“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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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 consent.
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)\(^2\); HRQL, measured using the lupus quality of life questionnaire (LUP-QOL)\(^2\); and disease activity, which was assessed using the Systemic Lupus Activity Questionnaire (SLAQ).\(^9\) 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\(^15,36\), 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 (AIH),\(^38\) 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 ratio in 1 group. A detailed description of eligibility and selection criteria is reported elsewhere.\(^14\)

**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 inductively 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
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