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# Using perceptual mapping methods to understand gender differences in perceived barriers and benefits of clinical research participation in urban minority HIV+ patients

Sarah Bauerle Bass<sup>a</sup>, Caitlin Wolak<sup>a</sup>, Judith Greener<sup>a</sup>, Ellen Tedaldi<sup>b</sup>, Aasit Nanavati<sup>a</sup>, Katey Ruppert<sup>c</sup> and Thomas F. Gordon<sup>c</sup>

<sup>a</sup>Department of Social and Behavioral Sciences, Temple University College of Public Health, Temple University, Philadelphia, PA, USA; <sup>b</sup>Department of Medicine, Temple University Hospital, Philadelphia, PA, USA; <sup>c</sup>Department of Psychology, University of Massachusetts Lowell, Lowell, MA, USA

#### **ABSTRACT**

Minority participation in HIV clinical trials research is critical to understanding the impact of medications or behavioral interventions, but little is known about gender differences in perceptions of participation. We surveyed 50 minority HIV+ patients from an urban clinic to assess perceived risks/benefits of clinical trial research participation and used innovative marketing methods to analyze results. Perceptual mapping and vector message-modeling, a method that creates 3-D models representing how groups conceptualize elements, were used to assess how male and female participants could be motivated to participate. Results showed men farther away from participation and more concerned with HIV disclosure and experimentation than women. Men expressed distrust of the medical system, doubted HIV's origin, and knew less about research implementation. Women were closer to participation in both behavior and medical trials and perceived medication issues as more significant, including fear of losing medication stability, medications not working, being in the placebo group, and experiencing side effects. Vector modeling shows that messages would need to focus on different aspects of clinical research for men and women and that interventions aimed at minority HIV+ patients to encourage clinical trial participation would need to be targeted to their unique perceptions. Understanding gender perceptions of HIV clinical research has significant implications for targeting messages to increase minority participation.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

HIV/AIDS; clinical trials; perceptions; perceptual mapping; minorities

#### **Background**

In the United States, an estimated 1.1 million people are living with HIV (amfAR, 2013), with racial and ethnic minorities representing more than 68% of diagnosed cases (Centers for Diseases Control and Prevention [CDC], 2013). Minority women are at particular risk, with African Americans accounting for nearly twothirds of new infections (64%) and Latinas accounting for 15% (CDC, 2012). Although these statistics demonstrate that the face of HIV in the United States is predominately of color, those participating in clinical medication or behavioral trials are not. This participation gap is most notable among African Americans, who represent only about 30% of participants enrolled in clinical studies (Castillo-Mancilla et al., 2014). Understanding how best to address this disparity is important (National Institutes of Health, 2013) since both medication and behavioral clinical trials are vital pathways to the discovery of effective new methods of prevention, treatment, and rehabilitation for many

diseases, including HIV (Baquet, Henderson, Commiskey, & Morrow, 2008).

Clinical trial participation is a multi-faceted decision, often the result of weighing perceived barriers against possible incentives (Adeyemi, Evans, & Bahk, 2009; Rivera-Goba et al., 2011). Noted facilitators that impact minority participation in HIV clinical trials (Adeyemi et al., 2009; Wendler et al., 2006) include the potential to help others, improving health status, and compensation (Adeyemi et al., 2009). Gwadz et al. (2010, 2013, 2014) have described a range of barriers - social, organizational, and structural - that hinder enrollment. On an individual level, barriers to enrollment for minorities and women often focus on issues of mistrust in researchers and pharmaceutical companies, as well as fears about involvement in medical research (Gwadz et al., 2014; Killien et al., 2000). Frequently, underserved populations believe that researchers do not take enough time to involve the community or utilize existing services and organizations the community has to offer, creating suspicion and disconnection from potential participants (Corbie-Smith, Isler, Miles, & Banks, 2012).

Past research has been mixed gender and has evaluated the barriers and motivators of participation either among ethnic groups or across genders, irrespective of ethnicity; there has been limited examination of the reasons for participation in HIV clinical trials across both variables (Gwadz et al., 2006; Menezes et al., 2011). Thus, the purpose of this study was to examine the differences between genders on the perceived barriers and facilitators of being involved in a clinical trial in urban patients of a large HIV clinic that serves predominantly minorities who have never participated in clinical research. Results were analyzed using innovative marketing methods - perceptual mapping and vector messagemodeling - which allow for creation of three-dimensional models of perceptions of decision-making and predict which elements are most important to focus on for behavior change. We discuss how these methods help elucidate specific differences in male and female perceptions about clinical trial research participation, and how these results can support recommendations for the development of targeted messages for interventions that will impact informed decisions.

#### **Methods**

#### Perceptual mapping and vector modeling

Data were analyzed using perceptual mapping methods that incorporate multidimensional scaling and vector message-modeling techniques. These techniques allow us to produce a graphic display of how participants perceive the relationships among risks and benefits of a decision to understand how attitudes and perceptions contribute to both cognitive and affective dimensions of decision-making. The resulting three-dimensional maps display the risks/benefits relative to each other and to "Self," which is a group average. This method builds on the Galileo approach of Woelfel and Fink (1980) and has a solid history as a mathematical modeling tool that can be used to identify optimum message strategies, based on the principles of increasing the attraction to, or repulsion from, particular concepts or attributes in a map. They have not been used widely in public health research (Bass et al., 2013, 2008), but have been noted by the Rand Corporation as being a superior technique to understanding perceptions and creating highly targeted message strategies (Larson et al., 2009).

Once maps are constructed, vector-message modeling helps us understand how to "move" individuals within the perceptual space toward a desired decision or

behavior. Because perceptual maps are mathematical models, vector analyses can be used to determine optimum associations to emphasize in a message or intervention in order to change the positioning of elements in the perceptual space. Vector modeling can help develop message "parsimony" by only focusing on those variables most important to the desired change, rather than employing the "kitchen sink" method of message/intervention development. If too many concepts are emphasized, the true motivators for change may get lost in a message or intervention that is unnecessarily complicated. The strength of this method is it allows researchers to look into the emotional and psychological barriers or facilitators of a decision to determine which one or several attributes are most important to the group so messages and/or interventions can be targeted to the specific needs of the population. This assessment is not based on statistical significance but rather on perceived associations among the concepts and perceived importance to the desired behavior, outcome, or decision. The result is then a graphic display of the data structure rather than the typical statistical summary tables associated with survey research. (For more information on health-related applications of perceptual mapping, see: http://sites.temple.edu/ turiskcommlab/.)

#### Survey instrument

The survey instrument was developed based on previous focus groups with urban minority HIV+ patients from the same clinic (Wolak, Bass, Tedaldi, Van den Berg, & Rohrer, 2012) and a review of the literature. As other HIV research has not made use of perceptual mapping methods, and instruments are different in scale, we created the instrument based on our qualitative research and literature review to make it specific to the population of interest. Content was assessed for face validity by physicians in the HIV clinic. The perceptual mapping questions were constructed to be conceptually related to each other, and included both barriers and facilitators to participation in clinical trials in two question blocks (Table 1). Respondents were asked to rate on a scale of 0-10 how much they disagreed or agreed with each statement, with zero meaning strongly disagree and 10 meaning strongly agree. Five demographic questions were also included.

#### **Participants**

Over two months, 52 HIV+ African American or Latino patients from a large urban HIV clinic completed the survey. The clinic is part of a large northeastern medical

#### Table 1. Perceptual mapping survey items.

Question Block One

- 1. In general, I wouldn't want to participate in a clinical trial because I don't trust doctors and researchers
- 2. It would be hard taking time out to participate in a clinical trial
- 3. I don't know too much about clinical trials and this keeps me from being in one
- 4. I don't think that researchers would want me to participate in a clinical trial
- 5. Participating in a clinical trial is a good way to help others with HIV/AIDS
- 6. Getting extra medical attention is a good reason to be in a HIV clinical trial
- 7. I wouldn't want to be in a clinical trial because HIV is a manmade virus and there is already a cure
- 8. I am afraid of being in the group that doesn't get the medicine
- 9. I would be more likely to participate if I were told more about the clinical trial and its risks and benefits
- 10. I am concerned that the medication will not work in my body
- 11. I worry that other people would find out my HIV status
- 12. I don't want to be in a clinical trial because I am doing well on the medicine I am taking and I don't want it to upset the balance
- 13. Clinical trials use people as guinea pigs to experiment on
- 14. It scares me to think that I will have lots of side effects to the medicine and this keeps me from participating in a clinical trial

#### Question Block 25

- 1. I would participate in a clinical trial because I could get new medicines that aren't available anywhere else
- 2. I would be more likely to participate if I were given an incentive like money
- 3. I don't want to be in a clinical trial because I don't want to take more medication on top of ones I'm already taking
- 4. I would be more likely to participate if I felt comfortable and I knew and trusted the doctor that was doing the trial
- 5. I would be more likely to participate in a clinical trial if a doctor I trusted recommended it
- 6. I would be more likely to participate in a clinical trial if my friends or family members told me to
- 7. I would be more likely to participate in a clinical trial if the medicine has already been tested and researchers show that it is pretty safe
- 8. Before participating, I think it would be important to hear from others who have been in clinical trials
- 9. I would be more likely to participate if researchers would tell me if I am going to get medication or not
- 10. I think I would be interested in participating in a HIV clinical drug trial where I was given medication
- 11. I think that I would be interested in participating in a HIV behavioral trial where I would be asked to attend an education session or support group
- 12. I would be much more likely to participate in a behavioral trial than a medication trial

system and provides care to over 900 HIV+ individuals, most of whom are ethnic minorities. Eligible participants were between 18 and 65 years of age, received their primary source of care at the clinic, and self-reported never participating in a clinical trial. Two individuals were excluded because of prior participation in an earlier phase of the study. The survey took approximately 15 minutes to complete and participants were given \$20. Patients were referred to our study by their clinic physician and were approached by study personnel and asked if they were interested in participating.

Interested patients were consented and then the survey was orally administered in either the waiting room in a quiet area or in the procedure room prior to or following the participant's scheduled appointment. To ensure that all participants understood the meaning of clinical trials, they were shown seven laminated slides, discussing what a clinical trial is, the difference between behavioral and medication trials with examples, and the benefits and risks of participation. All consent, educational material, and survey items were approved by the Institutional Review Board.

# **Analysis**

Responses from the perceptual mapping survey were entered into SPSS 18.0. Descriptive statistics such as race, gender, level of education, and age were compiled for the entire sample. Correlations were generated for

question Blocks 1 and 2 in the total sample and within men and women to be used in the perceptual mapping analysis. To construct the perceptual maps, software developed by the authors and based on the Galileo system was used (Woelfel & Fink, 1980). This program converts scaled judgments into distances used in the mapping. Input associations among the risks/benefits are derived from the inter-item correlations of all elements, where the absolute values of the correlations are converted to a 0-10 scale base. The software then performs a metric MDS analysis and produces graphic arrays of the distances among the elements. The graphic plots are displayed in three dimensions for visual inspection and interpretation.

# Results

#### **Participant characteristics**

All 50 participants were self-reported minority, with 94% (n = 47) describing their race as African American. Six percent (n = 3) described themselves as Latino, all of whom also considered themselves to be Hispanic. More women (56%, n = 28) participated than men (44%, n = 22). Twenty-two percent of participants reported not completing high school, 60% received their high school diploma or GED certificate, and the remaining 18% reported having some college. The participants' mean age was 47 years, with a range of 28-63 vears.

 $<sup>^{</sup>a}$ 0 to 10 scale; How much do you agree or disagree with the statement with 0 = totally disagree and 10 = totally agree.

### Perceptual mapping results

The perceptual maps (Figures 1-3) show how the total sample of minority HIV+ individuals, and how men and women individually, conceptualize the key elements of clinical trial participation. The group "self" variable is illustrated as a cylinder shape and the star shapes represent the likelihood of participating in a medication or behavioral trial as labeled. The other shapes represent specific barriers or facilitators to participating in clinical trial research. Similar shapes connote conceptually related elements to the participants, based on their proximity in the three-dimensional space (see Figure Key). The perceptual map is thus able to visually represent not only how these variables may be associated with the key participation constructs but how they interact with each other.

# Perspectives of clinical trial participation for total sample

The maps show that overall, participants conceptually structured the aspects of participating in a HIV clinical trial through a clustering of similar/related variables into meaningful groupings, demonstrating their integrity. Groupings of Block 1 questions include (1) concerns about research (don't trust research, won't be a guinea pig, HIV is a conspiracy), (2) concerns about medications (afraid meds won't work, afraid meds not safe, need more risk/benefit information), and (3) not wanting to change current therapy (don't want to change meds, afraid I'd get placebo). In addition, the two facilitators included in the Block 1 statements (I'd get extra care participating in a trial and participation may help others) are positioned close together. Block 2 groupings include (1) affirmation regarding clinical trial participation (recommended by doctor, trust the doctor doing the trial, hearing from others who have been in clinical trials) and (2) knowing more about the medicine (tell me if I am going to get medication or not, get meds that are not available anywhere else).

The likelihood of participating in a medication or a behavior trial is in close proximity and, therefore, similar attributes are associated with the decision to participate in both types of trials. For the overall group, barriers include the perception that HIV is a conspiracy, lack of trust in research, along with not having sufficient time to participate. Other barriers include the need for additional risk-benefit information and concern about eligibility. Facilitators include a recommendation from a trusted doctor, having a trusted doctor as part of the trial, and receiving assurance that the medication was tested and is safe.

# Perspectives of clinical trial participation by gender

#### Barriers to participation

Differences can be seen between genders in terms of the specific barriers to participation. Figure 2 illustrates men are farther away from both medication and behavioral trial participation than women. They expressed distrust of the medical system, were concerned about being experimented on, and doubted the origin of HIV. In addition, they felt that they did not have enough information about clinical trials, that they would be in a placebo group, and were concerned that their HIV status would be disclosed. In contrast, women were closer to the participation variables and perceived issues surrounding medication, rather than the medical system, to be significant obstacles to entering a trial. Medication barriers included fear of losing the stability that their current medication regime provided and the trial medication not working in their bodies. Women also grouped these concepts closely to being in the placebo group and experiencing side effects to the drug.

Using this perceptual mapping information, vectormodeling methods were then applied to understand how to best "move" individuals within the perceptual space toward the desired decision or attitude. Figure 2 shows the vector modeling for men and women. For male participants to "move" in the space towards considering a medication clinical trial, messages should focus on addressing the concern that HIV is a conspiracy, feelings of being a guinea pig, and fear of getting a placebo. For women, it would also be important to focus on concern around receiving a placebo, along with emphasizing the need for more information about clinical trials and the risks/benefits of participating.

### Benefits of participation

Figure 3 shows the facilitators of patient participation among men and women. Again, men are positioned further away than are women from the decision to participate in a medication or behavior trial. For men, facilitators of participation in a medication trial that should be emphasized include knowledge that more medication is not required, having a recommendation from family members or friends, and that an incentive to participate is provided. Women view the facilitators to participation in a medication trial as safety- and trust-focused, including awareness that the medication used has been tested and is safe, having a doctor's recommendation, and knowing a trusted doctor is part of the trial. Vector modeling illustrates that for male participants, it would be necessary to reinforce the fact

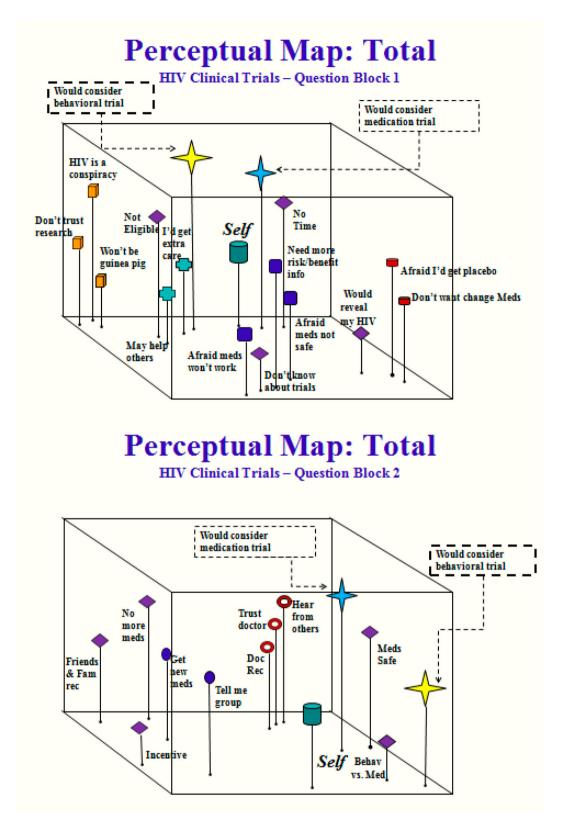


Figure 1. Perceptual mapping for total sample of HIV+ urban minority patients.

that a trusted doctor was part of the trial, the family and friend recommendation, and the incentive payment. For women, safety and trust would require reinforcement.

#### **Discussion**

The perceptual maps reveal that minority HIV+ men and women have different perceptions regarding the

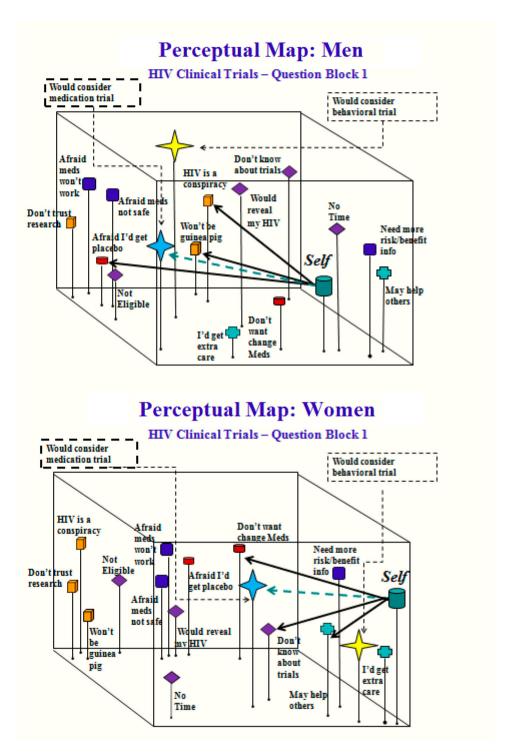


Figure 2. Question Block 1 – differences in perceptions to clinical trial participation between men and women and vector messagemodeling strategies.

barriers to and facilitators of participation in clinical trials. While this study finds that the barriers to participation for the total group of patients include the perception that HIV is man-made, a lack of trust in research, and insufficient time to participate, these same barriers are not as important to women when examining how they conceptualize the decision. Distrust and fear appear

to prevent participation among men, while issues surrounding the safety and efficacy of the medication represent barriers for women.

A number of the overall barriers to participation identified in our study are similar to findings from other studies with minority HIV+ patients (Andrasik et al., 2014; Sullivan, McNaghten, Begley, Hutchinson,

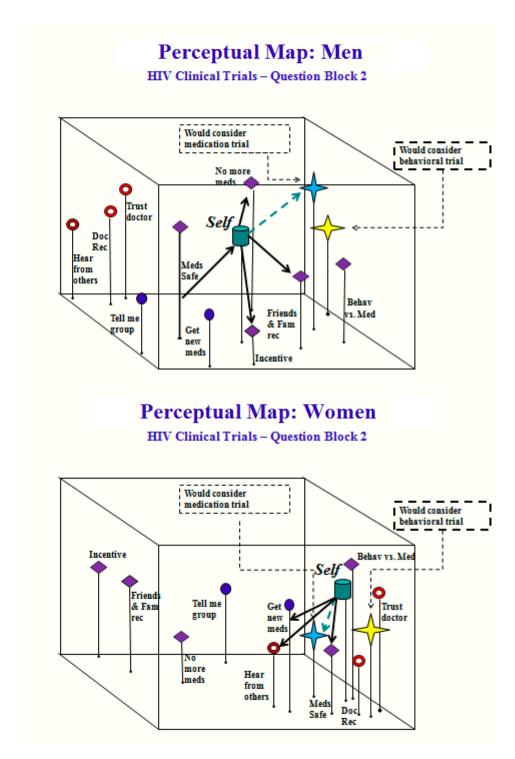


Figure 3. Question Block 2 – differences in perceptions of clinical trial participation for men and women and vector message-modeling strategies.

& Cargill, 2007; Zúñiga, Blanco, Martínez, Strathdee, & Gifford, 2007). Cargill and Stone (2005) and Newman et al. (2006) identified issues as mistrust of the healthcare system, past poor experience with the healthcare system, and concerns over being used as a guinea pig. A recent study by Castillo-Mancilla et al. (2014) importantly showed that African American HIV patients were

more likely to report never having been talked to about clinical trials. However, our study pointed out that these barriers, although important to the total group of participants, do not reflect gender-specific barriers. The needs of women, in particular, are often not addressed in western normative assumptions about medicine and care (Broyles, Colbert, & Erlen, 2005) and minority

women are further disenfranchised from medical care because of the way research is often conducted (Killien et al., 2000). With participation rates by minority HIV + patients in clinical trial research still low, especially among women, researchers and clinicians may be attempting to address issues related to participation in a too general, "one size fits all," approach (Fishbein, 2000). It is clear that the messages that would be constructed based on an understanding of the barriers and facilitators demonstrated by the total group of HIV+ minority patients would not emphasize a number of the key messages needed to be addressed for women, thereby diluting the power of the communication to motivate the desired behavior.

Gwadz et al. (2010) note four major barriers to minority participation in clinical trials, including low rates of recruitment and referral, lower rates of eligibility, and difficulty navigating the clinical trial system. Notably, a fourth barrier is that minorities are more likely to decline to participate when asked (Castillo-Mancilla et al., 2014). The objective, then, is to see this increased access and ability to enroll translate into participation. Research suggests that once potential minority participants are identified and engaged to participate in HIV clinical research, it is possible to enroll them at rates comparable to white participants (Gwadz et al., 2011; Sobieszczyk, Xu, Goodman, Lucy, & Koblin, 2009). Thus, understanding the barriers and facilitators not just of ethnic minorities as a group, but of men and women independently, will facilitate messaging to increase this engagement.

## Limitations

This study used a convenience sample of minority HIV+ adults living in a northeastern urban city. As such our results cannot be generalized beyond this study population. A larger study with more diversified clinic settings might provide a broader perspective of barriers and facilitators to clinical trial participation not captured in this study. In addition, since the survey was orally administered, participants could have found the study setting intimidating. This may have affected the way participants responded to the materials or caused them to feel they needed to respond in a certain manner. However, because this is a large clinic that engages in a number of socio-behavioral research studies, we do not believe this affected participation in this study.

# Conclusion

Addressing the inequity in HIV clinical trials is not just ethically important but medically important, since representation of minorities in clinical trials promises advances in diagnosis, treatment, and prevention specific to these underserved communities (Gwadz et al., 2014). The perceptual mapping analysis used in this study indicates that evaluating minority HIV+ patients as a group would yield a message strategy that is not well-tailored to men or women and could therefore dilute the power of the intervention developed. Rather, the novel approach used in this study shows that perceived barriers and facilitators are gender-specific and therefore suggests more targeted message strategies are required to motivate participation in clinical research.

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No potential conflict of interest was reported by the authors.

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