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An Examination of Community Members', Researchers' and Health Professionals' Perceptions of Barriers to Minority Participation in Medical Research: An Application of Concept Mapping

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Objective. *Some of the most promising medical treatments are currently being developed and used in clinical trials. In the US, rates of chronic disease among racial/ethnic minorities are disproportionately high. Unfortunately, the rates of minority participation in medical research are low, and the reasons are unclear. This study seeks to contribute to the body of knowledge that is currently available relating to the specific barriers to racial/ethnic minority participation in medical research through the conceptualization and measurement of these barriers.*

Design. *Study participants included a convenience sample obtained from the National Cancer Institute's Special Populations Networks, and consisted of practitioners, researchers and community members who specialize in research related to the treatment and prevention of cancer. A structured form of concept mapping (Trochim 1989) was the methodology used in this study. The concept mapping process has three specific phases: (1) project planning—development of project focus statements and sample selection (2) idea generation and structuring and (3) analysis and interpretation. This method is analogous to a more formalized and structured focus group approach, and involved the*

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gathering of 149 ideas and the sorting of 70 statements. Comparisons across participant demographics were conducted and are presented in the form of pattern matches.

Results. *The findings of this study suggest that there are two specific areas where barriers to minority participation may be addressed. The first area is the research system, specifically, the manner in which research studies are designed and implemented, including referral, recruitment and retention of racial/ethnic minorities. The data suggest that recruitment and retention will be aided by addressing patient concerns regarding the research process, and assuaging fears about clinical trials. The second area pertains to minority perceptions of the research process based on history and personal experiences.*

Conclusion. *There appears to be a difference in the barriers to participation as defined by community members themselves, and health professionals' perceptions of these barriers. Increased inclusion of minorities in the design, management, and implementation of medical research studies would help mitigate negative perceptions of the research process, and serve to increase participation among racial/ethnic minorities.*

Keywords: Minority Populations; Medical Research; Concept Mapping; Recruitment; Clinical Trials

Introduction

In the US, rates of chronic disease among racial/ethnic minorities (African American/ Blacks, Asians, Native Hawaiian/Pacific Islanders, American Indian/Alaska Natives, Hispanic/Latinos; US Office of Management and Budget 1997) are disproportionately high. Data demonstrate that racial and ethnic minorities are represented in cancer statistics at rates higher than their representation in the general population (Centers for Disease Control 2005). In 2000, the US Department of Health and Human Services (USDHHS) issued Healthy People 2010, a set of 10-year health objectives for the nation. The dual goals of Healthy People 2010 were (1) to increase quality and quantity of life; and (2) to eliminate health disparities (USDHHS 2000). Clinical trial participation is viewed as an important tool to address health disparities.

Some of the most promising cancer treatments are currently being developed and used in clinical trials. Given racial and ethnic variation in cancer incidence and mortality rates, it would be expected that the development and testing of new cancer therapies would include individuals from diverse racial and ethnic groups, yet this does not seem to be the case. Overall participation in cancer clinical trials appears to include only approximately 3% of the eligible population (Roberson 1994), and it has been noted that White, married, middle class, highly educated males are the group most often represented in clinical trials (Giuliano *et al.* 2000).

In an effort to increase low rates of minority participation in medical research, the National Institutes of Health (NIH) issued the NIH Revitalization Act of 1993, which among other things, requires the inclusion of women and minorities in all

NIH-funded clinical trials (NIH 1994). All applications for funding must also include any prior experience of recruiting and retaining the target population, or collaborations with investigators who have this experience. If, in the case of competitive applications, the recruitment and retention plans are inadequate, then the application will not receive funding until adequate retention and recruitment plans can be developed. As a result of these guidelines, researchers seeking NIH funding must increase their efforts to address the barriers to minority participation in clinical trials, and earnestly seek to recruit and retain racial/ethnic minorities in their research studies. Yet even with the establishment of the NIH guidelines, rates of participation in cancer clinical trials continue to be low for racial/ethnic minorities overall (Murthy *et al.* 2004; Du *et al.* 2006). Rates of clinical trial participation among African Americans specifically have been found to have declined in recent years (Murthy *et al.* 2004). In addition to continued low rates of participation, and despite NIH reporting guidelines, a review of published literature found that clinical trial participation rates are not being described according to race/ethnicity (Swanson & Bailar 2002; Corbie-Smith *et al.* 2003).

There is a growing literature about the factors responsible for low rates of minority participation in medical research. Studies examining perceptions of medical research among racial/ethnic minorities have found that minorities, in general, seem to have more negative feelings towards research than their White counterparts (Mouton *et al.* 1997; Kressin *et al.* 2000; Shavers *et al.* 2002). In contrast to this is the fact that some data indicate that the participation of African Americans, Asians, Hispanics, Native Hawaiians/Pacific Islanders, and American Indians/Alaska Natives in cancer treatment trials appears to be proportionate to their representation in the population (Goldberg & Goldberg 1996; Tejeda *et al.*, 1996). Furthermore, data suggest that the consent rates of racial/ethnic minorities in intervention studies are not statistically different from that of non-Hispanic Whites (Wendler *et al.* 2006), but these rates of participation are not seen in cancer control and prevention trials. Prevention trials refer to medical studies that evaluate preventive measures, and include screening and early detection studies. Response rates in prevention trials have been found to be significantly lower for racial/ethnic minority populations than for Whites (Giuliano *et al.* 2000). Data also suggest that African Americans and Hispanics are distrustful of prevention trials, and consider them a lower priority than treatment trials (Holcombe *et al.* 1998). It is possible that recruitment to treatment trials is approached more systematically than recruitment to prevention trials, thus resulting in lower rates of participation.

It is difficult to assess the reasons for low minority participation in medical research, since there is currently no centralized registry of all clinical trial data, and much of the literature does not disclose the racial/ethnic composition of study participants or of individuals who were ineligible to participate, or were invited to participate but declined (Weijer & Crouch 1999; Corbie-Smith *et al.* 2003). If such information was available, it would be useful to distinguish between racial/ethnic minorities who decline to participate, and those who are ineligible to participate. Currently, it is unclear whether or not minorities are less willing to take part in medical research or if eligibility requirements serve to reduce rates of participation, as some studies indicate (Adams-Campbell *et al.* 2004). Indeed, recent evidence suggests that despite lower participation rates, racial/ethnic minorities are as willing as Whites to participate in health research (Wendler *et al.* 2006).

Determining the reasons for low rates of participation is important for several reasons. First, involvement in medical research is critical for minorities, as many of the prevention strategies for diseases which impact minority communities have not been validated for use with these populations. Second, it is known that culture impacts health behavior, so it is important that researchers gain a clear understanding of how various interventions may impact these groups (Svensson 1989; Giuliano *et al.* 2000). Third, as Millon-Underwood *et al.* (1993) note, the greatest potential for reducing cancer mortality may be through participation in cancer trials. Lack of minority enrolment in medical research means that (1) researchers are not able to examine possible differences in treatment efficacy between groups, (2) researchers cannot be sure of the effectiveness of their interventions when applied to racial/ethnic minority groups, and (3) racial/ethnic minority groups are not gaining access to state of the art medical care offered by clinical trials (Giuliano *et al.* 2000).

Currently, the literature in this field primarily consists of descriptive and qualitative analyses of the reasons for low rates of racial/ethnic minority participation in medical research. There is relatively little data that attempt to measure the importance of the barriers in relation to each other. It is especially difficult to determine barriers to participation among racial/ethnic minority groups other than African Americans because there is comparatively little data available on these groups (Roberson 1994; Caban 1995). In addition, much of the literature focuses on barriers to racial/ethnic minority participation in medical research from the perspective of patients, the perceptions of researchers and health professionals have received comparably less attention (Hudson *et al.* 2005).

This study was designed to determine what impedes the participation of racial/ethnic minorities in medical research from the perspective of health professionals, researchers and lay community members through the conceptualization and measurement of these barriers, and is exploratory rather than confirmatory in nature. Specifically, the study sought to: (1) identify the barriers to participation faced by minorities across racial/ethnic subgroups as defined by various stakeholders, and (2) examine the congruence between these stakeholders with respect to their views about the importance of these barriers. The study used concept mapping, a mixed methods approach, to address the research questions of interest, as it is particularly valuable for addressing the subjective perceptual information from groups. This is particularly important because the issue of racial/ethnic minority participation in medical research is complex and does not appear to have one causal pathway.

Methods

Overview

Concept mapping utilizes a mixed-methods participatory approach that uses structured conceptualization to allow stakeholders to list barriers in their own language, organize them as they see fit, and integrates the results using multivariate analyses in a way that allows comparison across groups (Trochim 1989; Trochim & Kane 2005). This methodology is well suited to meet the study objectives because it is designed to measure complex constructs; it is participatory in nature, and is an integrated mixed methods approach. The concept mapping process has three specific phases: (1) project planning—development of project focus statements and sample selection; (2) idea generation and structuring; and (3) analysis and interpretation. The procedure for concept mapping is described in detail by Trochim (1989). Concept mapping typically requires participants to brainstorm a large set of statements relevant to the topic of interest, individually sort these statements into piles of similar ones, and rate each statement on one or more scales of interest (Weller & Romney 1988; Coxon 1999). Concept mapping integrates these group processes with several multivariate statistical analyses (e.g. multidimensional scaling and hierarchical cluster analysis), and involves the participants in a group interpretation of the conceptual maps (Trochim 1989). The maps and products that result provide a visual representation of the perceptions and ideas of the groups, how they are organized and their relative importance.

Subjects

In March 1999, the then titled NCI Office of Special Populations Research (OSPR) issued a request for funding applications (RFA) to develop and implement a variety of community-based cancer control and prevention activities, titled Special Population Networks for Cancer Control (SPNs).[1] Applicants with histories of community involvement were particularly encouraged to participate. The SPNs are a national network of organizations consisting of practitioners, researchers and community members who specialize in research relating to the treatment and prevention of cancer. The networks were created to increase cancer awareness, understanding of cancer research, and to foster minority participation in clinical trials through the development of collaborations with academic, community, and medical institutions (Center to Reduce Cancer Health Disparities 2006). One of the specific goals of the SPNs was the ‘Establishing of academic and/or clinical partnerships between the grantee and cooperating institutions to support enhanced education about clinical trials and promote participation of minority scientists in research’ (Chu & Jackson 2004). All networks had steering committees that directed the activities of the network. In addition, some networks also had community advisory boards, and regional advisory boards who assisted in the development of the network’s research agenda. The stated goals of the SPNs made them a particularly useful group with which to conduct this study. Of the 18 SPNs, only one network did not specifically target racial/ethnic minorities. Of the 17 remaining networks, 14 agreed to participate in the study. Each of the participating networks represents one of the racial/ethnic minority groups recognized by the Office of Management and Budget (OMB 1997). Across these 14 networks, a convenience sample consisting of steering committee members ($n = 20$), community advisory board members ($n = 16$), regional advisory board members ($n = 6$), and lay community members ($n = 5$) was utilized. In addition, one respondent who did not identify their network affiliation was included in the sample. These participants can be considered key informants for their respective networks. It is important to recognize that the sampling model used in this study is more akin to focus group design than to sample survey methodology. In this sense, concept mapping can be viewed as a mixed methods sophisticated form of focus group with participatory analysis and participation built in.

Participants were given the option to participate by utilizing a web-based program,[2] or by completing and submitting, by mail, manual brainstorming, sorting and rating packets. Participants to the study were recruited via email and via a presentation at a national SPN conference, therefore it is not possible to calculate the response rate as it is not possible to determine the exact number of individuals who were recruited from each network.

Procedures

Brainstorming

The brainstorming process took place over a six-week period. Participants were invited to submit their responses by logging onto a private web page, or by completing a manual brainstorming form (Osborn 1948). The brainstormed statements were generated in response to the focus prompt: 'One specific barrier to racial/ethnic minority participation in medical research is'. This process resulted in the generation of 149 statements. Twenty-nine statements were received via traditional mail, seven statements were received via email, and 112 statements were posted to the project website. The 149 statements were edited for clarity, and duplicate statements were eliminated. The original 149 statements were consolidated to the final set of 70 statements.

Sorting and rating

Participants were asked to log on to another web page to complete the sorting and rating tasks. Again, manual sorting and rating packets were provided for individuals who preferred to participate in this manner. Both groups were given instructions to group the statements in the way that made the most sense to them. The only restrictions for this sorting process were that: (a) each statement could not be placed in its own pile (thereby producing N piles); (b) there could not be one pile comprised of all statements; or (c) a 'miscellaneous' pile (all items which do not seem to fit into other piles must be put in its own separate pile) (Coxon 1999).

For the rating task, the statements were listed in questionnaire form, and each participant was asked to rate the statements with these instructions: 'Please rate the following statements according to how important each substantive issue is in preventing the members of the racial/ethnic minority population you work with from participating in medical research, where 1 = relatively unimportant (when compared with the other statements); 2 = somewhat important; 3 = moderately important; 4 = very important, and 5 = extremely important'. The importance rating data are averaged across individual to provide an average relative importance rating for each statement. Table 2 provides the top three rated statements in each cluster. Statement ratings are then averaged to provide an average cluster rating.

All participants were invited to take part in the brainstorming and in the rating portion of the study. To minimize the burden (e.g. amount of time) required of each participant, a subgroup was selected to conduct the more time intensive sorting task. It was important that the sorters represent the characteristics of the overall study sample, therefore sorters were selected that represented each network as well as the steering committee and community advisory board of each network (lay community members were used if the network did not have a formal community advisory board in place). To reduce the possibility of introducing bias, a list of each network's steering committee members and lay/community advisory board members was numbered, and a Table of Random Numbers was used to select a core group consisting of one steering committee member and one community member from each network. The core group conducted the brainstorming, sorting, and rating of statements. The extended group, which included all other participants, participated in all phases of the study except the sorting. Thirty-four respondents completed the rating task only, 14 participants performed the sorting task, and 13 participants performed both sorting and rating.

Data analyses and generation of the maps

The concept mapping analysis begins with a construction of the sort information of an $N \times N$ binary, symmetric matrix of similarities, X_{ij}. For any two items i and j, a 1 was placed in X_{ij} if the two statements were placed in the same pile by the participant, if not a 0 was entered (Weller & Romney 1988). The individual X_{ij} matrices were summed and a total $N \times N$ similarity matrix was obtained. Non-metric multidimensional scaling (MDS) with a two-dimensional solution was used to analyze the total similarity matrix T_{ij} (Kruskal & Wish 1978; Davison 1983). Concept mapping utilizes the decompositional approach most commonly associated with MDS, and, thus, only requires respondents to assess the similarities between the statements, and does not require an analysis or detailing of these similarities (Hair *et al.* 1998). The analysis yielded a two-dimensional (x,y) configuration of the set of statements based on the criterion that statements piled together most often are

Table 1 Statement List by Cluster

Cluster: Recruitment Issues

35) minorities are often unaware of the medical research that is being conducted
23) lack of cultural sensitivity in communications and approaches
1) lack of resources to treat uninsured participants if found to be sick
43) eligibility criteria that are often exclusive of minorities (e.g. STAR)
5) lack of strong relationship with physician
42) difficulty with research concepts such as randomization and probability
36) lack of compliance with testing and follow-up visits
7) lack of encouragement/support by community leaders

Cluster: Patient Concerns re: Research Process
65) lack of awareness of benefits to participation
62) sense that subjects only give and get nothing in return
14) concerns about signing informed consent
53) lack of time
Cluster: Fears re: Clinical Trials
48) fear of being a guinea pig
34) lack of access
17) fear of the unknown
55) socio-economic considerations (i.e. parking, transportation, childcare)
40) fear that privacy will be invaded
45) fear of adverse side effects
64) viewing clinical trials as a last ditch effort for treatment
2) concerns that their care will be different
30) lack of family support
11) reticence to self-report psychosocial information that may be viewed in a negative light by others
33) fear of being refused or told in uncertain terms that you are not a good candidate for medical research

Cluster: Psychosocial/Socioeconomic Issues
13) more pressing survival problems
4) cultural beliefs
20) religious beliefs
37) fear that research is government related and will affect other areas
56) hunger problems
51) substance abuse
58) mental illness
68) homelessness

Cluster: History/Past Experiences
54) previous negative experience, particularly around getting medical care, at large academic medical centers
49) literacy issues
3) mistrust due to discriminatory social/historical/legal experiences (e.g. Tuskegee)
9) among the medically underserved/uninsured, involvement in research is viewed in a negative light
32) fatalistic view that the trajectory of disease cannot be changed by research
22) intimidation by the bureaucracy of the health care system
59) lack of concern
44) research questions seem trivial and/or unimportant

Cluster: Resources/Financial Considerations
6) lack of health coverage to reimburse medical interventions in protocol
31) presentation at late stage for many minority patients

Table 1 (*Continued*)

28) dismal past record of translating research into practice particularly among minority and underserved populations
26) not enough health education
46) disparate treatment by health professionals and staff
21) additional cost associated with trying to utilize minorities in a study
12) no accountability by researchers if something goes wrong
61) research has not been universally approved in the African American community
15) no data management available at sites that treat minority patients

Cluster: Physician/Researcher Bias
63) physicians treating underserved populations lack time and staff to participate in medical research
69) relationship between medical institution and community
29) lack of follow-up
27) lack of support by community physicians because they fear losing their patients
60) negative attitudes by administrators in public institutions
67) not thinking of minorities as humans
8) prejudice by research faculty against enrolling minority patients
38) not wanting to 'give away' experiences and knowledge

Cluster: Research System Issues
24) lack of adequate physician education in providing patient's information about clinical trials
70) lack of incentive for overworked physicians caring for minority patients
39) inappropriate outreach methods
57) researcher/practitioner stereotypes about compliance difficulties among minority participants
16) lack of differentiation between preventive and treatment studies

Cluster: Issues in Research Method, Design and Management
66) not linking research on what minority communities 'need' with what they 'want'
25) lack of minorities as Principal Investigators and in leadership positions of research teams
41) poor recruitment to trials where disease burden is highest among minorities
50) lack of understanding the need of minority participation in research
19) lack of bilingual/bicultural researchers in the design, recruitment and implementation processes
52) failure to adapt principles of community-based participatory research in medical research
47) researchers lack of desire to include them because they constitute a small percentage of the population
18) lack of political clout to make including minorities in research a priority
10) lack of medical school support for research in public hospitals with minority patients

located more proximately in two-dimensional space, and those piled together less frequently were located further apart. Therefore, the maps produced from this unstructured sort data represent all the brainstormed statements where statements that are more similar are located closer together. Each numbered point on the map represents the statement of the same number. The x-y MDS co-ordinates are input into hierarchical cluster analysis, thus effectively partitioning the MDS space into non-overlapping regions (Everitt 1980). For the cluster analysis, Ward's algorithm, an agglomerative method, was used. The method begins with each statement representing an individual cluster, and combines clusters until all statements make up one cluster. A range of cluster solutions were systematically reviewed and a nine-cluster solution was selected as most appropriate. Participants in the sorting phase of the project created a name for each of their sort piles. The concept system generated a list of potential cluster titles based on the names provided by the participants in the

Table 2 Three Highest-rated Statements in Each Cluster

Cluster: Recruitment Issues	
35) minorities are often unaware of the medical research that is being conducted	4.50
23) lack of cultural sensitivity in communications and approaches	4.25
1) lack of resources to treat uninsured participants if found to be sick	4.23
Average cluster rating:	3.85
Cluster: Patient Concerns About Research Process	
65) lack of awareness of benefits to participation	4.33
62) sense that subjects only give and get nothing in return	3.88
14) concerns about signing informed consent	3.73
Average cluster rating:	3.88
Cluster: Fears About Clinical Trials	
48) fear of being a guinea pig	4.36
34) lack of access	4.21
17) fear of the unknown	4.17
Average cluster rating:	3.81
Cluster: Psychosocial/Socioeconomic Issues	
13) more pressing survival problems	4.40
4) cultural beliefs	3.94
20) religious beliefs	3.52
Average cluster rating:	3.30
Cluster: History/Past Experiences	
54) previous negative experience, particularly around getting medical care, at large academic medical centers	3.88
49) literacy issues	3.81
3) mistrust due to discriminatory social/historical/legal experiences (e.g. Tuskegee)	3.75
Average cluster rating:	3.58
Cluster: Resources/Financial Considerations	
6) lack of health coverage to reimburse medical interventions in protocol	4.04
31) presentation at late stage for many minority patients	3.98
28) dismal past record of translating research into practice particularly among minority and underserved populations	3.96
Average cluster rating:	3.68
Cluster: Physician/Researcher Bias	
63) physicians treating underserved populations lack time and staff to participate in medical research	3.96
69) relationship between medical institution and community	3.96
29) lack of follow-up	3.94
Average cluster rating:	3.52
Cluster: Research System Issues	
24) lack of adequate physician education in providing patient's information about clinical trials	4.21
70) lack of incentive for overworked physicians caring for minority patients	3.92
39) inappropriate outreach methods	3.90
Average cluster rating:	3.82
Cluster: Issues in Research Method, Design and Management	
66) not linking research on what minority communities 'need' with what they 'want'	4.27
25) lack of minorities as Principal Investigators and in leadership positions of research teams	4.21
41) poor recruitment to trials where disease burden is highest among minorities	4.21
Average cluster rating:	3.89

sorting process. The most appropriate cluster titles for the final nine clusters were selected from this generated list of potential cluster names.

Pattern matching

Comparison of ratings data across groups of respondents are accomplished through what is termed 'pattern matching' (Trochim 1985). Pattern matching graphs are used to visually examine the degree to which two groups are in agreement in their cluster ratings. Respondents answered seven demographic questions, one of which asked them to indicate their affiliation with their SPN (steering committee ($n=20$), regional advisory board ($n=6$), community advisory board ($n=16$), lay community member ($n=5$)). Another question asked them to indicate their occupation (academician ($n=6$), clinical practitioner ($n=3$), outreach worker ($n=7$), researcher ($n=3$), other health professional ($n=19$), other occupation ($n=9$)). Researchers and practitioners are commonly involved in the development of clinical trials, and many clinicians are also researchers, therefore for the purpose of comparisons with other groups, these two occupations were combined.

Pattern matches have two vertical axes, one for each group being compared. Each cluster from the map is represented by its own line on the graph and is listed vertically as a label. The labels, which are ordered from top to bottom, depict the rank ordering of the importance of the cluster. Pattern matching provides a Pearson Product-Movement correlation coefficient (r), which represents the degree of statistical correspondence between the data from the two groups. The r coefficient can range in value from 1 to -1. An r of 1 represents a perfect correlation. This would be depicted by the clusters being listed in the same order on both axis with horizontal lines drawn from each cluster to its corresponding cluster on the opposite axis. An r of 0 represents a poor correlation, and an r of -1 represents a perfectly inversed relationship. All of the pattern matches presented here are absolute, meaning that the actual minimum and maximum average ratings for each group are used to determine the axis high and low values.

Results

The usual statistic used to indicate the goodness of fit of the two dimensional configuration to the original similarity matrix is called the stress value (Kruskal & Wish 1978; Davison 1983). In this analysis, the stress value was 0.321. In a meta-analysis across numerous concept mapping projects, a mean stress value of 0.285 (SD $=0.04$) was calculated; the stress value of this project falls within 1 SD of that norm (Trochim 1993).

Figure 1 shows the two-dimensional solution with the nine-cluster arrangement. Each of the points on the map represents one of the brainstormed statements. Table 1 lists the statements by cluster. The map appears to be partitioned into two distinct

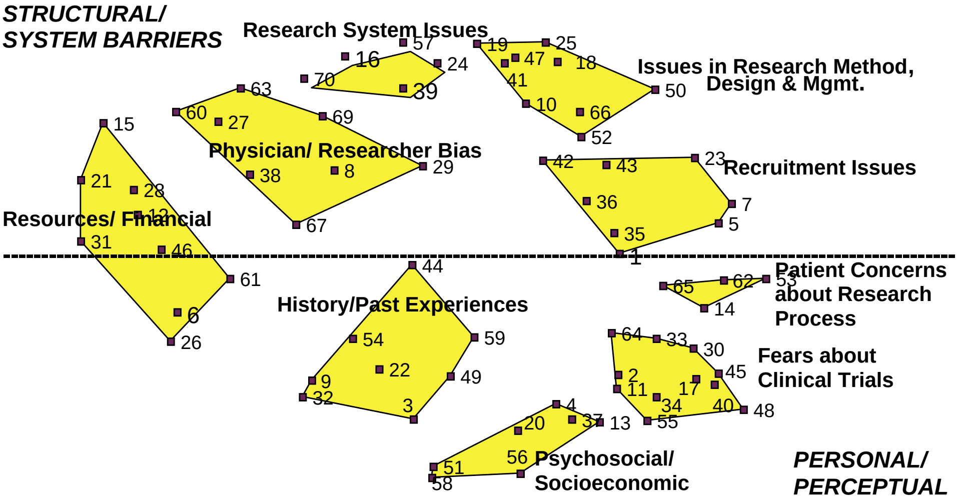


Figure 1 Final nine cluster solution.

parts. The top half of the map contains barriers that relate to the systemic or structural impediments to minority participation in medical research, while the lower half of the map contains barriers regarding the personal experiences and perceptions of medical research among racial/ethnic minority community members that impede participation in medical research. Specifically, the top of the map contains the clusters: Resources/Financial Considerations, Physician/Researcher Bias, Research System Issues, Issues in Research Method, Design & Management, and Recruitment Issues. These clusters contain statements that reflect difficulties within the research system, such as 'lack of cultural sensitivity in community approaches', 'not linking research with community needs', and 'physicians treating underserved populations lack time and staff to participate in medical research'. Similarly, the lower portion of the map contains the clusters History/Past Experiences, Psychosocial/Socioeconomic Issues, Fears about Clinical Trials, Patient Concerns about Research Process, which describe those statements that refer to the negative views many racial/ethnic minorities have toward medical research and the experiences that contribute to these perspectives (i.e. past negative experiences).

Figure 2 depicts the level of agreement between the outreach workers and the clinical practitioners and researchers. The clinical practitioners and researchers rated the statements in the cluster 'Patient concerns about Research Process' highest, whereas the outreach workers rated the cluster 'Issues in Research Method, Design and Management' highest. In addition, the clinicians and researchers rated 'History/Past Experiences' lowest, where the outreach workers rated the cluster 'Psychosocial/Socioeconomic Issues' lowest. The low level of correlation between the ratings data of these two groups is reflected in the r coefficient ($r = 0.29$). Both groups rated statements referring directly to the perspectives, opinions and experiences of racial/

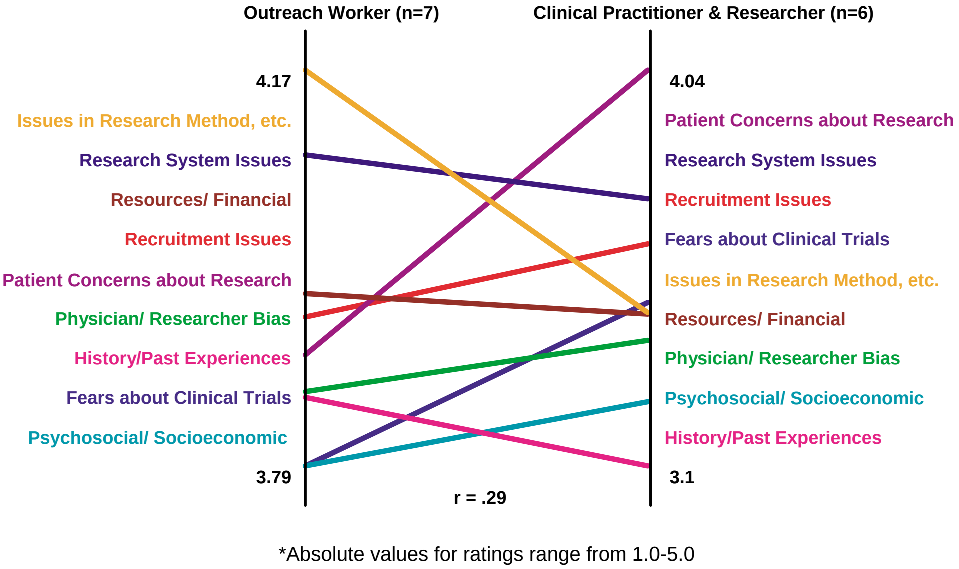
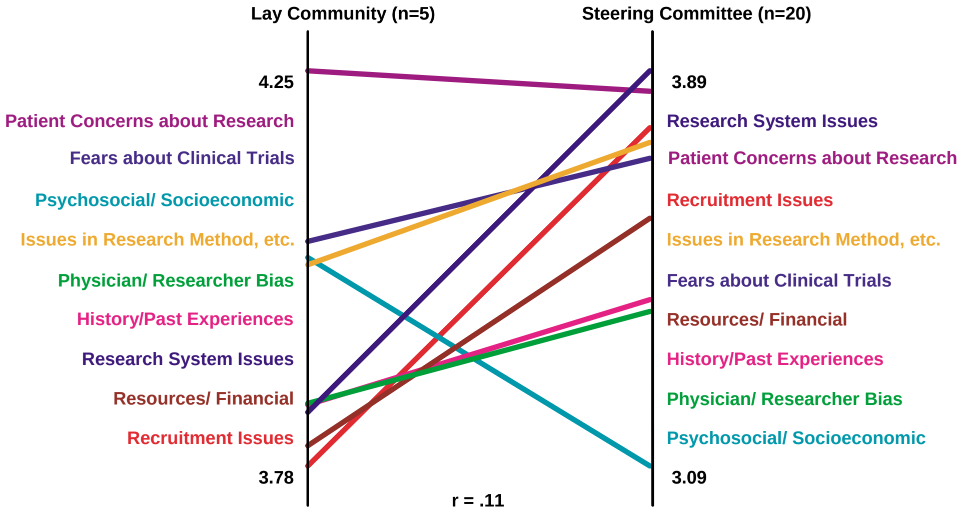


Figure 2 Pattern match: relative importance ratings of outreach workers and clinical practitioners and researchers. *Absolute values for ratings range from 1.0 to 5.0.

ethnic minorities, those clusters located in the lower portion of the map, lowest. The outreach workers rated all of the clusters pertaining to the entire research process highest, while the clinicians and researchers, on the other hand, rated the cluster pertaining to patient perceptions much higher. This disconnect suggests that the outreach workers consider problems with the research process to be of highest importance, while researchers and clinical practitioners consider the perspective or feelings of racial ethnic minorities to be considerably more important with respect to what prohibits racial/ethnic minority participation in medical research.

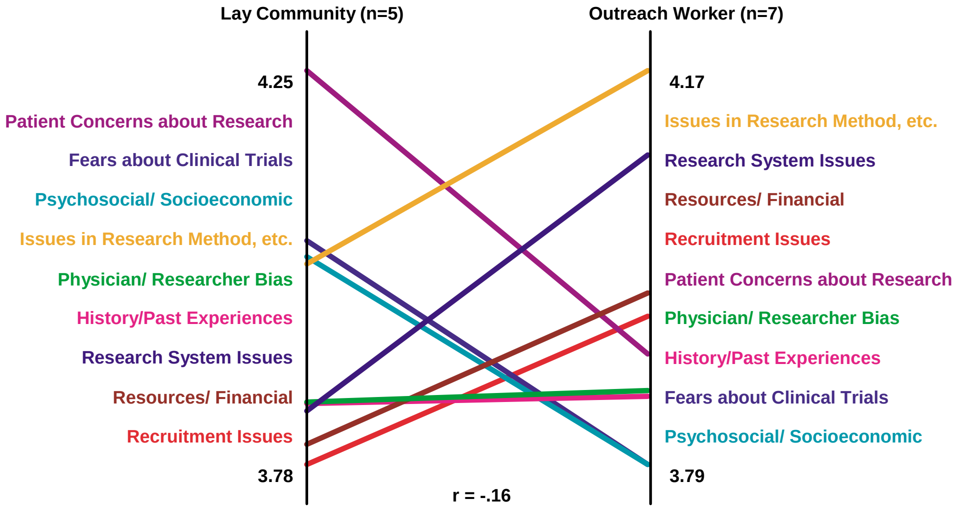
Of particular interest in this study was the level of agreement between lay community members and the steering committees of these networks. The steering committee represents the Principal Investigators and network advisors responsible for designing community interventions and determining the network's research agenda. Figure 3 demonstrates the apparent lack of agreement between the steering committee members and lay community members, as evidenced by the relatively low r coefficient ($r = 0.11$).

An examination of the rating of statements by lay community members and outreach workers is also quite telling. While it is assumed that these two groups would be more in sync with regard to the barriers that inhibit minority participation in medical research, the data suggest otherwise. Figure 4 demonstrates the level of agreement between these groups as being considerably low ($r = -0.16$), Items relating to the research system are rated highest by researchers, clinicians, health professionals and outreach workers. This is in contrast to the lay members who rated



*Absolute values for ratings range from 1.0-5.0

Figure 3 Pattern match: relative importance ratings of lay community members and steering committee members. *Absolute values for ratings range from 1.0 to 5.0.



*Absolute values for ratings range from 1.0-5.0

Figure 4 Pattern match: relative importance ratings of lay community members and outreach workers. *Absolute values for ratings range from 1.0 to 5.0.

concerns regarding the research process, fears about clinical trials, and socioeconomic and psychosocial issues highest.

Discussion

The statement set generated through the brainstorming process provides a thorough description of the barriers/issues/impediments to minority participation in medical research. The ratings of these statements allowed for an examination of the relative importance of the barriers listed in the conceptualization process. For example, the statements ‘Homeless’ (No. 68), ‘Mental Illness’ (No. 58), ‘Substance Abuse’ (No. 51), and ‘Hunger Problems’ (No. 56) were, on average, rated the lowest; however, statement No. 13 ‘More Pressing Survival Issues’ (which is located in the same cluster) was the second highest rated statement. It would seem that ‘survival issues’ do, in fact, relate specifically to those four statements despite the vast difference in ratings. It is, therefore, prudent to consider the average ratings assigned to clusters as well as to individual statements, with an understanding that all statements have some level of value to at least some participants.

Many of the statements represented in the final statement set have been mentioned in the literature with regard to specific racial/ethnic groups or with regard to specific types of research. All of the prevalent themes found in the literature, such as fear, mistrust, lack of recruitment, socioeconomic issues and lack of referral, were also listed in the brainstormed statement set. Consequently, it appears reasonable that the statement set accurately represents the problem of low minority participation in medical research. The structuring of the statements allowed for the grouping of these statements based on similarity. These groupings or clusters provide a better understanding of the relationship of these barriers to each other.

A major conclusion of this study is that there are two overarching areas where barriers to minority participation might be addressed. The first area is the research system, and the manner in which research studies are designed and implemented, including the recruitment and retention of racial/ethnic minorities. The second area pertains to minority perceptions of the research process.

These findings reiterate the commonly reported theme that the research community must improve its relationship with racial/ethnic minority communities if the rates of participation are to improve among these groups. While adjustments in the research process are certainly needed (i.e. increased emphasis on recruitment of minorities to studies and increased support for researchers in hospitals with minority patients), the data seem to suggest that improved relations between racial/ethnic minority communities and the medical community might be most effective. The most detrimental barrier, as defined by community members in this study, appears to be the concern of minorities about the research process, suggesting that increased recruitment and improved study design, though a part of the solution, may not be effective until the research community begins to build and/or improve upon their relationships with the communities they wish to serve. Developing relationships with minority communities should help to alter negative perceptions and provide researchers with opportunities to assuage fears regarding the research process in general and clinical trials in particular.

A second conclusion of this study is that there appears to be a difference in barriers to racial/ethnic minority participation in medical research as perceived by the research community and by lay community members. In an effort to examine levels of agreement between respondents, pattern matches between each of the networks are presented. While it is possible that these differences may be due to chance given the small sample size of the study in general, and of certain subgroups in particular, the comparisons provide useful insight into the perspectives of respondents based on their occupation and network affiliation. It is not surprising that Issues in Research Method, Design and Management is the highest rated cluster considering the majority of participants in this study work in the health profession and participate in the design and conduct of research studies ($n=38$). The average ratings conducted by steering committee members and lay community members, as shown in Figure 3, imply that there is a difference in the barriers to participation, as defined by community members themselves and health professionals' perceptions of these barriers. Both groups identified their own environment/setting as the place where targeted interventions would be most useful. One explanation for this finding is that respondents are most knowledgeable about the factors within their own communities (racial/ethnic, research, occupation, etc.) that need to be addressed, and, therefore, consider interventions in these areas as the most important to increasing rates of minority participation in medical research. As a result, it is possible that strategies to increase minority participation in medical research are focusing on the elimination of barriers that are considered by health professionals to be important, but are not addressing the barriers considered by many racial/ethnic minorities to be of crucial importance.

Limitations

The focus statement for this project asked participants to consider the barriers to medical research. While prevention trials and treatment trials are sometimes considered quite different, for the purpose of this research project, the aim was to explore the barriers that serve to inhibit minority participation in both prevention and treatment trials. To determine if, in fact, participants considered the barriers to participation in treatment trials to be different than those for prevention trials, this question was included in the ratings portion of the instrument. A small subsample of the participants ($n=9$) responded to this question, with 67% of participants responding 'yes' and 33% responding 'no'. Additional research with a larger sample to determine if the barriers to participation in treatment trials differ from those in prevention trials would be beneficial.

The methods used in this study are more similar to focus group methodology than to survey research, thus the limitations of the study are similar to those of focus groups. Convenience sampling was used to generate a small group of key informants, and it is possible that the 14 networks that opted to participate in this study differed from the three networks that did not participate. However, the sample obtained appears to be representative of the Special Population Networks as a whole. The study sample includes at least one network for each racial/ethnic minority group targeted by the SPNs and varies with regard to network size, organizational structure and experience promoting cancer awareness. The respondents also vary with regard to their occupation and network affiliation. While the results suggest differences between lay members and other network members, it is difficult to accurately assess the statistical significance of the apparent differences between these groups given the small sample size, therefore the conclusions drawn from this study should be interpreted with caution. Given that our intention was not hypothesis testing, but rather to gain a sense of the perspectives of various stakeholders, this limitation does not significantly impact the study findings.

Finally, concept mapping is fairly structured and, although advantageous, also poses some limitations. The methodology limits the conceptual domain through its use of a focus statement, provides limited opportunity to examine why statements were included, and there is little information around the statements. In this instance, distance also precluded the assemblance of participants for an interpretation session. One way to address such methodological limitations is to replicate the questions asked in this study with in-depth interviewing.

Conclusion

The main purpose of this study was not hypothesis testing, but rather to generate fresh ideas about a complex topic. These findings help provide a framework for formulating strategies to tackle the barriers to minority participation in medical research that are perhaps not currently being addressed (e.g. increasing incentives for physicians that provide care to minority patients, and seeking to build relationships between the research community and minority communities apart from recruitment activities). As a result of this study, three specific recommendations for increasing rates of minority participation in medical research emerge: (1) improve relationships between the medical research community and the communities they serve; (2) increase the levels and improve the nature of community involvement in the research process; and (3) efforts must be multi-dimensional, addressing both community interrelations and research process issues.

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Notes

[1] The Special Populations Networks ended their five-year performance period in March 2005. The program has been reorganized and renamed the Community Networks to Reduce Cancer Health Disparities.

[2] The Concept System and Concept System Global software are licensed through Concept Systems Incorporated. Ithaca, New York (http://www.conceptsystems.com).

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