



Published in final edited form as:

Lupus. 2019 July ; 28(8): 937–944. doi:10.1177/0961203319851559.

Cost effectiveness of a peer mentoring intervention to improve disease self-management practices and self-efficacy among African American women with systemic lupus: Analysis of the Peer Approaches to Lupus Self-management (PALS) pilot study

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Abstract

Objective: The Peer Approaches to Lupus Self-Management (PALS) program, was developed as a peer mentoring tool to improve health behaviors, beliefs, and outcomes in African American (AA) women with systemic lupus erythematosus (SLE). This study aims to assess the cost of the PALS intervention and determine its effectiveness when compared to existing treatments.

Methods: Peer mentors and mentees were paired on shared criteria such as life stage, marital status, or whether they were mothers. This 12-week program consisted of a weekly peer mentoring session by telephone. Cost of healthcare utilization was evaluated by assessing the healthcare costs

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Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

pre- and post-intervention. Validated measures of quality of life, self- management, disease activity, depression, and anxiety were collected. Total direct program costs per participant were totaled and used to determine average per unit improvement in outcome measures. The benefit cost ratio and pre- versus post- intervention hospital charges were examined.

Results: 20 mentees and 7 mentors were enrolled in the PALS program. All PALS pairs completed 12 sessions lasting an average of 54 minutes. Mentees reported statistically significant decreases in patient reported disease activity, depression, and anxiety with improved trends in patient activation or patient engagement in their disease and management. The total cost per patient was \$1,882.83 and \$91.14 per patient per week. There was a savings of \$23,426 per individual receiving the intervention with a benefit cost ratio of 12.44 per patient.

Conclusion: These findings suggest that the PALS intervention was effective in improving patient-level factors and was cost-effective. Future research will need to validate these findings in a larger sample.

Keywords

Cost effectiveness; African American; women; systemic lupus erythematosus; peer mentoring

INTRODUCTION

Systemic lupus erythematosus (SLE) patients experience significantly increased healthcare costs over the course of their life due to frequent doctor visits and a complex medication regimen (1–4). The mean annual cost for SLE patients can reach up to \$62,651 with pharmaceutical costs, inpatient costs, and outpatient cost accounting for up to 30%, 50%, and 56%, respectively (5). This presents a major challenge for all patients diagnosed with SLE, but it is compounded in African American women who experience the disease at greater rates than any other portion of the population and are also subject to a more severe disease trajectory (6). Effective interventions to reduce disease burden, severity, and healthcare costs for African American women are needed.

African American women with SLE have been previously documented as receptive towards peer mentoring interventions in other chronic diseases, but it is a modality that has not been previously applied either in research or clinical care (7). In other low income and minority populations peer mentoring interventions have resulted in notable improvements in behaviors such as breast feeding, smoking cessation, and increased physical activity (8, 9) along with improved medication adherence and blood glucose monitoring in trials of people with diabetes (10, 11). These studies highlight the potential of peer mentoring as a culturally sensitive means to improving health behaviors and outcomes in low income and minority groups.

Moreover, previous behavioral intervention studies have not achieved targeted health outcomes in rheumatic conditions, including positive affect, sleep, social coping, and perception of bodily pain (12, 13). However, there is a newly developed intervention, the Peer Approaches to Lupus Self-Management (PALS) program, which was developed as a

targeted peer mentoring approach to improving health behaviors, beliefs, and outcomes in African American women with SLE.

The current study aims to assess the cost of the PALS intervention, both direct and indirect, and determine its effectiveness when compared to existing treatments. The study team hypothesized that the PALS program would result in an overall cost savings while offsetting some standard treatment costs.

MATERIALS AND METHODS

Participants

PALS peer mentors and mentees were recruited separately. All peer mentors and mentees were of African American race/ethnicity and female gender, had a clinical diagnosis of SLE from a physician, were 18 years of age or older, and were able to communicate in English. Mentors were required to have a disease duration > 2 years; able to attend scheduled training sessions; at least some college education due to their role that involves counseling, modeling, and delivering education; and demonstration of a high level of coping/self-efficacy (score ≥ 7 , range=0–10) as assessed by the Arthritis Self-Efficacy Scale (14). Competence, maturity, emotional stability, and verbal communication skills were determined by the PI prior to participating as a peer mentor, using interview questions that incorporated validated scales (15) and observation during role-playing interactions. After mentors completed their screening interview and training, they were each matched with a maximum of three mentees. Mentees were required to have a lower level of coping/self-efficacy (score < 7, range=0–10) as assessed by the Arthritis Self-Efficacy Scale (14), but there were no criteria regarding mentees' disease duration.

Intervention

After initial enrollment and baseline assessments, peer mentors and mentees were paired based on shared criteria such as life stage, marital status, or whether they were mothers, in order to encourage compatibility. The PALS program consisted of 12 weeks of peer mentoring that included one standard educational session by telephone for approximately 60 minutes every week. The weekly educational sessions were structured in three parts: introduction, structured education, and problem solving. Weekly content was adapted from the six modules of the Chronic Disease Self-Management Program (CDSMP) (16), Arthritis Self-Management Program (ASMP) (17), and Systemic Lupus Erythematosus Self-Help (SLESH) Course (18). The material was 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 (19–21). A description of the weekly content can be found in Table 1.

Data Collection

Mentees were assessed during study visits at baseline, mid-intervention (6 weeks post-enrollment), and immediately following the intervention (12 weeks post-enrollment). Primary outcomes included quality of life as measured by the lupus quality of life questionnaire (LUP-QOL) (22), a lupus-specific health-related quality of life (HRQoL)

questionnaire consisting of 34 items grouped in 8 domains: physical health, pain, planning, intimate relationships, burden to others, emotional health, body image and fatigue; self-management as measured by the Patient Activation Measure (PAM) (23); and disease activity measured by two methods: 1) patient self-report by the Systemic Lupus Activity Questionnaire (SLAQ) (24) and 2) immunologic evidence as Th1/Th2 cytokine balance in blood draws that were conducted at baseline and directly following the intervention (a detailed description of this methodology has been reported elsewhere) (25). Depression was measured using the PHQ-9, a brief questionnaire that scores each of the 9 DSM-IV criteria for depression as “0” (not at all) to “3” (nearly every day) (26). Anxiety was measured using the 7-item General Anxiety Disorder (GAD) scale (GAD-7) (27). Other predictor variables assessed are described in Williams et al. (2018)(15).

Cost of Implementing Intervention Program

To estimate the cost of the intervention per individual, we totaled salary of the mentors, overhead cost for the academic medical center, and supplies/equipment required to conduct the intervention (28). In order to estimate the effectiveness (depression, anxiety, disease activity) and benefits (hospitalization charges offsets) of PALS, we examined the hospitalization charges two months pre- and post-intervention for the 20 individuals diagnosed with SLE for whom all outcome measures were reported. We first totaled the hospitalization charges for the two-month time period incurred for each individual in the study at one academic medical center prior to the intervention. We then totaled the hospitalization charges for the two-month time period incurred for each individual at the academic medical center after they completed the intervention.

Statistical Analyses

The primary outcome of economic evaluation is to estimate: $(C_{\text{new}} - C_{\text{usualcare}}) / (E_{\text{new}} - E_{\text{usualcare}})$ where C is cost and E is effectiveness. The benefit cost ratio (BCR) was assessed as the ratio between discounted value of incremental benefits to discounted value of incremental costs. These methods are approved by the World Health Organization (WHO) and the US Guidelines for Cost-Effectiveness Analysis (29, 30). Student t tests were conducted to examine the differences in depression, anxiety, disease activity scores, and hospitalization charges pre- and post-intervention. We used STATA version 15 and set significance at $p < 0.05$.

RESULTS

Baseline Characteristics and Adherence to Intervention

Table 2 shows the baseline characteristics of the 23 mentees and 10 mentors enrolled in the peer mentoring program. Three mentees and one mentor were lost to follow-up over the course of the study, and two mentors remained as back-ups, but did not actively mentor participants. Our resulting analytical sample included 20 mentees and 7 mentors. Six mentors were each matched with three mentees, and one mentor was matched with two mentees. The majority of mentees and mentors were older than 35 years, unmarried, and college-educated. About 22% of mentees had a pre-existing diagnosis of lupus nephritis or reported other indicators of renal involvement, and approximately 17% of mentees reported

a recent history (last 3 months) of severe flares. Every mentoring pair completed all 12 of the sessions; however, 17 were delayed and took place later than originally scheduled due to scheduling conflicts. Mentors made an average of 1.24 calls to their mentees each week. Once contact was made, sessions lasted an average of 54.1 minutes (range 0–105 min). Although the option was available for additional in-person contact outside of weekly phone sessions, travel burden precluded this for all pairs.

Significant Findings

According to findings reported in Williams et al. (2018), at post-intervention, mentees reported statistically significant decreases in patient-reported disease activity (change score of 24.70 or 25% change in patient global assessment of overall lupus disease activity, $p < 0.001$) and improved trends in patient activation or patient engagement in their disease and management. We also observed statistically significant decreases in depression (change score of 2.62 or 11% change in Personal Health Questionnaire-8 (PHQ-8) score, $p = 0.05$) and anxiety (change score of 3.52 or 15% change in Generalized Anxiety Disorder-8 (GAD) score, $p = 0.018$) (15). As reported in Williams et al. (2017), analyses to detect correlations between patient reported outcomes and immunologic markers associated with disease activity revealed strongest correlations between the Generalized Anxiety Disorder measure and Th1/Th2 cytokine balance and weaker correlations between depression and the Th1/Th2 cytokine balance (25).

Costs of the Intervention Program

Table 3 shows cost per patient and cost per patient per week, accounting for staff salaries, project overhead, supplies and equipment. The largest cost categories per patient were for participant incentives and cell phones. The total cost per patient was \$1,882.83 and \$91.14 per patient per week. The effectiveness of the intervention was demonstrated by significant depression, anxiety and disease activity score decreases shown in Table 4. The cost-effectiveness ratio for anxiety was \$3,423 per 1 unit decrease in the GAD score. The cost-effectiveness ratio for depression was \$818 per 1 unit decrease in the PHQ-8 score. The cost-effectiveness ratio for disease activity was \$85.74 per 1 unit decrease in the SLAQ score. The benefits of the intervention consisted of the difference in pre- and post- two-month hospitalization charges for each individual who received the intervention. There was a statistically significant difference in pre-hospitalization charges (\$24,289, 95% CI: \$55, \$48,524) and post-hospitalization charges (\$872, 95% CI: -\$324, \$2,070) ($p = 0.047$). This represents a substantial mean charge savings of \$23,426 per individual receiving the intervention. The benefit cost ratio was 12.44 per patient which implies that benefits were over 12 times higher than the cost per patient.

DISCUSSION

Our findings indicate that the PALS intervention was cost-effective, compared to standard treatment. The overall intervention cost per person was \$1,882, with each of the 12 sessions lasting on average 54 minutes. Compared to standard treatment, PALS offers \$23,426 cost savings per person following three months of intervention, according to pre- and post-intervention hospitalization costs. In addition to cost savings, the intervention resulted in

statistically significant decreases in patient-level factors such as depression, anxiety, and self-reported disease activity. Therefore, the PALS intervention appears to reduce disease burden, as well as healthcare costs.

Our results are consistent with studies, of predominantly low income and minority populations, showing that peer mentors help support healthy behaviors including breast feeding, smoking cessation, increased physical activity, and maintenance of weight loss (31–35), along with improved medication adherence and blood glucose monitoring in trials of people with diabetes (10, 11, 36–38). Until now, the extent to which peer mentors are effective in African American women with lupus had yet to be determined. PALS is the first peer mentoring intervention targeting African American women with lupus. This novel peer mentoring program built on previous literature outlining the potential benefits of peer mentoring in African American women living with lupus (39), and incorporated reciprocal relationships, mechanism for creating a complimentary social support network, sharing of knowledge and experience, and reinforcement of necessary self-management skills that led to improved outcomes (39).

These benefits are powerful because lupus disproportionately impacts African American women, and it is important to be aware of promising approaches that may minimize this disparity, while still being cost effective due to the use of peer social networks. The potential of this approach to cut costs is particularly meaningful in our study sample, since nearly a quarter of our participants reported renal involvement and recent severe flares. These characteristics are traditionally associated with higher costs. Khamashta et al. (2014) observed that patients with severe SLE had 2.2 times higher costs than patients with non-severe disease. SLE renal involvement and severe flares were associated with higher annual direct costs, indicating the need for early intervention to minimize renal disease impact and mitigate long-term costs (40). SLE patients diagnosed earlier experience lower flare rates, less healthcare utilization, and lower costs (41), and the peer mentoring approach also has the potential to encourage earlier and more comprehensive participation in the health care system.

Peer mentoring can have positive effects on cost, utilization, and health outcomes, and it may also increase access to culturally sensitive care for African American women living with lupus. Individuals tend to have less access to care based on several factors, including lack of transportation, childcare, or health insurance and also issues surrounding cultural or historical events (42). These issues compounded with lack of access to care are sometimes magnified for minorities (43) and people living with lupus (44). According to the Agency for Healthcare Research and Quality (2017), one component of receiving access to quality care is having communication and trust with health care providers (45). Peer mentoring may promote culturally sensitive care and allow minority women to discuss aspects of care they may not feel comfortable discussing with health care providers due to distrust in health care systems and providers. Women living with lupus mentioned how a peer supporter may offer help from feelings of isolation because they felt they could not discuss certain matters with their physician (7). One focus group participant mentioned how she felt the physician was impersonal and rushed her (7). The PALS peer mentoring program may, in fact, provide a

more convenient approach to accessing culturally sensitive care from supporters, ultimately increasing access to care, support, and health information regarding the disease.

Another benefit of the PALS peer mentoring program is the telehealth approach to providing support for African American women living with lupus. The characteristics of telehealth (e.g. remote conferencing) may increase access to care, reduce travel burdens, and enhance patient satisfaction regarding convenience and access to health information. Telehealth programs geared towards patients with chronic illnesses have seen increases in patient satisfaction for those living with asthma (46) and sleep apnea (47, 48). The PALS peer mentoring program has multiple advantageous features, including the telehealth component, culturally sensitive care, and patient-centered care that can impact various outcomes like access to health information, patient satisfaction, and costs. Since peer mentors are usually individuals who have successfully coped with the specified disease, they can be instrumental in identifying life goals and problem-solving (39, 49), as well as reducing pressure on providers (50) to assess and resolve ancillary life issues related to healthcare utilization costs.

As an exploratory pilot study, PALS is not exempt of limitations, which we have carefully considered and used as learning experiences to further refine the intervention program going forward. First, there was not a control group, which limits our ability to determine the effectiveness of the peer mentoring program compared with usual care of lupus patients. However, cost estimates two months before and two months after the intervention allowed evaluation of incurred costs with and without the intervention. Also, costs associated with other medical facilities and paid caregivers were not examined, along with direct non-medical care costs such as patient transportation, childcare if needed during visits, and costs incurred by other family members who may have been involved in transporting patients to visits. We were also unable to obtain indirect costs including costs associated with lost wages incurred from taking time off work for intervention visits. We also did not assess current medications, which could impact findings related to disease activity. Lastly, we did not collect patient reported outcomes from our mentors, and so were unable to assess how the program impacted their health and associated costs. All of these limitations have been addressed and corresponding information will be collected in the expanded PALS randomized clinical trial. Additional limitations that could potentially contribute to undetected bias include the study design, selection of a distinct SLE population who may be of higher education and income than the general SLE population, small sample size, and lack of multivariate analysis.

Overall, we were able to show that a peer mentoring program for AA women with lupus incorporating structured education and support improves relevant outcomes and reduces hospitalization costs. This suggests that if adopted on a larger scale, this approach has the potential to significantly reduce financial burden on both patients and medical facilities, as well as improve the quality of life of a high-risk patient population.

Funding

This work was supported by the South Carolina Clinical & Translational Research (SCTR) Institute, with an academic home at the Medical University of South Carolina CTSA, NIH/NCATS Grant Number UL1 TR001450 and the Rheumatology and Immunology MCRC NIH/NIAMS Grant Number AR062755.

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Table 1:

Weekly Session Content

Week	Session Topic	Detailed Content
1	Goal setting/ action planning	Introduction to SLE management and a chance for the mentee to get to know the mentor
2	Exercise	Appropriate exercise for maintaining and improving strength, flexibility, and endurance
3	Medication overview	Appropriate use of medications and evaluation of new treatments/ making informed decisions
4	Effective communication	Communicating effectively with family, friend, and health professionals
5	Nutrition/ healthy eating	Sessions five will stress nutrition and healthy eating
6	Stress relaxation techniques	Relaxation techniques to cope with chronic pain, manage sudden increases in pain and other symptoms and reduce flares
7	Coping	Coping, including problem solving and strategies for coping with pain, other lupus symptoms, and interpersonal issues
8	Body image	Body image issues, including concerns around hair loss, skin discoloration and scarring, and medication-induced weight gain
9	Complications	Complications (e.g. kidney disease, digestive issues, pregnancy outcomes) fatalism-fear of complications and how that impacts perception of survival, and self-efficacy
10	Self-monitoring	Self-monitoring and depression
11	Sexuality/ sexual health	Sexuality/ sexual health, including spousal interactions and dating
12	Trust	Perceptions of care from doctor(s), impact on adherence, seeking second opinions, perceived discrimination, and perceived cultural competence of provider(s); Review of material from all previous sections; Feedback on program, discussion of any progress made

Table 2:

Baseline characteristics of Mentees and Mentors

Variable	Mentee N (%)	Mentor N (%)	P value
Age (years)			0.39
<25	2 (8.7)	0 (0.0)	
25–34	2 (8.7)	3 (30.0)	
35–44	8 (34.8)	3 (30.0)	
45–54	5 (21.7)	1 (10.0)	
55–64	1 (4.4)	2 (20.0)	
>65	5 (21.7)	1 (10.0)	
Marital Status			0.15
Married	2 (8.7)	3 (30.0)	
Other	21 (91.3)	8 (80.0)	
Education			0.65
<High School	3 (13.7)	0 (0.0)	
High School	2 (9.1)	8 (80.0)	
Some College	3 (13.7)	0 (0.0)	
College Graduate	14 (63.6)	8 (80.0)	
Income			0.17
<\$15,000	5 (21.7)	0 (0.0)	
\$15,000–34,999	6 (26.1)	3 (33.3)	
\$35,000–64,999	5 (21.7)	1 (11.1)	
\$65,000	2 (8.7)	4 (44.4)	
Other/No response	5 (21.7)	1 (11.1)	
Renal involvement			
History of transplant	3 (13.7)		
History of dialysis	2 (9.1)		
Lupus Nephritis	5 (21.7)	5 (50.0)	
Flares in last 3 months			
None	6 (26.1)		
Mild	6 (26.1)		
Moderate	7 (30.4)		
Severe	4 (17.4)		

Table 3:

Costs of Implementing the Peer Mentoring Program

Variable	Cost Per Mentee	Cost Per Week Per Mentee
Lab Fees	\$35.75	\$2.97
Research Support	\$40.00	\$3.33
Consultant/Contractual	\$60.00	\$5.00
Participant Incentives	\$572.50	\$47.71
Cell Phones	\$494.58	\$24.73
Supplies	\$88.67	\$7.39
Total	\$1882.83	\$91.14

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Table 4:

Outcomes of the Peer Mentoring Program

Outcome	Pre-Intervention Mean (95% CI)	Post-Intervention Mean (95% CI)	P value	C/E
Depression	7.7 (5.25, 10.14)	5.4 (3.57, 7.22)	0.024	\$818
Anxiety	1.75 (1.11, 2.39)	1.2 (0.75, 1.64)	0.017	\$3,423
Disease Activity (SLAQ)	28.2 (13.83, 42.57)	6.25 (5.20, 7.30)	0.004	\$85.74
BCR				
Healthcare Costs	\$24,289 (55.51, 48524)	\$872 (-324, 2070)	0.047	12.44

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