Yoga in Systemic Lupus Erythematosus: Results of a Pragmatic Trial

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Abstract: *Objective*: To evaluate the feasibility and potential benefits of initiating a yoga program adapted for persons with systemic lupus erythematosus (SLE).

Methods: We conducted a pragmatic trial of standard treatment (control group) or standard treatment plus yoga classes (intervention group) in persons with SLE. The intervention consisted of 16 yoga classes over an eight-week period. Evaluation of feasibility and benefits included measurements of compliance and results of post-intervention surveys and focus group discussions following completion of the yoga intervention.

Results: The average age was 38.6±12.6, 96% were female, the mean SLE disease duration was 9.8±7.9 years, and mean SLE Disease Activity Index (SLEDAI-2K) score was 4.0±4.0. There were no significant differences between baseline characteristics between the groups. In the yoga intervention group, class attendance averaged 63% (range 39-87%); home practice averaged 1.2±1.3 hours/week. Results of post intervention surveys and focus group discussions indicated that all participants who had received the yoga intervention experienced improvement in physical and psychological well-being, including improvement in stress and pain management, improved sleep quality and decreased fatigue. Participants expressed satisfaction with the yoga program and recommended longer and more frequent classes. All yoga participants voiced interest in continuing the adapted program but were hesitant to try programs not tailored for chronic diseases like SLE.

Conclusions: Our adapted yoga program was well tolerated and positive effects were experienced. The results suggest that an adapted yoga program provides persons with SLE with an opportunity to experience yoga and its accompanying benefits.

Keywords: Systemic Lupus Erythematosus (SLE), yoga, intervention.

INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease characterized by numerous manifestations including painful joints and debilitating fatigue, and can potentially result in permanent organ damage [1-4]. Unpredictable increases in disease activity (flares) are common in SLE. The first-line treatment includes immunomodulating medications, with potential side effects. Not surprisingly, psychological distress is common in SLE [5], as is depression [6-9]. Interventions are needed to help persons with SLE cope with the physical and psychological challenges of their disease.

There is increasing interest in the physical and psychological health benefits of yoga. Recent reviews of yoga and related complementary therapies suggest that yoga may be safe and beneficial for persons with

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chronic rheumatic disease [10,11]. Although there have been no studies of yoga in SLE, yoga has been shown to reduce pain and improve quality of life in persons living with a wide variety of pain-associated diseases [10-12]. Studies that examined the benefits of yoga specifically for rheumatoid arthritis showed improvements in pain, global assessments, disease activity measures, medication use, and energy [13-18].

A recent survey within our large SLE clinic registry had suggested a role for yoga as a potential complementary therapy for standard care [19]. To address this issue, we conducted a pragmatic trial of standard treatment (control group) or standard treatment plus yoga (treatment group) in SLE. The primary goal of this study was to investigate the safety, feasibility, and potential benefits of an adapted yoga intervention for persons living with SLE. We report on the results of compliance measures and the post-intervention surveys and focus group discussions of patients in the yoga intervention group.

MATERIALS AND METHODS

Ethics approval to conduct this study was obtained from the Ethics Review Board of the McGill University Heath Centre. Recruitment took place at the McGill University Health Centre SLE clinic and recruited patients gave informed consent to participate. At our centre, patients with clinically confirmed SLE (by American College of Rheumatology, ACR criteria, prevalent and incident) are enrolled in a longitudinal study cohort. In addition to standard care, patients are systematically evaluated once a year for clinical outcomes and determinants, with a standardized protocol, including measurements of disease activity and damage using the SLE Disease Activity Index SLEDAI-2K [20] and the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI) [21], respectively. From 1978to the present date, more than 650 patients have consented to participate in the longitudinal study. Over half of these remain in active follow-up. Recruitment for the current trial was solicited from consecutive SLE patients attending their yearly assessment. Exclusion criteria included age >70 years, current participation in a yoga program, pregnancy, and history of hip replacement. Consenting participants were randomized to standard care, or standard care plus yoga intervention. Participants in the intervention group were asked to complete the eight-week yoga program and the control group continued with standard care (that is, no additional physical activity program was provided). The intervention was based Iyengar yoga, with special attention to correct body alignment to allow the body to move safely in and out of a pose. The adapted program was developed by a certified and experienced Iyengar yoga instructor (HL). A series of six gentle poses (avoiding stress to joints) were used, and these concentrated on relaxing muscles to release physical tension and to create mental relaxation. The major component of the yoga was restoration and relaxation by using poses to facilitate the natural breathing process, release physical tension, and to ease mental stress. From this perspective, the intervention would be suitable to most chronic illnesses. Each pose was introduced gradually to ensure that it would be mastered and easily replicated by the participants at home. Props, such as blocks and blankets, were used to allow all body types regardless of size, strengths and weaknesses to attain beneficial poses with ease. Each pose was introduced gradually to ensure that it would be mastered and easily replicated by the participants at home.

The yoga classes were held twice weekly for a period of 8 weeks. All classes took place at the United Yoga School (Montreal, Canada) and taught by a certified yoga instructor. Class size ranged five to six participants per class for each eight-week session. In total, there were three yoga sessions. Each session began when there were at least five participants recruited to the yoga intervention.

Outcome measurements of feasibility and potential benefits were assessed using measures of compliance (dropout rates, class attendance and hours of home practice) and results from post intervention surveys and focus group discussions held following the intervention.

The post-yoga intervention survey was administered following the last yoga class. The survey consisted of a series of statements to assess satisfaction with the yoga program and perceived benefits. Participants were asked to rate a series of statements based on a Likert scale (1=strongly disagree; 5=strongly agree). The focus group sessions were audio-recorded and led by an experienced moderator and co-moderator; in addition notes were made during the sessions to capture non-verbal information such as facial expressions and body language, for use when the audiotaped discussions were analyzed. The focus groups used open-ended questions (Table **1**) regarding impressions about the yoga program including teacher, allotted class times and location, perceived benefits and difficulties, and recommendations to improve the

Table 1: Focus Group Questions

1. What are your impressions about this yoga program?
a. The classes (location, format, style, time of day, level of difficulty, number of sessions)
b. The teacher (helpfulness, understanding, adequacy of explanations, knowledge, confidence)
c. Other?
2. In what ways, if any, did this yoga program affect you physically or mentally?
3. When this session is over, will you continue yoga in your life? How likely would you:
a. attend yoga classes at a studio?
b. practice yoga at home?
4. How satisfied were you with the yoga program?
5. In what ways could this yoga program be improved?

yoga program. At the end of each group discussion, the audiotapes were transcribed and reviewed independently by the moderator and co-moderator. Qualitative content analysis of the focus group transcripts, to identify recurring themes from focus group discussions, was performed based on grounded theory. The transcripts were independently coded by the moderator and the co-moderator and the results reviewed to arrive at a decision regarding major themes arising from the data. The frequency of occurrence of common issues raised during the discussion was categorized to determine themes.

RESULTS

Over a ten-month period, 220 potentially eligible SLE patients were approached at their annual clinic visit (Figure **1**). Of these, 15 did not meet criteria (12 practiced yoga, two were pregnant, and one had a hip replacement) and 42 patients could not participate because they lived at a distance too far to attend the yoga classes. Of the remaining 163 patients, 106 patients declined due to lack of interest (N=45), lack of time (N=40), and feeling unwell (N=21). Fifty-seven eligible patients consented to participate in the study.

The average age of the 57 participants was 38.6±12.6, 96% were female, mean disease duration was 9.8±7.9 years, mean SLEDAI-2K score was 4.0±4.0, and mean SLICC/ACR DI was 0.9±0.8-1.0. There were no significant differences between the control and yoga intervention groups in the variables measured (Table **2**).

Prior to administering the yoga intervention, 23 participants (11 in the yoga group and 12 in the control group) withdrew due to a long wait time (mean=62±33 days) due to the need for a sufficient number of subjects to be allocated to the intervention before initiating the yoga classes. At the start of the intervention, thirty-four participants remained (controls=17; yoga intervention=17) in the study. Those who had withdrawn did not appear to have significant differences from the overall group in terms of demographics (61% were Caucasian, all were female, with mean age 36.4 years, standard deviation, SD 10), disease duration (8 years, SD 6.1 years) or SLEDAI-2K scores (mean 3.0, SD 3.1).

Of the 17 participants randomized to the yoga intervention, one experienced upper back discomfort following the second class and discontinued. The remaining 16 continued with the yoga program to completion without adverse events. Class attendance averaged 63% (range 39-87%). Reasons for not attending classes included, work scheduling conflicts, bad weather, and feeling unwell. Home practice averaged 1.2±1.3 hours/week.

The results of the post evaluation survey are shown in Table **3**. Fourteen participants (83.4%) in the yoga intervention completed the post-intervention survey (the other two did not participate as they did not attend the last class and thus did not complete the survey). The characteristics of those who completed the survey were similar to the overall sample (all who completed the survey were female; mean age was 41.5 years, SD 16.5; 61% were Caucasian; SLE duration was 9.4 years, SD 7.9; baseline SLEDAI-2K score was 4.4, SD 3.9).

The responses indicated high satisfaction with the yoga program and instructor. Ratings for level of difficulty indicated that the program was considered neither too difficult nor too boring. Some participants reported difficulties attending the classes due to work schedules. Most agreed that the yoga program had helped them physically. Although ratings of improvement in mental health and depression were low, most agreed that the yoga program helped lift their spirits and engendered a feeling of being in control. Most participants agreed that they would continue the yoga program if available.

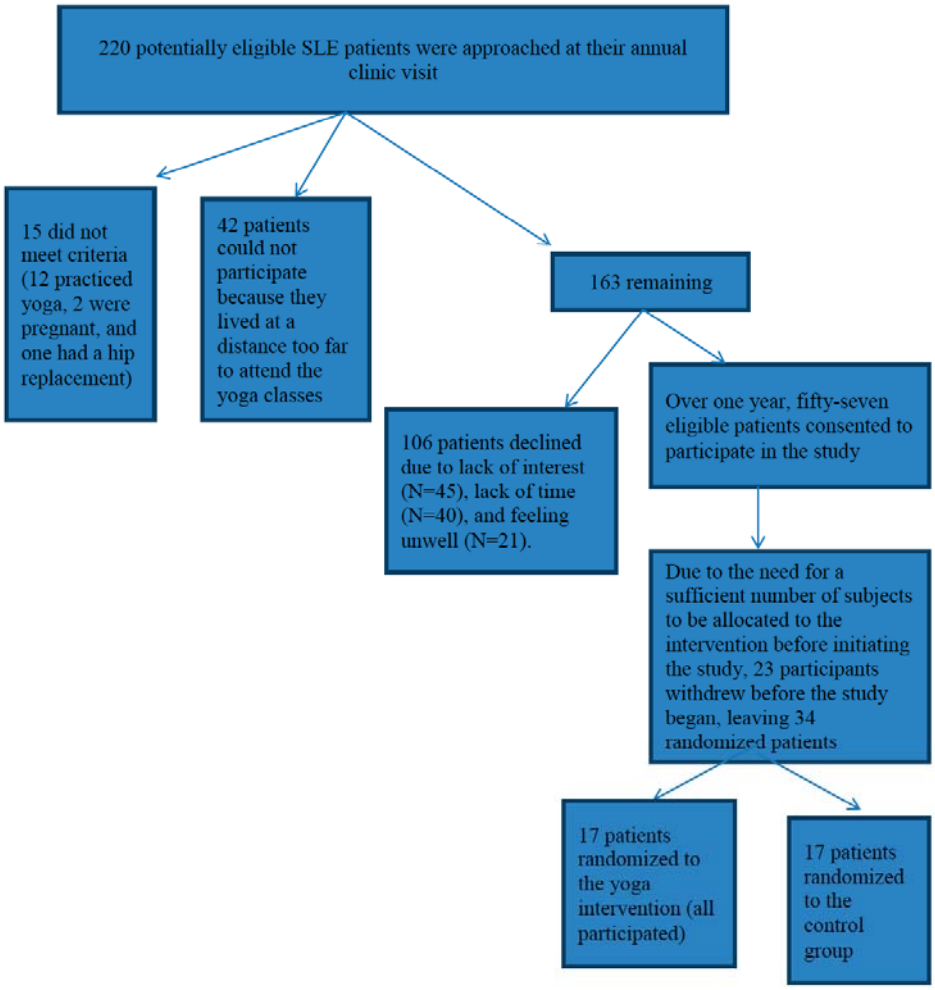

Figure 1: Flowchart explaining recruitment and eventual randomization.

Table 2: Baseline Characteristics of the SLE Subjects Randomized to either the Control Group or the Yoga Intervention Group

		Mean	95%	CI
Global SLE Activity Visual Analogue	Control	3.3	2.3	4.3
	Yoga	3.0	2.0	3.9
	Total	3.2	2.5	3.8
SLEDisease Activity Idex-2000	Control	4.7	2.9	6.4
	Yoga	3.3	1.9	4.7
	Total	4.0	2.9	5.1
Center for Epidemiologic Studies Depression Scale	Control	17.3	14.6	20.0
	Yoga	18.6	16.0	21.1
	Total	17.9	16.1	19.7
SF-36 Physical component Summary	Control	45.8	41.5	50.1
	Yoga	45.0	41.5	48.5
	Total	45.4	42.7	48.1
SF-36 Mental component Summary	Control	44.0	39.8	48.2
	Yoga	46.3	41.6	51.0
	Total	45.2	42.2	48.3

Table 3: Participant Ratings on Post-Yoga Intervention Survey (1=Strongly Disagree; 5=Strongly Agree)

	Median (IQR) ***IQR=Interquartile range**
The yoga program helped me feel more in control of my life	4.0 (2.3, 4.0)
The yoga program was boring	1.0 (1.0, 1.8)
The yoga program helped me manage my problems better	3.0 (3.0, 4.0)
The yoga program was too hard for me	2.0 (1.0, 2.8)
The yoga program helped improve my mental health	2.0 (1.0, 2.8)
The yoga program helped lift my spirits	4.0 (3.0, 4.0)
The yoga program took too much time	2.0 (1.0, 2.0)
The yoga program made me feel good physically	3.5 (3.0, 4.0)
The yoga program helped me with depression	3.0 (2.0, 4.0)
I would recommend the yoga program to a friend	4.0 (4.0, 5.0)
I am satisfied with the yoga program	4.5 (4.0, 5.0)
My needs were met by the yoga program	4.0 (3.0, 4.0)
The yoga teacher seemed to know what she was talking about	5.0 (4.0, 5.0)
The yoga teacher was friendly and warm	5.0 (4.0, 5.0)
The yoga teacher provided an adequate explanation	5.0 (4.0, 5.0)
The yoga teacher was not negative or critical	5.0 (40, 5.0)
The yoga teacher helped me solve any difficulties I was having	4.5 (4.0, 5.0)
The yoga teacher seemed to understand how I was feeling	4.0 (3.3, 5.0)
It was difficult for me to attend the yoga program (e.g.due to work)	3.0 (2.0, 4.0)
I practiced yoga during the week (outside of the class time)	4.0 (1.0, 4.0)
I plan on continuing with yoga on my own	4.0 (3.0, 5.0)
If a continuation of this course was available, I would take it	5.0 (3.0, 5.0)
The yoga program made me see that I can do yoga	5.0 (4.0, 5.0)
I liked the style of yoga that was taught	4.5 (4.0, 5.0)
I feel insecure about doing yoga	1.0 (1.0, 2.0)

Thirteen of the 16 (81.3%) participants in the yoga intervention attended the focus group discussions. Three focus groups were conducted, with three to five participants per group. These were held an average of 1 week after the end of the intervention. Three major themes emerged from the focus group discussions: 1) participants experienced physical and psychological benefits, 2) physical and psychological benefits were not immediate but occurred later in the program, and 3) tailoring yoga to meet the needs of persons with SLE is an essential component for a successful yoga program.

1) Physical and Psychological Benefits

All focus group participants reported an improvement in overall sense of well-being after completing the eight-week program. Participants reported having more energy during day-to-day activities, an increase in the quality of sleep, reduced fatigue, and improved pain management. One focus group participant noted, "*We get to know ourselves a bit more…(I am) getting to know my body and how it reacts...*"

Other benefits reported in the focus groups included improved stress management and healthier relationships, both in and outside of the workplace. One subject reported what she considered a remarkable psychological benefit: "*I have had lupus for twenty years and it was only then, lying there [on the floor of the yoga classroom] that I accepted lupus as part of who I am*."

This focus group finding was at least in part corroborated by the survey results (Table **3**) which as mentioned suggested that the yoga program had

helped the participants physically, as well as lifted their spirits and engendered a feeling of being in control (average response scores in terms of improvement in mental health and depression were less impressive).

2) Physical and Psychological Benefits Occurred Later in the Program

Most focus group participants stated that they first began to notice benefits well into the program and felt that class sessions should be extended beyond eight weeks. One focus group participant suggested, "*The benefits start when the classes stop.*" It was, also, suggested that the physical gains were noticed first, and the psychological benefits came later. Focus group participants additionally recommended that the one-hour class should be extended to two hours. They considered one hour not long enough to adjust to the pace and flow from pose to pose, especially during the first few sessions. They agreed that extending the length of the classes would have improved the program.

3) Tailoring Yoga to Meet the Needs of Persons with SLE is an Essential Component for a Successful Yoga Program

One focus group participant explained what happened to her when she participated in a yoga program that was not tailored for the needs of persons with SLE: "*I went to my gym and I found that the yoga instructor was pushing me way too much so that when I left there my knee was just swollen and my ankle was huge…So I paid for 6 months and did not go back because it did not meet my needs because the instructor just didn't understand*."

All participants expressed satisfaction with the yoga program content and instructor. All participants reported feeling at ease with the poses and yoga instructor. All participants agreed that the yoga instructor facilitated mindfulness by providing a healing rationale to the yoga poses. Participants also spoke about the yoga instructor's ability to promote self-confidence, further motivating them to adhere to the program. These elements of the focus group discussion were also found in the responses to the survey (Table **3**).

Most focus group participants expressed gratitude for the experience and stated they would continue if offered the same adapted program. However, they stated that they would be too apprehensive to take a yoga class that was not tailored for SLE.

DISCUSSION

To our knowledge, this study is the first to assess yoga in SLE. The randomized control trial design of our study was chosen to minimize confounding and bias, which may have occurred had patients self-selected their participation in the intervention. However, some selection bias is unavoidable, as patients who were not interested in yoga would most probably not consent to participate. However the study remains the best available effort to understand how yoga and similar complementary therapies might be experienced and potentially benefit the SLE population. Moreover we point out that other published studies have similar rates of participation, such as the work of Shapiro *et al.* on yoga in depression [22].

Other potential limitations should be noted. Although our sample represented a broad range of disease duration (mean=9.8±7.9 years), our sample was not necessarily representative of new-onset SLE. Also, the patient sample had primarily low to moderate disease activity.

Attrition was a challenge in this study, while patients awaited treatment allocation. However, it should be emphasized that of the 17 yoga participants, 16 (94.1%) remained to study completion. Similar to studies that investigated the effects of yoga in rheumatoid arthritis [12-14] and chronic back pain and fibromylagia [23,24], our participants reported important physical and psychological benefits, including reduction in fatigue and improvement in general well-being, sleep quality, stress reduction, and reduced fatigue. Surprisingly, our yoga participants recommended more and longer classes. Because debilitating fatigue is prevalent in patients with SLE, we had expected participants to be reluctant to attend the entire eight week program, but this seems not to be the case.

It is important to note that our participants experienced benefits well into their yoga classes. These findings indicate that modifications to the yoga intervention should include increasing the length of yoga class sessions well beyond eight weeks to ensure greater benefits. Also, classes should be increased to greater than 60 minutes in duration to allow enough time for participants to transition into sequential poses.

The importance of tailoring the yoga program to meet the needs of persons with SLE is essential in developing a successful yoga program. Most participants wished to continue with yoga but were

hesitant to try yoga classes that are not designed for persons with SLE. Similar results were found in a focus group study of a yoga program for rheumatoid arthritis[25]. Mainstream yoga classes are geared to average and physically fit individuals. There is an increasing prevalence of persons with musculoskeletal disease and an increasing need to provide programs to help persons self-manage these diseases. Adaptive programs are needed to help persons with SLE and other chronic diseases cope with their illness.

Although our yoga study was designed to assess feasibility, as opposed to demonstrate effects on health-related measures, we did collect baseline and follow-up information on sleep quality (as measured by the Pittsburgh Sleep Quality Index, where a global score > 5 indicates poor sleep quality), SF-36 scores, and the SLE Disease Activity Index (SLEDAI-2K). Interestingly, at the post-intervention assessment, the PSQI scores were worse in the controls (with 86.7% scoring poor sleep quality) than the yoga group (where 50% had scores indicating poor sleep quality, for a difference of 36.7%, 95% confidence interval 5.3, 68). At the post-intervention assessments, univariate analyses also suggested a slight (but not statistically or clinically significant) trend for better SF-36 physical component scores in the yoga group, versus controls. Finally, the post-intervention total SLEDAI-2K scores did show a trend in the yoga group (again, not statistically significant) towards decreasing activity (from an average of 3.4 initially to 2.6 at follow-up) while in the controls group, total SLEDAI actually trended up (from 4.4 at baseline to 4.7 in follow-up). Though promising, the effects of yoga on these measures are exploratory only, and need to be confirmed by other studies, designed specifically to test the hypothesis that yoga can improve these specific outcomes.

CONCLUSIONS

In conclusion, our adapted yoga program for persons with SLE was well tolerated and positive effects were experienced. Our results suggest that an adapted yoga program can provide persons with SLE with an opportunity to experience yoga and its accompanying benefits.

ABBREVIATIONS

SLE = Systemic Lupus Erythematosus

SLEDAI-2K = Systemic Lupus Erythematosus Disease Activity Index

ACR = American College of Rheumatology

SLICC/ACR DI = Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index

IQR = Interquartile Range

PSQI = Pittsburgh Sleep Quality Index

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

All authors meet the authorship requirements as all authors contributed to the collection of data and/or analysis and interpretation, as well as the preparation and approval of the manuscript.

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