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“We Would Still Find Things to Talk About”: Assessment of Mentor Perspectives in a Systemic Lupus Erythematosus Intervention to Improve Disease Self-Management, Empowering SLE Patients

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Abstract

Background: Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disorder with significant disparate impact on African American women. The current study sought to highlight how the Peer Approaches to Lupus Self-management (PALS) intervention worked bi-directionally wherein both women with SLE leading the disease self-management program (mentors), and those participants who served as mentees, were empowered toward greater disease self-efficacy.

Methods: Data was captured for this study in two formats from the seven mentors participating in the pilot study: 1) mentor logs and 2) mentor interviews with the principle investigator. This information was then analyzed for themes relating to their experience within the study.

Results: We found that empowerment was facilitated by mentors taking their mentorship responsibilities seriously and seeking several avenues for collaboratively developing success with their mentees. Mentors reported that although challenges arose, their desire for success resulted in multiple approaches to be flexible and responsive to the needs of their mentees. Additionally, reciprocity was found to be a vital element of the program.

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Conclusions: Key thematic areas supported our ability to demonstrate the usefulness of a peer mentoring program for SLE disease self-management on evoking empowerment through reciprocal relationships among mentors and mentees within our study population. Furthermore the feedback from PALS participants yielded very rich and contextual information that can be used as a thematic guide for developing and refining evidence-based interventions that seek to incorporate empowerment into disease self-management efforts for women suffering from SLE.

Keywords

Mentors; Systemic lupus erythematosus; Women; African American; Qualitative

INTRODUCTION

SLE is a chronic autoimmune disease with acute periodic flare-ups of symptoms impacting any organ system and resulting in potentially life-threatening complications.¹⁻³ Chronic disease self-management programs have demonstrated improvements in SLE symptoms and limitations.⁴⁻⁶ Specifically, evidence-based self-management interventions designed to enhance social support and provide health education, among lupus patients, have reduced pain, improved function, and delayed disability.⁵⁻²³ However, components of illness self-management programs that evoke empowerment as an overarching guiding principle are largely missing from this literature.²⁴⁻²⁶ The current paper describes a psychosocial intervention that focused on increasing disease self-management of SLE patients and highlights how the intervention worked bi-directionally wherein women with SLE leading the disease self-management program (mentors), and those who participated as mentees, were empowered toward greater disease self-efficacy.

METHODS

The Peer Approaches to Lupus Self-Management (PALS) study was a single arm, pre-post pilot in which 30 African American women with lupus were recruited from the Medical University of South Carolina (MUSC) SLE database (10 mentors and 20 mentees). The peer mentoring intervention lasted for 12 weeks. We conducted a qualitative study, based on responses from weekly one-on-one interviews and a focus group held as part of the PALS intervention. Prior to enrollment all participants provided informed consent and study procedures were carried out in accordance with the Declaration of Helsinki.

The overall goal of the intervention was to match African American women who had more experience managing their SLE with peers who were less experienced with disease self-management, and included mentor training in sharing disease-specific information through conversation and structured educational activities. Additionally, the intervention aimed to determine the feasibility and efficacy of providing a peer-to-peer intervention specific to African American women with SLE. Feasibility was assessed through evaluation of recruitment activities, compliance with phone sessions, cost assessment, and evaluations of participant satisfaction. Intervention efficacy was evaluated in terms of change in self-management, measured by the Patient Activation Measure (PAM)²⁷; HRQL, measured using the lupus quality of life questionnaire (LUP-QOL)²⁸; and disease activity, which was

assessed using the Systemic Lupus Activity Questionnaire (SLAQ).²⁹ We also assessed immunological Evidence of Disease Activity as Th1/Th2 cytokine balance, which was assessed by flow cytometry.

Six modules of the Chronic Disease Self-Management Program (CDMP),^{4,30} Arthritis Self-Management Program (ASMP),⁴ and Systemic Lupus Erythematosus Self-Help (SLESH)^{31,32} course were adapted and further tailored to African American women with six added sessions based on cultural issues reported as important to African Americans in earlier research conducted by the PI.^{5,9}

Qualitative inquiries and responses were meant to serve as our participatory process in further refining and culturally adapting the intervention protocol, in an effort to address any culture-bound myths about SLE in this cultural group. Lastly, we sought to demonstrate the cultural appropriateness of the intervention for African-American women suffering from SLE, furthering implementation science in the field.

Patients

All patients participating in the current study met diagnostic criteria for SLE based on the revised American College of Rheumatology criteria.^{33,34} PALS was a telephone-based peer mentoring intervention, in recognition of travel-related barriers for SLE patients identified in previous research^{35,36}; especially in South Carolina where the study was conducted.

Recruitment

Peer mentors were identified in a two-tier process. First, an extraction of potential mentors was conducted using the MUSC SLE database where rheumatologists and other clinicians identified patients deemed highly competent about SLE. Such patients are often invited to speak with media and other public engagement environments on behalf of the patient population. Second, the principal investigator sent recruitment letters and those that responded were interviewed face-to-face to assess maturity, emotional stability, and verbal communication skills. The interview schedule included questions from the psychological scales of the Arthritis Impact Measurement Scales (AIMS),³⁷ Arthritis Helplessness Index (AHI),³⁸ Wallston General Perceived Competence Scale,³⁹ University of California at Los Angeles (UCLA) Loneliness Scale,⁴⁰ Rosenberg Self-Esteem,⁴¹ Campbell Personal Competence Index,⁴² Carkhuff Communication and Discrimination Skills Inventories,⁴³ and the Applied Knowledge Assessment (AKA) scale.

Our target was 30 mentees and 10 mentors to have a 1:3 mentor to mentee ratio. Letters were mailed to 24 potential mentors, using the MUSC SLE database. Additionally, recruitment flyers were placed in MUSC lupus clinics. In our one-month recruitment period, 18 potential mentors responded, but 3 were deemed ineligible to participate, 1 withdrew, and 2 wished to serve as alternates. Our resulting study population included 7 mentors assigned to 20 mentees, corresponding with a 1:3 ratio in 6 groups, and a 1:2 ration in 1 group. A detailed description of eligibility and selection criteria is reported elsewhere.⁴⁴

Interviews & activity logs

A two-tiered approach for capturing qualitative data was utilized. Specifically, we implemented both interviews between mentors and mentees throughout the course of the study and a focus group that included both mentees and mentors at the end of the study. Data for this paper was extracted from weekly logs completed by mentors and discussed with the PI during weekly check-in interviews. Interviews were conducted after initial thematic areas were identified and ideas extracted. Thematic areas were instructively developed at the outset of the intervention. Specifically, the intervention included topical areas that allowed for identification of thematic areas post-intervention.

Initial interviews between mentors and the PI were conducted face-to-face in the office of the PI, or another private location. These interviews took approximately 60 min and covered diverse topics. Peer mentors then recorded weekly meetings with mentees, using an activity log. To decrease potential adverse events, or address adverse events that arose, the PI held face-to-face meetings with mentors throughout the study period. Thus data was captured for this study in two formats: 1) mentor logs and 2) mentor interviews with the PI.

Qualitative data analysis

Research seeking to highlight the perspectives of mentors within intervention research has suggested using both an inductive and deductive approach to qualitative data analysis.^{45,46} The current study utilized a deductive coding approach, as we identified thematic domains prior to the initiation of data collection and the intervention itself. These weekly topical thematic domains allowed us to develop further nodes to help contextualize the topical thematic domains. Specific qualitative methodological approaches guiding the research team centered on grounded theory and phenomenological approaches, which has been shown to be a useful tool in documenting empowerment processes within health research.⁴⁷ These approaches allow the voices of participants to be central. Grounded theory seeks to uncover the social conditions in everyday life, while simultaneously giving voice to those under specific study.^{48–50} Phenomenological conceptual frameworks centers on understanding individualized experiences of the social world.^{51,52}

To analyze the data collected, we utilized NVivo 10.1 software.⁵³ We developed a codebook, using the initial topical thematic guide. The thematic codebook was developed by two trained qualitative researchers independently and then combined; wherein reconciliation occurred if any themes identified individually differed. This process of cyclical thematic codebook development has been shown to improve precision in identification of particularly salient themes among participants within qualitative studies.^{54–56} As a result of the longitudinal nature of the intervention, the thematic codebook also allowed for multiple coverage of possible topics. Previous intervention research in this area has primarily focused on perspectives of participants.^{48,51,57} Although extremely important and informative, the current study focuses on findings among mentors in the PALS intervention.

RESULTS & DISCUSSION

In elucidating how empowerment developed throughout the course of our intervention, we highlight results from our qualitative data analysis. Our intention is to demonstrate how empowerment was developed in a reinforcing manner, and thus we start by showing data from the beginning of the intervention and subsequent evolution over the entire study. All 12 sessions were completed by all mentoring pairs. An average of 1.24 (0.53) call attempts were made by mentors to their mentees each week. The average length of sessions was 54.1 min (range 0–105 min). The mode of contact after an initial face-to-face meeting to be introduced to one another was telephone only for all mentoring pairs.

Mentor's logistic-related tasks & perceptions

To understand the effectiveness of the intervention in attempting to overcome geographic barriers and be as accessible as possible, we sought to understand perceptions of the intervention. Particularly we were concerned with understanding if the logistics of the intervention facilitated or inhibited the development of an empowering aspect among both mentees and mentors. During qualitative data analysis, it became clear that participants had extremely well-articulated feedback on the intervention, much of which was positive and seemed natural for understanding the development of empowerment among participants. One mentor highlighted that developing a schedule for the phone conversations with her mentee was initially challenging, but as the intervention progressed things became much more routine:

“..... sometimes I would forget to call so I'd have to make it up the next day. So scheduling, it wasn't bad but it got a little hectic at certain weeks.”

Another mentor reflected upon challenges in having a mentee that was less engaged and what she did to overcome such a challenge:

“my mentee was not, didn't wanna talk about it so we only talked for like 15 minutes since the last one, then we got on to it she wasn't very satisfied with that one. And then another time, for the length, one of my ladies, whenever I tried to talk to her she would get sleepy a lot. So then I would hold her, keep waking her up, and (?) could we just do another time? And she would say ok. So I just think that maybe with that individual we could do one day we'll do 30 minutes and the next day we'll do the other 30 minutes. I don't know how we'd be able to do that but.”

These two examples provide evidence of how empowerment began to take root within the study, especially in terms of cooperation and reciprocity being developed collectively for improving the effectiveness of the intervention. Data revealed that mentors took seriously their mentorship responsibilities and sought several avenues for collaboratively developing success with their mentees. Mentors reported that although challenges arose, their desire for success resulted in multiple approaches to be flexible and responsive to the needs of their mentees.

Setting the stage for understanding empowerment among SLE patients

Empowerment is a dynamic concept which is often rein-forced through reciprocal exchanges. Therefore, we begin by providing mentor responses to the intervention that highlight the types of engagement they were exposed to. This also serves to provide contextual background for the activities that could ultimately lead to empowerment. It was observed that mentors felt empowered through exchanges with mentees in terms of being able to discuss topics that they felt were often marginalized by healthcare professionals.

“True, but with my mentees we built a relationship. For me, family and church is my safety net, for some of them that wasn’t their safety net. So when it came to stress, I tried to be as generic as possible and not specific because I didn’t want them to start doing something and then it not work for them, so it was like when it came to giving examples of what to do I was very very generic because all of us are just at different places, at different ages and totally different parts of life.”

Additionally, mentees highlighted the usefulness of mentors in providing them with information that they might not have obtained from their healthcare providers. Specifically mentees elucidated that having access to mentors was useful beyond weekly check-ins, especially in terms of being able to gain clarity on healthcare related issues. One participant discussed:

“My mentor, through the weekdays you would get a text wanting to know how things were going, usually before we even started into our slides it was how has your week been how are you feeling and it was mainly the beginning of the conversation was always about you, what’s changed since the week before, and even trying to figure out problem solving..[my mentor took time] to look up things for me, so for me it was just a positive experience all the way!”

The above quote highlights a dynamic reciprocity between mentors and mentees wherein mentees were encouraged in having a patient, more experienced with managing SLE, there to help them through questions about their own disease self-management. This sets up a dynamic process uncovered in the qualitative analyses around discussions of topics not often considered in the day-to-day disease self-management process of participants.

Uncovering empowerment for daily living & self-management of SLE

Qualitative data analyses also revealed dynamics related to SLE self-management that may be situated at the margins of research in terms of the burden of SLE on patients. First, participants were able to discuss topics like sexuality and sexual behaviors with their mentors. One participant remarked how useful it was to have a mentor with whom to discuss the often “taboo” topic of sexuality among SLE patients and how their disease can impact spousal relationships:

“With your spouse too, and how they feel about you having lupus. Sometimes you aren’t in the mood to. you know. and sometimes you’re tired and don’t wanna get dressed and go out.”

Another participant highlighted how interpersonal sensitivity and interpersonal relationships can be impacted by SLE.

“I don’t know how it is for everybody, but I mean there’s time with my lupus, I can’t even have my kids touch me. I tell them even if you get close to me I’m in pain. Don’t touch my hands my arms, nothing. So it does create problems, I date, and sometimes I just have to tell my boyfriend, don’t come near me. It’s nothing wrong with you, it’s just this is one of these time where you just can’t touch me, not a hug don’t touch my shoulder, don’t even accidentally bump into me. Because it is that bad.”

Understanding the impact of SLE on patients’ lives and highlighting the process through which disease self-management occurs, we have provided a topical area less likely to be discussed with healthcare providers among SLE patients. Participants agreed that inclusion of topics such as sex and sexuality were warranted, especially in terms of giving voice to this area that is less studied and understood, while providing an optimal point of reciprocity between mentors and mentees. One mentor reported:

“I wouldn’t say take away the slide about sexuality and intimacy but I would say add a little bit more content. I guess becoming more confident to put yourself out there, because my mentees became my mentor during this slide. There’s lots that I don’t truly understand, like falling in love and going out dating and they have to coax me through this slide because there wasn’t a lot I could give them but there was a lot that they taught me which I told them I might try but. ehhhhh (unsure grumble). But I would say don’t get rid of it just add a little bit more content that helps people to want to go out more and meet people and date more and not let lupus take control of that part of your life.”

This topical area of sex and sexuality provides a clear example of reciprocity being important in empowering both mentees and mentors. Moreover, in assessment of whether this component of the disease self-management program should be included in future programmatic development, it is clear that participants found this area helpful. Empowerment of both mentors and mentees could have residual influence in shaping future encounters with healthcare providers and thus reinforce long-term effects of participating in a disease self-management program for SLE patients.

Grounding empowerment for disease self-management using a lens of reciprocity

Overall, perceptions of the disease self-management program were extremely positive from both mentors and mentees. One of the most important findings from the qualitative data centered on the intervention’s encouragement of reciprocity. Some participants highlighted that although they did not have “expertise” with specific topics, the structure of the intervention allowed for collective learning and consequently empowerment in relation to patient-physician encounters. A mentee remarked:

“That’s what it’s like and I. when we were trained not to cross that line. When you go to your doctor you say this, Im not there with her, only know what came out of her, what they’re telling me...?... when you’re a sickly person, no matter what you have, if you don’t have the support or you can’t medically defend yourself or ask the right questions, that’s a totally different situation from what we have her. I’m

glad I was her mentor, but you see. I supported the social questions to the questions that lingered on the line of medical advice you might have to give.”

Another mentor highlighted how the intervention’s focus on guided disease self-management, through the mentorship approach, produced a setting for empowerment that was both sustaining and reciprocal:

“It gave me an opportunity to outside of a doctor’s office actually talk and converse with someone who has lupus. Because usually if I’m talking to someone in the doctor’s office we’re both going through a crisis so it made it difficult you know, when someone’s not feeling well, you’re not feeling well but to meet someone in a non-doctor setting, that was a big change and I like that a lot better.”

Interpretation

Data gathered as part of this study provided a unique opportunity to evaluate the extent to which empowerment was synergistically present within a peer mentoring intervention to improve the disease self-management of African American women with SLE. The Peer Approaches to Lupus Self-management (PALS) intervention worked bi-directionally wherein both mentors and mentees were empowered toward greater disease self-efficacy. We found that empowerment was facilitated by mentors taking their mentorship responsibilities seriously and seeking several avenues for collaboratively developing success with their mentees. Mentors reported that although challenges arose, their desire for success resulted in multiple approaches to be flexible and responsive to the needs of their mentees. This is consistent with other studies that have observed empowerment resulting from a desire to collectively and collaboratively create a context wherein success of the program was central to the activities of all involved.^{58,59} Unique to our study population, mentors felt empowered through exchanges with mentees by being able to discuss topics that they felt were often marginalized by healthcare professionals. For example, mentors and mentees appreciated the opportunity to discuss sexuality, which corresponds with previous research that this is a valid concern for women with SLE. Morales et. al found that women suffering from SLE experienced lower sexual desire and arousal and such sexual functioning was also associated with social functioning and interpersonal sensitivity.⁶⁰ Such dynamic discussions served as a participative approach to determining which components of the intervention were most useful to participants and warranted sustained inclusion.

One of the most important findings from qualitative data was the intervention’s encouragement of reciprocity. Participants highlighted how the exchanges between mentors and mentees were valuable in completion of the intervention, and some reported that although they did not have “expertise” with specific topics, the structure of the intervention allowed for collective learning and consequently empowerment in relation to patient-physician encounters. This reinforces the importance of considering how clinical interventions may be used as a tool for empowerment that is reciprocal in nature for all parties involved, and provides preliminary evidence to support greater inclusion of patients within contexts seeking to deploy a precision medicine approach for improving clinical care of SLE patients.

While our study is highly informative, there are few limitations that warrant attention. Much of the qualitative data analysis used for the current study were derived from open-ended responses, but no specific protocol was established prior to the initiation of data collection that facilitated clarification of ideas supplied by participants, which makes it more difficult to connect thoughts across thematic areas and can contribute to results being disjointed. However, activity logs have regularly been utilized as a source of qualitative data in health research, particularly for capturing qualitative data from intervention-oriented research.⁶¹ The current study developed the activity logs to correspond with the weekly topical areas covered within the intervention, and to increase validity of these thematic areas, three independent expert researchers in the area of rheumatology reviewed intervention materials. The activity logs allowed the authors to longitudinally assess whether various topics were covered in multiple domains, and although each week presented a “new” topic, mentors often revisited topics covered in other weeks. Additionally, weekly check-ins between mentors and the PI created the opportunity to follow-up on the specific nature of some responses. Our findings should also be understood with respect to the context of the clinical settings and geographical limitations of the population included in our study. Our findings may not be entirely generalizable due to our study sample consisting of more highly educated African American women with SLE living predominantly in the area of Charleston, South Carolina. Thus, unique cultural experiences may have shaped the findings reported within our study. However, the PALS intervention utilized telephone-based delivery methods in an effort to not only minimize geographic disparities related to transportation burden and issues with SLE specialty care access in South Carolina,^{62,63} but also to promote greater participation of mentors and mentees in areas across the state.

IMPLICATIONS

These results provide foundational qualitative data that is useful for generating hypotheses to better understand how empowerment and reciprocity can be developed within clinical interventions aimed at decreasing negative impacts of SLE. Future studies might include engagement of healthcare providers within SLE disease self-management programs. Such inclusion could further our understanding of how self-management programs could be useful in terms of precision medicine. Additionally, findings will be useful to SLE patients, physicians seeking to improve patient empowerment, patient navigators, and others responsible for daily care of SLE patients. Feedback from PALS participants yielded rich contextual information that can be used as a thematic guide for developing and refining evidence-based interventions seeking to incorporate empowerment into disease self-management efforts for women with SLE. Key thematic areas supported our ability to demonstrate the usefulness of a peer mentoring program for SLE disease self-management on evoking empowerment through reciprocal relationships among pairs within our study population.

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