vaccinations, memories of historical or current (medical, governmental or societal) abuses did seem to positively or negatively contribute to the participant's view of the healthcare system. Hopefully, these experiences will help healthcare providers better understand their patient's beliefs about vaccinations and the healthcare system.

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