Barriers and Facilitators to Participate in Biomarker Research Among African Americans

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Background

There is a growth in the number of population-based research studies linking biomarkers to other measures of health. These findings illuminate the individual- and community-level variables (social, behavioral, psychosocial, and genetic) associated with the distribution of disease.

Racial and ethnic minorities bear a disproportionate burden of chronic disease; yet, they are underrepresented in virtually all aspects of studies collecting biomarker information. The literature suggests that low African American participation in biomarker research is due, in part, to factors such as mistrust of medical and clinical research investigators and lack of information specific to study procedures. Currently, however, researchers have not studied barriers to participation with regard to specific biomarker collection procedures.

This study sought to understand the barriers and facilitators related to African Americans’ participation in saliva and blood sample collection. These procedures were chosen for this study since they are the most frequently used biomarkers to assess health status, genetic risk, and diseases characteristics. Saliva collection uses non-invasive drool collection, while blood collection uses non-invasive saliva procedure and the more invasive blood collection. These procedures were found for both saliva and blood procedures.

Research Questions

What are the barriers and facilitators to African Americans’ participation in saliva and blood data collection procedures?

Do these barriers and facilitators differ between the non-invasive saliva procedure and the more invasive blood procedure?

Purpose of the Study

To understand the barriers and facilitators associated with African American participation in saliva and blood data collection procedures.

Methods

- Face-to-face interviews were conducted with 26 African American respondents, who were evenly stratified by age (25-45, 46-64, and 65 and older), education level (high school or less, some college, and master’s or above), and gender.
- All interviews were preformed by an African American graduate student.
- The interviewer first provided respondents with a definition of each data collection procedure and then asked the following questions:
  - “Would you be willing to participate in a research project that asks you for a sample of your saliva? Why or Why not?”
  - “Would you be willing to participate in a research project that asks you for a sample of your blood? Why or Why not?”
- All interviews were audio-taped and transcribed.
- Content analysis was used to identify and categorize the main themes and patterns found in the data. These themes and patterns were not predetermined; rather, they were allowed to emerge from repeated readings of the transcripts. Two researchers independently performed the coding to insure reliable.

Demographic Characteristics of Key Informant Participants

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<th>Age</th>
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<td>46-64</td>
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<td>Master &amp; Doctorate</td>
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Barriers Specific to Biomarker Studies that require a Saliva Sample

- Lack of information
- Misuse of African Americans for research

Barriers Specific to Biomarker Studies that require a Blood Sample

- Fear of needles
- Discomfort
- Risk to health
- Distrust of medical researchers and healthcare professionals

Facilitators Specific to Biomarker Studies that require a Saliva Sample

- Simple procedure
- Less invasive
- Not harmful or Risky
- Relevance of the research project
- Benefits to the individual, a family member, or others facilitate participation

Facilitators Specific to Biomarker Studies that require a Blood Sample

- Altruism
- Positive prior experience
- Appreciation or interest in research
- Sterile procedures and low risk of infection

Research Implications

- Time and effort must be given by researchers to establishing relationships and trust with a community prior to biomarker collection
- Information must be provided on the study purpose and its potential benefits for respondents and their community
- Discussions must be had with the community on the risk of a procedure and the actions that will be taken to reduce that risk (i.e., sterilization of items).

Major Findings

Similarities and differences with regard to barriers and facilitators were found for both saliva and blood procedures.

Barrier Themes:
- Distrust: For both saliva and blood samples, African American respondents reported distrust of medical research and researchers as a barrier.
- Invasiveness: Invasiveness served as a barrier for respondents when considering providing a blood sample.
- Lack of information: Respondents reported that not receiving information from the researcher about the study and its purpose would serve as a barrier for providing a saliva sample.

Facilitator Themes:
- Minimal risk: was reported as a facilitator for both saliva and blood.
- Beneficial: Respondents reported that they would provide a saliva or blood sample if the research would have benefits to themselves and others.
- Procedure’s simplicity and lack of invasiveness: This theme only emerged for the saliva collection procedure.

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African Americans' participation in saliva and blood data collection uses non-invasive saliva procedure and the more invasive blood procedure.