Published in final edited form as:

Am J Med Sci. 2017 June ; 353(6): 580–592. doi:10.1016/j.amjms.2017.01.011.

Effective Self-Management Interventions for Patients With Lupus: Potential Impact of Peer Mentoring

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Abstract

Systemic lupus erythematosus (SLE) is associated with significant mortality, morbidity and cost for the individual patient and society. In the United States, African Americans (AAs) have 3–4 times greater prevalence of lupus, risk of developing lupus at an earlier age and lupus-related disease activity, organ damage and mortality compared with whites. Evidence-based self-management interventions that incorporate both social support and health education have reduced pain, improved function and delayed disability among patients with lupus. However, AAs and women are still disproportionately affected by lupus. This article presents the argument that peer mentoring may be an especially effective intervention approach for AA women with SLE. SLE peers with a track record of success in lupus management and have a personal perspective that clinicians often lack. This commonality and credibility can establish trust, increase communication and, in turn, decrease disparities in healthcare outcomes.

Keywords

Systemic lupus erythematosus; Peer mentoring; African American; Women

INTRODUCTION

The Burden of Lupus

Systemic lupus erythematosus (SLE or lupus) is a significant global public health problem. The prevalence of lupus ranges from approximately 40 cases per 100,000 persons among Northern Europeans to more than 200 per 100,000 persons among blacks.^{1–3} In the United States, the number of patients with lupus exceeds 250,000. Although the life expectancy of lupus patients has improved from an approximate 4-year survival rate of 50% in the 1950s to a 15-year survival rate exceeding 80% today, a patient diagnosed with lupus at 20 years of age still has a 1 in 6 chance of death by 35 years of age.⁴ In the United States, the highest

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The authors have no conflicts of interest to disclose.

lupus morbidity and mortality rates are among African American (AA) women.^{5–7} SLE affects approximately 1 in 250 AA women of child-bearing age, and AAs overall have 3–4 times greater prevalence of lupus, risk of developing lupus at an earlier age and lupus-related disease activity, organ damage and mortality compared with whites.^{1–3,8–19} Annual costs associated with SLE are estimated to be \$10,000–50,000 more than those for patients without SLE, with severe flares and more major organ involvement incurring the highest costs.^{20–40} Major cost drivers include areas where AAs with lupus are disproportionately represented, such as inpatient hospitalizations,^{36,41,42} long disease duration, high disease activity and organ damage, poor physical and mental health and low education and employment levels.

SLE is a chronic autoimmune disease with periodic flare-ups of severe symptoms affecting any organ system and resulting in potentially life-threatening complications.^{43–45} Patients often experience a high degree of psychological symptoms (45–65% of patients), including anxiety, psychiatric and mood disorders, with depression appearing most frequently.^{46–54} All domains of the health-related quality of life in patients with SLE are significantly worse and decline at an earlier age when compared to females in the general U.S. population and patients with other common chronic diseases such as hypertension, diabetes and myocardial infarction.^{51,52,55–71}

AAs and Lupus

Studies have shown that the disproportionate burden of lupus among AAs negatively affects quality of life^{72–76} and coping ability.⁷⁷ Some have positioned elevated rates of SLE in AA women in the context of “immune cognition”. This suggests that the disease, for these women, is a physical manifestation of patterns of stress, discrimination and social disadvantage.^{58,74,75,78–92} In addition to managing disease-specific stressors, it has been suggested that AAs are exposed to a unique set of risk factors that lead to a pattern of cumulative disadvantage over time.^{78,79} High rates of unemployment, poverty, violent crime, incarceration and homicide among AA adults reflect this accumulation of disadvantage at multiple transition points during their development and across the life course.^{80–92}

Need for Culturally-Tailored Approach

Programs are needed to address the barriers AA women face in effectively managing their disease because of the implications of poor disease control in this population. Several studies have evaluated barriers to patient adherence. Most relate to understanding the medical regimen, trust in the provider and communication with providers. Much of this hinges on patient subjective norms, cultural, social support networks, mental health and education.⁹³ For instance, depression is an independent predictor of medication adherence and use of emergency room visits in patients with SLE.⁶⁸ Many patients lack the education, social support, self-efficacy and trust necessary for effective medication and appointment adherence.⁹⁴ Many of the differences in outcomes parsed by self-described race may not be genetic in origin and, therefore, may be modifiable. Thus, it is critical to address the modifiable risk factors in patients with SLE to reduce health disparities in this high-risk group. Peer mentoring interventions are effective in other chronic conditions that disproportionately affect minorities, such as diabetes, human immunodeficiency virus and

kidney disease, but there is currently no empirically tested peer mentoring intervention developed for patients with SLE. This review focuses on peer mentoring interventions for AA women with SLE as an approach to improving measures of disease condition.

Treatment of SLE

Although SLE has no known cure, successful treatment depends upon addressing both symptoms and the underlying inflammation. Treatment of SLE includes a variety of medications, including nonsteroidal anti-inflammatory medications, corticosteroids, antimalarials, cytotoxic agents, B-cell targeting biologics and immunosuppressive drugs.^{95–97} However, lifestyle modifications, such as avoiding overexposure to sunlight, stress management, smoking cessation and a diet low in saturated and trans fats, are also very important.^{95,96}

Evidence-based Prevention Programs

A large body of evidence has suggested that therapeutic interventions should be proposed to reduce psychological distress to improve quality of life and possibly moderate the evolution of chronic and unpredictable diseases like SLE.⁹⁸ Cognitive behavioral stress management techniques have resulted in short-term improvement in pain, psychological function and perceived physical function in SLE.⁸⁸ Additionally, psychoeducation⁹⁹ and graded aerobic exercise¹⁰⁰ have been shown to be useful in the management of fatigue. Programs designed to reduce stress levels of chronically ill patients have also included support therapy, lifestyle interventions incorporating elements of yoga or other similar disciplines and minisessions on depression, adaptive coping strategies and body image.^{88–90}

Disease self-management has also demonstrated significant impact on disease and general wellness.^{11,101–114} Evidence-based self-management interventions designed to enhance social support and provide health education, among patients with lupus, have reduced pain, improved function and delayed disability.^{11,101,103–115} Although there is no generally accepted self-management program available for SLE,⁵⁸ 2 programs that have been shown to be successful in improving conditions in patients with arthritis are the Arthritis Self-Management Program and the generic Chronic Disease Self-Management Program. Each program incorporates 6 weeks of peer-led sessions ranging in disease-specific and more general self-help content. Arthritis self-management education delivered by small-group, home study, computer and Internet modalities have demonstrated significant improvements in health distress, self-reported global health and activity limitation, with trends toward improvement in self-efficacy and mental stress management.^{92,112,117–138} AAs and women are still disproportionately affected by lupus.^{1,2,68,72–77,139,140} Persistent disparities may be due to the nonresponsiveness of existing programs to the unique needs of AAs and women with lupus.^{3,116,141–149}

Unmet Needs

As illustrated in the Figure, evidence suggests that many patients with SLE have treatment and disease management needs that are not addressed by current care methods. In a study of patients with SLE, Danoff-Burg and Friedberg⁵⁸ found that AA patients were more likely than white patients to have higher levels of unmet needs related to health services and

information. These domains included issues such as (1) receiving adequate information from medical staff about treatment side effects, (2) having access to telephone support and advisory services and (3) having assistance with knowing which symptoms should trigger a doctor visit.⁵⁸ Their findings have been supported by other studies that have documented similar patient concerns around unmet information and support needs.^{150–158}

Overall, AA patients with lupus face multiple illness-related problems, and evidence suggests that some of these problems can be ameliorated with cognitive behavioral interventions without adverse effect. Several studies have emphasized the need to design interventions that address barriers to participation and curtail noncompliance,^{159–162} particularly for AA patients. Practicing physicians continue to struggle with patient compliance, poor adherence to therapeutic regimens and failure of patients to keep scheduled appointments. For example, Gladman et al (2000) found that physicians rated African Americans as less globally adherent than whites (43.5% versus 66.3% adherent, respectively).¹⁶³ Compliance is also a persistent problem in standardized arthritis self-management education programs. One study reported that less than 50% of a closed eligible population participated, even when Internet and small-group programs were offered repeatedly over many years.¹⁶⁴ This suggests that interventions may not be reaching the largest portion of patients with lupus, and many vulnerable populations have not been included in study samples.^{122,124,127,132,165–168}

This combination of persistent unmet needs in AA women with SLE and evidence of the effectiveness of programming in reducing risk suggests that the ideal interventional approach for this unique population will reinforce self-management skills in a format that is socially and culturally consistent. For patients with SLE, the perception of not having their experience understood by others may lead to social isolation and otherwise negatively affect personal and professional interactions.^{3,141,142} Peers who have experience in managing their lupus may be in a better position to share knowledge and experience with which others may often not be able to relate. This can establish trust and, in turn, decrease disparities in healthcare outcomes. Table 1 summarizes the major benefits of peer mentoring presented and specific unmet needs of AA women with SLE that this model could potentially address.

The need for such a program is further reinforced by a qualitative study of predominantly AA women with SLE from medically underserved communities, in which 69% favored a peer support intervention to improve care.¹⁴⁹ This information indicates that a peer mentoring program for AA women with SLE is generally favored by the population affected and could lead to notable increases in positive health outcomes.

DISCUSSION

Evidence for Peer Mentoring

Peer support provides a mechanism for creating a social network on a small scale that augments existing social supports and in which a person receives “support from a person who has experiential knowledge of a specific behavior or stressors and similar characteristics”.^{169–172} Heisler has posited 7 variations of peer support which include professional-led group visits, peer-led self-management training, peer coaches, community

health workers, support groups, telephone-based peer support and web- and e-mail-based programs.¹⁷⁸

A more informal, flexible means of providing 1–1 peer support is through volunteer peer coaches or mentors. Peer mentors are usually individuals who have successfully coped with the same condition.¹⁷⁴ Informal peer mentoring is an essential element in Alcoholics Anonymous in which a person who has been sober for an extended time “sponsors” an individual struggling with sobriety. In formal interventions, coaches receive training focused on communication skills, including empathetic listening, helping mentees clarify life goals and problem-solving with the aim of having the mentor support the mentee.^{173,175}

The Impact of Peer Mentoring on Chronic Disease

Mentoring by trained peers reinforces self-management skills and activities and has led to enhanced patient engagement and resulted in improved outcomes among patients across a number of chronic conditions.^{175–186} Table 2 shows that peer mentoring efforts have demonstrated improvements in quality of life,^{187–189} adherence,^{191–193} self-management^{194–198} and disease activity^{197,198} in a variety of conditions. For example, peer support has been shown in patients with diabetes mellitus (DM) to improve medication adherence, diet, exercise and blood glucose monitoring.^{212–215} Interestingly, this relationship may be just as beneficial to the supporters as it is to the person being supported, as supporters themselves exhibit decreased depressive symptoms, improved self-esteem and improved health behaviors.^{115,216}

The success of peer mentoring has been attributed to the nonhierarchical, reciprocal relationship that is created by sharing similar experiences and the tendency of peer mentoring relationships to be consistent with the individual’s social and cultural beliefs.^{173,199,200} There is some evidence that peer mentors may be particularly effective in low-income and minority groups in whom trust in the healthcare system may be lower than in the general population.²⁰² In one study of peer mentors to promote advance directive planning in patients on dialysis, the influence of the peer mentoring intervention was only observed among AA patients and not among the white patients.²⁰³ In total, 45% of AAs in the peer mentor arm completed an advance directive compared with only 5% in usual care. Among AAs, peer mentoring had a variety of additional beneficial effects, increasing well-being, decreasing anxiety and decreasing suicidal ideation. In studies of predominantly low-income and minority populations, peer mentors have been shown to help support healthy behaviors including breastfeeding, smoking cessation, increased physical activity and maintenance of weight loss.^{178,179,183–185,187,188,190–193,203–210} These studies highlight the potential of peer mentoring as a culturally sensitive means to improving health behaviors and outcomes in minority populations,^{149,170,198,202,211,217} but there is no such peer mentoring intervention developed for patients with SLE. There is some evidence that peer mentoring has also led to improvements in positive affect, sleep, social coping and perception of bodily pain in rheumatic conditions.^{189,218}

Opportunities for Peer Mentoring in SLE

The closest documented effort to peer mentoring in SLE may be the Hospital for Special Surgery's Lupus-Line, a free telephone counseling service staffed by trained volunteers who have SLE or are close family or friends of people living with lupus.^{219,220} The service began in 1988 as a 2-year pilot program and offers ongoing emotional support by telephone to peers with SLE and their relatives. The mission of the program is to enhance coping, self-esteem, and health-related behaviors and to reduce feelings of isolation and anxiety common to individuals living with SLE. Contact must be initiated by the caller, who is then professionally screened by a social worker before being matched with a volunteer. In follow-up evaluations, more than 60% of respondents reported feeling better able to cope, more in control, less depressed, less anxious and less alone, along with better understanding and talking more comfortably with others about their lupus, and attributed these changes to the utilization of LupusLine,²²¹ but most callers (60%) have been white, whereas 16% of callers were AA.

Whether peer mentoring might be more effective at involving minority patients with SLE compared with other approaches has yet to be explored. However, empirical data on the effectiveness of peer support interventions in populations that have been traditionally harder to reach suggest that it may be more effective among these groups compared with other groups. In 5 studies of moderators,^{222–226} greater benefit of peer support occurred among those who were more disadvantaged (e.g., those with lower health literacy, socioeconomic status, social support, self-management, medication adherence, self-efficacy, education and rural area of residence). A peer-mentorship model may ensure more precise matching with respect to cultural background and be a good way to provide counseling if resources are limited.

Given rapidly rising healthcare costs, the efficacy and cost-effectiveness of peer mentoring programs in SLE should be studied further. The heterogeneity of disease manifestations and organ damage in SLE support the notion that mentoring approaches might be even more effective if they were tailored to different disease manifestations such as arthritis, nephritis and rash. Because psychosocial factors affect outcomes in SLE, and peer mentoring could positively affect these factors, further study could provide evidence on whether this approach helps to reduce avoidable, expensive care.

CONCLUSIONS

Given the success of the peer mentoring approach in many chronic conditions that disproportionately affect minorities, and its responsiveness to the needs of this unique population, more work into the effect of peer mentoring in specific disease populations where research is lacking, like SLE, could result in health improvements that have not been attainable with other interventions.

Patients with SLE are faced with a wide variety of symptoms that can have profound effects on their overall quality of life. Specifically, AA women have the highest risk of lupus and its complications. In addition to longer disease duration and greater disease activity, AA ethnicity has been associated with poorer treatment adherence and outcomes.^{159,160,163} In

addition to managing disease-specific stressors, it has been suggested that AAs are exposed to a unique set of risk factors that lead to a pattern of cumulative disadvantage over time^{78,79}. Thus, along with traditional medical treatments, self-management education delivered in a culturally sensitive way could improve clinical outcomes in patients at higher risk. Providing patients having lupus with information alleviates anxiety, enables the individual to cope, facilitates awareness, increases adherence and leads to improved self-management adherence.^{150,153,227} Peer mentoring may be an effective way to reinforce self-management techniques by having content shared and modeled in a reciprocal relationship. Mentoring goes beyond providing information. Patients are interested in obtaining an unbiased perspective of available treatments and learning about different coping strategies from independent organizations, such as support groups or patient organizations.^{156,228} Furthermore, it is well known that patients who are actively engaged experience improved health outcomes.^{229,230} In SLE, patients' ability to cope with their disease is also directly related to their quality of life,^{231–234} so a lupus peer mentoring program could incorporate important patient-centered information and better engage patients to increase their self-management and coping skills to improve disease condition. This could significantly reduce disparities and have considerable public health impact.

ACKNOWLEDGMENTS

This project was supported by the South Carolina Clinical & Translational Research (SCTR) Institute, with an academic home at the Medical University of South Carolina CTSA, National Institutes of Health/National Center for Advancing Translational Sciences Grant Number UL1 TR001450. The contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH or NCATS.

This project 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.

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FIGURE.
Conceptual model of the status of the field: Needs not met by current evidence-based prevention programs that peer mentoring could address.

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TABLE 1.

Potential impact of peer mentoring in African American women with SLE.

Unmet need addressed	Benefits of peer mentoring
Distrust in the healthcare system ^{93,94,204}	Reciprocal relationship that is created through sharing similar life experiences ^{106,201,202,218}
Having access to telephone support and advisory services ^{58,94,152-160}	Mechanism for creating a small social network that augments existing social supports ¹⁷¹⁻¹⁷⁴
Getting adequate information about treatment side effects, needing assistance with knowing when to see the doctor ¹⁵²⁻¹⁶⁰	Sharing of knowledge and experience; reliability ¹⁷⁵
Compliance and medication adherence barriers ¹⁶¹⁻¹⁷⁵	Reinforcement of self-management skills that has led to enhanced patient engagement and improved outcomes ¹⁷⁷⁻²⁰⁰

TABLE 2.

Peer mentoring style and its effect on various conditions and states of health.

Condition	Peer mentoring components	Associated outcomes in mentees	Reference
Chronic diseases	Various; concept analysis of 13 previous peer support studies	Sense of connection, experiential knowledge, finding meaning, reduced feelings of isolation, reciprocity, role satisfaction, changed outlook, behavior change and empowerment	202
<i>Diabetes</i>			
Diabetes	Experiential knowledge given from mentor to mentee	Treatment adherence and reduced uncertainty/fear	172
Diabetes	Face-to-face meeting and phone calls; development of action plans and self-management goals	Lower hemoglobin A1C levels	227
Diabetes	Discussions, self-care goals and actions plans to achieve them	More phone calls between mentors and mentees associated with greater impact on A1C levels	228
Type 2 diabetes	In-home visits from an experienced peer to newly diagnosed patients; set goals, provided support, self-management coaching	Improvement in self-efficacy, coping and saturated fat intake over time	229
Type 2 diabetes	Personalized feedback on physical activity, support and motivation from trained mentors; group and telephone contact	Higher daily pedometer readings, improvement in duration and frequency of moderate intensity physical activity, higher scores on the Physical Activity Scale for the Elderly and 6-minute walk test, and reported increased social support from friends	182
Type 2 diabetes	Information on physical activity, nutrition and education programming (structured education)	Significant reductions in observed waist circumference and BMI z scores, improvement in knowledge of healthy dietary choices	187
Diabetes	Large-group education sessions, small-group mentoring sessions, individual peer mentoring, structured education	Decrease in hemoglobin A1C and improved self-management	196
Diabetes	Diabetes foot care and self-management workshops led by peer mentors and healthcare professionals (structured education)	Increased knowledge and changes to foot care self-management behaviors	197
Diabetes	Interactive peer-led classes (structured education)	Reduced hemoglobin A1C, diastolic blood pressure and improvements in cholesterol levels	200
Diabetes	Face-to-face meeting, weekly phone calls focused on addressing barriers to behavior change and self-efficacy	Progress toward behavior changes	215
Non-insulin-dependent elderly diabetes patients	Structured education and peer support sessions	Increased levels of perceived support, moderate weight loss and reduction of glycosylated hemoglobin	216
Type 2 diabetes in African American women	Group sessions, monthly sessions with a nutritionist, monthly phone calls from a peer counselor (provided social support and reinforced behavior change goals)	Increased physical activity	217
Diabetes in African American veterans	Phone calls to provide support, encouragement and assist with goal setting	Reductions in hemoglobin A1C levels	221
<i>Cardiovascular</i>			
Old age	Informal and formal support to others	Increased personal control and reduced depressive symptoms	176
Old age	Exercise programs, support	Physical, mental and social functioning improvement	195

Condition	Peer mentoring components	Associated outcomes in mentees	Reference
Chronic heart and lung diseases	Lessons (education) and visual displays	Positive behavioral changes in the areas of physical activity, nutrition and tobacco use	180
Physical activity and cardiovascular fitness	Peer mentor co-led (coupled with study staff) lunches, active play (structured education, modeling, leadership), information, goal setting	Increased physical activity and improved VO ₂ max (indicator of cardiovascular health)	181
<i>Injury</i>			
Traumatic brain injury	Telephone or face-to-face contact mentors were trained to provide information (education) to their mentees	Improved behavioral control, less chaotic living environment, lower alcohol use, less emotion-focused and avoidance coping and improved physical quality of life	183
Traumatic brain injury	Semi-informal partnerships between trained mentors and mentees	Increased knowledge (about TBIs), improved quality of life, improved general outlook and enhanced depression coping	184
Spinal cord injury	Increased communication and relationship building	Improved self-efficacy, reduced complications and doctor visits	199
<i>Maternal and child health</i>			
Pregnant women living with HIV	Group sessions led by trained peer mentors	Increased likelihood to ask their partner to get tested for HIV, better protected their infants from transmission, less likely to have depressive symptoms or an infant with stunted growth	185,190
Pregnant women with HIV	Education about HIV, stigma, protecting their children, encouraging testing, etc. (prevention education, communication) Sessions of a culturally adapted cognitive behavioral intervention (structured education, coping) led by mentors; support of a trained mentor mother (increased communication)	Improved practices to prevent mother to child transmission, increased social support, reduced depression, trends toward better attendance to follow-up medical visits, improvements in positive coping, improved HIV knowledge scores	189
Breastfeeding	Meetings with a trained peer counselor	Increased rates of exclusive breastfeeding	207,209
Breastfeeding	Education about exclusive breastfeeding, general counseling	Increased breastfeeding rates	208
Breastfeeding	In-person and phone meetings with experienced and trained peer counselors	Increased rates of breastfeeding, lower rates of having stopped breastfeeding at follow-up	210
Breastfeeding in a low-income rural population	Prenatal home visit (structured education and screening for inverted nipples), daily perinatal visits (hands on demonstration of breastfeeding practices), postpartum home visits and telephone contact as needed (general support and counseling) Contact between trained mentors and mentees; prenatal sessions, postpartum visit to the hospital, phone numbers exchanged to encourage further communication	Higher breastfeeding initiation rates and duration	214
Smoking cessation among pregnant women	Peer counselors trained to encourage quitting, communicate care and concern, encourage coping and reinforce educational information	Reduced cigarettes smoked daily	212
<i>Cancer-related</i>			
Breast cancer (survivors)	Information, encouragement, and guidance from trained peer mentors	Higher physical function, emotional well-being, social functioning and vitality	171

Condition	Peer mentoring components	Associated outcomes in mentees	Reference
Smoking cessation among cancer survivors	Calls from a trained peer counselor to enhance self-efficacy, social support, education, goal setting, and feedback, tailored materials, free nicotine replacement therapy	More calls completed with the peer mentor was correlated with a higher quit rate	211
<i>Organ failure</i>			
Pediatric liver transplant patients	Trained mentors were paired with similar mentees, and interacted by text, e-mail, social media and face to face	Improvements in treatment adherence	192
Cystinosis	Informal mentoring, modeling, support	Medication adherence	177
Heart failure	Automated system to assist with calling/reminders, telephone intervention (support and increased communication)	Reduced depressive symptoms	173
Heart failure	Face-to-face meetings and phone calls	Improved self-management and self-efficacy	174
<i>Mental health</i>			
Recurring substance abuse in veterans	Open-ended individual contact and group sessions run by peer mentors (structured education, group meetings, coping, increased communication)	Increased attendance to follow-up medical appointments	194
Mental illness	Sessions facilitated by trained mentors	Improved knowledge and management of illness, feelings of being less powerless and more confident, connection with others and completion of an advance directive	198
Mental disorders	Online peer-assisted treatment maintenance program focused on support and sustained utilization of skills (psychotherapy)	Improvements in skills	230
<i>Rheumatic</i>			
End-stage renal disease	Peer delivered information about completing advanced directives (education); phones call and in-person meetings, informal support sessions (coping)	Increased completion of and comfort with discussing advanced directives (AD), improved subjective well-being and anxiety	203
Diffuse chronic pain	Phones sessions, slideshow presentations based on cognitive behavioral principles (coping, increased communication, social support)	Improved sleep health (slept longer and took less time to fall asleep), improvements in social coping, global mood measures, global health, behavior, self-esteem, reductions in bodily pain	191
Early inflammatory arthritis	Peer mentors were trained and paired with a mentee to receive weekly face-to-face or telephone support	Improvements in the overall arthritis impact on life, coping efficacy, social support and perceived emotional, informational, appraisal and instrumental support	223
SLE	Phone peer counseling service providing support and guidance from trained call takers	Most users reported feeling that they could better cope with lupus, better understood lupus, were more in control and felt less depressed, anxious or alone	224

BMI, body mass index; HIV, human immunodeficiency virus; SLE, systemic lupus erythematosus.