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Experiences with Complementary and Integrative Health Among People with Rheumatoid Arthritis and Systemic Lupus Erythematosus: A Qualitative Study

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Abstract

Background: Rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE) are chronic immune-mediated inflammatory diseases often complicated by persistent pain and fatigue despite cutting edge pharmacological treatments. Lifestyle medicine (LM) and complementary and integrative health (CIH) offer adjuvant therapies with potential to alleviate these symptoms, but little is known about patients' experiences with these modalities.

Methods: This qualitative study explored the use of LM and CIH among English- and Spanish-speaking patients with RA and SLE. We conducted five focus groups using an original semi-structured interview guide to examine participants' experiences with, and barriers to using, LM and CIH. Group discussions were recorded, transcribed verbatim, translated, and analyzed in a multi-step iterative process to identify frequencies and thematic trends.

Results: Thirty-nine participants with RA or SLE discussed using LM and CIH modalities to manage their disease in 130 mentions. Diet was the most frequently discussed lifestyle modality

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with participants noting specific foods that exacerbated or alleviated symptoms. Traditional Chinese Medicine (TCM) and natural products were the most discussed CIH approaches, and participants expressed a strong interest in exploring additional complementary modalities to mitigate symptoms. The primary barriers to using LM and CIH were uncertainty regarding safe and effective practices and high out-of-pocket expenses.

Conclusion: Patients with RA and SLE are highly interested in using LM and CIH to manage their conditions, but many are unsure which adjunctive treatment approaches are safe and effective. More research on LM and CIH modalities is needed to facilitate clear, evidence-based answers to these common patient questions.

Key Indexing Terms:

Qualitative Research; Rheumatoid Arthritis; Systemic Lupus Erythematosus; Lifestyle Medicine; Complementary; Integrative Health

INTRODUCTION

Rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE) are chronic immune-mediated inflammatory diseases (IMID) that are often complicated by decreased health-related quality of life, even among individuals receiving the latest guideline-directed treatments. For example, despite the advent of biologic disease modifying antirheumatic drugs (DMARDs) for the treatment of RA¹, fewer than ten percent of affected individuals achieve sustained disease remission, and a significant proportion continue to experience pain, functional disability, and fatigue^{2,3}. Similarly, people with SLE experience major unmet needs related to the treatment of pain and fatigue, and over half of affected individuals report chronic uncontrolled symptoms despite immunosuppressive treatment⁴. Further, adverse drug events from DMARDs are common⁵, and many people with RA and SLE report a preference for non-pharmacologic treatments to reduce symptom burden^{6,7}. The high prevalence of persistent symptoms despite pharmacologic treatment coupled with the significant incidence of medication side effects points to an important need for adjuvant nonpharmacologic treatment approaches in the management of these diseases.

Lifestyle medicine (LM) and complementary and integrative health (CIH) represent overlapping medical specialties that provide opportunities to mitigate disease related symptoms in people living with chronic rheumatic conditions. The American College of Lifestyle Medicine defines LM as “the evidence-based practice of engaging individuals and communities with 6 pillars of comprehensive lifestyle change that include healthy eating, physical activity, stress reduction, restorative sleep, positive social connections, and avoiding risky substances”⁸. CIH combines complementary evidence-based approaches such as natural products, mind-body medicine, and acupuncture with conventional medical approaches to treat disease and promote health.

Though prior studies have demonstrated beneficial effects of dietary modification^{9,10}, physical activity^{11–16}, omega-3 supplementation^{17,18}, and combined lifestyle interventions¹⁹ in RA and SLE, no recent studies have focused on the practical use of LM and CIH approaches among individuals with these diseases, or patient perspectives on these

adjunctive treatment strategies. More research is needed to understand patient experiences with LM and CIH to inform patient-centered care that maximally aligns with patients' preferences and needs. The objective of this qualitative study was to explore a) use of LM and CIH treatment modalities among patients with RA and SLE; b) patient perceived efficacy of those modalities; and c) barriers to implementing lifestyle and CIH approaches in these populations.

METHODS

Recruitment

Eligible patients were recruited from a university-based rheumatology clinic and a county hospital rheumatology clinic in San Francisco, California, as well as by contacting individuals who had previously participated in rheumatology research based at the University of California, San Francisco (UCSF) and had consented to being contacted for participation in future studies. Though UCSF offers an integrative rheumatology clinic that is separate from the general UCSF rheumatology clinic, patients were not recruited from the UCSF integrative rheumatology clinic given the risk that patients already receiving integrative treatments may have unique perspectives about CIH relative to the broader population of individuals living with RA and SLE. Eligible participants were 18 or older; spoke English or Spanish; had a physician-confirmed diagnosis of RA or SLE; and had access to a computer, tablet, or smartphone that could be used for Zoom video conferencing. Research assistants screened prospective participants for eligibility and scheduled those eligible to attend focus groups with other participants who shared the same rheumatic disease diagnosis and language. We initially planned to have four—one for each language and diagnosis combination—however we added a fifth focus group after the first focus group for English-speakers with RA had low attendance due to an unexpected extreme weather event.

Procedure

First, we created a draft of interview questions that we tested in semi-structured individual interviews with two English-speaking and two Spanish-speaking participants. Using information obtained during individual interviews, we refined interview questions and developed an original focus group guide (Supplementary Materials) that focused on three domains: Lifestyle Modalities (diet, sleep, exercise, and stress management); Integrative Modalities (natural products, mind-body medicine, and Traditional Chinese Medicine/acupuncture). The senior author (CJK) conducted all focus groups while the first author (SP) and research assistant (DR) observed and helped with substantive follow-up questions and logistical issues that arose during the groups. The senior author had no relationship with participants before the study. All participants participated in only one data collection occasion.

Focus groups were conducted and recorded online using the Zoom video conference platform²⁰. Participants who had not previously used Zoom for videoconferencing were provided with one-on-one language-concordant training in how to download, install, and operate the application. The study was approved by the UCSF Institutional Review

Board (IRB #20–32518), and all participants provided informed verbal consent prior to participation.

Data analysis

We used the theoretical tenets of naturalistic inquiry²¹ to analyze the data using qualitative description^{22,23} in a multi-step, iterative process. After interviews and focus groups were completed, recordings were sent for professional verbatim transcription. A research assistant (DR) compared transcripts with the recordings for accuracy and then anonymized the transcripts by replacing each transcribed participant name with a number according to the speaking order in each group. Next, four authors (SP, CJK, AI, DR) reviewed each recording with the transcript to comprehensively identify all participants' mentions of lifestyle and CIH modalities across focus groups. The unit of analysis was a participant's mention, defined as a verbal turn-at-talk during the focus group in which a participant refers to, describes, or discusses at least one lifestyle or CIH modality^{24,25}.

All mentions were copied into an Excel spreadsheet noting the focus group number, language, participant number, and timestamp. Each mention was reviewed, summarized, and classified deductively using a standardized list of LM and CIH treatment modalities²⁴, which was then used to tally modality frequencies (Table 3). Definitions of relevant LM and CIH terms are provided in the Supplementary Materials. We reviewed all mentions using constant comparison, discussed mentions among the analysis team, and compared them for similarities and differences across focus groups and participants. Finally, we identified rich segments, defined as particularly informative mentions consisting of meaningful experiences, participant's narratives, or unique perspectives relevant to at least one research question²⁶. In the results and associated tables, we summarize trends across all mentions and highlight selected rich segments—ensuring representation of participants across identities and languages—to illustrate the scope and range of experiences with LM and CIH.

The Consolidated Criteria for Reporting Qualitative Research (COREQ)²⁷ 32-item checklist was used to ensure methodologic rigor (see Supplementary Materials).

RESULTS

Thirty-nine participants who spoke either English or Spanish and had a diagnosis of either RA or SLE participated in this study (Table 1). Data characteristics from each focus group are summarized in Table 2. Participants described their experiences using lifestyle and complementary treatment modalities to manage their rheumatic symptoms with n=130 total mentions of their experiences across focus groups (Table 3).

Lifestyle Modalities

Participants had 80 mentions related to the four categories of lifestyle modalities (LM) across groups. While diet was the most discussed, participants frequently mentioned synergies across lifestyle modalities, such as stress and sleep impacting diet and physical activity. For illustrative quotations about LM, please see Table 4.

Diet. Diet was the most discussed lifestyle modality across groups (n=40 mentions). Participants recounted experiences of noticing distinct relationships between eating certain foods and their RA or SLE symptoms. In both disease conditions and languages, participants agreed that regular consumption of meat, alcohol, and sugar negatively impacted disease symptoms. Additionally, several participants noted that eating a Mediterranean diet seemed to improve symptoms. Many participants described experimenting with dietary modifications shortly after their diagnosis and, later, as an adjunctive approach to improve and to actively manage symptoms. Despite these commonalities, participants varied widely in their routine diets, which foods triggered symptoms, and which foods they enjoyed. Some participants shared their strategies for successfully changing routine diet habits, while others recounted their difficulties maintaining a healthy diet. Across groups, participants expressed interest in eating healthy, organic foods to mitigate symptoms and, ideally, decrease dependence on medications.

Physical Activity. Participants described various physical activities (n=15 mentions) ranging from swimming to light walking, and generally agreed that physical activity is important for disease management. Some participants described exercise as being helpful for managing symptoms. For example, a Spanish-speaking participant with SLE had found that water therapy was very helpful for reducing her pain. Participants also discussed barriers to maintain regular physical activity, including disease symptoms and limited time, especially on workdays. They identified two factors that supported engagement in physical activities: 1) having a clinician discuss the health benefits of physical activity; and 2) affordable access to convenient locations conducive to exercise, such as a discounted gym membership. Finally, participants described a desire for guidance on physical activities that were gentle and safe in the context of physical limitations.

Sleep. Participants discussed sleep duration and quality (n=13 mentions) as significant contributors to symptom severity, and many reported difficulty achieving regular restorative sleep. Both English- and Spanish-speaking participants mentioned using pharmacological sleep aids to assist with falling and staying asleep at night. Across groups and languages, participants described the impact of other lifestyle modalities on sleep. For example, participants reported difficulty sleeping during periods when they felt overwhelmed by work or family obligations and unable to manage stress associated with everyday life. Conversely, they noted that eating a healthy diet and engaging in regular physical activity often resulted in better quality sleep. Participants discussed the strategies they had tried to mitigate sleep disruption and reported the following strategies as effective: listening to “sleep stories” on a mobile meditation application, massage, acupuncture, taking a hot bath or shower in the evening, avoiding caffeine during the second half of the day, and exposure to natural sunlight in the morning.

Stress Management. Stress management was the least discussed of the lifestyle modalities (n=12 mentions). The techniques that participants described as helpful for alleviating stress included prayer, meditation, and exercise. Participants also noted the benefit of learning more about their disease, including how to best manage it, for alleviating stress and anxiety. Though there was relatively limited discussion about effective strategies

for stress management, participants engaged in an extensive discussion about challenges they had experienced while living with RA or SLE that caused stress and the impact of stress on their health. They described several sources of severe stress, including their symptoms, functional limitations they experience from their disease, and the negative impact of those limitations on their work.

Complementary and Integrative Health Approaches

The focus group guide explored participants' knowledge of and experience with six categories of complementary and integrative health (CIH) approaches: Traditional Chinese Medicine; Natural Products; Mind-Body Medicine; Psychedelic Plants & Drugs; Massage; and Spirituality. There were 51 mentions regarding CIH modalities across the five focus groups. While both English and Spanish-speaking participants had experience with complementary health approaches, English-speaking participants discussed a wider range of CIH approaches. For illustrative quotations about CIH, please see Table 5.

Traditional Chinese Medicine (TCM). Traditional Chinese Medicine (TCM) and natural products were the most discussed integrative modality (n=15 mentions for both). TCM has been used for over two thousand years to prevent, diagnose, and treat disease; it encompasses several treatment approaches including acupuncture, diet, herbal therapy, meditation, physical exercise, and massage²⁸. Across groups, multiple participants reported experience using TCM herbs and acupuncture in the treatment of their rheumatic condition either alone or in combination with other integrative modalities. Several participants who had tried TCM reported positive experiences using acupuncture for managing rheumatic symptoms, having noticed improvement in joint inflammation and mobility. Notably, three participants recounted contrasting experiences, claiming that acupuncture had exacerbated their symptoms, including causing an exacerbation of their pain. These participants raised other concerns about TCM, citing lack of insurance coverage, expense, lack of accessible practitioners, long appointment wait times, worry about potentially dangerous herb-medication interactions, and fear of acupuncture needles. Participants agreed that there is a need for more information about TCM and safe strategies for integrating TCM modalities with other treatment approaches.

Natural Products. Natural Products are substances of natural origin and their synthetic alternatives that are intended to have health benefits, including herbal medicine, vitamins, minerals, and probiotics²⁸. Across language and disease groups, participants discussed various natural products they had used to help manage rheumatic conditions. Multiple participants reported using turmeric, a root native to Southeast Asia commonly used both medicinally and in everyday cooking, as well as curcumin, the active ingredient in turmeric that gives it a yellow color and therapeutic benefits. Participants reported using turmeric in different formulations—including in tea, cooking, and as a dietary supplement—to combat swelling and inflammation. One participant shared that curcumin had been so helpful for managing their RA symptoms that they had decreased their use of prescription medications. Participants also used topical cannabidiol (CBD), vitamins (e.g. vitamin C and biotin), and probiotics to manage their symptoms. Some participants had trouble sleeping and relied on supplements such as melatonin to sleep through the night. Participants commonly expressed

a preference for “natural things” and were interested in exploring additional natural products but wanted help identifying products that would be safe and helpful.

Mind-Body Medicine: Mind-body medicine describes a diverse group of practices that focus on the interactions among the brain, mind, body, and behavior, with the intent to promote health²⁹; it includes mindfulness training, meditation, yoga, Tai chi, Qigong, and biofeedback. Mentions of mind-body techniques were primarily by English-speaking participants (N = 8 mentions). Several participants used Tai chi (Supp Table A) and described their practice as light exercise that helped maintain mobility. The Wim Hof method breathing exercises (Supp Table A) and meditation were discussed as helpful for reducing physical discomfort and for managing depression and anxiety. Three participants in the English-speaking lupus group discussed significant benefit from the Emotional Freedom Technique (Supp Table A), noting that it had helped them reduce their anxiety and “the kind of pain [for which] the origin is emotional.”

Psychedelics. Both English- and Spanish-speaking participants discussed using psychedelics to manage rheumatic symptoms (n=6 mentions). One participant mentioned taking microdoses of psychedelic mushrooms and using low-dose cannabis for depression and anxiety. One participant advocated for “therapeutic exploration” of psychedelics to help treat rheumatic conditions. Three participants expressed a desire for more information about the therapeutic benefit of psychoactive substances in the treatment of rheumatic conditions.

Massage. Four English-speaking participants discussed massage (n=4 mentions) as beneficial for improving their sleep and being able to relax. Most participants who had used massage did so in conjunction with TCM practices, such as acupuncture and acupressure, as well as breathing techniques. One participant reported improved sleep lasting for months due to these combined modalities. Another participant affirmed that her experience with massage was a spiritual experience that fostered an ability to be present and mindful.

Spirituality: Two participants—one English- and one Spanish-speaking—reported using prayer as a complementary health approach (n=2). They both shared that prayer had helped them manage stress, find meaning in living with a chronic disease, and re-frame their physical and emotional suffering as an experience that connects them with other people.

DISCUSSION

This is the first study to investigate the patient experience with, and demand for, LM and CIH among a multilingual sample of individuals living with RA and SLE. Among LM modalities, participants were the most interested in diet and generally agreed that dietary content associated with the severity of joint symptoms, though the specific food ingredients that exacerbated symptoms varied across individuals. Among the CIH modalities, participants reported the most experience with TCM and natural products, expressed a strong interest in trying additional complementary treatment strategies, and described a need for more information on safely combining natural products or herbs with their prescribed medications. Participants also described the significant emotional and

psychological impact of living with a rheumatic disease with many reporting the use of mind-body-medicine to cope.

Our study builds on a growing body of literature addressing the impact of diet in people with rheumatic diseases by adding patient's lived experience of the effect of dietary change on inflammatory symptoms. Notably, regardless of language (English or Spanish) or rheumatic disease (RA or SLE), most participants in our study perceived an association between the content of their diet and their rheumatic disease symptoms. Additionally, most participants agreed that alcohol, sugar, and red meat associated with more joint pain and swelling, and that a Mediterranean or plant-based diet improved their symptoms. Congruent with these findings, in a study that evaluated dietary changes and patient-perceived lupus symptoms, Knippenberg and colleagues found that participants who changed to healthier eating patterns with more vegetables and less processed food experienced improvements in musculoskeletal symptoms, mood, and fatigue³⁰. Given the perceived association between diet and disease-related symptoms among patients with RA and SLE in our study and others^{30–32}, more research is needed to define the optimal diet(s) for individuals with these conditions.

An important theme throughout the focus groups was the significant psychological toll of living with a rheumatic disease, and though this phenomenon has been documented in prior epidemiologic studies, few studies have examined the lived experience of unmet psychological needs in RA and SLE^{33–36}. Across all five focus groups—but particularly during the Spanish-speaking RA group—participants discussed the detrimental effects of their disease on their physical function, social connections, performance at work (especially for those who worked in physically demanding occupations), and the ability to care for themselves. For some, these challenges had created a vicious cycle of stress leading to poor sleep, which in turn exacerbated their pain and fatigue, ultimately causing more stress. Many participants had taken medications for emotional distress but preferred to improve their mental health through other means, leading them to try a variety of complementary modalities such as meditation, prayer, emotional freedom technique, and psychedelics. The nearly universally shared experience of disease-related stress among participants in our study points to the critical need for further research on non-pharmacologic strategies—for example, mindfulness-based interventions, which have shown benefit in other chronic conditions complicated by pain and fatigue^{37–40}—to address the emotional and psychological impact of living with RA and SLE.

An unexpected emergent theme was the therapeutic effect of sharing experiences through storytelling. Because RA and SLE each affect less than 1% of the population, many participants did not know another person with their diagnosis and expressed feeling socially isolated. However, during the focus groups, participants shared personal and compelling stories of challenges, fears, and victories in their lives. In particular, the Spanish-speaking RA participants created an intimate environment in which they shared one moving story after another about the professional, social, and domestic challenges they faced, as well as practical advice for navigating those challenges. This desire to share stories and learn from others with similar health challenges was also observed in a qualitative RA study by des Bordes et al. where they found that participants needed more peer support and preferred support from friends with a similar disease experience over non-sick close relatives³¹.

Similarly, in their qualitative study about self-management during RA flares, Kett et al. found that RA patients who had experienced a recent flare wished they had been in contact with other RA patients during the flare to receive guidance from an individual or group who had been in their position⁴¹. Taken together, these studies underscore the critical need for mechanisms to create and sustain community among individuals living with complex chronic illnesses both to mitigate social isolation and to support crowdsourcing of valuable information about disease management.

This study has limitations. Because we were interested in learning about patients' experience with several lifestyle and CIH modalities, focus groups covered several treatment modalities, precluding the opportunity for in-depth discussions about each modality or an exploration of potential reasons for positive versus negative experiences with specific CIH modalities across participants. The focus groups were conducted virtually using an online video conference platform, which may have deterred participation from individuals with lower technological literacy. However, we worked to mitigate this risk by providing one-on-one instruction on use of the platform with language-concordant study staff to any participant who was Zoom naïve. The study recruited individuals residing in the San Francisco Bay Area, and thus the perspectives and experiences expressed by participants in our study may not represent individuals' experiences with RA and SLE in other geographic regions. Additionally, though participants were not recruited from clinics that offer CIH treatments, it is possible that individuals willing to participate in a study about CIH and LM are biased toward greater interest in nonpharmacologic adjunctive treatments compared to individuals who declined to participate. Finally, the study may have been strengthened by including patient partners in the study design and interpretation of findings. Study limitations are offset by several important strengths including recruitment from multiple different healthcare settings (a university hospital, safety net hospital, and community clinic), inclusion of a diverse and multilingual study sample, a robust sample size relative to similar prior qualitative studies, and a rigorous analytical approach.

This study highlights several important future directions. The unmet information needs related to nonpharmacologic adjunctive treatments described by participants in this study reflects the overall low level of evidence at the intersection of rheumatology, integrative health, and lifestyle medicine¹¹. Many of the questions raised by focus group participants do not have evidence-based answers and underscore the need for adequately powered randomized controlled trials to determine whether popular CIH modalities (e.g. dietary modification, acupuncture, and natural products) improve disease activity and symptom burden in RA and SLE. Additional future directions include a follow-up study to identify underlying attitudes, beliefs, and cultural differences that influence patient experiences with LM and CIH, as well as research to identify patient factors that predict response versus nonresponse to acupuncture among this patient population.

In conclusion, among a racially and socioeconomically diverse sample of individuals with RA and SLE, we found a strong desire for lifestyle and complementary approaches to augment pharmacologic management of their conditions. We also identified major unmet information needs related to medication/supplement interactions, safe physical activities in the context of inflammatory arthritis, nonpharmacologic strategies for stress management,

and optimal dietary choices. These unmet needs call for an interdisciplinary model of rheumatic disease care—one in which rheumatologists work alongside nutritionists, physical therapist, and psychologists—and highlight the critical importance of future research at the intersection of integrative health and rheumatology.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Significance and Innovations:

- Up to two thirds of rheumatology patients use complementary and integrative health (CIH) or lifestyle medicine (LM) to help manage their condition, but little is known about how patients with rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE) experience these modalities.
- Patients with RA and SLE perceive a strong association between their diet and the severity of their inflammatory arthritis symptoms.
- Patients with RA and SLE have an unmet need for accessible and reliable information on supplement/medication interactions, optimal dietary choices, and physical activities they can safely perform without exacerbating musculoskeletal symptoms.
- It is common for patients with RA and SLE to use mind-body medicine as a tool for coping with disease-related psychosocial stress.
- More research is needed to evaluate the efficacy and safety of CIH interventions in the rheumatic diseases to inform evidence-based answers to important patient questions.

Table 1.
Characteristics of Patients Included in Focus Groups

Characteristics	Overall (N = 39)	SLE (N = 16)	RA (N = 23)
<u>Sociodemographic Factors:</u>			
Age, mean $\pm$ SD	56.7 $\pm$ 12.2	52.3 $\pm$ 11.6	59.7 $\pm$ 12.0
Female	34 (87.2)	16 (100.0)	18 (78.3)
Race			
Latinx	17 (43.6)	8 (50.0)	9 (39.1)
White	13 (33.3)	4 (25.0)	9 (39.1)
Asian or Pacific Islander	6 (15.4)	3 (18.8)	3 (13.0)
African American or Black	2 (5.1)	0 (0.0)	2 (8.7)
American Indian	1 (2.6)	1 (6.3)	0 (0.0)
Education < college degree	22 (56.4)	9 (56.3)	13 (56.5)
Marital Status			
Married or living w/ partner	29 (74.4)	12 (75.0)	17 (73.9)
Single	8 (20.5)	2 (12.5)	6 (26.1)
Divorced or Separated	2 (5.1)	2 (12.5)	0 (0.0)
Income, \$			
0–49,999	23 (59.0)	11 (68.8)	12 (52.2)
50–99,999	4 (10.3)	1 (6.3)	3 (13.0)
$\geq$ 100,000	11 (28.2)	4 (25.0)	7 (30.4)
Decline to Answer	1 (2.6)	0 (0.0)	1 (4.3)
<u>Rheumatic Disease Characteristics:</u>			
Disease duration, years, mean $\pm$ SD	22.5 $\pm$ 13.3	24.8 $\pm$ 10.6	20.9 $\pm$ 14.9
Any current systemic steroid use	20 (51.3)	10 (62.5)	10 (43.5)
Prednisone $\geq$ 7.5 mg/day	7 (17.9)	4 (25.0)	3 (13.0)
Current hydroxychloroquine use	9 (23.1)	9 (56.3)	0 (0.0)
Current methotrexate use	10 (25.6)	1 (6.3)	9 (39.1)
Current biologic DMARD use	14 (35.9)	2 (12.5)	12 (52.2)

Values in table are N (percent) unless otherwise indicated.

SLE – Systemic lupus erythematosus.

RA – Rheumatoid arthritis.

DMARD – Disease modifying antirheumatic drugs. Among patients with RA, the biologic DMARDs used were tofacitinib, adalimumab, etanercept, and tocilizumab. The two SLE patients using a biologic DMARD were taking belimumab.

Table 2.

Data Characteristics Summary

FG#	Condition	Language	Number of Participants	Focus Group Duration *	Verbatim Transcript Pages
FG1	RA	English	5	0:59:33	22
FG2	RA	English	9	1:04:08	24
FG3	SLE	English	8	0:59:18	18
FG4	RA	Spanish	9	1:10:30	19
FG5	SLE	Spanish	8	0:48:10	15
TOTAL			39	5:01:39	98

FG – Focus Group.

RA – Rheumatoid arthritis.

SLE – Systemic lupus erythematosus.

* The focus group duration is presented in [hours]:[minutes]:[seconds].

Table 3.
Range & Frequency of Lifestyle Medicine & Complementary & Integrative Health (CIH) Modalities

Focus Group (FG) Information	FG1	FG2	FG3	FG4	FG5	Total Mentions
Condition	RA	RA	SLE	RA	SLE	
Language	English	English	English	Spanish	Spanish	
Lifestyle Modalities						
Diet	9	16	6	6	3	40
Physical Activity	1	8	1	4	1	15
Sleep Improvement Practices	0	1	8	1	3	13
Stress Management	0	2	0	10	0	12
CIH Modalities						
Traditional Chinese Medicine (TCM)	0	4	6	3	2	15
Natural Products	5	2	0	4	4	15
Mind-Body Medicine	0	3	4	1	0	8
Psychedelics	1	0	4	0	1	6
Massage	0	1	3	0	0	4
Spirituality	0	0	1	1	0	2
TOTAL	16	37	33	30	14	130

Values presented are the number of participants' mentions, defined as a verbal turn-at-talk during the focus group in which a participant refers to, describes, or discusses at least one lifestyle or CIH modality.

RA – Rheumatoid arthritis.

SLE – Systemic lupus erythematosus.

Table 4.

Participants Experiences of Lifestyle Modalities

	English	Spanish	Spanish Translation
Diet (n=40 mentions)	I guess when you wake up and you're really in a lot of pain, and then you think, gee, what did I do yesterday to cause this? And then eventually you figure it out and then you can start putting the patterns together when you've had this a long time and you can see, oh, when I eat this, I seem to really have a bad reaction. (Participant 3, 79 years old, Female, English, RA, FG1, 32:30) When I stopped sugar, it changed everything, and I also reduced white flour. And that just seemed to work for me. And I think that's the trick for me is keep trying different things and re-eliminating them and see if that makes it better. And sugar was immediate...I can see it in my hands immediately. That's why I get puffy first in my hands. When I don't have sugar, my hands look normal sized. (Participant 9, 61 years old, Female, English, RA, FG2, 29:24)	Yo definitivamente, cuando voy de compras, yo me fijo en no comprar productos procesados y bajos en sodio. Y también, a mí, yo cocinar, yo bien poquita sal. A veces, una persona cuando viene aquí o van de visita, me dicen: ¿Pues qué tú no tienes sal? –Le digo: “No, yo no acostumbro la sal y eso a mí me ayuda mucho” (Participant 7, 47 years old, Female, Spanish, RA, FG4, 23:00) Yo todas esas cosas yo lo hago. Yo hago la cúrcuma, todo; puros naturales. Jugos naturales que hago con blueberries, fresas, perejil, apio, zanahoria, (inaudible), espinaca, todo eso, yo todas esas cosas. Yo las hago. Yo tengo ya para 30 años con lupus. (Participant 2, 71 years old, Female, Spanish, SLE, FG5, 12:30) Yo tengo unas preguntas. No sé cuáles alimentos son los que tienen gluten o... ¿cómo saber cuáles [alimentos] tienen gluten y cuáles no?...¿El gluten es malo para el lupus? (Participant 8, 51 years old, Female, Spanish, SLE; FG5, 26:00)	Definitively when I go shopping, I look to make sure not to buy processed and low-sodium foods. And in my cooking, I use very little salt. Sometimes when someone come here or come to visit, they say, “Well, you don't have salt?” I say, “No, I don't use salt anymore and that helps me a lot.” (Participant 7, 47 years old, Female, Spanish, RA, FG4, 23:00) All those things, I do them. I take curcumin, everything. Purely natural. I make natural juices with blueberries, strawberries, parsley, celery, carrot, (inaudible), spinach, all of that. I make all those things. I have had lupus for 30 years already. (Participant 2, 71 years old, Female, Spanish, SLE, FG5, 12:30) I have some questions. I don't know which foods that have gluten. How can I know which [foods] have gluten and which don't?...Is gluten is bad for lupus? (Participant 8, 51 years old, Female, Spanish, SLE; FG5, 26:00)
Physical Activity (n=15 mentions)	After I had my last surgery, they went into my intestines. The only exercise my doctor made me do three times a day is walk in the hospital. So, I do a lot of walking and I still have a lot of stiffness and soreness. (Participant 2, 59 years old, Female, English, RA, FG2, 12:00) Exercise helps me because we eat pretty well, I think. And probably getting the weight off...I've been having trouble in other ways so that I have not been able to be more active. I've been more sedentary and that just kills me because it gets harder and harder to get out and be more active. That's why I'm thinking maybe trying out Tai Chi. (Participant 3, 72 years old, Male, English, RA, FG2, 31:03)	Un día que yo no haga ejercicio, pues no, no... me siento más como un poco pesadita. Y yo digo: “Bueno, tengo que ir de compras, tengo que hacer ejercicio, tengo que dormir más.” Yo quiero hacer mi ejercicio, ir de compras y ya mejor pues me voy caminando a la tienda. Y yo digo, bueno, ya hice las dos cosas: mi ejercicio y mi mandado, y pues ya me siento más relajada. (Participant 7, 47 years old, Female, Spanish, RA, FG4, 13:00) A mí me ha ayudado mucho la terapia en el agua, la piscina; como ir a nadar. Me siento más relajada y siento que los dolores, me ayuda para los dolores en las camillas y todo. (Participant 8, 51 years old, Female, Spanish, SLE, FG5, 31:00)	One day when I didn't exercise, I don't, I feel a little heavy. I would say to myself, “OK, I have to go shopping. I have to exercise, I have to sleep more.” I want to exercise, go shopping, and maybe it's better for me to walk to the store. And I say, I do both things: exercise and my errands and then I feel more relaxed. (Participant 7, 47 years old, Female, Spanish, RA, FG4, 13:00) What has helped me a lot is water therapy. The pool, like going swimming. I feel more relaxed, and I feel that the pain, it helps me with the pain in my shins and everything. (Participant 8, 51 years old, Female, Spanish, SLE, FG5, 31:00)
Sleep (n=13 mentions)	I've had a hard time sleeping for years, and I used to take pills to help me with sleep. I've taken many pills, but now over the years, I've just realized you just have to learn how to sleep better. One of the things that's helped me is doing a meditation on the Audible.com [online platform]. It's called sleep stories for stressed out adults. And I swear it helps me fall asleep. So, I just want to spread the word to other people who might have a hard time sleeping. (Participant 3, 65 years old, Female, English, SLE, FG3, 16:18)	Para mí también es muy importante dormir, porque yo cuando yo no duermo, al siguiente día siento que yo no rindo en mi trabajo y pues siento que estoy trabajando con miedo, porque no me siento segura de mí, y siento que ando estresada. (Participant 7, 47 years old, Female, Spanish, RA, FG4, 13:00) A mí interesa el del sueño, porque tengo muchos problemas para dormir. Casi siempre, a veces tengo que tomar melatonin para poder dormir. (Participant 8, 51 years old, Female, Spanish, SLE, FG5, 4:00)	For me it's also important to sleep because I, when I don't sleep the next day I feel like I'm not doing well at work and I feel like I'm working in fear because I don't feel confident in myself, I feel I'm stressed. (Participant 7, 47 years old, Female, Spanish, RA, FG4, 13:00) I'm interested in sleep because I have a lot of trouble sleeping. Almost always, sometimes, I have to take melatonin to be able to sleep. (Participant 8, 51 years old, Female, Spanish, SLE, FG5, 4:00)
Stress Management	I've had rheumatoid arthritis for close to 15 years, and fortunately, I go to [LOCATION] and got better information	El estrés también lo inflama a uno demasiado. Al menos, yo trato de manejar el estrés de diferentes maneras, pero	Stress also makes you inflamed. At least, I try to manage stress in different ways, but it's hard because

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	English	Spanish	Spanish Translation
(n=12 mentions)	and better counseling and a wonderful physician. Stress management, I'm a family law attorney, so I can always use stress management. (Participant 6, 81 years old, Male, English, RA, FG2, 08:22) I feel as though I've got movement and exercise, diet nutrition, and sleep optimization pretty much under control. The one thing I don't focus on very much is stress management. I've done it in the past and I guess this seminar is a good reminder to get back into it. (Participant 3, 72 years old, Male, English, RA, FG2, 09:15)	es difícil porque cuando uno está acostumbrado a trabajar [pero ya no se puede]. Y, por ejemplo, mi artritis reumática es más de mis hombros a mis manos, entonces es lo que más uno usa para trabajar o para manejar, para bañarse, para cambiarse. Es importante aprender, necesito aprender cómo manejar mejor el estrés. (Participant 2, 60 years old, Female, Spanish, RA, FG4, 8:40)	when you're used to working [but can't]. And, for example, my rheumatoid arthritis is more from my shoulders to my hands, so it's what is used most to work or to drive, to bathe, to change clothes. It's important to learn, I need to learn how to handle stress better. (Participant 2, 60 years old, Female, Spanish, RA, FG4, 8:40)

Table 5.
Participants Experiences of Complementary and Integrative Health (CIH) Modalities

	English	Spanish	Spanish Translation
Traditional Chinese Medicine (n=15 mentions)	My sister does acupressure, so she always does acupressure and massage for me, and that is very helpful, acupressure. But I had an experience through acupuncture to help me to sleep and it worked like a magic. And it had like long lasting effect, like for months. I could not believe it. It was like I would come to bed and fall asleep like a baby. (Participant 3, 65 years old, Female, English, SLE, FG3, 27:01)	Yo traté, he tratado varias veces la acupuntura, y sí me ha trabajado. Sí me ha trabajado mucho, la estuve probando casi por seis meses, nomás que era muy cara. Y entonces dije: “No, es mucho dinero, no puedo [seguir] porque no estoy trabajando.” Entonces traté de agarrarla por medio de mi seguro médico y hasta la fecha estoy esperando. Pero la acupuntura sí me ayudó a mí mucho. (Participant 4, 44 years old, Female, Spanish, RA, FG4, 29:13) A mí no me funcionó la acupuntura, la verdad, porque me pusieron una vez en la rodilla, y al siguiente día, no sé, pero se me inflamó mucho; entonces yo no, no me cae bien la acupuntura, prefiero la... tomar algo natural. (Participant 7, 47 years old, Female, Spanish, RA, FG4, 33:00)	I tried, have tried acupuncture various times, and it's worked for me. Yes, it's worked a lot. I tried it for almost 6 months, not more because it was very expensive. And then I said, “No, it's a lot of money. I can't [continue] because I'm not working.” Then I tried to get it through my health insurance and up until today I'm still waiting. But acupuncture helped me a lot. (Participant 4, 44 years old, Female, Spanish, RA, FG4, 29:13) Acupuncture didn't work for me, to be honest, because they tried it once on my knee, and the next day, I don't know, but it got really inflamed. So, I don't, I don't like acupuncture. I prefer the...to use something natural. (Participant 7, 47 years old, Female, Spanish, RA, FG4, 33:00)
Natural Products (n=15 mentions)	People are saying they're taking turmeric. I'm taking this product called Curcumin, which is a highly concentrated form of turmeric. I got to a point where I could not have to take Humira anymore because I wasn't having problems. And then, you know, with COVID the [brick-and-mortar] place I would buy it at closed...I used to go into the shop and the person who worked there was, you know, trained in nutritional alternatives for things. And now that resource is gone, so I just have to figure that on my own, which is more challenging. (Participant 6, 54 years old, Female, English, RA, FG1, 20:12)	Pues a mí me gustan las cosas naturales y me ha ayudado mucho la cúrcuma con el <i>turmeric</i> para lo hinchado... Y ahorita estoy tomando ajo con zanahoria, limón y agua, en ayunas. A mí me está ayudando bastante. (Participant 3, 61 years old, Female, Spanish, SLE, FG5, 11:00)	Well I like natural things, and curcumin with turmeric has helped me a lot for swelling....right now I'm taking garlic with carrot, lime, and water while fasting. And it has helped me a lot. (Participant 3, 61 years old, Female, Spanish, SLE, FG5, 11:00)
Mind-Body Medicine (n=8 mentions)	I found EFT (Emotional Freedom Technique). If you guys haven't found EFT yet, and you have an emotional component of what you're going through, I highly recommend it. It's so user friendly, because you can do it on yourself in the moment when you're in pain and bring that love and compassion into yourself in the moment... so the EFT is tapping points on your upper body. You go through the sequence and it's just you communicating with your body through touch and just like with acupuncture your body balances itself out. So it really helps with pain, especially the kind of pain that the origin is emotional... I highly recommend it if you haven't tried. (Participant 5, 49 years old, Female, English, SLE, FG3, 34:40)	He tenido estrases al extremo. Apenas hace un mes, pasamos un robo a mano armada y creo que eso es una explosión para la enfermedad de nosotros. Me ha dicho el médico que es otra diferente mi manera de depresión, de estrés, y no me podía mover. Era una cosa que se sorprendía [al médico], y ya me enseñó a manejar eso: meditación bajo de luz, cada quien, ¿verdad? Porque no todos tenemos la misma religión, pero es el mismo, ¿verdad? (Participant 1, 56 years old, Female, Spanish, RA, FG4, 10:00)	I have had stress to the extreme. Barely a month ago, we went through an armed robbery, and I think that has exploded my illness. The doctor told me that my depression, my stress, is different, and I couldn't move. It was surprising [to the doctor], and he already taught me how to handle that: meditation under light, to each their own, right? Because not everyone has the same religion, but it's the same, right? (Participant 1, 56 years old, Female, Spanish, RA, FG4, 10:00)
Psychedelics (n=6 mentions)	Somebody had mentioned mushrooms. I've also used really, tiny doses of mushrooms and very, very low doses of THC to manage depression, anxiety, that sort of thing. And I've found it to be helpful as an accompaniment to the other things. (Participant 8, 49 years old, Female, English, SLE, FG3, 34:37) Well, it [psychedelics] has been tested. It has been tested on people with terminal diseases. It has been proven that even people who have only one controlled trip, they are leaving the world in a much happier, more balanced way... There are also many people who use it or say it's	En los productos naturales, he escuchado mucha gente que utiliza productos de cannabis, ¿podría servir? (Participant 5, 34 years old, Female, Spanish, SLE, FG5, 12:00)	About natural products, I have heard many people that use cannabis products. Might that help? (Participant 5, 34 years old, Female, Spanish, SLE, FG5, 12:00)

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	English	Spanish	Spanish Translation
	much better than psychotherapy. (Participant 5, 49 years old, Female, English, SLE, FG3, 46:10)		
Massage (n=4 mentions)	One thing that's worked in the past for me has been massage, which I put into that category of spirituality, because it forces you to focus. Slow walking and meditative walk, same thing. Which are things I'm building up on at the moment. (Participant 3, 72 years old, Male, English, RA, FG2, 13:53)		
Spirituality (n=2 mentions)	I wanted to speak to this spirituality as well. Right now, I have very, very lean health insurance. So, a lot of these treatments wouldn't be available to me, but I've found that having an active prayer life helps me to put things in context. So, it may or may not affect healing. It helps me to keep my life and suffering in the context of a much bigger picture. (Participant 8, 49 years old, Female, English, RA, FG3, 34:37)	Me pegó mucha depresión del inicio de mi enfermedad hasta ahorita. Y siempre estaba con medicamentos. Y yo un día dije: "Pues no voy a vivir siempre con medicamentos, ¿verdad?" "Tengo que buscar la manera. La encontré con él de Arriba (laughter), gracias a Dios...Lo mencionó usted: la oración. Esa es mi medicina. (Participant 1, 56 years old, Female, Spanish, RA, FG4, 10:00)	I was hit by a lot of depression from the beginning of my illness until now, and I was always on medication. And one day I said: "Well, I'm not always going to live with medication, am I right? I have to find a way." I found it with Him Above (laughter), thank God... You mentioned it: prayer. That is my medicine. (Participant 1, 56 years old, Female, Spanish, RA, FG4, 10:00)