

Coping strategies, illness perceptions, and relationship dynamics contribute to female sexual function and sexual distress in Sjögren's syndrome

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Abstract

Background: Sexual dysfunction and sexual distress are common complaints for women with the autoimmune rheumatic disease Sjögren's syndrome (SS); however, the role of psychosocial and interpersonal factors has not previously been explored in SS.

Aim: This study investigated whether psychosocial variables, such as coping strategies, illness perceptions, and relationship dynamics, contributed to sexual function and sexual distress for women with SS.

Methods: Participants with SS completed an online cross-sectional survey that included prevalidated questionnaires assessing sexual function, sexual distress, disease-related symptom experiences, cognitive coping strategies, illness perceptions, relationship satisfaction, and partners' behavioral responses. Multiple linear regression was used to identify factors significantly associated with sexual function (total Female Sexual Function Index [FSFI] score) and sexual distress (total Female Sexual Distress Scale score) for women with SS.

Outcomes: Study outcome measures were the FSFI, Female Sexual Distress Scale, EULAR Sjögren's Syndrome Patient Reported Index, numeric rating scale for vaginal dryness (0–10), Profile of Fatigue and Discomfort, Cognitive Emotion Regulation Questionnaire (CERQ), Brief Illness Perceptions Questionnaire (B-IPQ), West Haven–Yale Multidimensional Pain Inventory (WHYMPI), and Maudsley Marital Questionnaire.

Results: A total of 98 cisgender women with SS participated in the study (mean age = 48.13 years, SD = 13.26). Vaginal dryness was reported by 92.9% of participants, and clinical levels of sexual dysfunction (total FSFI score <26.55) were observed in 85.2% (n = 69/81) of cases. More vaginal dryness, lower CERQ positive reappraisal, and higher CERQ catastrophizing were significantly associated with poorer self-rated sexual function ($R^2 = 0.420$, $F_{3,72} = 17.394$, $P < .001$). Higher CERQ rumination, lower CERQ perspective, lower WHYMPI distracting responses, and higher B-IPQ identity were significantly associated with higher sexual distress ($R^2 = 0.631$, $F_{5,83} = 28.376$, $P < .001$).

Clinical Implications: This study suggests that interpersonal and psychosocial factors are important contributors to sexual function and distress in women with SS and that the development of psychosocial interventions for this population is warranted.

Strengths and Limitations: This study is one of the first to explore the impacts of coping strategies, illness perceptions, and relationship dynamics on sexual function and sexual distress for women with SS. Limitations of our study include its cross-sectional nature and narrow sample demographic, which limit the generalizability of our results to other population groups.

Conclusion: Women with SS who utilized adaptive coping strategies had better sexual function and lower levels of sexual distress than women who utilized maladaptive coping strategies.

Keywords: sexual function; chronic diseases; coping strategies; illness representations; relationship dynamics.

Introduction

Sjögren's syndrome (SS) is a rheumatic autoimmune disease that attacks the moisture-producing glands throughout the body.¹ The disease causes inflammation and dysfunction in glands such as the lacrimal and salivary glands, leading to symptoms of oral and ocular dryness.² Additionally, the systemic nature of the disease means that individuals may experience extraglandular manifestations, such as vaginal dryness, fatigue, myalgias, and arthralgias.³ SS is the second-most common autoimmune rheumatic disease,⁴ with current estimates suggesting that 3.1 million adults in the United States have SS.⁵ As with most autoimmune diseases, SS predominately

affects females (9:1), with onset occurring around 40 years of age.⁶

One aspect of life that SS can negatively affect is sexual function. A recent meta-analysis found that women with SS had significantly poorer sexual function than healthy controls, with disruptions observed in levels of desire, arousal, lubrication, orgasm, sexual satisfaction, and pain experienced during vaginal penetration (dyspareunia).⁷ Gynecologic investigations exploring possible causes of sexual dysfunction in women with SS have provided preliminary evidence to suggest that pelvic floor dysfunction,⁸ vaginal or cervical atrophy,⁹ severity of vaginal dryness,¹⁰ and lower levels of hormones

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Assessment measures

The ESSPRI was used to assess the severity of 3 symptoms over the previous 2-week period: dryness, fatigue, and pain (joint or muscular).²² An 11-point numeric rating scale from 0 (no symptom at all) to 10 (worst symptom imaginable) was used to capture the severity of symptoms from the patient's perspective. A total ESSPRI score was derived by calculating the mean score of the 3 domains. A higher score represents more severe symptom impact. While Cronbach alpha is just 0.68 for this study, ESSPRI has been shown to have good psychometric properties when used in clinical research of SS.²³

An additional numeric rating scale, compiled for this study, was included to assess the severity of vaginal dryness. Participants were asked to rate the severity of their vaginal dryness over the last 2 weeks on a scale of 0 (no symptom at all) to 10 (worst symptom imaginable). Higher scores indicate greater symptom severity.

The 19-item Profile of Fatigue and Discomfort (ProFaD) was utilized to assess disease-specific fatigue and discomfort.²⁴ The ProFaD assesses 3 domains of fatigue—somatic fatigue, mental fatigue, and general discomfort—and participants are asked to rate the severity of each symptom over the last 2 weeks. It is rated on an 8-item response scale ranging from 0 (no problem at all) to 7 (as bad as imaginable). The facet items within each domain were averaged to obtain a total domain score. Higher scores are indicative of greater levels of fatigue and discomfort. The ProFaD had excellent internal consistency in this sample (Cronbach $\alpha = 0.97$).

Sexual functioning was measured with the Female Sexual Function Index (FSFI).²⁵ The FSFI contains 19 items that assess 6 domains of sexual function over the previous 3-month period: arousal, desire, lubrication, orgasm, satisfaction, and pain (during penetration). Response options were on a 5- or 6-item Likert scale, with the response anchors differing by the context of the questions (eg, frequency, difficulty, satisfaction). The additional response option on the 6-item scale reflected either “no sexual activity” or “did not attempt intercourse.” Items within each domain were summed and multiplied by the domain factor value.²⁵ A total FSFI score was computed by summing domain scores, with a higher score indicating better self-rated sexual functioning. A total FSFI score < 26.55 was used as a cutoff value to identify clinical cases of sexual dysfunction.²⁶ The FSFI has been extensively used in research employing various clinical and nonclinical groups and has been shown to have excellent internal consistency,^{25,27-29} as found in this sample (Cronbach $\alpha = 0.96$).

The Female Sexual Distress Scale (FSDS)³⁰ was used to assess levels of distress associated with impaired sexual function. Respondents were asked to indicate on a scale of 0 (never) to 4 (always) how often they experience a variety of emotional and affective states regarding their sexual function. Responses to the 12 items were summed to compute a total score (range, 0-48). Higher scores indicate more self-rated sexual distress, with a cutoff score > 11 identifying high levels of sexual distress.³¹ In this sample, the FSDS had excellent internal consistency (Cronbach $\alpha = 0.96$), similar to previous studies that utilized the measure with women with sexual disorders (ie, hypoactive sexual desire disorder and female sexual dysfunction).^{31,32}

The 36-item Cognitive Emotion Regulation Questionnaire (CERQ) was used to assess the cognitive coping strategies that an individual uses to respond to a stressful life event.³³ In this

study, the CERQ was framed within a specific context, and participants were asked about their cognitive coping strategies when thinking about any difficulties that they may have experienced in their sexual lives.³³ Nine cognitive coping strategies are assessed: 5 adaptive strategies (acceptance, positive refocusing, positive reappraisal, putting into perspective, and refocusing on planning) and 4 maladaptive strategies (self-blame, rumination, catastrophizing, and blaming others). A 5-point Likert scale was used to capture the frequency of the thought on a scale ranging from 1 (almost never) to 5 (almost always). Items corresponding to each coping strategy were summed to compute a total score. Higher scores on a domain represent a greater frequency of use for that particular coping strategy. The internal consistency of 8 subscales was either acceptable or good (Cronbach $\alpha \geq 0.71$ and ≤ 0.87), while 1 subscale (positive refocusing) had questionable reliability (Cronbach $\alpha = 0.63$). However, the range of Cronbach α values for this sample is comparable to other studies utilizing the CERQ with healthy populations (Cronbach $\alpha \geq 0.68$ and ≤ 0.83)³³ and patients with primary SS (Cronbach $\alpha \geq 0.67$ and ≤ 0.81).³⁴

The Brief Illness Perceptions Questionnaire (B-IPQ) was used to assess the cognitive and emotional representations that respondents hold toward their illness.³⁵ The B-IPQ contains 9 items: 5 cognitive representations (consequences, timeline, personal control, treatment control, identity), 2 emotional representations (concern, emotions), and 1 item assessing illness comprehensibility (coherence). The remaining item, which assesses causal representations of the illness, was not included as it was irrelevant to the study's aim. Responses were captured on an 11-point scale, with anchor points from 0 (not at all) and 10 (extremely affected). Scores on the 8 items were summed to form a total B-IPQ score. A higher total B-IPQ score indicates greater perceived psychological burden of illness.³⁵ The internal consistency of the B-IPQ was acceptable for this sample (Cronbach $\alpha = 0.74$).

Relationship satisfaction was assessed with the 10-item marital subscale of the Maudsley Marital Questionnaire (MMQ).³⁶ A 9-point scale (0-8) was used to capture the participants' perceptions regarding the dynamics of their relationships over the previous 3-month period. The original questionnaire used the word “marriage” within the questions; however, the word “marriage” was changed to “relationship” to increase the applicability of the measure in this study. Scores on the marital subscale of the MMQ ranged from 0 to 80, with higher scores indicating greater relationship dissatisfaction. In this sample, the internal consistency of the marital subscale of the MMQ was excellent (Cronbach $\alpha = 0.94$), similar to values reported by previous research (Cronbach $\alpha = 0.90-0.93$).^{37,38}

Part II of the West Haven–Yale Multidimensional Pain Inventory (WHYMPI) was utilized to assess respondents' perceptions of the degree to which their partners display solicitous, distracting, or negative behaviors in response to their communicated pain.³⁹ Respondents were asked to indicate, on a 7-point Likert scale, how often their partners display a particular behavior in response to their pain behaviors and complaints (0, never; 6, very often). Mean scores were calculated for each behavioral domain. Higher scores represent a greater frequency of that category of behaviors. Internal consistency for 2 subscales, negative responses (Cronbach $\alpha = 0.62$) and distracting responses (Cronbach $\alpha = 0.69$), was lower in this study than in a previous one (Cronbach $\alpha = 0.84$ and 0.74 , respectively).³⁹ For the solicitous responses

Table 3. Spearman correlations for sexual function (FSFI) and sexual distress (FSDS) for women with Sjögren's syndrome.^a

	FSFI total (n = 81) ^b			FSDS total (N = 98)		
	ρ	<i>P</i> value	95% CI	ρ	<i>P</i> value	95% CI
Age, y	-0.270	.015	-0.467, -0.049	0.055	.592	-0.151, 0.256
Duration, mo						
Disease	-0.030	.793	-0.253, 0.196	-0.090	.379	-0.289, 0.116
Relationship	-0.180	.119	-0.396, 0.054	-0.060	.577	-0.269, 0.155
VAS: dryness						
Vaginal	-0.350	.001	-0.533, -0.136	0.236	.019	0.034, 0.420
Vulva	-0.414	.000	-0.584, -0.209	0.379	.000	0.190, 0.541
ESSPRI total	-0.165	.141	-0.376, 0.062	0.107	.295	-0.099, 0.304
Pain	-0.106	.344	-0.323, 0.121	0.011	.911	-0.193, 0.215
Fatigue	-0.117	.298	-0.333, 0.110	0.118	.247	-0.088, 0.315
Dryness	-0.168	.134	-0.378, 0.059	0.173	.089	-0.032, 0.364
ProFaD						
Somatic fatigue	-0.149	.185	-0.361, 0.079	0.106	.299	-0.100, 0.303
Mental fatigue	-0.294	.008	-0.486, -0.074	0.296	.003	0.098, 0.472
General discomfort	-0.141	.208	-0.355, 0.086	0.136	.182	-0.070, 0.331
CERQ						
Self-blame	-0.264	.017	-0.461, -0.042	0.548	.000	0.385, 0.677
Acceptance	-0.203	.070	-0.409, 0.023	0.089	.388	-0.119, 0.290
Rumination	-0.296	.007	-0.488, -0.077	0.619	.000	0.473, 0.732
Positive refocusing	0.139	.216	-0.088, 0.353	-0.062	.548	-0.265, 0.146
Refocus on planning	0.158	.158	-0.069, 0.370	-0.093	.369	-0.293, 0.116
Positive reappraisal	0.469	.000	0.273, 0.628	-0.433	.000	-0.587, -0.249
Perspective	0.341	.002	0.126, 0.525	-0.378	.000	-0.542, -0.186
Catastrophizing	-0.499	.000	-0.651, -0.310	0.554	.000	0.393, 0.682
Other blame	-0.147	.192	-0.359, 0.081	0.181	.078	-0.027, 0.373
B-IPQ total	-0.305	.006	-0.496, -0.086	0.515	.000	0.346, 0.652
Consequences	-0.237	.033	-0.438, -0.013	0.302	.003	0.102, 0.479
Timeline	0.096	.391	-0.131, 0.314	-0.033	.748	-0.238, 0.174
Personal control ^c	-0.288	.009	-0.481, -0.068	0.376	.000	0.184, 0.541
Treatment control ^c	-0.201	.072	-0.407, 0.025	0.240	.018	0.036, 0.425
Identity	-0.294	.008	-0.487, -0.075	0.297	.003	0.097, 0.475
Illness concern	-0.167	.137	-0.377, 0.060	0.317	.001	0.118, 0.491
Coherence ^c	-0.061	.591	-0.281, 0.166	0.193	.059	-0.014, 0.384
Emotional representation	-0.216	.053	-0.420, 0.009	0.395	.000	0.205, 0.556
MMQ ^d	-0.282	.013	-0.483, -0.054	0.361	.000	0.160, 0.533
WHYMPI total ^d	0.253	.027	0.022, 0.458	-0.238	.024	-0.429, -0.026
Negative responses	-0.252	.028	-0.457, -0.021	0.219	.038	0.006, 0.413
Solicitous responses	0.267	.020	0.037, 0.470	-0.259	.014	-0.447, -0.048
Distracting responses	0.311	.006	0.085, 0.506	-0.311	.003	-0.492, -0.105

Abbreviations: B-IPQ, Brief Illness Perceptions Questionnaire; CERQ, Cognitive Emotion Regulation Questionnaire; ESSPRI, EULAR Sjögren's Syndrome Patient Reported Index; FSDS, Female Sexual Distress Scale; FSFI, Female Sexual Function Index; MMQ, Maudsley Marital Questionnaire; ProFaD, Profile of Fatigue and Discomfort; VAS, visual analog scale; WHYMPI, West Haven-Yale Multidimensional Pain Inventory. ^aSignificant *P* values are presented in bold. ^bParticipants who did not have sexual intercourse in the last 3 months were excluded (n = 17). ^cReverse scored. ^dn = 90. Participants not currently in a relationship did not complete the measures assessing relationship satisfaction or partners' behaviors (n = 8).

sclerosis.⁴⁶ We also noted that increases in severity of vaginal dryness were significantly associated with increases in sexual distress, which, to our knowledge, has not been investigated for women with SS. Although not assessed in this study, vaginal dryness has been associated with increased pain during intercourse (dyspareunia) for women with SS.^{13,43} It is thought that repeated experiences of dyspareunia lead to hypervigilance of pain sensations within the sexual environment; this then has a knock-on effect on physiologic sexual responses, such as desire, arousal, and lubrication.⁴⁷ Future research should explore this mechanism to identify its role in sexual function in women with SS.

Regarding disease parameters, our study found that patient-reported symptoms of pain, fatigue and dryness (ESSPRI) were not significantly associated with sexual function or sexual distress, which is discordant with previous research.^{13,42} However, we acknowledge that the internal consistency of the ESSPRI measure was lower in our sample than in other

SS samples, which may account for the lack of consistency between findings. Our study also revealed that increases in mental fatigue were significantly associated with poorer sexual function and greater sexual distress, although no significant associations were found for somatic fatigue and general discomfort. A previous study that utilized the Multidimensional Fatigue Inventory to assess relationships between dimensions of fatigue and sexual function noted that greater mental fatigue was associated with reductions in sexual function and increases in sexual distress.¹³ Yet, the study also found that reduced motivation was significantly associated with both sexual parameters, which was not the case in this study or a study with women with SLE.⁴⁸ Despite the negative impacts of fatigue on female sexual functioning, the mechanisms of action of how it affects the sexual response cycle have not been widely investigated. In contrast, research involving women with chronic fatigue syndrome suggests that fatigue dampens sexual desire,⁴⁹ reduces sexual pleasure,

impairs ability to reach orgasm, and can lead to avoidance and reduced frequency of sexual activity.⁵⁰ Future research should explore the impacts of fatigue on the domains of sexual function and attain the lived experiences of women with SS to gain a greater understanding of the role of fatigue on sexual functioning parameters in SS.

Previous research investigating differences in sexual functioning for women with SS based on menopausal status found that postmenopausal women with SS had significantly poorer overall sexual function than premenopausal women with SS.⁴³ This finding was corroborated in this study. Furthermore, we identified that postmenopausal women with SS had significantly lower levels of desire, reduced levels of vaginal lubrication, higher levels of pain during vaginal intercourse, and reduced levels of sexual satisfaction than premenopausal women with SS. We did not find any evidence to suggest that levels of arousal or ability to reach orgasm were affected by menopausal status in SS, with both subgroups displaying an average score suggesting that in most sexual interactions, they are able to become aroused and reach orgasm. This is noteworthy, given that the presence of vaginal dryness and the increases in dyspareunia observed in this population would typically be perceived to affect these sexual response phases.^{51,52} While it is important to consider the possible mechanisms that could account for this, our ability to do so is hindered due to a lack of reporting of the subdomains of sexual functioning in pre- and postmenopausal women with SS.^{13,43} However, in other disciplines, menopausal women, with and without chronic illness, tend to experience significantly poorer functioning across all subdomains of the FSFI, including arousal^{53,54} and orgasm.⁵⁵ Additional comparative research is therefore needed in SS to unpack the underlying explanations that would account for the observed differences between pre- and postmenopausal states. Previous studies that utilized a control group comparison to explore differences in the sexual functioning of pre- and postmenopausal women with SS noted that premenopausal women with SS have significantly poorer sexual function than premenopausal controls.⁴³ Although menopausal women with SS experienced sexual dysfunctions, these did not significantly differ from those experienced by healthy postmenopausal women.⁴³ This suggests that the sexual difficulties experienced by premenopausal women with SS may not be attributed to their menstrual status, unlike menopausal women, whose sexual difficulties are typically attributed to increases in age,⁵⁶ reductions in hormone levels (eg, estrogen, testosterone, dehydroepiandrosterone sulfate),¹¹ and vaginal atrophies.⁹ Further examination is needed of the reasons why premenopausal women with SS experience atypical sexual functioning in comparison with menstrual-matched healthy controls.

In this study, we investigated associations between sexual functioning and various psychosocial and interpersonal parameters. Regarding coping strategies, we found that various strategies were associated with sexual function and distress for women with SS. First, maladaptive coping strategies—such as blaming self for the sexual issues (self-blame), having repeated thoughts and negative feelings about the sexual issues (rumination), and emphasizing the awfulness of the sexual situation (catastrophizing)—were all significantly associated with poorer sexual function and higher levels of sexual distress. In regression analyses, catastrophizing was significantly associated with poorer sexual function, and rumination was significantly associated with higher levels of

sexual distress. Adaptive coping strategies—such as attaching a positive meaning to the sexual experiences (positive reappraisal) or downplaying the seriousness of the sexual issues as compared with other problems (perspective)—were significantly associated with better sexual function or less sexual distress. Previous research has identified a similar pattern, whereby certain adaptive and maladaptive coping strategies were associated with improvements or declines in sexual function¹⁵ and sexual distress.⁵⁷

Moreover, we identified several significant associations between various illness representations and sexual function and distress. We found that women with SS who perceived their illness to affect their lives more severely (consequences), who had a lack of personal control over their illness (personal control), who attributed more severe symptoms to their illness (identity), or who had a more threatening view of their illness (B-IPQ total) also had significantly poorer sexual functioning and experienced significantly higher levels of sexual distress. Additionally, greater levels of sexual distress were experienced by those individuals with SS who perceived poor treatment efficacy (treatment control), were more concerned about their illness (illness concern), or had more emotional distress as a result of SS (emotional representation). In regression analyses, only illness identity was significantly associated with sexual distress. No such associations were identified for sexual function. Our results are discordant with previous research, which found that 4 illness representations significantly determined sexual functioning in women with SLE: emotional representation, consequences, coherence, and treatment control.¹⁸

Furthermore, we investigated associations between a partner's response behaviors and sexual function and distress for women with SS. We found that negative responses were significantly associated with poorer sexual function and higher levels of sexual distress, consistent with previous research.⁵⁸ We also noted that solicitous responses and distracting responses were significantly associated with better sexual function and reductions in sexual distress. Yet, similar research with women with provoked vestibulodynia revealed no evidence of an association between a partner's solicitous behaviors and sexual function.⁵⁸⁻⁶⁰ The subdomain distracting responses has not been assessed in relation to sexual function. Regression analyses in this study also found that a partner's use of distracting behaviors was significantly associated with less sexual distress for women with SS. However, regression analyses identified no such associations for sexual function, also consistent with previous research.^{58,59} Regarding relationship satisfaction, significant associations were found between relationship dissatisfaction and sexual function and distress, in accordance with previous research.¹³ However, once other factors were entered into the regression analysis, relationship dissatisfaction was not significantly associated with sexual function or sexual distress in this study or in previous research with women with SS.¹³

This study analyzed the role of various psychosocial and interpersonal factors on female sexual functioning and sexual distress in SS. Coping strategies, illness perceptions, partners' response behaviors, and relationship satisfaction were examined as direct contributors to the sexual outcomes; however, evidence suggests that these factors may be implicated in mediating pathways. For example, an individual's coping strategies have been found to mediate the relationship

between illness perceptions and sexual functioning, as proposed by self-regulation theory.⁶¹ Moreover, Rosen and Bergeron proposed a more recent theoretical perspective on the mechanisms by which some of the psychosocial and interpersonal variables investigated in the current study play a role in sexual function.²⁰ The interpersonal emotion regulation model of women's sexual dysfunction views sexual function from a biopsychosocial perspective and acknowledges the important role that psychosocial and interpersonal variables play in sexual function. The model describes how distal factors (relating to overarching traits or predisposing aspects of the relationship) and proximal factors (relating to what occurs before, during, and immediately following painful sexual activities) affect an individual and the couple's emotional regulation, which then has a bearing on the sexual outcomes. For example, distal factors such as catastrophizing, intimacy, attachment, and sexual communication, as well as proximal factors such as partners' responses to pain, anxiety, depression, and sexual motivation, reciprocally influence the individual's regulation and the couple's co-regulation. Those with less adaptive emotion regulation strategies, such as avoidance, suppression, catastrophizing, and emotional outbursts, are more likely to display negative outcomes, such as greater sexual pain, poorer sexual function, more sexual and psychological distress, and less sexual and relationship satisfaction. Yet, those with more adaptive strategies (eg, reappraisal, acceptance, mindfulness, problem solving) are less likely to experience negative outcomes, reporting better sexual function and sexual and relationship satisfaction, as well as less psychological distress and pain during sexual activity.²⁰ In light of this model, we can see that our findings draw several parallels and differences.

Regarding coping strategies, we found evidence to suggest that sexual functioning and levels of sexual distress were related to the coping strategies elicited by an individual. In particular, maladaptive coping strategies (catastrophizing, rumination, self-blame) were associated with poorer sexual outcomes, and better sexual outcomes were associated with more adaptive coping strategies (positive reappraisal, perspective). In contrast, our evidence regarding a partner's response behavior was discordant with the model, which posits that solicitous and negative partner responses disrupt emotion regulation and lead to poorer sexual outcomes, as both behaviors reinforce avoidance of pain in a sexual situation, thereby creating a negative feedback loop further modulating and maintaining sexual dysfunctions. However, our study found that only negative partner responses were associated with poorer sexual outcomes. We noted that solicitous behaviors were associated with better sexual function and lower sexual distress in women with SS. Perhaps those with a chronic illness such as SS interpret solicitous behaviors as being more helpful in the sexual environment and less of a hindrance.⁶² It would be beneficial for research to explore this potential explanation in qualitative research or use dyadic diary methods with women with SS. We also assessed relationship satisfaction, although this model suggests that this factor was more appropriate as an outcome variable rather than an independent factor, which may explain why it was nonsignificant in this study. Future research should analyze the mediating pathways suggested by this recently proposed model via structural equation modeling to determine the contribution of psychosocial and interpersonal factors to sexual dysfunction in SS. Future research would benefit from including the partners'

perspectives and their contributions to sexual functioning in this population with chronic illness.

This study shows that further exploration is warranted of the impacts that psychosocial and interpersonal factors have on sexual functioning and sexual distress in women with SS. Previous intervention research has found that cognitive-based therapies have successfully modified negative illness perceptions^{19,63} and maladaptive coping strategies,⁶⁴ leading to improvements in adjustment and functioning. It is not unreasonable to suggest that the modification of coping strategies and illness perceptions could lead to better sexual outcomes for women with SS. Our findings may guide interventions by providing information concerning what types of coping strategies, illness perceptions, and partners' response behaviors to target in future interventions.

Our study has some limitations. First, the study was cross-sectional, therefore limiting interpretations about causality. As such, we cannot draw definitive conclusions regarding the directionality of the associations identified in this study. However, this design was useful for establishing preliminary evidence that can be used to inform future research into sexual functioning in SS. Another limitation is that we did not include or control for other psychosocial or interpersonal variables previously shown to contribute to sexual function in other chronic illness populations—for example, depression,¹³ anxiety,⁴³ body image concerns,⁶⁵ and sexual communication.⁶⁶ It would be beneficial for future research to better understand the mediating relationships and interactions between the variables in this study and sexual functioning in SS. The use of self-report data in this study was also a limitation. Future research may include other sources of information, such as laboratory measurements, to provide some objectivity to the subjective reports. Additionally, participants self-reported their diagnosis of SS, and no attempts were made by the research team to externally confirm the status. Future research should confirm the diagnosis through medical records or by utilizing a disease classification tool, such as the European Sjögren's Syndrome Disease Activity Index,⁶⁷ to measure disease activity objectively. However, there was no practicing clinician within the research team, so we could not include this measure in the current study. Another limitation is that some measures (ie, ESSPRI) and specific subscales (ie, CERQ positive refocusing, WHYMPI negative responses and distracting responses) displayed moderate levels of internal consistency. Therefore, results pertaining to these measures should be interpreted with caution. Researchers may want to consider either using more reliable measures to evaluate coping strategies (eg, Brief COPE)⁶⁸ or assessing sexual communication instead of partners' response behaviors (eg, Dyadic Sexual Communication Scale)⁶⁹ with SS samples. Our study was also limited to cisgender women in mixed-sex relationships. Future research should evaluate the sexual functioning of cisgender men and transgender populations with SS and those in same-sex relationships.

Conclusion

This study is one of the first to explore the impacts of coping strategies, illness perceptions, and relationship dynamics on sexual function and sexual distress for women with SS. Our study found that individuals using adaptive coping strategies had better sexual function and lower levels of sexual distress than those using maladaptive coping strategies. We also found

that certain response behaviors elicited by the partner were significantly associated with better sexual function and less sexual distress. The findings from our study suggest that interpersonal and psychosocial factors are important contributors to sexual function and distress in women with SS and that the development of psychosocial or interpersonal interventions for this population is warranted.

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Author contributions

Conceptualization: J.L.M., K.L.H., V.D., T.L.C. Methodology: J.L.M., K.L.H., V.D., T.L.C. Investigation: J.L.M. Formal analysis: J.L.M., D.W.L., K.L.H., V.D., T.L.C. Writing—original draft: J.L.M., K.L.H., V.D., T.L.C., D.W.L. Writing—review and editing: J.L.M., K.L.H., V.D., T.L.C., D.W.L. Supervision: K.L.H., V.D., T.L.C., D.W.L. Project administration: J.L.M.

Supplementary material

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Data availability

The data underlying this article are available in the article and its online supplementary material.

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