

Supplementary Material

Focus Group Semi-Structured Interview Guide:

INTRODUCTION

INTRODUCTION & OVERALL PURPOSE

Thank you for coming today. My name is X. I'll be the moderator for this group. We call these events "focus groups" but they really are more of a group conversation that takes place over about 90 minutes. I want to start with a brief explanation about why we're doing this.

We are developing new resources to support patients with **RHEUMATOID ARTHRITIS/SYSTEMIC LUPUS**. As a first step, we want to hear directly from people like you to learn how we can best help you improve your health while living with a rheumatic disease. Specifically, we hope to learn which topics about complementary and integrative health (CIH) are most important to you. Just to be clear, complementary, alternative, and integrative medicine are all terms to describe medical care that uses a non-mainstream approach. For example, some people use acupuncture, massage, meditation, yoga, and even dietary changes, including supplements/herbs. Many times, these approaches are combined with conventional or standard medical treatment.

We are asking about these topics because very little research exists on how people with RA/SLE use complementary and integrative health treatments to manage their conditions. We selected you to participate because we are interested in hearing about your experiences related to this topic.

Let me say a little about the format. We come together as individuals. Each of us have different experiences, views, and perspectives. I will ask questions on topics, and there are no right or wrong answers. My job is to make sure everyone who wants to talk can. Part of the benefit of a group like this is that you can also learn from other people's experiences. I may call on you, but feel free to either talk or to pass if you wish.

This group is both private and confidential. What is said here today stays private. We will not identify you by your name or your identity. Instead, we will make sure your identity is protected. Finally, you may choose to stop at any time, and there is no penalty to you if you do stop. If you complete the interview, we will send you a gift card to thank you and reimburse you for your time.

[PAUSE TO ASK FOR QUESTIONS AT THIS POINT]

RESPECTFUL CULTURE

We recognize that values, culture and individual experiences shape what is important, and we're trying to get a better idea about what's important to you. It's OK to have different opinions. And it's OK to disagree with one another. It's important to let everyone know that we will foster a respectful atmosphere so that everyone's voice can be heard.

PARTICIPANTS' SELF-INTRODUCTIONS

Tell us how you like to be called during the session and something you are proud of in your life. The goal here is for us to learn something about each person in this group. Please don't be offended if I suggest moving on to the next person. We'll have plenty of opportunity for everyone to speak.

CURRENT AND PAST EXPERIENCE WITH INTEGRATIVE HEALTH MODALITIES

We would like to hear from each of you about your prior experience with integrative medicine. What approaches—like dietary modification, stress management, exercise, supplements, and acupuncture—have you tried in addition to medications for managing your RA/SLE?

Do you currently receive treatments for your rheumatic condition from people other than your rheumatologist? Examples may include an herbalist, acupuncturist, nutritionist, ayurvedic specialist, functional medicine practitioner, and manual medicine/massage.

How effective do you think the lifestyle or complementary treatments you have tried have been for managing your RA/SLE symptoms?

- Have you noticed any associated improvements in pain or fatigue?
- Did you find that it made any of your RA/SLE symptoms worse?

Can you think of any potential obstacles to using integrative health treatments?

What challenges have you faced in learning about lifestyle or complementary health options?

Have time or financial constraints affected your ability to adopt these approaches?

GROUP ACTIVITY TO EXPLORE INTEREST IN SPECIFIC LM AND CIH MODALITIES

Next, we will share some slides about specific kinds of complementary and integrative modalities. We have two slides, and I will show them one at a time. After showing you the slide, I will ask you a few questions.

[SHOW SLIDE #1 Listing the following Lifestyle Medicine Modalities: diet; physical activity; sleep; stress management]

Complementary and integrative health can include different kinds of wellness practices. On this first slide, we present some lifestyle modalities. Take a look at the items for a moment.

[30-60 SECONDS PAUSE]

I am now launching a Zoom poll. On the poll, please indicate your level of interest in trying or learning more about each of these lifestyle modalities.

[PAUSE FOR POLL COMPLETION]

OK, everyone has now answered the poll.

Would someone like to share which item they are most interested in learning more about and why?

Specific Questions

- Why do you all think this group is most interested in [IDENTIFY ITEM HERE]?
- I noticed only a few people are interested in [IDENTIFY ITEM HERE]. Why do you think the group is least interested in learning more about that?
- For those of you who have tried lifestyle changes to manage your rheumatic condition, what did you try and how effective was it? Did you notice any specific changes in pain, fatigue, or other symptoms?

OK, let's transition. The next slide will list several common complementary medicine modalities. We will do the exact same thing we just did. I will show you the slides, ask if you have questions, do a quick poll, and then we will discuss the different modalities.

[SHOW SLIDE #2 Listing the following Complementary Medicine Modalities: natural products; mind-body medicine; Traditional Chinese Medicine/acupuncture]

In addition to lifestyle changes, complementary and integrative health includes other wellness modalities and healing approaches from different cultures. This slide has a partial list of some of these other modalities. As we did before, take a look at the items for a moment.

[30-60 SECONDS PAUSE]

I am now launching a Zoom poll. On the poll, please indicate your level of interest in learning more about each of these other wellness modalities.

[PAUSE FOR POLL COMPLETION]

OK, everyone has now answered the poll.

Would someone like to share which item they are most interested in learning more about and why?

[INVITE THE REST OF THE GROUP TO SHARE]

Specific Questions

- Why do you all think this group is most interested in [IDENTIFY ITEM HERE]?
- I noticed only a few people are interested in [IDENTIFY ITEM HERE]. Why do you think the group is least interested in learning more about that?
- For those of you who have tried complementary treatments to manage your rheumatic condition, what did you try and how effective was it? Did you notice any specific changes in pain, fatigue, or other symptoms?

FEEDBACK ON DIET AND NUTRITION GUIDE

Thank you for your input and the great discussion. We are going to transition to a discussion about your experiences, if any, using diet to help manage your rheumatic disease. We will also ask for feedback on the nutrition pamphlet you received in the mail called "Nutrition for People with Rheumatic Diseases."

I want to start by asking some questions about the guide.

What was most interesting about the booklet? What stuck out to you?

Were there things you did not understand in the booklet? Was there anything confusing?

Is the information provided in the book enough to make changes to the way you eat on a daily basis?

- If yes, what changes will you make?
- If no, what additional clarification and resources are needed?

How many of you have tried to change your diet to improve you RA/SLE symptoms?

- For people who answer YES:
 - o What specific changes did you make?
 - o How long did you maintain the changes?
 - o Do you notice any difference in your RA/SLE symptoms? What differences did you notice?
- For people who answer NO:
 - o Are there particular reasons why you have not?
 - o Have you tried to make other kinds of changes besides diet (to help your RA/SLE symptoms)?

For those of you who HAVE TRIED to change your diet (to manage your RA/SLE), what has helped maintain the change(s)?

- Facilitators for maintaining change(s)
- Challenges to maintaining change(s)

Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-items

Domain 1. Research team and reflexivity

Personal Characteristics

1	Interview/Facilitator	Senior author conducted both semi-structured interviews and focus groups.
2	Credentials	First author has BA and MD. Senior author has BA, two MAs, and PhD.
3	Occupation	Senior author Health Services Researcher and professor who teaches qualitative research methods, health communication, and academic writing. First author is a physician scientist and practicing rheumatologist at a large university health system who studies the application of integrative health in rheumatology.
4	Gender	First author is female, and senior author is male.
5	Experience & training	First author is a physician scientist with formal training in internal medicine, rheumatology, integrative health clinical practice, integrative health research, and clinical research methodology. She is on faculty in the UCSF Department of Medicine, Division of Rheumatology, and runs a lab studying adjunctive nonpharmacologic treatment approaches for rheumatoid arthritis (RA) and systemic lupus erythematosus (SLE). Senior author is a PhD in qualitative methodology with over 20 years' experience designing, implementing, and disseminating qualitative health-related research.

Relationship with Participants

6	Relationship established	None of the authors had relationships with patients who participated in the focus groups (FG) for this study prior to the start of the study. Dr. Patterson treated one of the patients who participated in a semi-structured interview that was used to inform the development of the FG guide, however Dr. Patterson did not conduct the interview and individual interviews were not included in the formal analysis for this manuscript. Only FG transcripts were formally analyzed for the current manuscript.
7	Participant knowledge of the interviewer	Participants did not have a personal or professional relationship with the interviewer/facilitator before the interviews and focus groups.
8	Interviewer characteristics	At the beginning of interviews and focus groups, the interviewer/facilitator explained his role as a collaborator in the research process, his experience investigating RA/SLE in the past, his own experience of having a rheumatologic condition, and his relationship with the first author as a collaborator.

Domain 2. Study Design

Theoretical Framework

9	Methodological orientation and theory	Qualitative description informed by the theoretical tenants of naturalistic inquiry.
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Participant Selection

10	Sampling	See Methods Recruitment section in the manuscript.
11	Method of approach	
12	Sample size	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.
13	Non-participation	Among the sixty individuals with RA or SLE screened for participation, 21 declined to participate. Reasons for non-participation cited during the screening process included scheduling conflicts, time constraints, health challenges, concerns about confidentiality, and discomfort with group discussions.

Setting

14	Setting of data collection	Interviews and focus groups were conducted via Zoom.
15	Presence of non-participants	The first author and a research assistant were included in focus groups.
16	Description of sample	See Table 1 in the manuscript.

Data Collection

17	Interview guide	See appended focus group guide.
18	Repeat interviews	Interviews were conducted only once for all participants. Interview participants were not included in focus groups. Focus group participants only participated once.
19	Audio/Visual recording	Focus groups were video and audio recorded via Zoom.
20	Field notes	The senior author/interviewer/facilitator wrote post-interview and focus group reflective memos after each event. These memos were used to refine the research questions and subsequent focus group pacing.
21	Duration	See Table 2. Focus Groups lasted between 48 minutes and 1 hour 11 minutes with a total data set of 5 hours 2 minutes.
22	Data saturation	Saunders et al. (2018) characterize saturation “as a criterion for discontinuing data collection and/or analysis.” According to this definition, we did not use saturation for collecting data nor for the resulting analysis as all focus group transcripts were included in the analysis and exhaustively reviewed line by line in the analysis. The goal of this analysis was to create

		a comprehensive empirical inventory of all LM and CIH mentions using consensus definitions. Reference: Saunders, B., Sim, J., Kingstone, T. <i>et al.</i> Saturation in qualitative research: exploring its conceptualization and operationalization. <i>Qual Quant</i> 52, 1893–1907 (2018). https://doi.org/10.1007/s11135-017-0574-8
23	Transcripts returned	Transcripts were not returned to participants, as the informed consent procedures did not include asking participants to participate in data management and data analysis activities.

Domain 3: Analysis and Findings

Data Analysis

24	Number of data coders	Four authors were involved in coding the data.
25	Description of coding tree	We used a combination of deductive and inductive classification. Deductively, we used the National Center for Complementary and Integrative Health (NCCIH) definitions of LM and CIH provided in supplementary table A. Then, all transcripts for participants' mentions were reviewed, summarized, and classified deductively when they fit the NCCIH criteria and inductively when participants' mentions were not included in the NCCIH standardized list of LM and CIH treatment modalities. We used the resulting list to tally modality frequencies across focus groups. See Table 3.
26	Derivation of themes	While Thematic Analysis, popularly systematized by Braun & Clark (2006) is one of the most common approaches to analyze qualitative data and a common type of finding for qualitative data analysis, themes are not the only way to report or present qualitative findings. In this study, we identified participant mentions regarding experiences with LM and CIH modalities to inductively classify them using consensus definitions and terms. The results are not themes, but rather an inventory of experiences classified according to current and past use of LM and CIH. Reference: Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. <i>Qualitative Research in Psychology</i>, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa
27	Software	The research team used Microsoft Excel to classify interview segments.
28	Participant checking	Participants were not involved in the data interpretation process.

Reporting

29	Quotations presented	Quotations are included in Tables 4 and 5, which have been edited for additional concision.
30	Data and findings consistent	We carefully reviewed all quotations to ensure different participants are represented across both English and Spanish languages. In Tables 4 and 5, we include quotations from n=9 English-speaking and n=10 Spanish-speaking participants. Therefore, 48.7% (19/39) of our total participant sample is represented by quotations in the presented tables.
31	Clarity of major themes	Major and minor themes are clearly presented in the Results and further described in the Discussion.
32	Clarity of minor themes	

Table A. Definitions of Relevant Complementary and Integrative Health (CIH) Terms

1. **Acupressure:** A non-invasive therapy with similarities to acupuncture. Meridian points or acupoints are massaged to “promote a smooth flow of Chi (Qi) energy to balance the Yin and Yang energy in the body stimulating the release of endorphins.” (1)
2. **Acupuncture:** “A technique of insertion and manipulation of fine needles in specific points on the body to achieve therapeutic purposes. Acupuncture has been practiced widely in China for more than 4000 years and is an integral part of traditional Chinese medicine.” (2)
3. **Biofeedback:** “A mind–body technique in which individuals learn how to modify their physiology for the purpose of improving physical, mental, emotional and spiritual health.” (3)
4. **Complementary and Integrative Health:** Complementary medicine is the use of “non-mainstream practices” alongside conventional medical treatment. Integrative health is defined by the US National Center for Complementary and Integrative Health (NCCIH) as the “bringing together of conventional and complementary approaches in a coordinated way.” Integrative health focuses on the whole person, including lifestyle behaviors, to support physical and mental healing. (4,5)
5. **Emotional Freedom Technique:** A non-pharmacologic treatment used for a variety of psychological conditions that involves the stimulation of acupoints. As an example, in the treatment of post-traumatic stress disorder (PTSD), the client may be asked to engage in cognitive reprocessing of a traumatic memory while tapping or massaging a set of acupoints. (6)
6. **Herbal Medicine:** “The use of plants, plant parts, their water or solvent extracts, essential oils, gums, resins, exudates or other form of advanced products made from plant parts used therapeutically to provide proactive support of various physiological systems; or, in a more conventional medical sense, to treat, cure, or prevent a disease in animals or humans.” (7)
7. **Lifestyle Medicine:** “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)
8. **Massage:** “Using various degrees of pressure with the hands to systematically manipulate muscles and soft tissues through rubbing, kneading, stroking, and stretching.” Massage “is intended to relieve muscle pain and stiffness.” (9)
9. **Meditation:** “A family of complex forms of cognitive and affective mental training cultivated for various ends, in particular to decrease human suffering and to increase well-being and

human flourishing". Meditation can take many forms, including mindfulness, compassion, and transformative approaches. (10)

10. **Mediterranean Diet:** A dietary style from the areas around the Mediterranean emphasizing fruits, whole grains, root vegetables, legumes, nuts, seeds, olive oil, moderate seafood and poultry, and a low consumption of red meat and processed food. (11)
11. **Mind-body medicine:** A set of techniques or practices such as yoga, deep breathing exercises, meditation, and qigong that "focus on the relationships among the brain, mind, body, and behavior, and their effect on health and disease. These practices often offer stress relief and relaxation." (12)
12. **Mindfulness-based Interventions (MBIs):** Mindfulness is the present moment awareness of "thoughts, feelings, bodily sensations, and surrounding environment". Mindfulness-based interventions (MBIs) utilize practices such as breathing, sitting, walking, or body scan to improve physical or mental health outcomes. (13)
13. **Natural Products:** "A large family of diverse chemical entities with a wide variety of biological activities that have found multiple uses, notably in human and veterinary medicine and in agriculture. They originate from bacterial, fungal, plant, and marine animal sources." Natural products include dietary supplements. (14,15)
14. **Psychedelics:** "Powerful psychoactive substances that alter perception and mood and affect numerous cognitive processes." (16)
15. **Qigong:** A broad term encompassing "traditional Chinese energy exercises and therapies". Internal qigong involves movement, meditation, and breathing control exercises to achieve a flow of qi energy for health wellness. (17)
16. **Sleep Improvement Practices:** Practices to promote sleep quality and duration, including "maintaining a consistent sleep/wake schedule, a regular bedtime routine, engaging in regular exercises, and adopting a contemplative practice". Additionally, these practices may involve avoiding caffeine, alcohol, and excessive light exposure later in the day. (18)
17. **Spirituality:** "A dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices" (19)
18. **Stress Management:** Skills to relieve individuals from the "harmful effects of stress". Techniques include identification of causes of stress like thought patterns and social situations as well as relaxation techniques such as muscle relaxation, deep breathing, and meditation. (20)

19. **Tai Chi:** “An ancient mind–body practice evolving from China that incorporates meditation, breathing, and movement.” (21)
20. **Traditional Chinese Medicine:** A systematic healthcare system that relies on theories and practices for disease treatment and health improvement: including acupuncture, Chinese herbal medicine, dietetics, and non-medication treatments or therapies. (22)
21. **Wim Hoff Method Breathing:** A multi-disciplinary approach to physical and mental well-being combining cold exposure, breathing exercises, and meditation. (23)
22. **Yoga:** A practice that provides opportunities for mind-body connection, spiritual growth, physical exercise, and holistic movement. (24)

Table A References:

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