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Compliance in the Peer Approaches to Lupus Self-Management (PALS) Study: Program Evaluation and Comparison to Existing Support Modalities for Patients with Rheumatic Conditions

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Abstract

Background: Peer Approaches to Lupus Self-Management (PALS) was a peer support program tailored to the population most affect by systemic lupus erythematosus (SLE); African American women.

Methods: Compliance in the PALS study was measured as weekly phone call sessions completed by each mentoring pair. Additional compliance data were collected from other interventions providing peer support and education with the purpose of improving quality of life and/or disease activity. Compliance data were compared to determine factors associated with higher levels of compliance in this disease population.

Results: PALS proved to be a highly acceptable intervention with regard to the counseling, support, and education extended to lupus patients. Compliance data from the program showed that it was highly accessible with 100% of users in the study period completing all of the weekly mentoring sessions. Compared to other interventions, which reported compliance rates ranging from <50-82%, patients in the PALS program were much more compliant to protocols and schedules. PALS compliance was most similar to that of the LupusLine® peer support telephone program, which achieved 97% compliance.

Conclusions: Despite limitations, results indicate patient satisfaction, positive impact, and increased compliance with the approach of the PALS study. Other programs in similar populations struggle with compliance, whereas PALS and LupusLine® users were highly compliant. A factor common to both programs was the use of trained peers to deliver support via telephone calls, possibly indicating that this delivery method may be particularly effective for promoting compliance in this population.

Keywords: Systemic lupus erythematosus; Peer mentoring; Program evaluation; Social support; African American; Women; Compliance

Introduction

Systemic lupus erythematosus (SLE) is a complex chronic autoimmune disorder that causes substantial morbidity and mortality and results in significantly reduced health related quality of life among those affected [1]. Primarily the disease manifests in inflammation that can affect any organ system or part of the body and most often occurs in periods of flares interspersed by periods of reduced disease activity [1]. Noteworthy advances in the treatment of the disease have been implemented in recent decades and have wrought important improvements in life expectancy and quality of life, however no cure yet exists and traditional medical treatments carry notable side effects [2]. For these reasons, other disease management modalities have gained increasing attention in research and patient care [3-6].

One such example is peer mentoring, which may provide specific benefits to patients disproportionately affected by the disease, such as African American women [6]. Furthermore, phone support programs specific to individuals with chronic diseases have been posited and previously tested, in conditions such as cancer and retinal diseases, as a

cost effective means to provide support and education [7-10]. The Peer Approaches to Lupus Self-Management (PALS) intervention is one such program that combines these two strategies in order to provide an intervention that is easily accessible to patients with SLE. This investigation seeks to assess PALS participant compliance with the weekly phone support regimen that the program entailed. Additionally, by comparing compliance data from PALS to several other support and management modalities in SLE and rheumatic disease, this work seeks to explore the relationship between compliance and delivery methods in order to better understand the needs of rheumatic patients and how best to deliver non-pharmaceutical interventions.

Methods

Detailed Description of PALS

The PALS feasibility pilot study enrolled 27 African American women with SLE, 7 of which served as mentors while the remaining 20 served as mentees. Sample size was not determined for statistical power as the primary aim of the study was to determine program feasibility and acceptability. The sample was limited to African American women due to the disproportionate severity and frequency

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of SLE therein as well as evidence supporting the notion that social support interventions may be particularly impactful among this cohort [11-14]. Participants were recruited using invitational letters sent to eligible patients in the Medical University of South Carolina's lupus database and through advertisement flyers posted in rheumatology and research clinics at The University. Mentors were deemed competent in the self-management of their condition by their rheumatologist whereas mentees were individuals whom were less competent and confident with disease self-management. Mentors were assigned mentees based on shared demographic criteria such as age, marital status, and geographic location, among other characteristics. This matching resulted in 6 groups of 1 mentor with 3 mentees, and 1 group of 1 mentor with 2 mentees. Mentors spoke to each of their mentees weekly for approximately 1 hour in sessions that consisted of 3 distinct parts: introduction/discussion, structured education, and problem solving. Materials to be covered each week were dictated ahead of time by study staff based on previously validated programs. Weekly structured education sessions were guided by PowerPoint slideshows that study staff provided in both physical and digital formats [15].

Data Collection and analysis

Mentors in the PALS pilot kept weekly logs that served as records of their interaction with their mentees. This included the number of calls they attempted with each mentee every week, the duration of the calls, and any other notes they felt were important from that week's sessions. Reports in the mentor records were validated by weekly contact with the principle investigator of the study and weekly contact with mentees by a study coordinator. Qualitative data are not reported here in order to center the examination on programmatic delivery methods and associated compliance; for qualitative finding the reader is referred to [16,17].

Selection of comparison studies

Studies were selected for the narrative review based on their relevance to support and self-management strategies for lupus and rheumatic patients. Evidence-based self-management programs designed to encourage social support and promote health education, among lupus patients, have resulted in reductions in pain, improvements in function, and delays in disability [3,15,18-26]. Specifically, arthritis self-management education delivered in smallgroup, home study, computer, and Internet formats have yielded significant improvements in health distress, self-reported global health, and activity limitation, with trends toward improved self-efficacy and stress management [3,4,25,27,28]. Although there is no single widely used evidence-based self-management intervention for lupus patients [29], two programs that have been successful in improving outcomes in patients with arthritis are the Arthritis Self-Management Program (ASMP) and the Chronic Disease Self-Management Program (CDSMP). Other interventions have been developed or adapted, and subsequently tested and reported in the scientific literature. Generally, these interventions are also characterized by education/counseling sessions delivered over several weeks or months, but they are highly heterogeneous in their approach and the content they deliver. The studies presented in the current report are broadly representative of existing intervention modalities tested to improve psychosocial, selfmanagement, and self-efficacy outcomes for SLE and other rheumatic patients. Studies that did not report patient compliance or adherence rates were not included in the comparative review, but are mentioned

to expand the discussion of the outcomes of such interventions. Compliance is assessed as the percent of study sessions (or comparable metric) completed, unless another condition suffices as intervention completion according to discrete study protocols. Methodologies, study populations, and compliance data are compared in order to reveal factors associated with improved intervention compliance and outcomes.

Description of the lupusLine®

The LupusLine®, a telephone-based peer counseling service, appears to be the closest effort to a lupus-specific peer mentoring intervention in the U.S. to date [30,31]. The Hospital for Special Surgery's LupusLine[®] is a free telephone counseling service staffed by trained volunteers who have SLE or are close family or friends of people living with lupus. The service began in 1988 and offers ongoing emotional support and education by telephone to peers with SLE and their loved ones. The mission of the program is to enhance coping, self-esteem, and health-related behaviors, and reduce feelings of isolation and anxiety common in people 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. Matching is based on shared experiences (e.g., parenting, work-related concerns, life stage, and demographic characteristics) and peer counselor availability. Volunteer training consists of an 8-week, 20-hour program focused on listening skills and the impact of SLE, followed by monthly presentations to ensure program quality. Once matched with a peer counselor, LupusLine[®] callers access the service by scheduled appointments [30,31]. Over the last 20 years, more than 19,000 client contracts have been established [32]. The most frequently cited reasons for calling were treatment related concerns and emotional concerns, and callers reported that the most helpful features of LupusLine® were emotional support/empathy and increased knowledge/understanding of lupus

Description of the systemic lupus self-help (slesh) course

The Systemic Lupus Self-Help (SLESH) Course teaches coping skills and information about SLE, provides support, fosters problem solving, cognitive reframing, decisions making, and efficacy enhancement to SLE patients. The intervention is delivered through 7 weekly classes consisting of groups of 8-18 adult lupus patients lasting approximately 2 ½ hours each [26].

Description of the arthritis self-management program (ASMP)

The ASMP is a 6 week course that is targeted towards improving self-efficacy, pain symptoms, and care utilization among arthritis patients. The course is led by a trained instructor for 2 hours weekly. Attending 4 of the 6 classes constitutes program completion [27,34].

Description of the chronic disease self-management program (CDSMP)

Similar to the ASMP, the CDSMP is a course involving six weekly sessions led by two trained instructors that focuses more broadly on the skills related to self-care and self-efficacy in patients managing chronic illness. Each of the weekly classes lasts approximately 2 ½ hours. Also similar to the ASMP, completion of at least 4 of the 6 sessions constitutes course completion [35,36].

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Description of general therapy interventions

While many studies seeking to understand how best to improve selfmanagement practices and convey support to rheumatic patients follow the model of previously validated programs, this is not always the case. As such these interventions are heterogeneous in nature but must also be considered. In one study, supportive psychotherapy group sessions were conducted by trained therapists according to methods previously utilized in a ten year study at Stanford University [37]. Supportive-expressive therapy involves coping skills training in addition to group support coupled with interpersonal existential therapy. Topics covered in the 15 therapy sessions included medical status and treatment, doctor-patient relationships, family and social networks, group therapy issues, illness coping skills, fatalism, life values and principles, and self-image. The first 12 sessions were held weekly, with the remaining 3 serving as booster sessions held monthly at the end of the initial 12 weeks. Patient centered counseling provides supportive therapy to the participants and according to the authors "formal [counseling] techniques are minimized while the therapeutic relationship is the main emphasis" [37].

Results

Pals compliance assessment

While some of the weekly sessions were delayed, all 12 sessions were completed by the 7 mentoring groups yielding a compliance rate of 100%. An average of 1.24 (SD=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 was telephone only for all mentoring pairs [19].

Comparison with lupusline®

According to an initial follow-up evaluation to assess current user demographics, reasons for calling, satisfaction, and impact on behaviors and feelings, 36 users were matched with a peer counselor during 2005. Most respondents (92%) were female, 64% of callers were between the ages of 31 and 50, and the majority (60%) were white (16% African American, 8% Latino, 8% Asian American, and 8% other). 40% were employed fulltime. 88% of callers had lupus themselves and 12% were family members. Time since diagnosis averaged 6.8 years 56% of callers reported that lupus interfered with their lives most or all of the time. About half (48%) used LupusLine for 6 or more phone sessions, with 36% using the service for more than 12 sessions. 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* [33]. More recently, between January and February of 2017 there were 204 calls to the LupusLine® and its 8 volunteer counselors. Of these callers, 73 were SLE patients or their family members calling for the first time, 41 of whom did not require matching and indicated their needs were met after the initial interaction with the screening social worker. The remaining 32 individuals were matched with a peer counselor, 31 of whom followed through with their scheduled initial counseling sessions yielding a compliance rate of 96.68% (Table 1) [38].

Comparison with the systemic lupus self-help course

Between 1987 and 1990 the course was tested at 17 sites across the United States on a total of 313 SLE patients. This study sample was 96% female, was an average age of 45.8, and predominantly white (83% white, 8% black, 9% other races) (see Table 1). Following the intervention, participants experienced decreased depression, increased enabling skills, and increased time spent relaxing and exercising. Compliance data was only available for 104 of the participants; on average they attended 5.6 of the 7 classes and ranged from attending only 1 of the classes, to all 7. For the purposes of comparison the compliance rate will be considered 71.43%, which is the average percent of the classes that study participants attended [26].

Comparison with arthritis self-management program (ASMP)

As shown in Table 1, in a randomized controlled trial, 104 RA patients were assigned to either a usual care or treatment group which participated in the ASMP. The intervention cohort (n=51) was predominantly African American and over 75% female with an average age of 54.2. The six week course was delivered by a trained instructor identified by the Georgia Chapter of the Arthritis Foundation. 25 of 51 (49.02%) participants who were placed in the intervention group and received the intervention attended at least 4 of the sessions. A dose response was observed in this study wherein patients who completed the course were more likely to achieve significant clinical improvements; however those who did not complete the course experienced no significant improvements [34].

Lorig and colleagues performed a complex randomized controlled trail that tested the effectiveness of a tailored self-management intervention based on the ASMP and delivered by mail as compared to the traditional ASMP described above in a population of rheumatoid (RA) and osteoarthritis patients. This trial included two arms, one which tested the effectiveness of the tailored intervention against a usual care condition and the other tested the tailored intervention against the classic ASMP. In the first arm, 522 individuals were randomized to the treatment condition (tailored arthritis selfmanagement mailing) whom were an average age of 62.2 and 77% female, racial data was not provided. Of these participants, 65.5% completed at least 3 of the 4 mailing and overall the group experienced no short term improvements in their disease condition. In the second arm 341 participants were enrolled, these patients were an average age of 65.2 years old and were 75% female, racial data was not provided. Of those assigned to the ASMP treatment condition 30% did not attend any of the six sessions and the group attended an average of 4.6 sessions. The number of mailings completed by those individuals in the tailored intervention condition was not presented in the same way as in the first arm, however it is noted that 12% did not participate at all, which is elevated as compared to the first arm in which only 10.7% did not participate. Overall the compliance rate for this study will be considered < 70% [27].

Comparison with chronic disease self-management program (CDSMP)

Table 1 shows one study of the CDSMP that was carried out among a cohort of low-income African American women with SLE (average age of 43.8) and did not include a control arm or comparison group. Of the 57 individuals who consented to participate, 47 (82.46%) attended at least 4 of the sessions. Following the intervention participants

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experienced improved health related quality of life, self-efficacy, self-management behaviors, treatment adherence, and had fewer outpatient medical visits than prior to baseline [35].

Another similar study tested the effectiveness of the CDSMP as compared to the ASMP (NB: Geoppinger et al refer to it as the Arthritis Self-Help Course which is a semantic rather than methodologic discrepancy) in a population of 416 arthritis patients, of whom, 365 (87.74%) were African American, >75% were female, a mean age of 64 years old and an average of 4 comorbid conditions. 231 of these participants were enrolled in the ASMP, 173 (74.89%) of whom completed 4 or more of the classes whereas 185 participated in the CDSMP, of which 147 (79.46%) completed at least four of the classes. ASMP participants had significant improvements in selfefficacy, stretching and strengthening exercises, aerobic exercise, and general health following the intervention whereas individuals in the CDSMP improved in the domains of self-efficacy, disability, pain, and general health. At four month post-intervention improvements conferred in the CDSMP cohort remained stronger than that of the ASMP, however by 1 year post-intervention, improvements were minimal [36].

Comparison with general therapy interventions

While many studies seeking to understand how best to improve self-management practices and convey support to rheumatic patients follow the model of previously validated programs, this is not always the case. As such these interventions listed in Table 1 are

heterogeneous in nature but must also be considered. In one study of supportive-expressive therapy, 133 female SLE patients living in Canada were recruited for the study. 64 participants were randomized to the therapy group, whom were an average age of 42 at baseline, 87% were white with the other 13% made up of all of all other races (not parsed by original authors). They attended an average of 12.02 (SD=2.98) out of the 15 (80.13%) sessions offered. There were no differences in outcome measures observed between the experimental group and control group at any of the time points assessed in the study [39].

Maiskiak and colleagues tested the effectiveness of a personcentered, nondirective, telephone based counseling intervention in patients with SLE or RA. Over the course of six months, patients completed monthly calls with trained, masters-level counselors in sessions that lasted between 30 and 15 minutes. The study under review randomized patients into either a patient-centered counseling group (8 SLE patients, 28 RA patients) or a control condition (7 SLE, 30 RA). All participants in the study were female; the SLE patients in the counseling group were all white and were a mean age of 40.43, whereas the RA patients in the same group were 43% white and a mean age of 52.97. Only one patient was lost to follow-up and every participant (100%) in the counseling group completed at least 4 of the sessions with 26 (72.22%) completing at least 5 sessions, and 10 (27.78%) completing all sessions. Following the intervention improvements in psychological status were observed in SLE patients but not RA patients [40].

Refere nce	Method	Population	Outcomes	Reported Complian ce			
Peer approaches to lupus self-management							
Tsokos [1]	12 week feasibility pilot of SLE self- management intervention, trained peer mentors delivering weekly education content to mentees	27 African American SLE patients	Reduced anxiety and depression, trends towards reduced disease activity	100.00%			
LupusLine®							
Rosari o et al. [2], Greco et al. [3]	Telephone based peer counseling service. SLE patients call a trained peer volunteer who matches them with a social worker to deliver support.	109 SLE patients or their family members, 92% female, 64% aged 31-50, 60% white (16% African American, 8% Latino, 8% Asian American, and 8% other), 40% employed full time, 88% had lupus themselves and 12% were family members, average time since diagnosis was 6.8 years	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	96.68%			
Systemic lupus self-help course							
Lorig et al. [4]		313 SLE patients (compliance data only available for 104), 96% female, average age of 45.8, 83% white, 8% black	Decreased depression, increased enabling skills, and increased time spent relaxing and exercising	71.43%			
Arthritis self-management program							
Willia ms et al. [5]	6 week Arthritis Self-Management Program. Weekly 2 hour sessions led by a trained instructor covering self-efficacy, pain symptoms, and care utilization.		Outcome observations hampered by low compliance rate. Clinically significant disease improvements among patients who attended the most classes	49.02%			

Willia ms et al. [6]	Randomized controlled trial comparing Arthritis Self-Management Program with a tailored self-management course delivered by mail	341 patients (average age of 65.2 years and were 75%	No short term improvements in Arm 1. Results were mixed for Arm 2 and varied over time, but improvements were observed in both treatment groups	<70%			
Chronic disease self-management program							
Balasu brama nian et al. [7]	6 week Chronic Disease Self-Management Program designed to improve disease self- management and self-efficacy. Single arm, pre/posttest design		Improved health related quality of life, self-efficacy, self-management behaviors, treatment adherence, and had few outpatient medical visits	82.46%			
Comparative effectiveness of ASMP and CDSMP							
Turner et al. [8]	Multi-site study testing the comparative effectiveness of the Arthritis Self-Management Program and Chronic Disease Self-Management Program among arthritis patients	416 arthritis patients, 87.74% African American, >75% female, average age of 64 years	Significant improvements in general health and self-efficacy among both groups, improvement maintained longer among CDSMP patients	ASMP: 74.89% CDSMP: 79.46%			
Suppor	tive expressive therapy						
Lee et al. [9]	Randomized controlled trial of a supportive- expressive group psychotherapy intervention. 12 weekly sessions and 3 subsequent monthly booster sessions	133 Canadian female SLE patients, 64 randomized to intervention group, average age of 42 and 87% white	No significant differences in any outcomes measured between experimental and control group at any time point	80.13%			
Patient centered counseling							
Viau et al. [10]	Randomized controlled trial of a monthly person centered telephone based counseling interventions delivered over the course of 6 months		Improvements in psychological status among SLE patients in the intervention group, other outcomes showed no improvements for SLE or RA patients	27.78%			
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Table 1: Program descriptions and reported compliance rates.

Studies not reporting compliance/adherence data

The vast majority of studies reviewed for this article did not report compliance data, or did not report those data in a way that was conducive to comparison. Nevertheless, many of these interventions were effective in improving disease status and management in rheumatic patients. These interventions led to significant improvements in depression [20,21,23,41], patient limitations or physical functioning [3,4,20,41,42], health distress [4; 20,41], fatigue [4,20,23,41,43], pain [3,4,20,41], self-efficacy [4,20,28,41,43,44], anxiety [21], stress [4,21,45], quality of life [21], vitality and health perceptions [42], mental health [42,43], self-esteem [22], psychological or psychosocial functioning [3,22], illness intrusiveness [25], communication [43], coping [23,43], social support [43], distress [45] [44], and health status [28].

Discussion/Conclusion

The Peer Approaches to Lupus Self-management (PALS) intervention program was a highly feasible and acceptable program that has the potential to provide benefits not yet achieved by other evidence based support and self-management interventions currently available to African American women with SLE [46]. Compliance data suggest that this intervention modality is highly accessible to SLE patients seeking additional social support and disease education. While compliance is very high for PALS participants (i.e., 100% compliance), comparatively, SLESH, ASMP, CDSMP, and other interventions fell well below this level, ranging from approximately 82% to below 50%.

This is consistent with past findings that despite recommendations from numerous national agencies that self-management education complement medical care [25,47-51], arthritis self-management education has reached a limited number of people. Many Arthritis Foundation chapters have had difficulty disseminating arthritis self-management education programs. Additionally, many vulnerable populations have not been included in study samples [24,25,36,52-55]. Compliance has been cited as a persistent problem in standardized programs [34]. 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 [56], suggesting that interventions may not be reaching the largest portion of lupus cases.

In contrast, the LupusLine® program managed to achieve nearly 97% compliance, using their telephonic peer counseling delivery method. Many of the intervention modalities reviewed required in-person attendance that necessitates participant travel. Travel has been noted as a significant barrier to treatment for SLE patients, suggesting that it may likely be a major factor reducing study compliance [57-59]. The accessibility and convenience of telephone-delivered interventions by the Lupusline® and in the PALS study eliminates travel burden, which in turn appears to have a positive effect on participation and compliance. While overall compliance did not reach the levels achieved by PALS and LupusLine®, the one study reviewed that conveyed its intervention by phone had just one non-completer and all participants participated in 4 or more intervention calls [40].

It is unlikely that differences in compliance were due to intervention content, as the PALS intervention included adapted educational

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content from the SLESH, CDSMP, and ASMP and treatment credibility and acceptability measures for each of the studies discussed were generally high [46,60,61].

However, PALS educational content was further tailored to African American women with six added sessions based on cultural issues reported as important to African Americans in earlier research [20,62] and documented unmet needs in the African American SLE patient community [63,64]. To address unmet needs around understanding the medical regimen, including considerations around depression, medication concerns (possible side effects and interactions), and physical symptoms (pain and fatigue), culturally relevant sessions on 'Complications' and 'Self-monitoring' were developed. In response to unmet needs around trust in the provider, communication with providers, and receiving adequate information from medical staff about treatment side effects, so too were sessions on 'Coping' and 'Trust' developed. Lastly, unmet needs around having access to telephone support and advisory services and having assistance with knowing which symptoms should trigger a doctor visit [29,65,66] are addressed by the PALS study design (i.e., telephone delivery of intervention) and sessions devoted to less frequently discussed topics of 'Body image' and 'Sexuality/sexual health'.

Cultural relevance and acceptability of PALS content that was uniquely fitted to African American women with SLE may have further contributed to participant compliance, and other studies have highlighted the potential of peer mentoring as a culturally sensitive means to improving health behaviors and outcomes in low income and minority groups in whom trust in the health care system may be lower than in the general population.[65,67-71] The success of relationship-centered peer mentoring has been attributed to the non-hierarchical, 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 [72-74]. 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 [72]. This can establish trust and in turn decrease disparities in health care outcomes [75].

PALS and LupusLine® have two important methods in common; 1) peer mediated delivery and 2) delivery by phone. As previously noted, peer mentoring is an intervention delivery method posited to have particular impact in minority populations across a variety of conditions [76-88]. The fact that LupusLine® and PALS are different programs with varying entry methods, time commitments, and activities required of participants, provides insight into important factors to consider in the delivery of support and management interventions for SLE patients; 1) Accessibility to the intervention is crucial to its utilization and 2) Peer-to-peer delivery continues to be a viable and acceptable means by which to engage these patients. While there are important limitations to take into account with these conclusions, such as small and mostly homogenous populations in the various studies discussed, the lack of compliance data for many studies, as well as the majority of data being self-reported by patients, our findings further support the potential impact of peer mentoring in patient populations with rheumatic diseases. In practice and research, peer mentoring interventions can be an effective means to provide education, support, and resources that often lie beyond the scope of traditional medical regimens. Together, with an easily accessible delivery method (i.e., by telephone) future interventions using these modalities may provide health and quality of life improvements that have not yet been attainable and serve as a sustainable solution to

persistent disparities in the rheumatic disease population and particularly among African American women.

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References

- Tsokos GC (2011) Systemic lupus erythematosus. N Engl J Med 365: 2110-2121.
- Rosario C, Seguro L, Vasconcelos C, Shoenfeld Y (2013) Is there a cure for systemic lupus erythematosus? Lupus 22: 417-420.
- Greco C, Rudy T, Manzi S (2004) Effects of a stress-education program on psychological function, pain, and physical function of systemic lupus erythematosus patients: A randomized controlled trial Arthritis Rheum 51: 625-634.
- Lorig K, Ritter P, Plant K (2005) A disease-specific self-help program compared with a generalized chronic disease self-help program for arthritis patients. Arthritis Rheum 53: 950-957.
- Williams E, Bruner L, Adkins A, Vrana C, Logan A, et al. (2015) I too, am America: A review of research on systemic lupus erythematosus (SLE) in African Americans. Lupus Sci Med 3: E000144.
- Williams E, Egede L, Oates J (2017) Effective self-management interventions for patients with lupus: Potential impact of peer mentoring. Am J Med Sci 353: 580-592.
- Balasubramanian D, Yoong J, Vrijhoef H (2014) Telephone support and adherence in patients with chronic disease: A qualitative review of reviews. Smart Homecare Technology and Telehealth 3: 107-118.
- Turner A, Hartoonian N, Sloan A, Benich M, Kivlahan D, et al. (2016) Improving fatigue and depression in individuals with multiple sclerosis using telephone-administered physical activity counseling. J Consult Clin Psychol 84: 297-309.
- Lee PS, Tsao LI, Liu CY, Lee CL (2014) Effectiveness of telephone-based counseling for improving the quality of life among middle-aged women. Health Care for Women Int 35: 74-86.
- Viau K, Jones J, Murtaugh M, Gren L, Standford J, Bilder D (2016) Phonebased motivational interviewing to increase self-efficacy in individuals with phenylketonuria. Mol Genet Metab Rep 18: 27-33.
- 11. Lau C, Yin G, Mok M (2006) Ethnic and geographical differences in systemic lupus erythematosus: An overview. Lupus 15: 715-719.
- 12. Pons-Estel G, Alarcón G, Scofield L, Reinlib L, Cooper G (2010) Understanding the epidemiology and progression of systemic lupus erythematosus. Semin Arthritis Rheum 39: 257-268.
- Lin J, Thompson M, Kaslow N (2009) The mediating role of social support in the community environment-psychological distress link among low-income african american women. J Commun Psychology 37: 459-470.
- Wu C, Prosser R, Taylor J (2010) Association of depressive symptoms and social support on blood pressure among urban african american women and girls. J Am Acad Nurse Pract 22: 694-704.

- Williams E, Kamen D, Penfield M, Oates J (2014) Stress intervention and disease in african american lupus patients: The balancing lupus experiences with stress strategies (BLESS) Study. Health 6: 71-79.
- 16. Faith T, Flournoy-Floyd M, Ortiz K, Egede L, Oates J, Williams E (2018) My life with lupus: Contextual responses of African American women with systemic lupus participating in a peer mentoring intervention to improve disease self-management. BMJ Open Under Review.
- 17. Flournoy-Floyd M, Ortiz K, Egede L, Oates J, Faith T, Williams E (2018)
 We would still find thing to talk about": Assessment of mentor
 perspectives in a systemic lupus erythematosus intervention to improve
 disease self-managment, empowering SLE patients. J Natl Med Assoc 110:
 182-189.
- Bae S, Hashimoto H, Karlson E, Liang M, Daltroy L (2001) Variable effects of social support by race, economic status, and disease activity in systemic lupus erythematosus. J Rheumatol 28: 1245-1251.
- Williams E, Voronca D, Hyer M, Rameshkrishnan V, Faith T, et al. (2017)
 Peer-to-peer mentoring for African American women with lupus: A feasibility pilot. Arthritis Care & Research.
- 20. Williams E, Penfield M, Kamen D, Oates J (2014) An intervention to reduce psychosocial and biological indicators of stress in african american lupus patients: the balancing lupus experiences with stress strategies study. Open J Prev Med 4: 22-31.
- Navarrete NN, Ramírez MP, Sánchez JS, Coín M, Ortega HR, et al. (2010)
 Efficacy of cognitive behavioural therapy for the treatment of chronic stress in patients with lupus erythematosus: A randomized controlled trial. Psychother Psychosom 79: 107-115.
- Ng P, Chan W (2007) Group psychosocial program for enhancing psychological well-being of people with systemic lupus erythematosus. J Soc Work Disabil Rehabil 6: 75-87.
- Sohng K (2003) Effects of a self-management course for patients with systemic lupus erythematosus. J Adv Nurs 42: 479-486.
- Haupt M, Millen S, Janner M, Falagan D, Fischer-Betz R, ET AL. (2005) Improvement of coping abilities in patients with systemic lupus erythematosus: A prospective study. Ann Rheum Dis 64: 1618-1623.
- Edworthy S, Dobkin P, Clarke A, Da Costa D, Dritsa M, et al. (2003) Group psychotherapy reduces illness intrusiveness in systemic lupus erythematosus. J Rheumatol 30: 1011-1016.
- Braden C, McGlone K, Pennington F (1993) Specific psychosocial and behavioral outcomes form the systemic lupus self-help course. Health Educ Q 20: 29-41.
- Lorig K, Ritter P, Laurent D, Fries J (2004) Long-term randomized controlled trials of tailored-print and small-group arthritis selfmanagement interventions. Medical Care 42: 346-354.
- Lorig K, Ritter P, Laurent D, Plant K (2008) The internet-based arthritis self-management program: A one-year randomized trial for patients with arthritis or fibromyalgia. Arthritis Rheum 59: 1009-1017.
- Danoff-Burg S, Friedberg F (2009) Unmet needs of patients with systemic lupus erythematosus. Behav Med 35: 5-13.
- Horton R, Peterson M, Powell S, Engelhard E, Paget S (1997) Users evaluate LupusLine, a telephone peer counseling service. Arthritis Care Res 10: 257-263.
- Peterson M, Horton R, Engelhard E, Lockshin M, Abramson T (1993)
 Effect of counselor training on skills development and psychosocial status of volunteers with systemic lupus erythematosus. Arthritis Care Res 6: 38.44
- (2008) LupusLine-peer support for people with lupus. Lupus Outcome Study.
- Salomon J, Rose J, Horton R, Paget S, Flics S (2007) LupusLine peer phone counseling service: A program evaluation paper. American College of Rheumatology Annual Meeting.
- Conn D, Pan Y, Easley K, Comeau D, Carlone J, et al. (2013) The effect of the arthritis self-management program on outcome in African Americans with rheumatoid arthritis served by a public hospital. Clin Rheumatol 32: 49-59.

- Drenkard C, Dunlop-Thomas C, Easley K, Bao G, Lim S, et al. (2012)
 Benefits of a self-management program in low-income African-American women with systemic lupus erythematosus: Results of a pilot test. Lupus 21: 1586-1593.
- Geoppinger J, Armstrong B, Schwartz T, Ensley D, Brady T (2007) Self-Management education for persons with arthritis: Managing comorbidity and eliminating health disparities. Arthritis Rheum 57: 1081-1088.
- Spiegel D, Spira J (1991) Supportive-expressive group therapy: A treatment manual of psychosocial intervention for women with recurrent breast cancer. Psychosocial Treatment Laboratory.
- 38. Toral P, Flores M, Horton R, Rose J (2017) Evaluation of a longstanding telephone peer counseling service on people with systemic lupus erythematosus and their loved ones. Am College of Rheumatology Annual Meeting.
- Dobkin P, Costa DD, Joseph L, Fortin P, Edworthy S, et al. (2002) Counterbalancing patient demands with evidence: Results from a pancanadian randomized clinical trial of brief supportive-expressive group psychotherapy for women with systemic lupus erythematosus. Ann Behav Med 24: 88-99.
- 40. Maisiak R, Austin J, West S, Heck L (1996) The Effect of person-centered counseling on the psychological status of persons with systemic lupus erythematosus or rheumatoid: A randomized, controlled trial. Arthritis Care Res 9: 60-66.
- Barlow JH, Turner AP, Wright CC (2000) A randomized controlled study of the arthritis self-managment programme in the UK. Health Educ Res 15: 665-680.
- Navarrete NN, Ramírez MP, Sánchez JS, Egea Im, Ruis As, et al. (2010) Quality-of-life predictor factors in patients with SLE and their modification after cognitive behavioural therapy. Lupus 19: 1632-1639.
- Karlson E, Liang M, Eaton H, Huang J, Fitzgerald L, et al. (2004) A Randomized clinical trial of a psychoeducational intervention to improve outcomes in systemic lupus erythematosus. Arthritis Rheum 50: 1832-1841.
- 44. Lorig KR, Ritter PL, Stewart AL, Sobel D, Brown B, et al. (2001) Chronic disease self-managment program: 2-year health status and health care utilization outcomes. Med Care 39: 1217-1223.
- 45. Goodman D, Morrissey S, Graham D, Bossingham D (2005) The application of cognitive-behaviour therapy in altering illness representations of systemic lupus erythematosus. Behavior Change 22: 156-171.
- 46. Williams E, Voronca D, Hyer M, Rameshkrishnan V, Faith T, et al. (2017) Peer-to-peer mentoring for African American women with lupus: A feasibility pilot. Arthritis Rheum.
- O'Donnell M (2004) Health Promotion behaviors that prmote selfhealing. J Altern Complement Med 10: S49-S60.
- Carter E, Nunlee-Bland G, Callender C (2011) A patient-centric, provider-assisted diabetes telehealth self-management intervention for urban minorities. Perspectives in Health Information Management 8: 1-9.
- Derose S, Nakahiro R, Ziel F (2009) Automated messaging to improve compliance with diabetes test monitoring. Am J Manag Care 15: 425-431.
- Franklin V, Waller A, Pagliari C, Greene S (2006) A randomized controlled trial of Sweet Talk, a text messaging system to support young people with diabetes. Diabet Med 23: 1332-1338.
- 51. Hanauer D, Wentzell K, Laffel N, Laffel L (2009) Computerized automated reminder diabetes system (CARDS): Email and SMS cell phone text messaging reminders to support diabetes management. Diabetes Technol Ther 11: 99-106.
- Gaab J, Sondergger L, Scherrer S, Ehlert U (2006) Psychoneuroendocrine effects of cognitive-behavioral stress management in a naturalistic setting a randomized controlled trial. Psychoneuroendocrinology 31: 428-438.
- Austin J, Maisiak R, Macrina D, Heck L (1996) Health outcome improvements in patients with systemic lupus erythematosus using two telephone counseling interventions. Arthritis Care Res 9: 391-399.

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- Pena-Robichaux V, Kvedar J, Watson A (2010) Text messages as a reminder aid and educational tool in adults and adolescents with atopic dermatitis: a pilot study. Dermatology Res Pract 1-6.
- De Abreu M, Gafni A, GFerraz M (2009) Development and testing of a decision board to help clinicians present treatment options to lupus nephritis patients in Brazil. Arthritis Rheum 61: 37-45.
- Bruce B, Lorig K, Laurent D (2007) Participation in patient selfmanagement programs. Arthritis Rheum 57: 851-854.
- 57. Williams E, Ortiz K, Zhang J, Zhou J, Kamen D (2016) The systemic lupus erythematosus tavel burden survey: Baseline data among a South Carolina cohort. BMC Res Notes 9: 1-9.
- Williams E, Ortiz K, Browne T (2014) Determinants of health, the chronic care model, and systemic lupus erythematosus. Int J Chronic Dis 1-7
- Ortiz K, Floyd FF, Williams EM, Bruner L, Kamen D (2015) Systemic lupus erythematosus observations of travel burden (SLEOTB): A qualitative inquiry. Int J Rheum Dis 18: 751-760.
- Faith TD, Egede L, Williams EM (2018) Research ethics in behavioral interventions among special populations: Lessons from the peer approaches to lupus self-management (PALS) pilot study. Am J Med Sci 355: 104-112.
- Flournoy-Floyd F, Ortiz K, Egede L, Oates J, Faith T, et al. (2018) 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. J National Med Asso 110: 182-189.
- 62. Chinman M, McCarthy S, Mitchell-Miland C, Daniels K, Youk A, et al. (2016) Early stages of development of a peer specialist fidelity measure. Psychiatr Rehabil J 39: 256-265.
- MUSC Office of Public Relations (2011) Patients, families with lupus receive support. In The Catalyst. (Charleston, SC, Medical University of South Carolina.
- 64. Queen Quet (2017) Lupus awareness day the gullah/Geechee Way! In.
- 65. Feldman C, Bermas B, Zibit M, Fraser P, Todd D, et al. (2013) Designing an intervention for women with systemic lupus erythematosus from medically underserved areas to improve care: A qualitative study. Lupus 22: 52-62.
- Moses N, Wiggers J, Nicholas C, Cockburn J (2005) Prevalence and correlates of perceived unmet needs of people with systemic lupus erythematosus. Patient Educ Couns 57: 30-38.
- 67. Armstrong K, McMurphy S, Dean LT, Micco E, Putt M, et al. (2008) Differences in the patterns of health care system distrust between blacks and whites. J Gen Intern Med 23: 827-833.
- 68. Philis-Tsimikas A, Fortmann A, Lleva-Ocana L, Walker C, Gallo L (2011) Peerled diabetes education programs in high-risk Mexican Americans improve glycemic control compared with standard approaches: A Project Dulce promotora randomized trial. Diabetes care 34: 1926-1931.
- Long J, Jahnle E, Richardson D, Loewenstein G, Volpp K (2012) Peer mentoring and financial incentives to improve glucose control in African American veterans: A randomized trial. Ann Intern Med 156: 416-424.
- Ghahramani N (2015) Potential impact of peer mentoring on treatment choice in patients with chronic kidney disease: A review. Arch Iran Med 18: 239-243
- Shaw E, Kaczorowski J (1999) The effect of a peer counseling program on breastfeeding initiation and longevity in a low-income rural population. J Hum Lact 15: 19-25.

- Heisler M (2006) Building peer support programs to manage chronic disease: Seven Models for success. California Health Care Foundation.
- Dennis CL (2003) Peer support within a health care context: A concept analysis. Int J Nurs Stud 40: 321-332.
- Embuldeniya G, Veinot P, Bell E, Bell M, Nyhof-Young J, et al. (2013) The experience and impact of chronic disease peer support interventions: A qualitative synthesis. Patient Educ Couns 92: 3-12.
- Perry E, Swartz J, Brown S, Smith D, Kelly G, Swartz R (2005) Peer mentoring: A culturally sensitive approach to end-of-life planning for longterm dialysis patients. Am J Kidney Dis 46: 111-119.
- Thomas R, Lorenzetti D, Spragins W (2013) Systematic review of mentoring to prevent or reduce tobacco use by adolescents. Acad Pediatr 13: 300-307.
- 77. Goldenberg D, Payne L, Hayes L, Zeltzer L, Tsao J (2013) Peer mentorship teaches social tools for pain self-management: A case study. J Pain Manag 6: 61-68.
- 78. Jerson B, D'Urso C, Arnon R, Miloh T, Iyer K, et al. (2013) Adolescent transplant recipients as peer mentors: A program to improve self-management and health-related quality of life. Pediatr Transplant 17: 612-620
- Woodbury M, Botros M, Kuhnke J, Greene J (2013) Evaluation of a peerled self-management education programme PEP talk: Diabetes, healthy feet and you. Int Wound J 10: 703-711.
- Ljungberg I, Kroll T, Libin A, Gordon S (2011) Using peer mentoring for people with spinal cord injury to enhance self-efficacy beliefs and prevent medical complications. J Clin Nurse 20: 351-358.
- 81. Sandhu S, Veinot P, Embuldeniya G, Brooks S, Sale J, et al. (2013) Peer-topeer mentoring for individuals with early inflammatory arthritis: feasibility pilot. BMJ Open 3: e002267.
- 82. Chomutare T, Arsand E, Hartvigsen G (2011) Mobile peer support in diabetes. Stud Health Technol Inform 169: 48-52.
- 83. Hibbard M, Cantor J, Charatz H, Rosenthal R, Ashman T, et al. (2002) Peer support in the community: Initial findings of a mentoring program for individuals with traumatic brain injury and their families. J Head Trauma Rehabil 17: 112-131.
- 84. Richter L, Rotheram-Borus M, Van Heerden A, Stein A, Tomlinson M, et al. (2014) Pregnant women living with HIV (WLH) supported at clinics by peer WLH: A cluster randomized controlled trial. AIDS Behav 18: 706-715.
- 85. Williams R, Bambara J, Turner A (2012) A scoping study of one-to-one peer mentorship interventions and recommendations for application with Veterans with postdeployment syndrome. J Head Trauma Rehabil 27: 261-273.
- 86. Cully J, Mignogna J, Stanley M, Davila J, Wear J, et al. (2012) Development and pilot testing of a standardized training program for a patient-mentoring intervention to increase adherence to outpatient HIV care. AIDS Patient Care STDS 26: 165-172.
- 87. Tracy K, Burton M, Nich C, Rounsaville B (2011) Utilizing peer mentorship to engage high recidivism substance-abusing patients in treatment. Am J Drug Alcohol Abuse 37: 525-531.
- 88. Anderson A, Damio G, Chapman D, Perez-Escamilla R (2007)
 Differential response to an exclusive breastfeeding peer counseling intervention: The role of ethnicity. J Human Lactation 23: 16-23.