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Exploring the Perceived Impact of the Chronic Disease Self-Management Program on Self-Management Behaviors among African American Women with Lupus: A Qualitative Study

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Objective. To qualitatively explore the processes through which the Chronic Disease Self-Management Program (CDSMP)—a peer-led, group-based educational intervention for people with chronic conditions—affects self-management behaviors among African American women with systemic lupus erythematosus (SLE).

Methods. Using a longitudinal pre- and postintervention design, we conducted two waves of one-on-one, semistructured interviews with 24 purposefully sampled participants. Wave 1 interviews explored self-management behaviors at baseline; wave 2 interviews focused on changes in these behaviors postintervention. Transcripts were analyzed using thematic analysis methods.

Results. Study participants perceived the CDSMP to be a valuable resource that helped them improve fundamental self-management behaviors, including exercise, relaxation, diet, and medication adherence. We found, with few exceptions, that in this sample, women's reported changes in self-management behaviors did not vary by participant age, education, SLE disease severity, or depression status. Our analysis suggests that the CDSMP had the most widespread perceived effects on relaxation and exercise. Strategies that generated improvements in relaxation and exercise included goal setting, action planning, encouragement to pursue low-impact physical activity, and introduction of mindfulness techniques to better manage SLE symptoms.

Conclusion. Our findings suggest that African American women with SLE perceived the CDSMP as an effective educational self-management intervention. The program can potentially catalyze improvements in self-management behaviors in this population, regardless of demographic or disease characteristics.

INTRODUCTION

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Systemic lupus erythematosus (SLE) is a chronic autoimmune disease of little understood etiology, characterized by heterogeneous symptomatology and variable course. Health problems stemming from SLE range from mild to life threatening. In addition to causing pain, fatigue, and skin rashes in most patients, SLE can target vital organs (1). Mortality is 3 to 4 times higher among people with SLE compared with the general population (2,3). SLE disproportionately strikes women of childbearing age and African Americans (4–7). African Americans with SLE are also more likely than their white counterparts to experience comorbidities and a higher mortality (2,3,8–11).

As SLE care advances, patients are expected to engage in self-management activities to control their symptoms, reduce flares, and mitigate comorbidities. Effective self-management contributes to reduced mortality and disability, improvement in quality of life, and lower health care costs (12). Consequently, self-management programs are a fundamental part of the chronic disease standard of care (13–17). Given the complexity of health problems associated with SLE, patient education is critical to promoting positive self-care practices (18), particularly among high-risk individuals (19). However,

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SIGNIFICANCE & INNOVATIONS

- Adopting effective self-management practices is critical to control symptoms, promote health, and improve outcomes in high-risk individuals with systemic lupus erythematosus (SLE). However, African Americans living with SLE face formidable barriers to accessing self-management education.
- The Chronic Disease Self-Management Program (CDSMP) is a well-established, widely disseminated self-management intervention with the potential to reach a large African American female population with SLE in the United States and to positively impact their self-management behaviors.
- African American women living with SLE perceived benefits from participation in the CDSMP through enhancements in relaxation behaviors, exercise, medication adherence, and diet.

African American people face formidable barriers to accessing health care and self-management education (20). Moreover, there are currently no widely available, evidence-based self-management interventions designed for those with SLE (21).

Although emerging SLE-specific self-management interventions are being examined (22,23), African American people living with SLE can widely access the Chronic Disease Self-Management Program (CDSMP) (24). The CDSMP is a worldwide, cost-effective intervention designed to enhance the skills necessary to managing health problems among people with chronic conditions (eg, arthritis, heart disease). Conducted among small groups in the community by two certified peers, the program consists of six weekly classes, each lasting 2.5 hours. Classes are designed to enhance self-efficacy through weekly action plans, behavior modeling, vicarious learning, problem solving, and peer support. The CDSMP addresses self-management challenges that are universal across chronic conditions, including pain and fatigue, healthy eating, physical activity, and effective communication with health care professionals.

Studies suggest that CDSMP participation may improve self-management behaviors and health-related quality of life among African American women with SLE (25,26). This qualitative study was designed to learn about African American women's perspectives on the processes through which the CDSMP affected their SLE self-management behaviors.

MATERIALS AND METHODS

We used a pre- and postintervention qualitative design to explore our research question with a sample of African American women living with SLE. We chose to use qualitative methods because they excel at capturing perceptions and processes (27).

Participant recruitment. Participants were recruited from the Women Empowered to Live with Lupus (WELL) study, a longitudinal study of the CDSMP's impact on SLE-related outcomes among African American women (Figure 1). WELL randomly sampled 150 African American women from the Georgians Organized Against Lupus (GOAL) cohort; GOAL is representative of the full disease and sociodemographic spectra of those living with SLE in the Southeastern United States (28). We sought to purposefully sample 25 women from the WELL cohort to take part in this qualitative substudy. Past studies with SLE women regarding their perceptions of health-related quality of life, illness representation, and health care have reached saturation on key topics, with 10 to 36 participants (29-31). Based on this past research, we expected to reach theoretical saturation on key themes with 25 women. We employed a rolling recruitment strategy: 28 WELL cohort members were contacted, 24 women agreed to participate in interviews, and 4 declined participation. Consistent with purposive sampling, the qualitative substudy sought variation in the sample in participant characteristics that might affect responses to the CDSMP, including baseline depressive symptoms, SLE disease activity, age, and education (32-38). Data on these characteristics were drawn from WELL surveys.

Data collection. We conducted two waves of one-on-one, semistructured, in-person interviews with each participant. The first interview ("wave 1" or "baseline") was conducted in the month before the participant started the CDSMP; the second interview ("wave 2") was conducted 2 to 6 weeks after the CDSMP had ended. This pre- and postintervention design allowed us to explore African American women's perceptions of their self-management behaviors in real time, before and after participating in the CDSMP, learning about their assessment of the processes by which the CDSMP had affected the aforementioned behaviors. To foster rapport building and trust, each set of interviews (waves 1 and 2) was conducted by the same interviewer for a given participant, with the exception of two participants for whom this was not possible because scheduling conflicts.

Interview guides were developed following a review of SLE self-management literature and additional topics of interest to the research team, including participants' expectations of the workshop. The guides were piloted with two African American women from the Lupus Patient Advisory Research Council (LPARC) who also provided input on question suitability. The interview guides were subsequently revised to improve clarity and reduce ambiguity. The wave 1 guide covered women's perceptions of 1) the SLE diagnosis experience, 2) SLE symptoms and how they affected the woman's health-related quality of life, 3) self-management behaviors, and 4) health services engagement and doctor/patient communication. The wave 2 guide covered participant perceptions of 1) the CDSMP and 2) and changes in self-management behaviors. When participants did not attend all six sessions, we asked about reasons



Figure 1. Description of recruitment of African American (AA) women into the qualitative study.

for missing sessions. When wave 2 participants only attended one class, interviewers did not probe perceptions of CDSMP impact.

Two trained interviewers, AT and AS, conducted all interviews, which were audio recorded and verbatim-transcribed. Wave 1 interviews lasted approximately 85 minutes, whereas wave 2 interviews lasted approximately 65 minutes.

Analysis. To aid analysis, the first 11 interviews were transcribed by members of the research team. The remaining interviews were transcribed verbatim by a professional transcription service and reviewed for accuracy. Transcripts were analyzed using thematic analysis methods (39), and we searched for patterns by participant age, educational attainment, patient-reported depressive symptoms (referred to hereafter as depression), and severity of SLE activity. When self-management practices were reported 1.5 times or greater more frequently in one group (eg, women with severe SLE) than another (eg, participants with mild or moderate SLE), we considered this a possible pattern.

Given that some participants did not attend all CDSMP sessions, we also examine variations across participants by the number of sessions attended. To create a preliminary wave 1 codebook, the first three transcripts were read repeatedly by AT, AS, and HC to develop a list of codes and their definitions. Two analysts (AT and AS) then independently applied these codes to these three transcripts. Intercoder differences in coding were discussed, consensus was reached, and the codebook was refined. Thereafter, AT and AS each coded half of all wave 1 transcripts; to enhance intercoder agreement, every third transcript was "double coded" by AT and AS, and coding differences were identified and resolved. From the coded transcripts, the team created memos (ie, analytical notes based on the data) detailing each participant's reported experience of self-management behaviors in wave 1 and wave 2 interviews. From these memos, self-management behaviors commonly noted throughout the data (eg, "taking it easy": meditation, diet) were identified and labeled as preliminary themes. Following further memo notation and analysis, a set of preliminary themes

(eg, "taking it easy": meditation) were grouped as one major theme (eg, relaxation), with subthemes (eg, "taking it easy": mindfulness, which in turn encompassed meditation, distraction, and breathing).

A wave 2 codebook was developed and applied using the same process. Analyses were conducted using MAXqda version 12.3.2 (40). As noted in Table 1, some participants (n = 7) only attended one session, and interviewers did not probe perceived CDSMP impact. We excluded these individuals from the wave 2 analysis unless they volunteered information on perceived CDSMP impact on a particular self-management behavior. At the conclusion of the analysis, we conducted member checks (ie, systematically returning data and study conclusions to study population to ascertain their resonance with findings (41)) with two African American women living with SLE. We also reviewed all transcripts to seek "negative cases" (ie, elements

of the data that did not fit the body of evidence emerging from data analysis (42)).

Ethics. The study was approved by the Emory Institutional Review Board and Grady Health System Research Oversight Committee. All study participants signed informed consent.

RESULTS

Participant characteristics. Twenty-four women participated in the baseline interviews, and 23 also completed wave 2 interviews. The sample's mean age was 48.6 (SD = 13.5), and participants had been diagnosed with SLE, on average, about 14 years ago (SD = 8.1; Table 1). Nearly 50% had an annual income lower than \$20000; most (91.7%) were currently employed. By design, the sample was balanced with regard to education,

Table 1. Demographic information for African American women in WELL sample (n=24)

	Characteristic	Value
Current age, years, mean (range)		48.6 ± 13.5
Age at diagnosis, years, mean (ran	ge)	34.5 ± 8.7
Years since diagnosis, mean ±SD		14.1 ± 8.1
Educational attainment, no. (%)		
	Less than high school	2 (8.3)
	High school/some college	10 (41.7)
	Completed college	12 (50.0)
Depressed, no. (%)	completed college	12 (00.0)
Depressed, NO. (%)	No (DDOMIC SERA Depression Tesora (EG)	12 (5 4 2)
	No (PROMIS SF8a Depression T-score <56)	13 (54.2)
	Yes (PROMIS SF8a Depression T-score \geq 56)	11 (45.8)
Severity of disease activity score (C (0.5. c)
	Mild disease activity (score 0-10)	6 (25.0)
	Moderate disease activity (score 11-16)	7 (29.2)
	Severe disease activity (score \geq 17)	11 (45.8)
Current household income, no. (%		
	Less than \$10,000	3 (12.5)
	\$10, 000-\$19,000	8 (33.3)
	\$20,000-\$29,000	5 (20.8)
	\$30,000-\$39,000	4 (16.7)
	\$50,000-\$59,000	1 (4.2)
	\$60,000-\$69,000	1 (4.2)
	\$70,000+	1 (4.2)
	Refuse to answer	1 (4.2)
Γ	Rejuse to unswer	1 (4.2)
Employment, no. (%)	Marking full time or part time	
	Working full-time or part-time	22 (91.7)
	Unemployed/retired/student/homemaker/disabled	2 (8.3)
Insurance status ^a		
	No insurance or under-insured	11 (45.8)
	Insured	13 (54.2)
Below 100% poverty ^a		
	No	14 (58.3)
	Yes	10 (41.7)
Number of CDSMP sessions atten	ded, no. (%)	
	1 session	7 (29.2)
	2 sessions	-
	3 sessions	2 (8.3)
	4 sessions	1 (4.2)
	5 sessions	6 (25.0)
	6 sessions	6 (25.0)

Abbreviations: PROMIS=Patient Reported Outcomes Measure System; SLAQ = Systemic Lupus Activity Questionnaire. ^aInsurance status and poverty data obtained from GOAL surveys. All other demographics were obtained from WELL Baseline survey.

Subtheme	Wave 1 Example Quote	Wave 2 Example Quote
1. "Taking it easy"	 (i) "And soI pay attention to my body. Um, I know if I have like a really raspy voice and my hands are so flush, I'm either like close to a flare and so what I have to do is pull back. I have to say, "I'm not doing anything this day, I'm gon' rest." (Age 53, High School+, Mild/Moderate Lupus, Not Depressed) 	 (ii) " now instead of trying to push through the pain I stop, and I go ahead, and sit down. And I will, or lay down, and start relaxing. Um, cause I think before it was always you got to do this, you got to do this, you got to do this. And I kept pushing trying to push through. Uh, and that I guess always made it worseit [the workshop] told me to stop, and sit down, and be still, and not worry about whatever it is. Take time, cause if I don't take time for me then I won't be here, so." (Age 50, College+, Severe Lupus, Depressed)
2. Mindfulness a. Yoga	No data	(ii) " Um, I've incorporated [yoga and meditation] definitely in the
d. 10gu	No data	morning 'cause' I get stiff in the morning sometime as the winter comes along, so, uh, we do – you were told [at the workshop] to do a plank [exercise position] and I'd never done a plank. Well, I'd heard about, you know, planking, but it's pretty hard, but I'm getting better. I'm getting better, so it was that - that's the part [of the workshop] that I liked that wanted to do it and, um, I'm doing it" (Age 54, College+, Mild/Moderate Lupus, Not Depressed)
b. Meditation	 (i) "since diagnosis [I've] gotten into more meditation and just taking the meditation time, particularly in the morning and at night." (Age 54, College+, Mild/Moderate Lupus, Not Depressed) 	 (ii) "Well I've been having like a lot of pain when I sleep at night and so I'm not sleeping very wellit [CDSMP meditation CD] relaxed me to the point where – because it's hard for me to sleep during the day. I'll rest but I can't sleep and And I'm sitting down but I'm not really relaxed. Because if your mind is not relaxed then you're not relaxed. And I was just listening to the tape and I was doing everything she ((62)) said to Think of the ocean and all of that. And it actually put me to sleep I was really shocked." (Age 61, High School+, Severe Lupus, Depressed)
c. Breathing	No data	 (ii) "before the workshop I would just pop pills and self medicate, honestly Um, the breathing techniques and the relaxation, try and breathe, I love music. So now I grab some music, put on some music, and lay there and just breathe. Music can get me through a dayI can't tell you the last time I took a pain pill I just breathe my way through it honestly now Now if I'm feeling somethingI don't want to take too much medicine anymore. So the class helped me with that. There's other ways to deal with pain than medication." (Age 32, High School+, Severe Lupus, Depressed)
d. Distraction	 (i) "I'm a gardener, I love to be outside in the yard I'll start doing something and I know I'm in pain but I've blocked it out of my mind and I'm still working on it, um, just to push myself beyond what the symptoms are because I have control. My mind is stronger than my body." (Age 54, College+, Mild/Moderate Lupus, Not Depressed) 	 (ii) "Interviewer:You also said you learned ways to cope with your pain? Respondent: Yes. Relaxation and meditation, little techniques, different ways like that or, um, what's the word - distraction. Focus on your mind on something else. Try not to focus on the pain. Like music or make yourself do something. Draw or, you know, the breathing techniques and stuff rather than always self-medicating or just laying in pain or something. You know, try to do something else." (Age 32, High School+, Severe Lupus, Depressed)

Table 2.	Examples of gu	otes illustrating	CDSMP impact	on relaxation behaviors

depression, and SLE severity. Reasons cited for low attendance (3 sessions or fewer; N = 9) included perception of classes as not useful or helpful (n = 4), health problems (n = 2); competing time commitments (eg, work; n = 2), and forgetfulness (n = 1). Participants who attended one session were more likely to be younger women (aged 49.6 years and below; six out of seven participants who attended one session).

Qualitative findings. The qualitative analysis identified four distinct themes of perceived CDSMP impact: relaxation, exercise, medication adherence, and diet. We describe findings theme by theme, presenting baseline findings and then wave 2 changes

within each theme. We note the number of participants who were excluded from each theme's wave 2 analysis.

Relaxation. <u>Wave 1</u>. At baseline, 21 of 24 participants reported engaging in some type of relaxation to manage their SLE. The analyses revealed two types of relaxation behaviors: "mindfulness activities" and/or "taking it easy." Our analysis found that baseline relaxation behaviors did not vary across the sample by age, education, SLE activity, or depression (Supplementary Tables S1–S4).

Within this theme, 17 women reported exclusively "taking it easy" to manage their SLE. We define "taking it easy" as the practice of reducing the intensity and/or frequency of daily activities, such as cooking, to avoid aggravating SLE symptoms. "Taking it easy" included resting activities, such as laying on the couch, watching television, and interspersing shopping trips, as well as "sitting" breaks. Ten women shared that rest was important both during or when on the verge of experiencing a flare (Table 2, sub-theme 1i). Obtaining sufficient rest was important, particularly during flares as well as to prevent them.

Four participants reported engaging in mindfulness activities to manage stress and pain; all four women also "took it easy." Here, "mindfulness" refers to "a process of openly attending, with awareness, to one's present moment experience" (43). We used "mindfulness" to encompass yoga, meditation, and breathing techniques explicitly performed to manage SLE. We also included distraction techniques under "mindfulness" because participants in this study linked "distraction" to relaxation and mindfulness, either explicitly (n = 1; Table 2, subtheme 2dii) or implicitly (n = 2). Mindfulness activities reported at baseline included distraction techniques (N = 3) such as gardening (Table 2, subtheme 2di), meditation (n = 2), and yoga (n = 2) (Table 2, subtheme 2bi).

Two participants did not report engaging in any form of relaxation to manage their SLE at baseline. When in pain, they chose to push themselves through daily activities.

<u>Wave 2</u>. Fourteen out of 19 women reported that the CDSMP helped them enhance their relaxation efforts. Four participants were excluded from wave 2 analysis for this theme

(Supplementary Table 1). Seven women learned new mindfulness techniques during the CDSMP, including breathing (n = 6; Table 2, subtheme 2cii), meditation (n = 4), distraction (n = 3), and yoga (n = 1). The CDSMP distributed a meditation CD, and several participants observed that it was an effective sleep and relaxation aid (Table 2, subtheme 2bii).

Among participants who reported using meditation and distraction techniques at baseline (N = 4), two learned novel forms of mindfulness (yoga, meditation; Table 2, subtheme 2aii), one had rekindled her desire to practice breathing techniques, and one reported no change in mindfulness activities.

Following the CDSMP, participants who "took it easy" at baseline increased the frequency and range of these activities (N = 10), often in conjunction with mindfulness techniques (N = 6). Participants reported that discussions with CDSMP lay leaders reinforced the importance of balancing activity with "taking it easy," (Table 2, subtheme 1ii), managing others' expectations of them, and prioritizing self-monitoring (ie, regular self-appraisal to detect changes in symptoms like joint pain).

Listening to other participants relay personal strategies for prioritizing self-care encouraged two women to devise their own strategies to "take it easy." For example, one participant decided to prepare meals in advance and then enlist help to reheat dishes at mealtime. Three women learned to "listen to …[their] … body,"

 Table 3.
 Examples of quotes illustrating CDSMP impact on exercise

Subtheme	Wave 1 Example Quote	Wave 2 Example Quote
1. Little or no exercise	 (i) "See like, my mind tellin' me "oh I can do that, I wanna do it."Cause he [partner] always in the yard doing something. [Partner said:] "Get your exercise, come out in the yard and do some." I said, "It ain't that simple." [laughs] It ain't that I don't want to, I said, I would love to bend down and stuff like that. I can't really lot of time, can't even really tie my shoeeither I have to sit a certain way to try to if I stretch this leg out and, and do thisI'm feelin' the pain" (Age 64, High School+, Severe Lupus, Not Depressed) 	 (ii) "Interviewer: Were you going to the gym before the classes? Respondent: Not regularly, you know; just – I maybe e-every couple of months or – you know what I mean? It-it wasn't consistent, but now [after the CDSMP] it's like – it's refreshing, um, it helps me sleep at night, um, it'sIt strengthens me, it helps my appetiteI go to church on Sunday, and I rest on Monday. Tuesday I go to the gym, bible study on Wednesday, volunteer at the hospital on Thursday, go to the gym on Friday I'm trying to get to three days a week." (Age 61, High School+, Mild/Moderate Lupus, Not Depressed)
2. Regular exercise	 (i) "I do e-, try to exercise, I walk. I can walk a mile without being out of breath,If I get on the treadmill, it's, uh, the 'lliptical, mm. I think I could maybe do one or two minutes on that darn thing, I, I just, that wears me out Yeah I try to do that maybe um two or three times a week" (Age 58, High School, Severe Lupus, Depressed) 	 (ii) " I had already set a goal on looking at another alternative to exercise, and that was yoga. And so when I came back to class and told them about yoga, those same skills that they were talking about in the book were also techniques used fordoing the things in yoga. So it was very easy to apply itTo start doing yoga in January and see a major difference, that was like a key in that book that helped, and it just said – It was confirmation. It was confirmation." (Age 55, College+, Severe Lupus, Depressed)
2a. Regular exercise (action planning)	No data	 "[after the CDSMP] Um, the strategies [for getting regular exercise] haven't changed some of the tactics might have changed. For instance, like, you know, being more deliberate about actually planning exercise,Ive joined an exercise, I mean, what you call it? A line dancing class So I do that on Tuesdays, and I try to walk on two other days of the week for half an hour. It doesn't matter what two days, but – um, so, that's, that's my new exercise plan." (Age 68, College+, Mild/Moderate Lupus, Not Depressed)

(ie, pay attention to changes in their body indicative of stress or the need to rest). One of the two participants who reported not "taking it easy" at baseline described learning to balance activity with relaxation (Table 2, subtheme 1ii).

The analysis revealed variations in perceived CDSMP impact on relaxation by participant characteristics. Many women in this sample who reported adopting new mindfulness techniques had attended three or more classes (N = 7). College-educated women and participants with mild/moderate SLE activity reported engaging more frequently in both mindfulness and "taking it easy" post CDSMP.

<u>No reported change</u>. One of the two participants who reported not "taking it easy" at baseline reported no change in relaxation behaviors.

Exercise. <u>Wave 1</u>. At baseline, 15 of 24 participants reported engaging in little or no exercise, whereas 9 women exercised regularly to manage their SLE. Women's responses were patterned by age and education. Younger participants (N = 9) and women with fewer years of education (less than college) in this sample were more likely to report engaging in little or no exercise (Supplementary Tables S1 and S3). Joint pain and perceptions about gym equipment as "not considerate of people with disabilities" were cited as barriers that hindered regular exercise (Table 3, subtheme 1i). The nine participants who reported engaging in regular physical activity typically did low-impact activities like yoga or walking (Table 3, subtheme 2i).

<u>Wave 2</u>. Twelve of 21 participants reported that the CDSMP helped to either initiate or increase how frequently they exercised. Two participants were excluded from the wave 2 analysis (Supplementary Table 2). Analyses indicate that, in this sample, wave 2 responses were not patterned by CDSMP attendance or participant characteristics. After the CDSMP, 7 of the 15 women reporting little exercise at baseline experienced an increase in the range (n = 3; eg, introduced stretching) and frequency

of physical activity (n = 5; eg, walking, gym workout sessions; Table 3, subtheme 1ii). Strategies that women found effective included suggestions of low-impact exercises; incorporating physical activity into daily routines; and setting personal weekly exercise goals, referred to as "action planning" by participants. For example, a participant designed her own action plan featuring weekly line dancing classes; prior to the CDSMP, she had held a gym membership but barely used it because of her SLE symptoms (Table 3, subtheme 2i).

Among women reporting regular exercise at baseline, five of nine stated that the CDSMP helped them increase range (n = 2; eg, line dancing) and frequency (n = 3; eg, walking, stretching) of physical activity. Strategies discussed included low-impact exercises (Table 3, subtheme 2ii) and goal setting.

<u>No reported change</u>. Nine participants reported no change in exercise self-management behaviors; each cited a unique reason including limited mobility (n = 1), lack of drive (n = 1), did not need advice about exercise (n = 1), and prior engagement in physical activity (n = 1). Two participants had contemplated exercise but did not report initiating physical activity.

Medication adherence. <u>Wave 1</u>. At baseline, all but one woman reported taking medications to manage SLE and/or its side effects. Of the 21 women for whom we gathered baseline adherence data, 7 reported not having missed a pill in the past month; 4 had missed a pill in the past month; and 10 disclosed missing a pill but did not mention when. Participants reporting past-month adherence were more likely to have severe disease activity, depression, or both. Women reporting past-month medication adherence at baseline described a number of strategies that aided them, including setting cellphone reminders, using labeled pill boxes, and situating medications at conspicuous locations within the home (eg, kitchen).

Participants reporting medication nonadherence (N = 14) cited both unintentional causes (eg, forgetfulness [n = 9], delayed

Table 4.	Examples of	f quotes illustrating	CDSMP impact	t on medication adherence
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Subtheme	Wave 1 Example Quote	Wave 2 Example Quote
1. Ever missed a pill, including in the past month	 (i) "Interviewer:thinking about the past month or so, have you missed any pills? Respondent: Mm-mm. No. Oh, well. Uhh, let me see. Plaque, the Plaquenil I, I do sometimes [exhales] forget to take or. Because sometimes when I take it seems like to me, I get nauseous [pause] so I might skip that, that pill" (Age 63, High School+, Mild/Moderate, Depressed) 	 (ii) "[before the workshop] I would just pour a bunch of pills and not count them but one of the coaches [lay leaders] said put seven days, seven days, seven days, and I wasn't doing it. And sometimes I would go out of my bedroom and come back in and I couldn't remember did I take it or did I not take it. So it makes sense to put seven days in there and if I take it – well, she said do seven days and if you take it three times a day put that amount in there. So if you can't remember if you tok it at night then you go back and count and that way you know and so that works." (Age 61, High School+, Severe Lupus, Depressed)
2. Never missed a pill in the past month	No Data	 (ii) "Respondent: And also I set, like, a reminder on my phone, so when it's time to take-take my medicine. Interviewer: How did you learn about these? Respondent: The-the work-, the workshop. Interviewer: Okay. How has it helped you? Respondent: It helped me stay on top of my meds" (Age 23, High School+, Severe Lupus, Depressed)

Table 5. Examples of quotes illustrating CDSMP impact on diet

Subtheme	Wave 1 Example Quote	Wave 2 Example Quote
No subtheme	 (i) "I take care of my lupus, by being conscious of what I'm eating, to eat a lot of fruits and vegetables each day Um, I kind of avoid meat. I just eat vegetables and fish. That's about it I drink a lot of, um, I drink a lot of, um, the herbal tea, like a ginger. Ginger tea to manage mywhen I do have inflammation or pain, knowing how much better people feel when they don't have meat and how much importance vegetables and fruit has to the body and that those are things that I want my body to have to be able to operate better. The better they operate, the better the lupus will be." (Age 46, College, Mild/Moderate Lupus, Not Depressed) 	 (ii) "So every week I try to still do a little activity plan of action plan of what I want to do that weekUm, that was getting us to cut out bad habits. So now I eat more fruit versus the candy I used to always eat 'cause that was one of my goals in, um, class and workshop. And I stuck with that so now I'm buying like bowls of fruit instead of bags of candy. And then, um, just eating right, watching what you eat." (Age 32, High School+, Severe Lupus, Depressed)

Abbreviation: CDSMP, Chronic Disease Self-Management Program.

refills [n=2]) and intentional reasons (eg, unwanted medication side effects (n = 3) such as nausea, weight fluctuations, and drowsiness [Table 4, subtheme 1i]).

<u>Wave 2</u>. After the CDSMP, 10 of the 20 women who were asked about medication-taking behaviors indicated that the classes helped them improve medication adherence, 7 reported no change, and 3 reported changes in adherence unrelated to the CDSMP. Women who had attended at least three classes (n = 8) were more likely to report enhanced medication adherence compared with those who had attended fewer than three classes (n = 2); other patterns were not observed.

Eight of the 14 participants who reported ever missing a pill at baseline improved adherence. Three of these women reported that the class taught them strategies to help overcome forgetfulness, including using a pill box (Table 4, subtheme 1ii). Among the seven women reporting past-month medication adherence at baseline, the program seemed to provide additional strategies to facilitate adherence behaviors (eg, using pill boxes) when participants had not used such methods previously. The CDSMP also reinforced the importance of setting medication reminders for some women (Table 4, subtheme 2ii).

<u>No reported change</u>. Seven participants (n = 5 from baseline nonadherence group; n = 2 from baseline adherence group) reported no change in medication adherence. Two women perceived that they had effective adherence behaviors prior to CDS-MP, two stated that they missed pills intentionally at baseline, and three did not expound further.

Diet. <u>Wave 1</u>. At baseline, 23 of 24 participants discussed using diet as a SLE self-management tool. Some women had adopted vegan or pescatarian diets, eliminated red meat, and/ or increased their intake of fruits and vegetables (Table 5, subtheme 1i). The extent to which women in this sample used diet to manage SLE at baseline was not patterned by disease or demographic characteristics.

<u>Wave 2</u>. Seven of 17 participants reported that the CDSMP helped them improve their diet. Five of these seven women attended four or more classes; our analysis did not reveal additional patterns by disease or demographic characteristics. Six participants were excluded from wave 2 analysis for this theme (Supplementary Table 4). Through the CDSMP, women learned to control portion sizes (n = 4), incorporate more fruits and vegetables (n = 4), and drink more fluids (n = 3). For four of these seven women, the classes served as a reminder of the significance of diet as a self-management tool. CDSMP strategies and skills that aided women included portion size control (n = 3), food label reading (n = 1), and goal setting or "action planning." Over the 6-week program, participants reported that the CDSMP lay leaders asked each participant to set personal weekly goals, which for some were diet related, and to report on their progress to fellow attendees. Many women perceived this goal-setting strategy as effective and continued to utilize it after the CDSMP (Table 5, subtheme 1ii). Reported CDSMP impact was not patterned by demographics or health status.

At the conclusion of wave 2 interviews, participants were asked to reflect on which parts of the CDSMP they perceived to have most influenced their ability to live with lupus. Participants reported that the CDSMP had the most valuable effects through exercise (n = 5), relaxation techniques (meditation, breathing, distraction, and "taking it easy") (n = 3), diet (n = 2), and medication adherence (n = 1).

<u>No reported change</u>. Ten participants reported no change in their diet after attending the CDSMP, citing prior knowledge of and adherence to a healthy diet; one participant attributed improvements in her diet since baseline to her own desire for longevity rather than the classes.

DISCUSSION

Findings from this qualitative analysis indicate that African American women living with SLE perceived the CDSMP as a valuable resource to adopt or improve fundamental self-management behaviors, including relaxation, exercise, medication adherence, and healthy eating. These findings resonate with previous results from a pilot study that suggested that the CDSMP may be effective among low-income African American women with SLE (25). We also found, with few exceptions, that changes in self-management practices did not vary by participant sociodemographics or health status.

The most valuable and widespread CDSMP effects perceived by African American women were related to their relaxation and exercise practices. Although exercise was viewed by participants in our study as an overall health-promoting behavior, it was not generally perceived as having a direct impact on SLE symptoms. Relaxation practices, in contrast, were perceived as valuable tools to prevent or control flares, representing one of the most common behavioral changes reported after the CDSMP. A growing body of research suggests the promise of mindfulness techniques to reduce the effects of stress and improve outcomes in people with SLE (44.45). As making daily life adjustments to control physical and mental symptoms has emerged as a key theme among African American women with SLE (46), our findings support the importance of the using CDSMP to introduce African American women living with SLE to mindfulness practices. Distraction or attention refocusing was also brought by participants as another helpful cognitive technique to manage pain. "Distraction" is a chronic pain management technique that involves focusing attention away from the pain in order to achieve temporary relief from symptoms (47). This technique is taught in the CDSMP program as part of cognitive practices to manage symptoms, and study participants discussed this technique in connection with relaxation and mindfulness (48). The CDSMP program addresses distraction as a strategy that works best for short activities in which symptoms (eq. pain, sleep problems) can be anticipated (48). However, the evidence supporting a beneficial role of this technique on pain has been controversial (49-51), and a recent meta-analysis concluded that attention-based strategies are not effective in altering the pain reported by patients with chronic pain (52). Interestingly, women who self-reported depressive symptoms were more amenable to learning the new relaxation techniques taught during the CDSMP. Because depression is often underdiagnosed and undertreated in the African American population with SLE (53), and because mindfulness practices may benefit people with anxiety-depressive disorders (54), the CDSMP can be an encouraging resource for patients with SLE at high risk for mental health comorbidities.

Although healthy eating and taking medications emerged as significant self-management need among the majority of participants at baseline, positive changes related to these two themes were not consistently attributed to the CDSMP. These findings can be partially explained by the complexity of these two behaviors. Treatment adherence is a composite construct that can be facilitated by the individual perceptions of the value of medications to preserve health, how medications are viewed by and negotiated with physicians, and medication costs (18). Similarly, dietary changes can be facilitated by multiple mechanisms, including knowledge, perceived risk, and consequences of nonhealthy eating on SLE outcomes (55). Not surprisingly, women who had attended at least three classes were more likely to report enhanced self-management strategies in these two themes. These results support the key role of the CDSMP strategies, including "practice and

feedback" throughout the program, to enhance self-management skills and promote behavioral change (56).

This analysis found that perceived CDSMP impact on medication adherence was experienced equally for women with and without depression. Because recent research indicates a strong association between depression and both low treatment adherence (57) and greater disease activity (58) in patients with SLE, our results suggest that the CDSMP may be a promising intervention to enhance medication consumption among patients with SLE and depression. Moreover, these findings add to a growing corpus of research that posits that individuals with depressive disorders may be more responsive to group-based interventions that utilize goal setting and action planning compared with other types of interventions (33,59,60).

These findings should be considered in view of the study's limitations. As with qualitative studies generally, our findings may not be generalizable to the broader population of African American women diagnosed with SLE who live outside of the southeastern United States, more newly diagnosed African American women (sample mean age since diagnosis is 14 years), or patients who are male. Consistent with purposive sampling, however, we were able to explore variations in themes by participant age, depression, and SLE severity. Most GOAL participants have graduated from high school, however, so we could not achieve our aim of exploring differences in CDSMP experiences by high school graduation status; instead, we have variation by college graduation, which may be less salient to self-management and CDSMP experiences than high school graduation. In addition, sample sizes for wave 2 analysis varied for each theme because some participants attended only one CDSMP session and were not asked about perceived CDSMP impact on account of their low exposure. These participants were excluded from the theme-bytheme analyses unless they volunteered theme-related information, hence causing the disparities in sample size. Moreover, we employed an "emic" approach (ie, study of a phenomena through the perspective of members of the system or context under study (61)) to grouping strategies and to determine whether they were effective. However, given the current evidence, some of those strategies may have different levels of effectiveness. For instance, mindfulness meditation has been found to improve health-related quality of life themes in patients with SLE, whereas the evidence for distraction and "taking it easy" is either scarce or controversial (41,49-51). Although our findings suggest participants added to their repertoire of effective coping strategies (eg, breathing, meditation) through the CDSMP, discerning the extent to which potentially ineffective coping strategies were replaced by more valuable ones was outside the scope of our study.

Our study has several strengths. Interviews were audio recorded and transcribed verbatim to strengthen descriptive validity (ie, the data's accuracy and completeness) (41). To improve interpretive validity (ie, hewing to participant perspectives), we conducted member checks with two African American women living with SLE, both of whom corroborated our findings. The study's longitudinal design further enhanced its interpretive validity. The study's longitudinal design, with a high retention rate (95.8%), also supported valid comparisons of self-management behaviors reported by participants, pre- and postintervention.

In conclusion, this longitudinal, qualitative study suggests that African American women living with SLE, a population vulnerable to high rates of SLE morbidity and mortality, perceive benefits from CDSMP participation. Should additional quantitative studies reach similar conclusions, African American women with SLE should be encouraged to participate in CDSMP workshops. Because the CDSMP is widely disseminated and available to the adult U.S. population through community centers, it may be a suitable and accessible option for African American women with SLE, even though it is not specifically tailored to SLE.

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