Published in final edited form as:

Lupus. 2013 ; 22(1): 52–62. doi:10.1177/0961203312463979.

Designing an Intervention for Women with Systemic Lupus Erythematosus from Medically Underserved Areas to Improve Care: A Qualitative Study

Candace H Feldman, MD, MPH^a, Bonnie L Bermas, MD^a, Melanie Zibit, MEd, MBA^a, Patricia Fraser, MD^a, Derrick J Todd, MD, PhD^a, Paul R Fortin, MD, MPH^b, Elena Massarotti, MD^a, and Karen H Costenbader, MD, MPH^a

^aDivision of Rheumatology, Immunology and Allergy, Department of Medicine, Brigham and Women's Hospital, PBB-B3, 75 Francis Street, Boston, MA 02115

^bDivision of Health Care & Outcomes Research, Toronto Western Research Institute, University Health Network, Toronto, ON Canada

Abstract

Objective—Systemic lupus erythematosus (lupus) disproportionately affects women, racial/ethnic minorities and low-income populations. We held focus groups for women from medically underserved communities to discuss interventions to improve care.

Methods—From our Lupus Registry, we invited 282 women, > 18 years, residing in urban, medically underserved areas. Hospital-based clinics and support groups also recruited participants. Women were randomly assigned to 3 focus groups. 75-minute sessions were recorded, transcribed and coded thematically using interpretative phenomenologic analysis and single counting methods. We categorized interventions by benefits, limitations, target populations and implementation questions.

Results—29 women with lupus participated in 3 focus groups, (n=9, 9, 11). 80% were African American and 83% were from medically underserved zip codes. Themes included the desire for lupus education, isolation at the time of diagnosis, emotional and physical barriers to care, and the need for assistance navigating the healthcare system. 20 of 29 participants (69%) favored a peer support intervention; 17 (59%) also supported a lupus health passport. Newly diagnosed women were optimal intervention targets. Improvements in quality of life and mental health were proposed outcome measures.

Conclusion—Women with lupus from medically underserved areas have unique needs best addressed with an intervention designed through collaboration between community members and researchers.

Keywords

Disparities; qualitative research; African Americans; systemic lupus erythematosus

Corresponding author: Candace H. Feldman, Brigham and Women's Hospital, 75 Francis Street, PBB-B3, Boston, MA 02115; Phone: 617-732-5325, Fax: 617-732-5766, chfeldman@partners.org.

Disclosures: The authors have no conflicts of interests or disclosures relevant to this work. Dr. Fraser is employed by the Genzyme Corporation.

Introduction

Systemic lupus erythematosus (lupus) disproportionately affects women and vulnerable populations.^{1,2} The prevalence, morbidity, and mortality associated with lupus are highest among racial and ethnic minorities, the poor, and those lacking medical insurance and education.²⁻⁷ In particular, the highest lupus morbidity and mortality rates in the U.S. are among African American women.^{8,9} Lack of access to healthcare, especially in medically underserved communities, may be responsible for many of the observed disparities.^{10,11}

Interventions including peer support programs, educational initiatives, patient navigators, and “health passports” have been designed to improve the health of individuals with chronic diseases.¹²⁻¹⁶ Patient navigators, individuals with both an understanding of the community and knowledge of the healthcare system, have been shown to reduce obstacles to diagnosis and treatment.¹⁷ The use of a “health passport,” a tool containing personalized health information, was used to improve diabetes and hypertension control.¹⁸⁻²¹ One study suggested that placing medical subspecialists at community health centers also improved care.²²

Among lupus patients, efforts to enhance social support, health education, and self-efficacy to take charge of one’s health, improved physical function, disease activity and mental health.^{5,23-25} The LupusLine, a telephone-based peer counseling service,²⁶ the CaNIOS Lupus Health Passport, a notebook containing a personalized treatment plan, preventive health tips and health information,²⁷ and a partner support program, have been piloted at academic lupus centers.²⁴

Through a health educational forum and focus groups, we aimed to build a relationship with women with lupus living in medically underserved urban neighborhoods. Medically underserved areas are federally designated based on the number of primary care physicians, infant mortality rate, percentage of the population with incomes below the poverty level, and percentage of the population over age 65.²⁸ We hypothesized that women from these communities would be uniquely positioned to describe the barriers faced and to partner with academicians to develop an intervention to reduce disparities in lupus care.

Participants and Methods

To recruit participants, we used the Brigham and Women’s Hospital Lupus Registry, with information on over 1800 patients with lupus, validated according to the American College of Rheumatology Criteria for the Classification of Systemic Lupus Erythematosus.^{29,30} Inclusion criteria included age ≥ 18, female sex, physician-confirmed lupus diagnosis, and residence in an urban, medically underserved zip code. We excluded men because of the higher prevalence of lupus among women, our prior relationship with two female lupus support groups that we hoped to build upon, and our attempt to minimize differences between focus group participants to facilitate an open discussion of potentially sensitive topics. In addition, we hypothesized that certain barriers to healthcare specifically pertained to women, such as childcare responsibilities. Due to limited resources, non-English speaking individuals were also excluded. Approval for this study, and all materials used, was obtained from the Partners Healthcare Human Research Committee.

We mailed flyers to 282 women from 11 medically underserved zip codes in urban Boston, Massachusetts. The neighborhoods of Roxbury, Dorchester, and Mattapan were targeted because of their high poverty rates and majority African American and Hispanic populations. Physicians at Brigham and Women’s Hospital’s Lupus Center, Arthritis Center and Nephrology Clinic also recruited patients based on our criteria. In addition, leaders of

two lupus support groups of primarily African American women based in these neighborhoods invited their members.

Participants attended an educational talk on new lupus therapies, a topic chosen based on key-informant interviews with support group leaders. They were then invited to join a 75-minute focus group with a 15-minute wrap-up session. Focus groups were held at the Dimock Health Center, in Roxbury, MA. The Human Research Committee waived the need for written informed consent. We provided an information sheet explaining our study, and potential risks and benefits (Appendix 1) and obtained verbal consent prior to the focus groups. Participants received \$30 gift cards.

We randomly assigned participants to three groups, each led by a trained moderator with prior focus group experience (MZ (Group 1), KHC (Group 2), CHF (Group 3)). Moderators followed a detailed guide with scenarios that outlined potential interventions to improve lupus care (Appendix 2). The four interventions discussed were: a patient navigator (an individual who would help guide lupus patients through the healthcare system), a peer supporter, a Lupus Health Passport (developed by the Canadian Network for Improved Outcomes in SLE, CaNIOS),²⁷ and the placement of rheumatologists at local community health centers. Following the focus groups, we joined the three groups and briefly reviewed the interventions discussed.

The focus group sessions were tape-recorded and transcribed verbatim (CHF, MZ, KHC). To preserve anonymity, we identified participants by the order of their first comment and by their focus group (Group 1, 2 or 3). We coded and examined the transcripts based on interpretative phenomenological analysis, allowing common themes to emerge from the transcripts. This method is used to analyze focus groups to better understand how participants perceive their own health and their health services, without preconceived hypotheses.³¹⁻³³ The analysis relies on a descriptive (“phenomenological”) component, stemming from the patterns seen, and then, on an explanation (“interpretation”) of the dialogue, and the meaning derived from this.³¹ Each transcript was read and annotated based on significant statements and associations (CHF, KHC). Overarching themes emerged across scenarios and focus groups. Single counting was also used to quantify statements related to each theme, and components of each intervention.³⁴⁻³⁶ In addition, we categorized each intervention by perceived benefits, limitations, ideal target populations, and implementation questions. Transcripts were coded separately by two of the authors (CHF, KHC) and themes, counts and analyses were reconciled and confirmed.

Results

Twenty-nine women participated in focus groups: 9 (Group 1), 9 (Group 2), and 11 (Group 3). 80% self-identified as African American, 10% as Hispanic, and 10% as White. Twenty-four participants (83%) were from urban, medically underserved zip codes and four (14%) were from neighborhoods in close proximity to medically underserved zip codes. The mean age was 51 years (± 18 , range 25-81). All of the women had been diagnosed with lupus; the mean age at diagnosis was 35 (± 15).

Using interpretative phenomenological analysis, four themes repeatedly emerged: the desire for lupus education, isolation at the time of diagnosis, emotional and physical barriers to care, and the need for assistance navigating the healthcare system. In addition, the focus groups specifically discussed each intervention’s potential benefits and limitations, the ideal target populations, and questions regarding future implementation (Table 1).

Overarching Themes

The need for improved lupus education was a central theme reiterated by multiple participants across the three focus groups (18 of 29 participants (18/29)). Specifically, 13/29 stated that information, such as a packet of information at the time of diagnosis, was lacking. In addition, 5/29 emphasized the need for better educational resources to inform family and friends about clinical manifestations of lupus. Isolation, particularly at diagnosis, but also throughout the disease course, was a second key theme (6/29). Isolation was inextricably linked to the third theme, that of emotional and physical barriers that limited access to care (9/29). Depression heightened isolation and prevented women from reaching out to family members or physicians when medical attention was needed (3/29). Physical pain (4/29) and fatigue (2/29) further increased perceived distance from family members who did not understand lupus, and from physicians, who frequently did not offer treatments.

The complex healthcare system and the need for navigation assistance was a fourth repeated theme. Specifically, 7/29 vocalized the challenge of coordinating their healthcare and 3/29 described a health professional who could advocate on their behalf, answer questions, attend appointments, and direct them to resources. There was agreement (16/29) that a trained individual in this role could mitigate the stress of both the illness and the healthcare system.

These themes recurred throughout the focus group discussions. The barriers faced by participants were closely linked to their views on the proposed interventions, as outlined below:

Intervention 1: Patient Navigator

The themes of the need for improved education (5/29) and difficulty navigating the healthcare system (7/29) were integral to the patient navigator discussion. Five of the 29 vocalized disappointments with information at the time of diagnosis; 3/29 pointed to the limited time and accessibility of physicians. In response, 9/29 agreed that a navigator would be able to fill this gap by providing education; 4/29 suggested a role as a personal motivator, and 3/29 emphasized an advocacy component.

Of the 5/29 that described the need to better educate patients' family and friends, participant 4 (Group 3) specified that a navigator could reduce isolation by educating family members:

“When I was diagnosed, it was very scary because you didn't understand what it was and people looked at you and didn't see anything wrong with you. Only when I had flares, people saw it, and understood better...Maybe an educator for family members too. My family said put that cane away you don't need that. But they don't know.”

The role of the navigator as a motivator, both to empower women to perform daily activities and to improve self-efficacy, was highlighted (4/29). For example, participant 4 (Group 1) described the physical and emotional limitations patients with lupus face, and the ways a navigator could help:

“It would help to have someone help you exercise. It can be difficult. You need help getting out of bed. Your mind isn't on stretching. You need someone who will help motivate you. Someone who will come into your house and help you.”

Of the 3/29 that proposed the role of the navigator as an advocate, participant 3 (Group 3) specified the benefits at diagnosis:

“If there was an advocate who knew about the disease at the time of first diagnosis, it would make it much easier to navigate the system. You wouldn't stop asking questions or doing research, but at the onset, this would make it easier.”

Multiple participants also raised concerns about a patient navigator (8/29). Five of 29 expressed the need for this person to be well trained in lupus-specific issues and connected to the healthcare community. Participant 4 (Group 2) felt that a navigator could only be useful if he/she had a “passion” and a “mission” to help patients with lupus. Participant 2 (Group 3) thought she would not benefit from a navigator because she was “on top of her disease.” Participant 3 (Group 1) felt a navigator was unnecessary because “the best advocate is the patient.”

Intervention 2: Peer Supporter

The theme of isolation featured prominently in discussions of the peer supporter intervention; 6/29 described an inability to turn to their friends, family and physicians for support or information. Participant 5 (Group 3) articulated this:

“I’m only 25...I’m having trouble coming to terms with it. My friends don’t understand and I feel alone. Even when I talk to my doctor, they are impersonal and they want me in and out.”

Similarly, participant 4 (Group 1) spoke of a period of denial at the time of diagnosis and stated that she “felt alone, like an island.” Seven of the 29 women affirmed that a peer supporter would provide emotional support by validating fears, answering questions and sharing experiences. For example, participant 5 (Group 2) stated:

“A few years ago when I was frustrated and all over the place it would have been great to have someone to come with me just to validate my feelings and ask questions I don’t even know to ask.”

When asked directly, none of the participants felt that peers should be matched by race, ethnicity, or geographic proximity. Four of 29 supported matching peers by other factors. Specifically, participant 5 (Group 3) and participant 3 (Group 1) suggested matching by age, whereas both participant 4 (Group 3) and participant 5 (Group 1) felt that age at diagnosis was more important. Participant 5 (Group 3) also proposed that peers could be paired by lupus-related symptoms. Nine of the 29 preferred this intervention immediately at the time of diagnosis. However, 2/9 (Group 2) noted that first, the patient should be “out of denial” (Participant 2) and “past an initial period of feeling overwhelmed” (Participant 7).

Three of 11 (Group 3) also expressed a desire to determine the amount of contact they would have with a supporter. Participant 4 felt it should be “intensive at first” and then you would “control how much you need.” Participant 3 said that she would get “annoyed” if a supporter “kept calling and nothing changed.” Similarly, participant 2 proposed that the intervention should have a predefined time period after which a person would “graduate.”

The potential dual role of a trained individual as a peer supporter and as a patient navigator was described (5/29). In Group 2, participants discussed the amount of training required for this person, and the degree of medical knowledge expected (4/9). Three of these 9 felt that the supporter should be highly knowledgeable about lupus. For example, participant 8 stated:

“The person has to be trained. People sometimes can’t navigate the internet or the health system. I wouldn’t want to talk to just anyone with lupus...I think training would help...Doctors have 20 minutes with you, but someone you can call at a different time that has gone through that and is available to you, and has some medical knowledge that could serve as back up.”

However, participant 5 was concerned that the supporter would try to provide medical advice without the skills to do so:

“Sometimes people want to say ‘do that’ or ‘do this’ but you’re not a doctor. You wouldn’t want to give advice about stuff you don’t know.”

Similar to the navigator intervention, 5/29 described peer supporters as motivators. One example of this was participant 9 (Group 3) who suggested that the supporter should not solely be a person to commiserate with, but rather a person to be active with:

“I’d like a peer supporter but don’t want to sit and cry with them. I want to do things with them. Go shopping, go the gym with them. I’d prefer to do something, not have someone to just talk about everything because I’ll get into a deep state of depression.”

Three of the 9 participants in Group 2 raised concerns about the peer supporter intervention. Participant 2 noted that the supporter’s involvement could be limited by her own illness. Participant 3 agreed and instead, suggested training a friend or family member without lupus because his/her participation would not fluctuate with disease flares. Participant 5 expressed concern about remuneration and noted that volunteer work is not feasible if a person has financial difficulties:

“If you were offered a stipend, that would help. A lot of us can’t workllbut we could earn money and use the knowledge gained with this illness in a positive way... Because in your heart you want to, but realistically if you can’t take care of your bills at home, its adding to your stress and making your lupus worse. If there was some kind of stipend, people would stay more dedicated to it and be more consistent.

Intervention 3: CaNIOS Lupus Health Passport

The theme of access to lupus information permeated the discussion of the health passport (6/29). Thirteen of 29 verbalized support for this intervention and felt that the combination of disease information and a place to keep track of medical advice and health concerns between appointments would be helpful.

Spaces to fill in active symptoms, blood test results and up-to-date medication lists were considered most essential (5/29). Participants 5 (Group 1) also felt that explanations of medical terminology were important:

“I like the information and the explanation of health terms in normal wording. When I get my blood tests back, I don’t know what the terms mean.”

In addition, 5/29 expressed their interest in the passport’s ability to help link the care received from different providers. Specifically, participant 2 (Group 3) explained:

“If you were visiting different hospitals, it might be useful since doctors ask the same questions and don’t share information.”

The major criticism of this intervention was participants’ need for assistance filling in the passport’s information (6/29). These participants proposed that a physician, nurse, family member, or either the peer supporter or patient navigator previously discussed, could keep their passport updated. There was also interest in an internet-based version instead of the hard copy (6/29), or a choice between the two (2/29).

Intervention 4: Rheumatologists at Community Health Centers

In Group 1, when participants were polled, 1/9 stated she would go to a community health center for rheumatologic care if available, whereas 8/9 received care at academic hospitals and would not change providers. In Group 2, 1/9 received her care at a community hospital and 8/9 had rheumatologists at academic hospitals. Similarly, in Group 3, 11/11 received

care at academic centers. Nearly all participants described longstanding, positive relationships with their rheumatologists and would not switch to a different provider, regardless of location (27/29).

Three of 29 noted that placing rheumatologists at local health centers might facilitate physician communication and improve coordination of care. Participant 2 (Group 3) however, preferred a hospital setting for this same reason but thought that women with more physical limitations might find it easier to travel to a health center:

“I think it might help people who have trouble getting around and getting to a larger hospital. I prefer a larger hospital. Lupus affects so many parts of the body and rheumatologists don’t always have all the answers. They can just call someone who is one floor up, ask a question and make you an appointment. They have a relationship with your doctor and are in communication.”

Of the 3/29 that specified the benefits of receiving care at hospital centers, participant 2 (Group 3) appreciated the availability and convenience of “advanced testing.” Participant 6 (Group 2) valued the choice of physicians and was concerned that she would be limited to a single rheumatologist at a community health center. Participant 9 (Group 3) emphasized the benefits of anonymity and her desire to keep her illness private:

“I don’t need to run into people at the bus stop and then in the clinic waiting room. I want it to be separate. Everyone doesn’t need to know I have lupus.”

During the discussion of this intervention, 3/29 also raised concerns about their primary care providers’ up to date knowledge about lupus-related tests and treatments. These participants emphasized the need for continuous physician education.

Overall Intervention Preferences

Following the three separate focus groups, participants were brought together to discuss their preferred interventions. In a poll that allowed participants to vote more than once, 4/29 (14%) favored a patient navigator; 20/29 (69%) voted for a peer supporter, 17/29 (59%) voted for the Lupus Passport, and 4/29 (14%) preferred to place rheumatologists at community health centers.

Proposed Outcome Measures

To measure the success of an intervention, 3/29 proposed improvements in quality of life and ability to perform daily life activities, maintain a healthy diet, and exercise regularly. All Group 1 participants (9/9) when asked directly agreed that better mental health and self-efficacy to take charge of one’s own health were also important outcome measures.

Discussion

In this study, we engaged women with lupus, the majority of whom were African American and from medically underserved communities, to discuss barriers to care and strategies for improvement. The need for better lupus education both for patients and their families was a significant theme. Struggles with chronic pain and depression were emphasized as obstacles to quality care. The challenges posed by pain, depression, denial, and insufficient health education have been similarly described among patients suffering from other chronic diseases.³⁷⁻⁴² Our findings of lack of information and support at the time of diagnosis were also in line with a prior qualitative lupus study.⁴³

To address these issues, our focus group participants emphasized strategies that included improved educational materials, peer support, and coordination of care through patient

navigators. In a cohort study of lupus patients that examined relationships between race, socioeconomic status, clinical and psychosocial factors, disease activity and health status were most closely linked to psychosocial factors.²³ Similarly, prior studies have shown that empowerment through health education and active involvement of members of the community affected by a disease is integral to health improvement.^{44,45}

While all of our participants were able to obtain rheumatologic care, our discussions demonstrated that interventions to improve healthcare delivery and psychosocial support are still necessary. While participants expressed a need for a navigator, there were differing views as to this person's exact role, which may also explain the lower overall vote (4/29 (14%)) in support of this intervention. Descriptions of a navigator and a supporter overlapped, suggesting that one trained individual might feasibly serve both roles. The CaNIOS Lupus Passport was seen as a way to help coordinate care between physicians and to provide accessible, practical lupus education. Participants felt however, that the passport was not a stand-alone intervention and instead proposed combining it with a navigator or peer supporter.

There were limitations to this qualitative study. Despite living in medically underserved areas, 27/29 participants received care at academic medical centers and in general, felt they had access to lupus care. However, living in underserved, low-income communities did allow these women to describe the specific barriers they had faced and strategies they used to overcome them. Several women had participated in past research studies and focus groups.⁴⁶ Two women were also part of the leadership of an established lupus support group and therefore had a specific interest in the peer supporter intervention.

While over two hundred women were invited to participate, only twenty-nine women attended. A degree of selection bias was likely, as women who participate in such events may be healthier, better educated, and have higher self-efficacy than other women with lupus. However, it was apparent that many participants had rather severe lupus, with multiple past hospitalizations and medical complications. In addition, due to financial limitations, our inability to provide language interpreters and childcare may have restricted participation. This was also the first event that connected this group of academicians with community members and it is plausible that skepticism about research in general may have limited participation. Additionally, we note that the findings of these focus groups apply only to adult women with lupus living in these medically underserved areas and may not be generalizable to other groups. Future studies that include men, adolescents and rural locations could provide important related insights.

In summary, it was clear that our participants felt that a community-based intervention to improve lupus education, decrease isolation and facilitate better healthcare coordination would have a positive impact on their lupus care. Based on these findings, our next step is to train individuals from this community to serve the joint role of a peer supporter and patient navigator. Educational materials, particularly in the form of a lupus passport, will be a central component. Further studies are needed to assess the feasibility, cost-effectiveness, and psychosocial and clinical health impact of this intervention.

Acknowledgments

Drs. Feldman and Costenbader had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the analysis. Study concept and design: Drs. Feldman, Bermas, Fraser, Todd, Fortin and Costenbader and Ms. Zibit.

Acquisition of data: Ms. Zibit and Drs. Feldman and Costenbader

Analysis and interpretation of data: Drs. Feldman and Costenbader

Drafting of the manuscript: Drs. Feldman and Costenbader

Critical revision of the manuscript for important intellectual content: Drs. Feldman, Bermas, Massarotti, Fraser, Todd, Fortin, and Costenbader, and Ms. Zibit

Qualitative data analysis: Drs. Feldman and Costenbader

Study supervision: Dr. Costenbader

Previous Presentation: Presented in part at the American College of Rheumatology Conference, November 2011

Role of the sponsors: This work was funded by a grant from the Martin P. Solomon Fellowship, Brigham and Women's Hospital, Department of Internal Medicine and NIH R01AR 057327. The funding sources played no role in the design, conduct, interpretation or report of these analyses.

Other acknowledgements: The authors would like to thank all of our participants for their time and valuable thoughts. The authors would also like to acknowledge Deborah Brome, PhD, of Global Evaluation & Applied Research Solutions (GEARS) Inc., who provided helpful input on the design and conduct of the focus groups. The authors thank Nicholas Nassikas and Pearl Hines, as well as the Women of Courage and Daughters of Comfort Support Groups, for their invaluable assistance in organizing these focus groups and recruiting participants.

Appendix 1: Participant Information Sheet, Approved by the Partners Healthcare Human Research Committee

Why is this project being done?

We want to better understand what gets in the way of your getting quality medical care for your lupus. We are asking you to participate because you are a woman with lupus and you can help us understand problems with getting medical care. About 50 women will take part in this project. This project is supported by the Brigham and Women's Hospital Department of Medicine Martin P. Solomon Primary Care Award.

How long will this take?

The first part of this will be educational. You will have the opportunity to hear Dr. Elena Massarotti talk about updates in lupus care. This will last for about 30 minutes. During the second part, you will be asked to join a group discussion. This is the research study part of the project. This will last for about one hour.

What will happen in the discussion groups?

After the talk, you will be asked to join a group of approximately 10 women. These will be small group chats that give you a chance to talk with a few other women about ways to improve your access to health care. A member of our research team will lead each group. You do not have to stay for the small group chat if you prefer not to. You will be asked at each session to provide your name and phone number so that we can contact you in the future for other meetings. This information will not be connected to anything you say during the discussions. The group chats will be tape-recorded but no names will be used so that we can review the ideas you bring up in the group chat. The tapes will be kept in a locked file cabinet and only the three members of the research team will be able to listen to them.

What are the risks of being a part of this project?

The risk of this study is that other women who participate will know that you have lupus and will hear you talk about the problems you have faced. Also, some of the topics discussed may be uncomfortable and may make you feel frustrated or upset temporarily.

What are the possible benefits?

You may or may not benefit from taking part in this study. If you do benefit, it will likely be from the talks with tips about how to live a healthy life with lupus. You might also benefit from hearing what other women say about their experiences with lupus and with getting health care. We also hope that the information you share with us during this study will help us think about ways to improve access to health care for other women living in your community with lupus.

What other treatments or procedures are available for my condition?

You do not have to take part in this project to be treated for lupus. This study does not offer any form of treatment or medications for your illness. There are other ways to get educated about lupus, including from your primary care doctor, from your rheumatologist or from the American College of Rheumatology.

What if I don't want to participate in the research part of the project?

You are welcome to stay for the educational talk and leave before the group discussions. This will not change the medical care you get within Partners and it is entirely up to you if you decide to participate. You can also choose to leave at any time during the event.

Will I be paid to take part in this project?

Women who participate in the small group discussions will receive \$30 gift certificates. A light dinner will also be served to all women who attend.

What will I have to pay for if I take part in this project?

The only cost to you will be transportation to and from the event.

If I have questions or concerns about this project, whom can I call?

You can call us with your questions or concerns. Ask questions as often as you want. Dr. Karen Costenbader is the person in charge of this study. You can call her at XXX-XXX-XXXX Monday through Friday between 9AM and 5PM. If you want to speak with someone **not** directly involved in this project, please contact the Partners Human Research Committee Office. You can call them at XXX-XXX-XXXX.

Appendix 2: Moderator's Guide Scenarios

We first distributed information sheets (Appendix 1) approved by the Partners Healthcare Human Research Committee that outlined the goals of the focus groups and the risks and benefits of participation.

Verbal consent was obtained after each participant read the information sheet. Participants introduced themselves, but as described in the information sheet, no names were recorded. Tape-recording began following the introductions.

The following hypothetical scenarios were presented:

1. You have been told that your local health center has started a program for people with lupus where trained individuals from your community help guide you through

the healthcare system, make home visits, come with you to doctor's appointments and help you sort through your medicines.

- a. What do you think about this program?
 - b. Would you participate?
 - c. If your health center had a person like this, a "patient navigator" or a "community health worker," what would you want him/her to do?
 - d. What do you think this person would be able to help you with?
 - e. Are there specific patients who would benefit most from this?
2. A new project was started that creates a peer support network for women with lupus. When a woman is diagnosed with lupus, she would be partnered with a woman who was diagnosed in the past.
 - a. Would you volunteer to participate in this?
 - b. Do you think having a peer assigned to you when you were first diagnosed with lupus would have helped you? In what ways would this have been helpful?
 - c. Do you think your peer supporter should be similar to you in age? In gender? In race/ethnicity? In neighborhood community? Which factor would be the most important to you? Is there anything you would want to be different?
3. You have been given a little booklet-a "Lupus Passport"-which contains information about lupus and spaces for you to record your blood tests, your doctor's appointments, your medications, and your questions. (Passport copies distributed to participants)
 - a. What do you think of this passport?
 - b. Is this something you would use?
 - c. What parts would be helpful?
 - d. What parts do you think you could do without?
4. You find out that there is an internet-based version of this "Lupus Passport" that can be accessed in a secure way ONLY by you and your doctors. Rather than carrying around this booklet, both you and your doctors can view and update it on the computer.
 - a. Would you like this better than an actual booklet you can carry around with you?
 - b. What do you think are the most important things for this website to contain?
5. You find out that your local community health center is going to have a rheumatologist start to work there once a month.
 - a. How many of you go to a community health center for your primary care?
 - b. Do you think that you would like to have a rheumatologist work in your neighborhood at the same place as your primary care doctor?
 - c. Do you think that having a rheumatologist at your health center would improve your ability to keep appointments

- d. Do you think it would help your doctors communicate with each other so you don't have to have the same tests done multiple times?
- 6. We would like to ask you for other ideas. What do you think a successful program to improve the health of women with lupus should include?
 - a. Do you think a program to improve your health should take place in your home, in your community or at a hospital?
 - b. What would be the best way to get members of the lupus community to participate in a program? How would you advertise to members of your community?
 - c. What do you think would be good measures of a successful lupus program?

References

1. Fessel WJ. Systemic lupus erythematosus in the community. Incidence, prevalence, outcome, and first symptoms; the high prevalence in black women. *Arch Intern Med.* 1974; 134:1027–35.
2. Fernandez M, Alarcon GS, Calvo-Alen J, et al. A multiethnic, multicenter cohort of patients with systemic lupus erythematosus (SLE) as a model for the study of ethnic disparities in SLE. *Arthritis Rheum.* 2007; 57:576–84. [PubMed: 17471524]
3. Gillis JZ, Yazdany J, Trupin L, et al. Medicaid and access to care among persons with systemic lupus erythematosus. *Arthritis Rheum.* 2007; 57:601–7. [PubMed: 17471527]
4. Yazdany J, Gillis JZ, Trupin L, et al. Association of socioeconomic and demographic factors with utilization of rheumatology subspecialty care in systemic lupus erythematosus. *Arthritis Rheum.* 2007; 57:593–600. [PubMed: 17471526]
5. Bae SC, Hashimoto H, Karlson EW, Liang MH, Daltroy LH. Variable effects of social support by race, economic status, and disease activity in systemic lupus erythematosus. *J Rheumatol.* 2001; 28:1245–51. [PubMed: 11414264]
6. Ow MY, Ho PC, Thumboo J, Wee HL. Factors associated with health services utilization in patients with systemic lupus erythematosus: a systematic review. *Clin Exp Rheumatol.* 2010; 28:892–904. [PubMed: 21122271]
7. Odutola J, Ward MM. Ethnic and socioeconomic disparities in health among patients with rheumatic disease. *Curr Opin Rheumatol.* 2005; 17:147–52. [PubMed: 15711226]
8. Campbell R Jr, Cooper GS, Gilkeson GS. Two aspects of the clinical and humanistic burden of systemic lupus erythematosus: mortality risk and quality of life early in the course of disease. *Arthritis Rheum.* 2008; 59:458–64. [PubMed: 18383420]
9. Pons-Estel GJ, Alarcon GS, Scofield L, Reinlib L, Cooper GS. Understanding the epidemiology and progression of systemic lupus erythematosus. *Semin Arthritis Rheum.* 2010; 39:257–68. [PubMed: 19136143]
10. Andrus DP. Access to care is the centerpiece in the elimination of socioeconomic disparities in health. *Ann Intern Med.* 1998; 129:412–6. [PubMed: 9735070]
11. Zuvekas SH, Taliaferro GS. Pathways to access: health insurance, the health care delivery system, and racial/ethnic disparities, 1996–1999. *Health Aff (Millwood).* 2003; 22:139–53. [PubMed: 12674417]
12. Steinberg ML, Fremont A, Khan DC, et al. Lay patient navigator program implementation for equal access to cancer care and clinical trials: essential steps and initial challenges. *Cancer.* 2006; 107:2669–77. [PubMed: 17078056]
13. Lebwohl B, Neugut AI, Stavsky E, et al. Effect of a patient navigator program on the volume and quality of colonoscopy. *J Clin Gastroenterol.* 2011; 45:e47–53. [PubMed: 21030874]
14. Robie L, Alexandru D, Bota DA. The use of patient navigators to improve cancer care for Hispanic patients. *Clin Med Insights Oncol.* 2011; 5:1–7. [PubMed: 21339858]
15. Philis-Tsimikas A, Fortmann A, Lleba-Ocana L, Walker C, Gallo LC. Peer-led diabetes education programs in high-risk Mexican Americans improve glycemic control compared with standard

- approaches: a Project Dulce promotora randomized trial. *Diabetes care*. 2011; 34:1926–31. [PubMed: 21775748]
16. Wu CJ, Chang AM, Courtney M, Shortridge-Baggett LM, Kostner K. Development and pilot test of a peer-support based Cardiac-Diabetes Self-Management Program: a study protocol. *BMC Health Serv Res*. 2011; 11:74. [PubMed: 21481274]
 17. Haideri NA, Moormeier JA. Impact of patient navigation from diagnosis to treatment in an urban safety net breast cancer population. *J Cancer*. 2011; 2:467–73. [PubMed: 21915191]
 18. Dijkstra RF, Braspenning JC, Huijsmans Z, et al. Introduction of diabetes passports involving both patients and professionals to improve hospital outpatient diabetes care. *Diabetes Res Clin Pract*. 2005; 68:126–34. [PubMed: 15860240]
 19. Dijkstra R, Braspenning J, Grol R. Empowering patients: how to implement a diabetes passport in hospital care. *Patient Edu Couns*. 2002; 47:173–7.
 20. Vaczy E, Seaman B, Peterson-Sweeney K, Hondorf C. Passport to health: an innovative tool to enhance healthy lifestyle choices. *J Pediatr Health Care*. 2011; 25:31–7. [PubMed: 21147405]
 21. Simmons D, Gamble GD, Foote S, Cole DR, Coster G. The New Zealand Diabetes Passport Study: a randomized controlled trial of the impact of a diabetes passport on risk factors for diabetes-related complications. *Diabet Med*. 2004; 21:214–7. [PubMed: 15008829]
 22. Cook NL, Ayanian JZ, Orav EJ, Hicks LS. Differences in specialist consultations for cardiovascular disease by race, ethnicity, gender, insurance status, and site of primary care. *Circulation*. 2009; 119:2463–70. [PubMed: 19398667]
 23. Karlson EW, Daltroy LH, Lew RA, et al. The relationship of socioeconomic status, race, and modifiable risk factors to outcomes in patients with systemic lupus erythematosus. *Arthritis Rheum*. 1997; 40:47–56. [PubMed: 9008599]
 24. Karlson EW, Liang MH, Eaton H, et al. A randomized clinical trial of a psychoeducational intervention to improve outcomes in systemic lupus erythematosus. *Arthritis Rheum*. 2004; 50:1832–41. [PubMed: 15188360]
 25. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev*. 1977; 84:191–215. [PubMed: 847061]
 26. Horton R, Peterson MG, Powell S, Engelhard E, Paget SA. Users evaluate LupusLine, a telephone peer counseling service. *Arthritis Care Res*. 1997; 10:257–63. [PubMed: 9295455]
 27. Fortin P. Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus. 2010
 28. HRSA. Medically Underserved Areas & Populations (MUA/Ps). 2011
 29. Tan EM, Cohen AS, Fries JF, et al. The 1982 revised criteria for the classification of systemic lupus erythematosus. *Arthritis Rheum*. 1982; 25:1271–7. [PubMed: 7138600]
 30. Hochberg MC. Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythematosus. *Arthritis Rheum*. 1997; 40:1725. [PubMed: 9324032]
 31. Hale ED, Trehan GJ, Lyons AC, et al. “Joining the dots” for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. *Ann Rheum Dis*. 2006; 65:585–9. [PubMed: 16219711]
 32. Pringle J, Drummond J, McLafferty E, Hendry C. Interpretative phenomenological analysis: a discussion and critique. *Nurse Res*. 2011; 18:20–4. [PubMed: 21560922]
 33. McParland JL, Eccleston C, Osborn M, Hezsetline L. It’s not fair: an Interpretative Phenomenological Analysis of discourses of justice and fairness in chronic pain. *Health (London)*. 2011; 15:459–74. [PubMed: 21169206]
 34. Pollard LC, Graves H, Scott DL, Kingsley GH, Lempp H. Perceived barriers to integrated care in rheumatoid arthritis: views of recipients and providers of care in an inner-city setting. *BMC Musculoskelet Disord*. 2011; 12:19. [PubMed: 21241497]
 35. Lempp HK, Hatch SL, Carville SF, Choy EH. Patients’ experiences of living with and receiving treatment for fibromyalgia syndrome: a qualitative study. *BMC Musculoskelet Disord*. 2009; 10:124. [PubMed: 19811630]
 36. Seale, C. *The quality of qualitative research*. Sage Publications; London: 1999.

37. James BD, Boyle PA, Bennett JS, Bennett DA. The Impact of Health and Financial Literacy on Decision Making in Community-Based Older Adults. *Gerontology*. 2012
38. Murphy LB, Sacks JJ, Brady TJ, Hootman JM, Chapman DP. Anxiety and depression among US adults with arthritis: Prevalence and correlates. *Arthritis Care Res*. 2012; 64:968–76.
39. Moussavi S, Chatterji S, Verdes E, Tandon A, Patel V, Ustun B. Depression, chronic diseases, and decrements in health: results from the World Health Surveys. *Lancet*. 2007; 370:851–8. [PubMed: 17826170]
40. Garay-Sevilla ME, Malacara JM, Gutierrez-Roa A, Gonzalez E. Denial of disease in Type 2 diabetes mellitus: its influence on metabolic control and associated factors. *Diabet Med*. 1999; 16:238–44. [PubMed: 10227570]
41. Anthony H, Valinsky L, Inbar Z, Gabriel C, Varda S. Perceptions of hypertension treatment among patients with and without diabetes. *BMC Fam Pract*. 2012; 13:24. [PubMed: 22448772]
42. Kaltsouda A, Skapinakis P, Damigos D, et al. Defensive coping and healthrelated quality of life in chronic kidney disease: a cross-sectional study. *BMC Nephrol*. 2011; 12:28. [PubMed: 21689443]
43. Waldron N, Brown S, Hewlett S, Elliott B, McHugh N, McCabe C. 'It's More Scary Not to Know': A Qualitative Study Exploring the Information Needs of Patients with Systemic Lupus Erythematosus at the Time of Diagnosis. *Musculoskeletal care*. 2011; 9:228–38. [PubMed: 21993962]
44. Israel BA, Schulz AJ, Parker EA, Becker AB. Community-based participatory research: policy recommendations for promoting a partnership approach in health research. *Educ Health (Abingdon)*. 2001; 14:182–97. [PubMed: 14742017]
45. Lantz PM, Viruell-Fuentes E, Israel BA, Softley D, Guzman R. Can communities and academia work together on public health research? Evaluation results from a community-based participatory research partnership in Detroit. *J Urban Health*. 2001; 78:495–507. [PubMed: 11564852]
46. Karlson EW, Watts J, Signorovitch J, et al. Effect of glutathione S-transferase polymorphisms and proximity to hazardous waste sites on time to systemic lupus erythematosus diagnosis: results from the Roxbury lupus project. *Arthritis Rheum*. 2007; 56:244–54. [PubMed: 17195228]

Table 1
Intervention Analysis by Category

Proposed Intervention	Benefits	Limitations	Target Population	Implementation Questions
Patient Navigator	<ul style="list-style-type: none"> Liaison between doctor and patient Patient advocate Directs patients to available resources 	<ul style="list-style-type: none"> Different needs throughout their disease course, role hard to define Potential lack of knowledge about lupus 	<ul style="list-style-type: none"> Newly diagnosed women Women later in their disease course who are sicker or frustrated with their care 	<ul style="list-style-type: none"> Would the navigators be trained healthcare workers or laypersons? Would they navigate in person, or by telephone? Would they be paid or volunteer?
Peer Supporter	<ul style="list-style-type: none"> Reduces isolation Serves as a motivator and an advocate Directs patients to available resources Potential benefit to both peers 	<ul style="list-style-type: none"> Peers will also have lupus; participation may be limited during disease flares Lack of knowledge about medical conditions 	<ul style="list-style-type: none"> Newly diagnosed women 	<ul style="list-style-type: none"> Would peers be paid? How would the peers be trained? Could peers decide on their preferred method of communication and on their degree of participation?
CaNIOS Lupus Health Passport	<ul style="list-style-type: none"> Small size Combines personal information with education Helpful for patients who see many physicians who do not share medical records 	<ul style="list-style-type: none"> Unable to fill this out during a doctor's appointment without assistance Privacy and security of internet version 	<ul style="list-style-type: none"> Everyone with SLE 	<ul style="list-style-type: none"> Would there be a healthcare worker at the appointment who could help fill this out? Who would have access to the online version?
Rheumatologist at Community Health Center	<ul style="list-style-type: none"> Improves coordination and communication between providers 	<ul style="list-style-type: none"> Easier to have all specialists at an academic center Less choice of providers Less privacy and anonymity at a CHC 	<ul style="list-style-type: none"> Newly diagnosed patients with less severe disease Older patients unable to travel 	<ul style="list-style-type: none"> Would patients have to give up their rheumatologists at medical centers? Could primary care providers receive more education about SLE and provide interim care?