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Urban-dwelling Community Members' Views on Biomedical Research Engagement

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Abstract

In this study, we explore community members' overall understanding and experience with biomedical research engagement. We conducted a qualitative analysis to explore a concept that emerged, but was not specifically addressed in a pre-existing dataset obtained using four focus group sessions with 30 urban-dwelling community members. Transcripts were read in an iterative process and an emergent content analysis performed. Five main themes were identified: (a) engaging in research to contribute to personal or greater good; (b) hierarchy of trust; (c) the importance of disclosure and transparency; (d) practical barriers to research engagement; and (e) fear of research procedures. Community members view research engagement as a collaborative process whereby community members and researchers are involved in all stages of the investigation. Focusing on research engagement, and not merely participation, may enhance community knowledge of the research process and advance scientific knowledge.

Keywords

research; collaborative; research participation; minorities; qualitative emergent analysis; northeast region

While the burden of morbidity and mortality in the United States (US) disproportionately impacts racial/ethnic minorities, these individuals are underrepresented in biomedical

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research (i.e., clinical trials, or research involving the collection of biospecimens) (Wendler et al., 2006; Wissing et al., 2014). In October 2001, the National Institutes of Health (NIH) amended its policy on the inclusion of women and racial/ethnic minorities in research to ensure their representation in all NIH-funded biomedical research (National Institutes of Health, 2001). Despite this legislative mandate, minority participation in NIH-funded research remains low (Chen, Lara, Dang, Paterniti, & Kelly, 2014; Geller, Koch, Pellettieri, & Carnes, 2011). A previous study among HIV-infected patients reported that while 62% of adults participating in HIV medication trials were white, only 23% were black (Gifford et al., 2002). Similarly, a study of minority participation in biobanking found that only 10% of specimens for cancer research was collected from non-White patients (Simon et al., 2014). Disparities in research participation highlight the need for effective strategies to improve community-academic partnerships and increase minority representation in biomedical research. Enhancing minority participation in biomedical research may reduce health disparities by generating scientific knowledge of disease etiology and treatment of underrepresented groups.

In previous studies, researchers have identified several barriers and motivators to minority participation in research. Reasons for underrepresentation in biomedical research may vary across racial/ethnic groups. While the recollection of historical abuses (e.g., Tuskegee syphilis trial) and racial discrimination are more likely to deter African-Americans from participating in biomedical research (Byrd et al., 2011; Dancy, Wilbur, Talashek, Bonner, & Barnes-Boyd, 2004), language and fear of deportation are distinct barriers among immigrant Latinos (Calderon et al., 2006).

Recently, the concept of community engagement in research, or research engagement, has gained much support. There are several models for research engagement, including community-based participatory research (Faridi, Grunbaum, Gray, Franks, & Simoes, 2007; Israel, Schulz, Parker, & Becker, 1998) and community action research (Reeb, 2006). Research engagement refers to community involvement in the research process, including research design and dissemination (Holzer, Ellis, & Merritt, 2014; Szilagyi et al., 2014). Thus, research engagement encompasses more than participation; it is a collaborative process of building partnerships to achieve common goals (Szilagyi et al., 2014; Zakus & Lysack, 1998). Strategies such as the use of recruitment facilitators (e.g., clinicians and community organizations), outreach via community events and door-to-door canvassing, and referrals to research projects by friends, have been shown to encourage participation of ethnic/racial minorities and vulnerable populations in research (Bonevski et al., 2014; Holzer, Ellis, & Merritt, 2014). Whether community members' view of research engagement supports these strategies has been understudied. Therefore, the aim of this qualitative investigation was to explore with community members who had some or no participation in research their overall understanding and experience with engagement for biomedical studies.

Methods

Design

We conducted a qualitative analysis to explore a concept that emerged but was not specifically addressed in the primary study within the original time period of the approved

institutional review board protocol at Columbia University Medical Center (Lucero et al., 2015). The primary study focused on potential risks and benefits of personal health information for secondary clinical and non-clinical use and included a question on preferred mechanisms for research involvement and engagement (i.e. telephone contact, approach by health professional, approach by other community member, home mailings), thus making this an appropriate dataset for this secondary analysis. In this article, we focus on the broader significance of research engagement and provide valuable insight into informants' thoughts and experiences with biomedical research. A qualitative secondary analysis is a valuable approach to maximize use of existing data and generate new knowledge (Heaton, 2008; Noble, Price, & Porter, 2014).

Setting and Informants

The primary study was described previously (Lucero et al., 2015). Individuals age ≥18 years and living in Washington Heights or Central Harlem communities of New York City were eligible for inclusion. Informants were recruited by staff at community-based organizations or in primary care waiting rooms at Columbia University Medical Center and its surrounding neighborhood. Informants were provided with food and beverages during each session and compensated $25 for their participation. Community members of different gender, age, race/ethnicity, primary language, educational levels, and experience with clinical research (i.e., participated in past research, never considered participating, refused to participate) were invited to focus group sessions that were conducted at a community space used for research, education, and health promotion activities.

Data Collection

All primary study original focus group transcripts were used in this secondary analysis. Primary study data collection methods were described previously (Lucero et al., 2014). In brief, data were collected using a minimally structured focus group interview guide (Lucero et al., 2014). Four, two-hour focus group sessions (two in Spanish and two in English) were conducted by bilingual (i.e. Spanish/English) focus group facilitators (i.e. study principal investigator and co-investigator). A senior research team member with previous experience in focus group methods moderated each session, and an observer/note taker was present. Focus groups were audiotaped for verbatim transcription, and transcripts were de-identified. Demographic information was collected at the beginning of each focus group using a self-administered questionnaire.

Data Analysis

A qualitative secondary analysis was performed using an emergent approach. Transcripts were analyzed in their original language. Two bilingual (English and Spanish) coders reviewed original transcripts in an iterative process to obtain a sense of the data as a whole. The coders independently reviewed the data and took notes on their first impressions (Hsieh & Shannon, 2005). Coders met weekly to define and refine codes until reaching consensus on a coding scheme. A single coder then analyzed the rest of the transcripts. Codes were organized into themes, and quotes identified from the data to exemplify these themes. Quotes from the Spanish-speaking focus groups were translated into English by a single coder. Data analysis was performed using NVivo10 qualitative software.

Scientific Rigor

Scientific rigor, or trustworthiness, was enhanced using the criteria developed by Lincoln and Guba (1985): credibility, transferability, dependability, and confirmability. Confirmability (or neutrality) was enhanced by continual reflexivity of the researchers while conducting the study and analyzing the data (Krefting, 1991). Peer debriefing, which took place during weekly meetings with the research team, enhanced credibility and dependability of the study. A thick description of the phenomenon is provided to address transferability. Dependability was assured by keeping an audit trail of the research process. Lastly, to further ensure rigor, an expert qualitative nurse researcher served as a consultant to the team.

Results

Thirty community members participated in the primary study's focus groups. Informants were predominantly Hispanic/Latino, between 51 and 60 years of age, and primarily spoke Spanish (Table 1). Fifty-three percent of informants had participated in a research study prior to the focus group.

Data analysis revealed five main themes about community members' understanding of engagement in biomedical research. These included: (a) the idea that participation in research may contribute to personal or greater good; (b) the hierarchy of trust in research; (c) the importance of disclosure and transparency; (d) practical barriers to research engagement and participation; and (e) fear of research procedures.

Contributing to Personal or Greater Good

Some informants perceived participating in biomedical research as an opportunity to gain knowledge about specific medical conditions or health in general. This knowledge might be of direct and immediate benefit to themselves, their families, or their communities. Research topics were more attractive if they were personally relevant: "It has to be something specific to me that relates to me, my medical condition or psychiatric condition . . . or to learn, yeah, and keep up with new stuff going on."

Informants also viewed research as a partnership that could potentially yield knowledge dividends of benefit to themselves, their families, and their communities in the longer term:

> Well, I think that if you attend one of these focus groups and you have a neighbor, a friend, somebody...you can give her information on the stuff that you just studied at the focus group and give it to her because it might be beneficial to her.

Informants' comments about the expected benefits of research engagement suggested they might be at risk of overestimating the direct health benefits they might experience. This was a particular risk for the minority of informants in the Spanish-language focus groups who conflated research and medical diagnosis and treatment. Such confusion may emanate from the word for research, "investigación," also being used generically to signify 'looking into' or 'checking out' something as in the pursuit of additional clinical information for diagnosis. Confusion between terms was evident when one informant mentioned: "What can I say, I'm not afraid; if they have to check me out, for example, an arm, then let's check it out, because

I'm up for it.” As a methodological note, the use of more specific terms like ‘investigación científica’ (scientific investigation) or ‘estudio científico’ (scientific study) may help clarify confusion with general academic terms like investigation with lay non-English speaking community members.

Most informants verbalized a general willingness to be contacted by researchers and looked upon the idea of participating favorably because they saw it as a contribution to the greater good. “If they are going to do a study and with my results I can contribute to humanity, than for something I stayed alive. So, I'm not selfish. I think that my community, if that will help them, [then] 100 percent.”

Informants valued privacy, but were willing to give up some of it in exchange for direct personal benefit (e.g., knowledge, financial incentives) and/or for the greater good. Ideally, the proposed exchange would be perceived by all parties as equitable. However, the subjective equality of exchange (i.e., the greater the loss of privacy, the greater the compensation) could be compromised by the participant's circumstances. When discussing the choice to relinquish more personal information than anticipated due to financial need, one informant stated: “If people ask you questions you don't want to answer, you don't answer them. If you need the money that bad, then answer.” Although “contributing to personal or greater good” was vital when deciding whether to participate in research studies, monetary compensation was also described as an important factor in Spanish and English-speaking focus group sessions.

Informants tended not to feel a sense of ownership about their biospecimens, but rather hoped they would be scientifically useful. Informants adopted the attitude that once relinquished, biospecimens were no longer of any personal concern: “I think they may [have] held onto my blood or something like that in this study that I'm doing, but I don't have a problem with that. I don't know why they would want my blood because my blood isn't perfect.” Aside from demonstrating lack of ownership of biospecimens, this statement indicates a lack of understanding of the research protocol (i.e., not knowing if blood was collected for a research study) and the reason for collecting the biospecimen.

Hierarchy of Trust

Informants described reacting differently to invitations to engage in research depending upon the level of trust afforded a relationship. Family, close friends, and clinicians were at the top of the hierarchy and remote strangers (e.g., unknown research staff) were at the bottom. Recruitment was viewed more favorably if the invitation to participate came from a known person: “It would be better for someone that you had prior contact with to call you.”

Informants’ preferences were related to their concerns about falling prey to fraud, scams, and identity theft. Concerns were allayed to varying degrees by the quality of evidence of affiliation with the medical center or university; an invitation on official letterhead might engender trust, but not as much as an office housed within the affiliate institution.

> Personally, if you see one another ‘face-to-face’ with that person, face-to-face and talk, then things would change and more so if I go to the hospital directly, because

> there I know that he really has his identification and I can feel good 100 percent that it's a person who really is part of the [hospital].

For some informants, reaching the necessary level of trust required more than an institutional affiliation. They were unlikely to engage in a dialogue with researchers unless they saw a person of their race or ethnicity on the research team:

> I think it's more or less maybe a racial thing of ethnic groups. ‘I don't believe nothing they gonna say. I don't believe what they say,’ and so I think it's more of that. ... so the panel should be maybe more of a mixture of who's giving it—somebody more or less in that group, lives in that community, those kind of people should be given a—giving the research or have somebody at the table that at least look like me.

It was clear that informant's viewed the patient-clinician relationship as on marked by a higher level of trust when compared to other relationships. When asked with whom they would consult when deciding to participate in a research study, one informant responded: “To the doctor to see if it benefits me, ‘cuz they have more knowledge of my medical condition and stuff and would tell me ‘yes’ or ‘no’ or ‘maybe’ or give me feedback on it.” Some informants mentioned that they would consult their primary clinician to determine if the proposed research is safe and meets with the clinician's approval: “ . . . they'd have to talk with one's primary physician, come to an agreement with him.” As such, primary clinicians were seen as the ideal initial source of invitations to participate in research. Second best would be an invitation extended on behalf of or with the prior authorization of the clinician.

Disclosure and Transparency

Informants consistently valued disclosure and transparency from researchers. They wanted to be told in advance if the results of the proposed research were likely to be commercially profitable. Informants also wanted to know how their contact and medical information had been obtained and used: “I would kinda wonder why are you interested in me. Is it somethin’ about me that you know that you want to study about me?” Full disclosure would help informants understand the purpose of the study and the reason for being asked to participate, which would build trust in investigators.

Practical Barriers

Many of the barriers to research engagement cited were practical ones, such as language barriers and knowledge deficits. Informants stated plainly that they lacked general knowledge about research, the variety of forms that research engagement might take, and how one goes about participating in a study: “Well, a lot of times the community is not aware of certain programs that the hospital has and they have to either find out about it through friends who have gone through it and tell them about it.’”

Issues related to transportation and mobility also were perceived as barriers to participation: “Well, as far as the barriers are concerned. I think a person who's on a walker, who's on a wheelchair, it's very difficult to attend these meetings.”

Fear of Research Procedures

Informants expressed a variety of personal limits to the types of research activities they would be willing to undertake. For example, one informant would consent to ingest medications, but would stop short of undergoing a surgical procedure whereas another informant drew the line at medications: “I would never participate in a research study that involves me taking medicines or anything like that. I would never do that.”

Other informants had more generalized fear and mistrust of even responding to invitations to participate in research, possibly owing to a lack of knowledge about the informed consent process and the possibility of withdrawing from a study at any time. Their comments evince a fear of being trapped in an undesirable situation:

> Participant 1 (P1): You don't know what you're getting into or how deep you're gonna get into it.
>
> Participant 2 (P2): Yeah. What's behind it? How much I'm getting involved with, and how much I wanna go through.
>
> P1: Suppose I get involved in that . . . What are the consequences that I will suffer?

DISCUSSION

Trust is a key thread common to many of the identified themes. In this analysis, we found that a hierarchy of trust exists among community members, with clinicians enjoying a high level of trust from their patients because of the privileged nature of the relationship. Informants showed a strong preference for their clinicians to act as go-betweens in the research process. However, it may be impractical, especially in overburdened primary care practices, to ask clinicians and their staff to take on additional roles in the community. Furthermore, dependence on clinicians as gatekeepers closes the door on other potentially fruitful recruitment avenues that leverage participants’ existing, trusted social networks. These challenges might be mitigated through community-based participatory research and/or community-specific strategies that may help develop trust in researchers. For example, a recent investigation of HIV/AIDS risk among immigrants in NYC found that building rapport with community members prior to data collection improved research participation (Shedlin, Decena, Mangadu, & Martinez, 2011). Developing rapport with the community may enhance trust by legitimizing research studies and investigators. Additionally, as one of the informants pointed out, credibility with participants and the community is enhanced when the composition of research teams reflects the diversity of the community in which studies are performed. Similarly, a previous study found that diversifying research teams and increasing community trust boosts minority participation in research (Ford et al., 2013). The promotion of diversity in research teams, especially in senior leadership positions, and the shoring up of trust in a research institution requires long-term investment and sustained commitment.

With informants emphasizing the value of disclosure and transparency in research, recruitment policies that focus on full disclosure of research aims and protocol may support an environment of trust. Educational outreach and recruitment materials must balance

thorough descriptions of research procedures against the need for brevity and explanations of the research's potential significance to the community against the risk of overpromising benefits that may not come to fruition. In addition, our informants indicated they preferred to be advised in advance if a research study would have commercial applications. Disclosure of commercial applications is considered a “best practice” by the National Cancer Institute, but federal regulations do not require it (National Cancer Institute., 2011).

In this study, we highlight some potential logistical and ethical challenges in research engagement. Costs (e.g. transportation) associated with research engagement have been previously reported as a barrier to participation in biomedical research (Calderon et al., 2006; Ford et al., 2013). Although informants did not identify monetary compensation as the sole reason to engage in research, it was a major contributor to the decision to participate, and the degree of participation. Our findings underscore the delicate ethical balance researchers must strike between offering attractive and appropriate incentives to respondent burden but are not so substantial that they become functionally coercive. This balance is hard to achieve when there are no federal guidelines, no single model of payment for research participants (Grady, 2005), and there is a wide range of incomes represented in the participant pool. An amount that is sufficiently attractive to a middle- or high-income individual may lead a low-income individual to participate beyond their comfort zone, as described by one informant.

None of our informants expressed concerns about engaging in research entailing the collection of biospecimens nor was there confusion or need for clarification regarding the term biospecimen among our informants. During the introductory period of the focus groups, we defined and explained for the informants what we meant by using the term biospecimen. It is unlikely, however, that they were aware of the ethical and legal disputes with respect to biospecimens because our informants seemed to be unaware of the difference between biospecimen collection for clinical assessment and research. Nonetheless, our informants’ willingness to allow use of biospecimens in research is likely based on the assumption that their biospecimen would generate scientific knowledge (Morrison, Farah, & Hock, 2013) and that privacy will be maintained. This assumption may no longer be safe in an era of rapid, inexpensive DNA sequencing. In a recent study, researchers were able to deduce the identities of almost 50 research participants by using Y-chromosome DNA sequences from large, publicly available datasets (Gymrek, McGuire, Golan, Halperin, & Erlich, 2013).

Previous studies have identified several facilitators to minority engagement in research. Willingness of African-Americans and Latinos to participate in research may be driven by a sense of civic duty, monetary compensation, and disease burden in the family or community (Byrd et al., 2011; Calderon et al., 2006). Similar motivators emerged in our study including trust, disease burden, monetary compensation, and community benefits. In addition, this study revealed that community members do not perceive their role in biomedical research solely in terms of participation; they described their engagement throughout the research process as helping investigators recruit other participants, participating in study procedures, and disseminating findings to other community members. The involvement of community members throughout the research process has been described previously in the analytic

framework for community-based participatory research (Viswanathan et al., 2004). The findings from our study reflect community members' view of research engagement and preference to be involved in each step of the research process described by Viswanathan et al (2004).

Our study findings can be translated into practical solutions to enhance research engagement among underrepresented groups. Institutions can take concrete steps to establish, maintain, and improve the level of trust with the community. The themes of "Disclosure and Transparency", "Contributing to Personal or Greater Good", and "Fear of Research Procedures" suggest these strategies should include a community education campaign to improve informants' admitted lack of knowledge about research, the informed consent process, and human subjects protections. Based upon study findings, this campaign should entail: a) a description of scientific research and the ways in which it differs from medical treatment; b) examples of the many forms of participation in human subjects research; c) a description of the informed consent process with an emphasis on the voluntariness of participation at all phases of a study; d) a description of standard human subjects protections and the role of institutional review boards; and e) an explanation of the types of systemic risks associated with research participation and the measures taken to mitigate those risks. These findings are particularly telling given that avoiding coercion and enhancing privacy are essential aspects of the informed consent process and institutional review board application. Community-academic partnerships can help ensure that research protocols effectively address these issues, both from the perspective of the community and academic unit, and that community members are well informed of their rights as research participants.

There were several limitations to this study. First, since this was a secondary analysis, investigators had no direct contact with informants to clarify the interpretations of findings. Next, since most informants had previous experience with research, the views of people who would be opposed to research, even in minimal risk circumstances like a focus group, cannot be assessed directly in this investigation. A third limitation was the possibility of self-selection bias of informants who agreed to participate in the primary study, leading to an uneven representation of participants across the four focus groups. Lastly, since focus group participants were largely Hispanic, transferability may be an issue.

Trust of research teams and institutions are necessary to develop and maintain community involvement in research. Diversifying research teams, including culturally competent community lay health workers, so that they mirror underrepresented communities in research is one strategy to promote trust. Community engagement in research may help increase minority participation in research and procurement of biospecimens from underrepresented individuals. Minority participation in research may reduce health disparities by increasing study generalizability (Paskett et al., 2008) and generating evidence regarding the treatment and prevention of disease in underrepresented groups. Hence, research institutions and academic medical centers can reduce health disparities and improve the health of the surrounding community by recognizing the importance of engaging community members throughout the research process. Furthermore, focusing on community engagement in research, and not merely participation, may help increase community

knowledge of the research process and advance scientific knowledge by enhancing generalizability of findings.

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Table I

Characteristics of Primary Study Informants (N=30)

Variable	n (%)[a]
Gender	
Female	15 (50)
Male	14 (47)
Age	
18-30	1 (3)
31-40	4 (13)
41-50	4 (13)
51-60	8 (27)
61-70	4 (13)
71-80	6 (20)
80+	1 (3)
Education	
Some High school or less	11 (37)
High school	7 (23)
Some college	7 (23)
College degree	3 (10)
Race/Ethnicity[b]	
White	4 (13)
Black	5 (17)
Asian	0 (0)
Latino	20 (67)
Other[c]	2 (7)
Primary language	
English	9 (30)
Spanish	21 (70)
Marital Status	
Single	4 (13)
Widowed	2 (7)
Married	14 (47)
Separated/Divorced	8 (27)
Cohabitating	1 (3)
Previous research participation	
Yes	16 (53)
No	13 (43)

[a] Categories may not add to 100% due to missing data.

[b] Adds up to > 30 because participants could self-identify as belonging to more than one race/ethnic group.

[c] Other language was not specified.