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Patients' and Community Leaders' Perceptions Regarding Conducting Health Behavior Research in a Diverse, Urban Clinic Specializing in Rheumatic Diseases

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Abstract

Background—Disparities in the incidence, prevalence, severity, care, and outcomes for rheumatic diseases exist among racial and ethnic groups compared with White Americans.

Objective—This paper describes a community-based participatory research (CBPR) approach engaging researchers, community leaders, and patients in purposeful dialogues related to the implementation of health behavior research in an urban rheumatic disease clinic.

Methods—Seven focused discussions were led in either English or Spanish. Discussions were audiotaped and transcribed verbatim.

Results—Six community leaders and nine patients participated in the seven scheduled focused discussions. Transcripts uncovered five major themes that assisted with study design: trust, patient–provider relationship, study implementation suggestions, decreased functional capacity, and access to healthcare.

Conclusions—Engaging community partners and patients in informal and formal discussions from early phases of research design through implementation, followed by systematic application of these insights, may serve to accelerate the potential for translation from findings into improved clinical practice and optimal outcomes.

Keywords

Community health partnerships; community-based participatory research; community health research; health disparities; rheumatic diseases; musculoskeletal diseases; urban population

Rheumatic diseases are among the most common health problems in the United States.^{1,2} Marked differences in the incidence, prevalence, severity, processes of care, and outcomes in a number of rheumatic conditions exist among racial and ethnic groups as compared with White Americans. Furthermore, access to health care and treatment also differs by community. Rheumatic diseases are a diverse group of disorders, with several shared characteristics. Among the rheumatic diseases, rheumatoid arthritis and osteoarthritis are the most frequent, but serious and potentially life-threatening disorders such as systemic lupus erythematosus and scleroderma are also included. These diseases have a long course and can affect many aspects of a patient's life. Among the effects are impairments in activities of daily living, occupational and social functioning, and cognitive ability.³

Data from the Behavioral Risk Factor Surveillance System indicates that people with arthritis have significantly worse health-related quality of life and report more than twice as many unhealthy days as well as three times as many days with activity limitations than those

without arthritis.⁴ Additionally, arthritis is strongly associated with major depression, possibly through its role in creating functional limitations.⁵

Examining the racial/ethnic disparities in the prevalence and impact of arthritis is important to identifying priority populations for community-based public health interventions.⁶ To examine these differences in the prevalence and impact of arthritis, the U.S. Centers for Disease Control and Prevention (CDC) combined data from the 2002, 2003, and 2006 National Health Interview Surveys and then analyzed racial/ethnic differences. After adjusting for age, gender, and body mass index, results indicate that arthritis disproportionately affects racial/ethnic minorities. Arthritis-attributable activity limitation, arthritis-attributable work limitation, and severe joint pain were higher for non-Hispanic Blacks, Hispanics, and multiracial or other respondents with arthritis compared with non-Hispanic Whites with arthritis.⁷

In a CDC analysis of the 2002 National Health Interview Survey, where racial and ethnic differences in the prevalence and impact of arthritis were examined, when asked about joint pain (excluding the neck or back), nearly one in four (24.6%) adult respondents with arthritis reported severe joint pain during the preceding 30 days.⁸ Blacks with physician-diagnosed arthritis had a higher prevalence of severe pain attributable to arthritis, compared with Whites (34% vs. 23%). A greater proportion of Hispanics with physician-diagnosed arthritis reported severe joint pain, compared with Whites (33% versus 23%).⁸ Although important clinical and psychosocial differences have been reported between Hispanic and non-Hispanic patients with regard to rheumatoid arthritis and systemic lupus erythematosus, there are few published data on the prevalence or characteristics of other rheumatic diseases in the U.S. Hispanic population.⁹

Despite efforts to quantify the prevalence and impact of rheumatic diseases, it is difficult to disentangle the reasons for racial and ethnic disparities for specific diseases, including arthritis. The underlying causes span the range of possibilities from genetic predisposition to environmental exposures to behavioral and social etiologies.¹⁰ Attention is focused on the identification of potentially modifiable environmental and social/behavioral factors behind racial and ethnic disparities in disease manifestations and outcome.¹⁰

This paper describes a formative, qualitative study using focused discussions and a CBPR approach to engage researchers, community leaders from a health partnership program (HPP), and predominantly Hispanic and African-American patients in purposeful dialogues focused on the implementation and dissemination of health behavior research in an urban rheumatic disease clinic. Six community leaders and nine patients participated in seven different discussions. These discussions were the second phase of a three-phased study entitled Health Beliefs and Health Practices Among Minorities with Rheumatic Disease (NCT00069342). The first phase of the study involved the validation of patient reported outcomes, including an inventory to assess participants' complementary and alternative medicine (CAM) use through cognitive interviews.¹¹ Once the cognitive interview phase of the study was complete, community leaders from an HPP and patients attending an urban community clinic were recruited to participate in focused discussions to evaluate and provide recommendations for the implementation of phase three of the study which involved the quantitative evaluation of patient reported outcomes over a 6-month period.

The community leaders included in the first and last of the focused discussions were part of the HPP, a collaborative effort between the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and Washington, DC, area community organizations and representatives.¹² The HPP was initially proposed to engage community leaders in addressing health disparities in arthritis and other rheumatic diseases and

promoted community-based medical research by focusing on public health education, patient care, access to clinical investigations, and recruitment to research careers. This partnership was developed with the goal of opening a NIAMS ambulatory urban clinic site from which to launch research exploring the natural history of rheumatic diseases. Previous to the HPP, researchers had visibility through professional ties to advocacy organizations such as the National Arthritis Foundation and the National Fibromyalgia Association; however, overall community visibility and knowledge of the National Institutes of Health remained low in this urban community. HPP partners included local government agencies, schools, universities, faith-based organizations, civic and community groups, voluntary and professional organizations, and private businesses. These partners offered input on the HPP's direction and helped promote NIAMS research, training, and education resources. The NIAMS Community Health Center (CHC), located in the Unity Health Care, Inc.'s Cardozo Clinic in northwest Washington, DC, was part of the HPP and served as the platform for its research, education, and training activities. All patients at the CHC were enrolled in the Natural History of Rheumatic Diseases in Minorities study, an observational study designed to gather information on how minority populations are disproportionately affected by rheumatic diseases. This study was approved by the NIAMS Institutional Review Board. Participants provided written informed consent to participate in this study.

Before scientific and human subjects review of this study, community leaders and patients who attended the clinic were asked to provide feedback in the design of the health behavior and health beliefs study. It was during collaborative meetings that the community leaders emphasized the importance of conducting a focused discussion phase to the study to gain insight into the potential study participants and the community at large. This type of CBPR is an appropriate approach to provide researchers and clinicians with insights into the local context of a community, including information about policies or norms of conduct, as well as methodological considerations, including best practices for recruitment and retention of participants and venues in which to conduct the research.^{13,14} Community partnerships often allow researchers to gain access to communities where there are real or perceived barriers to recruitment of participants through a collaborative approach to generating new research hypotheses and culturally relevant interventions.¹⁵ These participatory strategies that develop relationships with the community being studied are often characterized as “reflexive, flexible, and iterative,” thus offering substantial opportunities to engage the communities as active contributors while simultaneously exploring local knowledge and perceptions.¹⁶ When patients are also included in this participatory process, researchers gain an “insider's” perspective into the nature of their disease as well as insight into the relevancy of variables selected for assessment and proposed outcome measures.¹⁷ Additionally, CBPR approaches such as those we will describe help rebuild and maintain trust in vulnerable communities with past history of being analyzed, stereotyped and exploited by outside groups. Since trust is vital in the success of any research projects in these communities, it is critical that all groups or partners take action to build and maintain trust.¹⁸

To better understand the community as a whole, the community leaders and the clinic patients served by a federally funded, outpatient specialty clinic for rheumatic diseases, our objectives for the formative study phase described in this paper included identifying the following from both community leaders' and patients' perspectives.

1. Potential facilitators and barriers in conducting community health research in minority patients with rheumatic diseases and to develop strategies that could facilitate a study that explored health beliefs and behaviors among minority patients with rheumatic diseases.
2. Best methods for assessing health beliefs and behaviors including CAM practices in minority patients with rheumatic diseases.

METHODS

Sample

Seven focused discussions were conducted in either English (five) or Spanish (two) with each group led by one bilingual moderator and at least one facilitator (Table 1). Six community leaders and nine patients for a total sample size of 15 participated in the seven scheduled focused discussions. Two of the seven discussions included community leaders and were held as the first and last of the seven discussions so that the investigators could explore any additional themes raised during the five patient discussions.

Data Collection

A moderator led each discussion according to a Moderator's Guide that included preselected questions and probes (Table 2). The participants were encouraged to ask questions or further develop discussions spontaneously. The questions were grouped in categories recommended by Krueger¹⁹: Opening, introductory, transition, key, and closing. The facilitator took notes, made observations, and managed the equipment (tape recorder, microphones, etc.). Moderators with similar racial and ethnic, cultural, and linguistic backgrounds as the participants were selected and trained to conduct the focused discussions. The selection of concordant moderators was essential to facilitate communication and identify cultural nuances.¹¹

Data Analysis

Focused discussions were taped and transcribed verbatim. In addition to the transcripts of the recordings, the facilitator's field notes were used to verify and provide additional contextual information supporting the transcribed data. Transcript-based analysis of the data was considered to be the most rigorous choice for analyzing the information generated during the discussions and was undertaken by two independent reviewers.²⁰ Field notes taken by the facilitator during the discussions and debriefing sessions with the moderators and facilitators were also examined. The general analysis plan included the following: identifying the major themes, considering the choice and meaning of the words, considering the context, and observing for the consistency of responses. A thematic analysis was conducted by an independent evaluator to decrease the potential for investigator bias followed by a second independent evaluator who conducted a qualitative computer analysis utilizing NVivo Version 6.0 as an additional tool to index and cross-reference the thematic analyses. The independent thematic analyses were then verified and consensus was met with the agreement of the original discussion moderator and facilitators.

RESULTS

Thematic analysis of the focused discussions yielded five major themes by community members and patients that assisted in guiding subsequent study design and implementation: trust, patient-provider relationship, study implementation suggestions, issues surrounding decreased functional capacity and access to care (Tables 3 and 4). The following section will be divided into community leaders' perspectives followed by patients' perspectives with illustrative quotes presented in Table 3 and Table 4, respectively.

Community Leaders' Perspectives (Table 3)

Trust—Community leaders provided the research team with their perspectives regarding potential trust issues related to conducting research in their community. The ethical issues surrounding the U.S. Public Health Service Tuskegee Study, such as mistrust in researchers and being used as "guinea pigs," were spontaneously raised during the discussions.

Community leaders also offered suggestions for facilitating research in their community, such as the need for researchers to be visible and involved when it came to community activities beyond research. The importance of including church leaders in the research process and the importance of using racially concordant interviewers to optimize trust was also discussed.

Trust was discussed in the context of the researchers' community involvement. Community leaders felt it was important for the research team to be visible to the community beyond the focus of the research implementation. Leaders explained that individuals need to perceive a direct benefit for themselves, their family or the community at large.

Church leaders were described by the community leaders as individuals who could be trusted in the community and should be sought after for endorsement and support of research activities within their church community. It should be noted that the HPP included leaders from faith-based organizations in the Black and Hispanic communities. Community leaders also raised the issue of researcher and subject concordance. They emphasized that trust could be enhanced through racial/ethnic and language concordance.

Patient–Provider Relationship—It has been suggested that doctors can dominate patient–provider interactions simply because they may be more knowledgeable than patients.²¹ However, *shared* decision-making in healthcare is ethical²² and has been shown to lead to better health outcomes.^{23,24}

During the discussions, community leaders conveyed their views surrounding the importance of a good patient–provider relationship when eliciting answers about patients' health behaviors, including CAM use. In addition to spending time with patients, community leaders emphasized the need for patients' impressions of their provider to be positive and friendly.

Study Implementation Suggestions—In congruence with the themes of patient–provider relationships, communication, and trust, community leaders unanimously indicated that face-to-face interviews would be the best method for data collection when compared with paper-and-pencil, web-based, or mailed surveys. Community leaders also suggested allowing participants to be accompanied by a person of their choosing to the face-to-face interviews to reduce their apprehension with the interview process. Invaluable suggestions regarding the length and complexity of the questionnaires, particularly the inventory for CAM practices, were incorporated in an effort to reduce respondent burden. The consensus among the community leaders was that the shorter and more concise the interview questionnaires, the better.

Decreased Functional Capacity—Community leaders discussed functional capacity among the rheumatic disease patients in terms of potential changes in self-care. They emphasized the need for researchers and providers to understand the contextual environment in which the patients live and their responsibilities of daily living. They also mentioned lack of knowledge of technical health definitions among patients and the need for communicating clear healthcare and behavior change options. These recommendations could include options such as “exercise,” which admittedly may sound daunting to patients with low mobility.

Access to Health Care—In referring to their healthcare experience, community leaders expressed the importance of understanding that in a growing environment of managed care, the one-size-fits-all, in-and-out physician visit does not meet patients' needs. The lack of access to rheumatology specialty clinics was also addressed as a barrier. Furthermore, the

NIAMS CHC was identified as one of the only sources for rheumatology specific care for those living in this community.

Patients' Perspectives (Table 4)

Trust—In general, trust was less of a concern for patients than it was for community leaders. Rather than bringing up historical events that could potentially reduce the trust they feel with their providers, patients who attended the NIAMS CHC spoke of trust as a core requirement upon which their relationship with their provider was built. One issue raised was the fear of switching doctors owing to discomfort with any type of change.

Patient–Provider Relationship—Overall, patients conveyed satisfaction with their current situation with regard to patient–provider relations. Patients described the importance of feeling that they were more than just “a patient” with the opportunity to take time to discuss their illness. For at least one patient, the fact that her physician knew and remembered her mother and sister was extremely important. The existence of two-way interactions with their provider made patients feel valued.

Study Implementation Suggestions—In terms of implementation strategies, patient participants reminded the research team of the importance of being cognizant of respondents' level of discomfort during the interview process based on their own pain and symptom experiences, which would make sitting for longer than a half an hour nearly impossible without additional pain and stiffness. Some patients felt that 90-minute interviews would be too much in one sitting and recommended taking short breaks. Patients also requested that interviews be held in a location that is comfortable and in general did not feel like a doctor's office.

Decreased Functional Capacity—Patients conveyed frustration with regard to limited ability to perform everyday tasks, sometimes in a cyclic pattern. One emerging theme was physical limitations causing interrupted or reduced work schedules and the financial ramifications for the patient and family. Some patients also spoke of how decreased functional capacity and decreased independence contributed to emotional suffering and depression.

Access to Health Care—Patients expressed feelings of being completely on their own in navigating what they believe is a confusing healthcare system. Some patients also identified the clinic as a sole source of guidance for their care.

LESSONS LEARNED

One of the most important lessons learned during this process of community engagement through collaborations with community leaders and patients was that of community-research “fit.” After reading the text and quotations in this paper one cannot help but notice that both community leaders and patients expressed their views of research within the context of their health status and their access to healthcare. The fact that this partnership was initiated by a team conducting clinical research at the National Institutes of Health potentially added further to issues surrounding program sustainability over time. How would the data be used? Would the community benefit directly from the research? Approaching the relationship as fragile from its inception provided the community with the time needed to evaluate the fit for the proposed research.

For this community, like many others who have experienced disparate health outcomes, and particularly when it comes to the burdens of chronic disease, engaging in research must have

more immediate applicability and translation into improved individual and community outcomes for it to be embraced as a true partnership. By meeting informally at “town hall”-type gatherings for updates followed by a more formal focused discussion process, we were able to anticipate potential barriers and facilitators for the design and implementation of the third phase of our study. When specific elements of the study did not seem to “fit,” our research team needed to be open to changing our approach. These changes toward a better fit ranged from how we structured the planned discussions (community members suggested that we include them in the first and last groups rather than including only patients) to what types of incentives would be appreciated by the research participants (they suggested jar openers and pens designed especially for individuals with functional disabilities).

Including patients in the research partnership from the design phase of the study was instrumental to our success. Whereas the community leaders helped to guide our research implementation process with suggestions from how to approach the clinic patients to best methods for collecting data, the patients also offered us a “window” into their lives as individuals with a chronic illness and what was important to them such as having access to specialty care and understanding how to navigate complex health systems.

The community leaders, particularly African-American leaders, voiced more concerns about issues of trust and research participation than the patients did. Although the community leaders expressed concerns related to the infamous Tuskegee Study, where African-American men with syphilis did not understand the purpose of the study nor did they realize that they were deprived of effective treatment for the disease when penicillin became available in the 1950s,²⁵ they also offered suggestions for increasing trust both in the community and with individual research participants. Their readiness to provide suggestions and guidance for improving trust in research seemed to imply the fact that in this context research was recognized as having potential to improve health in their community. These underlying beliefs informed the community leaders’ willingness to contribute to the success and value of the proposed research study.

In addition to their strong belief that researchers need to be consistently engaged and visible in the community, our community and patient partners raised the importance of researcher and subject concordance in the context of building trust. This view is supported by previous studies of patient-provider concordance where, if the provider was of the same ethnicity/race as the patient, the patient would be more satisfied and more likely to use healthcare services.²⁶ Blacks were more satisfied with their provider, more likely to receive preventive care, and more likely to receive necessary medical care when the provider was Black. Although Hispanic patients paired with Hispanic physicians did not differ in their physician satisfaction ratings, they were more satisfied with their overall health care, but only if there was someone Hispanic in the provider’s office.²⁶ This concept of the importance of concordance has also been described in participants’ decisions to enroll in research studies.²⁷

CONCLUSION

Engaging community partners in informal and formal discussions from the early phases of research design through implementation, followed by systematic application of these insights, may serve to accelerate the potential for translation from findings into improved clinical practice and ultimately optimal patient and community outcomes. Clinical research partnerships between communities, providers, and patients are fragile and require vigilance and ongoing communication, as well as transparency. From the earliest stages, the research team must be willing to engage the community in a collaborative research design and work toward a community research “fit.” Community leaders and patients were able to provide

valuable insight into barriers and facilitators such as improved accessibility to participation that could be adjusted to improve the “fit” and thus improve the quality and value of the information collected. Without this fit, each of the steps in the research process runs the risk of stalling and gaining momentum in the already difficult research to translation continuum is further compromised. Our research team continues to engage patient and community leaders as partners in research as we move from exploratory health behavior studies to self-care intervention studies.

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Table 1

Participant Demographics

Variable	<i>n</i>	%
Gender		
Female	9	60
Male	6	40
Age (yrs)		
Range	22–74	
Mean $\pm$ SD	51.4 $\pm$ 13.9	
Ethnicity		
Non-Hispanic	10	67
Hispanic	5	33
Race		
Black/African American	7	47
White	2	13
Asian/Pacific Islander	1	7
More than one race	1	7
Other	2	13
Unknown or not reported	2	13
Country Where Born		
United States	9	60
El Salvador	2	13
Nicaragua	2	13
Ecuador	1	7
Guyana	1	7

Table 2**Focused Discussion Questions****Issues Related to Your Illness/Condition (Health Beliefs)^a**

How do you think [specific disease] works?

How do you think you got, or why do you think you got [specific disease]?

How do you think you got, or why do you think you got [specific disease]?

Why do you think it started when it did?

What are your major concerns related to [specific disease]?

What do you fear about [specific disease]?

What are the main problems your illness has caused for you?

Explore Issues Surrounding Disease Severity^a

How severe is your illness?

Do you feel your illness will take a short duration or a long duration?

Knowing you have this condition, how do you see your health in the next 6 months?

In the next year...

In the next 5 years...

In the next ten years...

Prognosis: acute or chronic?

Issues Related to the Treatment of Your Illness^a

What kind of treatment are you receiving (home or at the clinic)?

What kind of treatment do you think you should receive?

What kinds of foods, teas, spices, or other home remedies do you use to try to make the symptoms that you experience feel better?

Have you used any others in the past?

What kinds of foods, teas, or spices do you avoid to try to make the symptoms that you experience feel better?

Do you recommend remedies you have found to be helpful to others with the same symptoms?

How have they responded to your suggestions?

Are there special dietary practices such as fasting or weight control measures you have used to control or treat [specific condition]?

Who, or where, do you go for advice or remedies for [specific illness]?

Have you ever mentioned your use of any of these remedies you use to the clinic staff?

What kind of response did you get?

Issues Regarding Human Subjects Research in Your Community

What are some of the important issues we should be aware of as we begin this study?

What do you see as potential ways to facilitate the study?

Where should patient focus groups be located?

What method do you see as most effective of gathering information (face-to-face, telephone, paper/pencil)?

Where should personal interviews take place if the recommendation is made to use face-to-face interviews?

What do you see as potential barriers to the study?

Participants' time commitment?

Length of the interview/questionnaire? What is "too long?"

Access to patients? Patients' mobility/moving?

When it comes to trust and the NIAMS Community Health Center, what do you think the views of the members of the community are?

How have members within the community experienced trust with their health care system/service providers?

How does culture influence trust?

Issues Related to Exploring Health Beliefs and Health Behaviors

What are your thoughts regarding the length of the questionnaire?

Is it possible that any of the items may be considered too personal or too offensive to answer?

Which items?

Why?

What suggestions for questionnaire improvements do you have?

Were any questions regarding health beliefs or health behaviors left out that you would like to see included?

Closing Questions: Wrap-up

If you were in charge of a research project to explore the health beliefs and health behaviors of patients with rheumatic diseases at the NIAMS Community Health Center, what would be the single most important advice you would give us before beginning the study?

Are there any other things about your experience as a member of this community and/or as a member of the NIAMS Community Health Partnership that we haven't discussed but you would like to share?

^a Denotes questions asked to only patients. All other questions were asked of both patients *and* community leaders.

Table 3

Community Leaders' Focused Discussion Themes and Illustrative Quotes

Theme	Illustrative Quotes
Trust	"One of the other things is that people have to know about what it is what you are going to do, again that goes back to the trust issue because that's a major problem in the Black community and stems from some earlier studies. The Tuskegee situation, I mean that is what people cite most often they don't want to be used as guinea pigs, they can't see benefits. They think that you are going to use them in a different way."
	"So you'll go in that community and recruit people you'll be better able to do because they know that you're there. But first of all you have to be in the community that people know who you are and what you plan to do. What are you going to do for me? What am I going to get out of this?"
	"Because Latinos think that when you mention research study, you're going to be the guinea pig, and there is no benefit for you, you're going to be harmed. So, they're afraid. As soon as you mention 'research study,' like oh-oh. No, thank you. They probably become very motivated but as soon as you mention research study, maybe if you just mention we're doing a study to help the community, to help people in that community ... I mean, if you don't do it for your community, do it for your family. I always mention do it for your family because the family is very important for us."
	"When you talk about doing research and Blacks have always been used as guinea pigs ... So they're not going to be rushing to go into any research. They do check with the ministers, the churches they go to. If they're in organizations, depending on the social standing in the community, whether they do social clubs or whatever, you need to go where they go to have people where they trust and centers and what have you. The information can go a long way when the pastor gets up into the church and says 'this is a program that I've been to'."
	"I think they need to see someone who looks like them doing a lot of the research. You know. And (someone) that can understand the language, their language, what they're meaning."
Patient-Provider Relationship	"I think it depends a lot also on the group that you're working with. With Latinos, there are many fears. Income is one of the things, but also the legal status. You never ask what's your legal status, but some people ask like how long are you living in the United States. So, they start thinking why's he asking me?"
	"Patients want someone to spend time with them."
	"I think is a lot with the providers and I think a lot is back to health care environment and people not having an opportunity to know their physician."
	"A lot of that goes back to the personalities of the people how you project yourself to people."
Study Implementation Suggestions	"Attitude is the key of any success. Attitude. Because in my country I remember that they say there is not a medicine that could cure a patient but maybe a smile for that."
	"I'd say face-to-face (referring to paper and pencil vs. face-to-face interviews). It's a trust factor, again. They get to put a face with the person who's asking the questions. They get to dispel the fact that you may be using it to do something against them later on. They can see you, and again, giving them the options of having someone there with them, of their choosing when they do it. I think the face-to-face is better. Most people are going to ignore something that comes into the house, because, as I said, invasion of people's privacy is so enormous nowadays. Nobody going to fill out something to send it back."
Decreased Functional Capacity	"[F]ocus on medicine, but how about some of the things that they can do just to help themselves. How much exercise? And a lot of people think it has to be in a treadmill or in a gym, but it can just be walking, or, you know, sometimes they get up, they got little kids around the house, they can't even get up."
Access to Healthcare	"Health care system now managed care"
	"You're in, you are out."
	"Is like a revolving door."
	"Five minutes later you're walking out nobody's talked to you. They give you some pills like you said 'come back if it doesn't work.' And the first question asked is, what kind of insurance do you have?"

Table 4

Patients' Focused Discussion Themes and Illustrative Quotes

Theme	Illustrative Quotes
Trust	<p>"Oh, yeah, that's why I am here. Because I trust you guys. I trust my health care because they have experience."</p> <p>"I trust my doctor, my medical doctor, I want someone that I'm familiar with. It's hard for me to trust people, and I need someone that I can at least trust. As for my rheumatologist, when she switched on me to another doctor when I was here, I felt really nervous and really shaky because I didn't know if she knew what she was doing about putting those shots in my knees. Let's put it this way, I hate change."</p>
Patient-Provider Relationship	<p>"You know, I'd walk in and he knew my mom and he knew my sister and ... he told me from the start, he's like, 'I want you to feel like we're married. You know? The way a couple tells each other when something's bothering them. I'm going to tell you when something's bothering me about your blood work, and you tell me if something's bothering you about being in pain or whatever.' So, that, I had like a really good relationship with him or whatever."</p> <p>"So far the experience I've had here has been very pleasant, like I said about having a doctor who's treating me as more than just a patient, like being able to have that time to explain myself. Like ... because a lot of times, you know, the doctors ask you questions, and then they have all their answers and then they get up and leave."</p> <p>"Cause if you make me feel like I'm just your patient, then I'm not going to want to open up and tell you what's usually bothering me. I mean, I'll tell you that, yeah, I'm in pain, ... I've only been here a couple of times and they already know who I am, so I like that a lot."</p>
Study Implementation Suggestions	<p>[Referring to length of the survey] "Hour and a half? Some people, it's like taking a test. Thirty minutes, take a couple of minutes break, come back, finish the rest. But sitting there an hour and a half just constantly asking questions, it gets kind of hectic sometimes for some people, even with myself."</p> <p>[Referring to where to conduct the interviews] "I think this is fine. I haven't been to this clinic that much, but at least I'm familiar with it, it's not like where I'm going to a place where I've never been before. I think another thing is, like, this room, like, this carpet, it feels, it's comfortable, I guess, instead of having it somewhere where it feels like, I don't know what the word is, but just 'sterilized?'"</p>
Decreased Functional Capacity	<p>"I remember when I was first, before I was even diagnosed, actually, my hands were first starting to get swollen. Now I look at my hands, they don't even look like my own. I can't do anything, makes the little mundane tasks like eating, everything else, just so difficult."</p> <p>"I wanted to die instead of being the way I am now. I couldn't arise from the bed, even with a helping hand. That was terrible for me. I used to be self-sufficient, active, but not at that time. If I went out, in the street, I needed to hold on to walls, and seized the chance to seat when I find a place to rest. The time went by, I now feel better."</p>
Physical Pain	<p>"My major concern is that I want to go ahead with my life painlessly. I know it's not going to be totally out of my life, but to get back to my normal movement because my left arm is important to me and I just can't get it up. It's like eight out of ten to me because I feel it. The scale like if you have ten and you say like five is half. If I can say five is half I'm not doing so bad, but when I say eight it means it's more than I can take sometimes of the pain and the lack of movement. I can do stuff with the right hand. I can go round, up, down, side, but I can't go with the left arm. If I'm where the pain is."</p> <p>"When I came here Tuesday for them to check my knees, I didn't know whether they were going to give me a shot, or not. And I was in so much pain, I mean I was slumped over in her office, in the waiting room. It hurt to just stand up. And when she gave me those shots, I was still in a little pain, I was still numb, but whew, it never hurt me now. I thank goodness for that shot, 'cause I wouldn't be able to walk."</p>
Emotional Distress/Depression	<p>"Oh, emotional distress, lack of movement, I have to get help to put my stuff on, my clothes on, my underclothes. And my job, frustrating for me most times that I have it."</p> <p>"... especially, depression symptoms that go along with being incapacitated and not being able to get around the way you used to, a lot of joint stiffness."</p>
Access to Healthcare	<p>"And then Children's Medical Services only covered me until I was twenty-two, and then after that, I wasn't going to have any options. And for someone like me that need medication every single day, they told me I could apply for medical assistance."</p> <p>"I'm just new here. So that's why I came. Because I don't have insurance and I didn't have a job and I'm not very educated to have a good job. I can only do small jobs. For, I have been searching and I have been asking, and I had a case worker and she told me about the clinic here and she set me up so I can get my help here."</p>