

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

Jemma L. McCready, MSc^{1,*} , Vincent Deary, PhD^{2,3} , Tracy L. Collins, PhD¹ ,
Dennis W. Lendrem, PhD⁴ , Katie L. Hackett, PhD^{1,3} 

¹Department of Social Work, Education and Community Wellbeing, Faculty of Health and Life Sciences, Northumbria University, Newcastle upon Tyne, NE7 7XA, United Kingdom

²Department of Psychology, Faculty of Health and Life Sciences, Northumbria University, Newcastle upon Tyne, NE1 8ST, United Kingdom

³Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, NE7 7DN, United Kingdom

⁴Translational and Clinical Research Institute, Newcastle University, Newcastle upon Tyne, NE1 7RU, United Kingdom

*Corresponding author: Northumbria University, Faculty of Health and Life Sciences, Department of Social Work, Education and Community Wellbeing, Coach Lane Campus, Newcastle upon Tyne, NE7 7XA, United Kingdom. Email: j.mccready@northumbria.ac.uk

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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(eg, estrogen and testosterone)¹¹ may all be correlated with poorer sexual function in SS. However, there is a sparsity of research, with these factors being examined in only 1 or 2 studies, as well as an inconsistency of the significance of such factors across studies. Moreover, a recent study conducted a regression analysis to assess the weight of some of these gynecologic manifestations (vaginal dryness; presence of atrophy in the vagina, cervix, and labia; parity and gravidity) in predicting sexual dysfunction as measured by the FSFI in women with SS.⁹ The study found that although these gynecologic variables (except vaginal dryness) correlated with sexual functioning, the only significant predictors of sexual function were depression and parity (ie, the number of pregnancies that resulted in delivery of a live or stillbirth at ≥ 24 weeks' gestation).⁹ This finding suggests that psychological variables may play a more important role in sexual dysfunction than some of the gynecologic characteristics observed in women with SS (eg, vaginal atrophy).

The relationship between depression and sexual dysfunction in SS has been explored,¹²⁻¹⁴ with studies typically finding significant associations between the variables.^{12,14} Furthermore, a path analysis revealed that depression mediated the relationship between SS and sexual dysfunction; however, the effects of the disease itself had a greater impact on sexual dysfunction than depression.¹⁴ Although the role that other psychological or interpersonal factors have on sexual dysfunction has not previously been examined in SS, such factors have been researched in healthy women, as have other chronic health conditions.

For example, Crisp et al¹⁵ investigated the coping strategies of healthy women and found evidence to suggest that one's coping styles (ie, the cognitive and behavioral strategies used to manage stressors), particularly maladaptive strategies such as denial and self-blame, were associated with poorer sexual function. Yet, the authors also noted that adaptive coping strategies, such as acceptance and emotional and instrumental support, were significantly associated with better sexual function.¹⁵ As individuals with SS are more likely to display a dispositional coping profile reliant on maladaptive strategies,¹⁶ it could be hypothesized that they may be more at risk of experiencing sexual dysfunction. Insights into adaptive coping strategies may be useful to inform subsequent interventions in managing female sexual dysfunction in SS.

Another important aspect is the way in which individuals perceive their illness and the beliefs that they hold about the causes, consequences, and controllability of the illness. These illness perceptions differ among people with the same condition and are an important determinant of behavior, influencing the way that they manage their illness, adhere to treatments, and make progress in functional recovery.¹⁷ Previous research with women with systemic lupus erythematosus (SLE) found that individuals with negative illness perceptions (ie, perceived a greater impact of disease or a lack of understanding and an uncontrollability of the illness) had poorer overall sexual function than those with more positive illness perceptions. Additionally, those with SLE who were more emotionally affected by their illness experienced lower sexual and body esteem and perceived themselves as less attractive.¹⁸ The authors concluded that one's illness perceptions were a greater predictor of sexual functioning than other previously identified factors, such as sociodemographic characteristics or disease activity.¹⁸ Identifying whether illness perceptions play a role in the sexual function of women with SS would be

worthwhile. Previous research has shown that brief cognitive behavioral interventions have successfully modified negative illness perceptions, leading to improvements in adjustment and functioning,¹⁹ which may be an avenue of sexual dysfunction management in SS.

In addition to the role of psychosocial factors, certain interpersonal factors have been implicated in female sexual dysfunction. One example is the impact that a partner's response behaviors (ie, the behaviors that a partner displays in response to the other partner's pain behaviors) can have on sexual function and sexual satisfaction.²⁰ In an 8-week diary study, Rosen et al²¹ found that the sexual function of women with vulvodynia was significantly impaired when their partners displayed more negative behaviors (expressions of hostility or frustration) or solicitous behaviors (expressions of attention and sympathy). In contrast, their sexual functioning improved when their partners displayed facilitative behaviors, such as affection and encouragement.²¹ Such evidence provides support for the exploration of the role of a partner's response behaviors in SS.

The research outlined here suggests that psychosocial and interpersonal factors may play an important role in developing and maintaining female sexual dysfunction. Therefore, there is a need to understand the role of psychosocial and interpersonal variables in predisposing, perpetuating, and precipitating sexual dysfunction in SS. Identifying influencing factors in this patient group may help the development of nonpharmaceutical interventions that facilitate the successful management of sexual dysfunction for women with SS. This explorative study aimed to address the gap in the literature by investigating whether coping strategies, illness perceptions, and relationship dynamics (ie, relationship satisfaction and partners' response behaviors) were associated with sexual function and sexual distress for women with SS.

Methods

An online cross-sectional survey was conducted between July and December 2021. Ethical approval was obtained from the Ethical Committee at Northumbria University (26288). All participants provided written informed consent in compliance with the Declaration of Helsinki. No compensation was provided for participating in the study. Recruitment advertisements were displayed on Twitter, in SS-specific groups on Facebook, and in member newsletters or websites of SS associations in the United Kingdom, United States, Canada, and Europe. Cisgender females aged ≥ 18 years and diagnosed with SS were invited to participate. The study did not exclude participants based on country of residence, although participants needed to be proficient in reading and writing in English. Potential participants were preinformed about the sexual nature of the questions in the study to ensure that no unnecessary distress was caused to them and that they could make an informed choice regarding their comfortability with answering questions about their sexual function and sexual lives. Informed consent was given by 139 respondents. However, 41 dropped out (without providing a reason), yielding a total of 98 participants (response rate = 71%). Retained participants and dropouts did not significantly differ in age, disease duration, relationship duration, menopausal status, subscales on the EULAR Sjögren's Syndrome Patient Reported Index (ESSPRI), or vaginal dryness (all $P > .05$).

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

subscale, internal consistency was higher than that previously reported (Cronbach $\alpha = 0.83$ vs 0.78).³⁹

Statistical analyses

An a priori power calculation estimated that a sample size of 89 was adequate to achieve the specified parameters ($\alpha = 0.05$, $1 - \beta = 0.80$, $d = 0.5$, 2-tailed).⁴⁰ A medium effect size was employed for the calculation due to it being the smallest effect size of interest. This ensures an achievable sample size and the ability to detect a meaningful difference that has practical importance.⁴¹ An additional 10% was included to account for data attrition. Three cases with missing data (>10% on ≥ 3 questionnaires) were removed prior to analysis. Data analysis was performed with SPSS version 28.0 (IBM). Descriptive statistics were calculated for all variables. The Fisher exact test and Pearson chi-square test were used for categorical variables. Independent samples *t*-tests and Mann-Whitney *U* tests were used (as appropriate) to assess group differences based on menopausal status. Data for the menopausal women were not included in the group comparisons due to the limited sample size. Participants who were not sexually active in the previous 3-month period ($n = 17$) were not included in any inferential analyses that involved the FSFI. The reason was that sexually inactive participants would score 0 or 1 for most questions on the FSFI, resulting in a low total FSFI score, which may be incorrectly construed as sexual dysfunction. Including sexually inactive participants in the analysis of this measure would likely lead to an overestimation of the prevalence of sexual dysfunction in the sample.⁴² The associations of sexual function (FSFI) and sexual distress (FSDS) with the other outcome measures were assessed with Spearman rho correlation coefficients. Variables significantly associated with each dependent variable were entered into a backward stepwise multiple regression to identify any factors associated with sexual function (total FSFI score) and sexual distress (total FSDS score). Raw, unadjusted *P* values are presented to allow researchers to make adjustments for multiple testing in future analyses. The threshold for significance was set at $P < .05$.

Results

A total of 98 cisgender females participated in the study (Table 1). Participants were predominantly from the United Kingdom (47%), United States (23.5%), Europe (13.3%), and Canada (11.2%) and were aged between 21 and 73 years (mean = 48.13, SD = 13.26). The majority of the sample were of White ethnicity (91.8%), identified as heterosexual (91.8%), and were in a relationship (91.8%) with male partners (100%). Approximately half of the sample was premenopausal (43.8%) and the other half was postmenopausal (48.0%). Primary SS was the most common diagnosis (70.4%). A small number of participants were diagnosed with another autoimmune rheumatic disease (eg, rheumatoid arthritis, 16%; SLE, 14.6%; osteoarthritis, 8%).

The majority of the sample was considered sexually active, as it had engaged in sexual activity within the previous 3-month period ($n = 81$, 82.7%). A small subset of the sample ($n = 17$, 17.3%) had not engaged in any sexual activity within the last 12 months ($n = 8$, 47.1%) or 5 years ($n = 7$, 41.2%) and were therefore classified as being currently sexually inactive. Comparisons between the sexually active and inactive groups

Table 1. Sociodemographic and disease characteristics of the sample ($N = 98$).

Demographics	No. (%) or mean (range)
Location of residence	
United Kingdom and Ireland	46 (47.0)
United States	23 (23.5)
Europe	13 (13.3)
Canada	11 (11.2)
Asia	2 (2)
South America	1 (1)
Australia	1 (1)
New Zealand	1 (1)
Age, y	48.13 (21-73)
Ethnicity	
White	90 (91.8)
Mixed or multiple ethnic groups	4 (4.1)
Black, African, Black British, Caribbean	2 (2.0)
Asian or Asian British	2 (2.0)
Sexual orientation	
Heterosexual	90 (91.8)
Bisexual	8 (8.2)
Sex of partner: male	98 (100)
Relationship status	
In a relationship	90 (91.8)
Not in a relationship	8 (8.2)
Relationship duration, mo	215 (0.5-612)
Disease classification	
Primary Sjögren's syndrome	69 (70.4)
Secondary Sjögren's syndrome	9 (9.2)
Not classified as primary or secondary	20 (20.4)
Disease duration, mo	80.39 (3-348)
Comorbid disease	
Yes	75 (76.5)
Fibromyalgia	15 (20.0)
RA	12 (16.0)
IBS	11 (14.6)
SLE	11 (14.6)
No	23 (23.5)
Medication	
Yes	80 (81.6)
HCQ	43 (53.8)
Analgesics	33 (41.3)
Pilocarpine	12 (15.0)
Corticosteroids	12 (15.0)
No	18 (18.4)
Menopausal status	
Premenopausal	43 (43.8)
Menopausal	8 (8.2)
Postmenopausal	47 (48.0)
Age at menopause, y	45.42 (29-55)
HRT treatment	
Yes	24 (43.6)
No	31 (56.4)
Contraception usage	
Yes	34 (66.7)
No	14 (27.5)
Currently pregnant	3 (5.9)

Abbreviations: HCQ, hydroxychloroquine; HRT, hormone replacement therapy; IBS, irritable bowel syndrome; RA, rheumatoid arthritis; SLE, systemic lupus erythematosus.

revealed that they were broadly similar, though the sexually inactive group was significantly older, with higher self-reported ESSPRI fatigue and dryness scores (all $P < .05$). Vaginal dryness was self-reported by 92.9% of women with SS. The severity of vaginal dryness was described as mild to moderate in 30.8% and severe to very severe in 69.2%. A clinical level of sexual dysfunction (total FSFI score < 26.55) was

Table 2. Differences in sexual parameters for pre- and postmenopausal women with Sjögren's syndrome.^a

	Women with Sjögren's syndrome, median (IQR)		U	Z score	P value	ES (r)
	Premenopausal	Postmenopausal				
FSFI total ^b	20.60 (10.80)	17.30 (11.05)	417.50	-3.017	.002	-0.35
Desire	3.60 (2.40)	2.40 (1.80)	453.50	-2.665	.007	-0.31
Arousal	3.90 (2.40)	3.30 (3.15)	520.50	-1.929	.054	-0.22
Lubrication	3.00 (2.40)	1.80 (2.25)	477.00	-2.400	.016	-0.28
Orgasm	4.40 (2.80)	4.00 (3.50)	572.50	-1.381	.169	-0.16
Satisfaction	4.40 (2.40)	2.40 (3.00)	496.50	-2.188	.028	-0.25
Pain	3.20 (2.00)	1.60 (3.10)	384.00	-3.386	.001	-0.39
FSDS ^c	23.00 (26.00)	25.00 (16.00)	923.00	-0.707	.482	-0.07

Abbreviations: ES, effect size; FSFI, Female Sexual Function Index; FSDS, Female Sexual Distress Scale. ^aSignificant *P* values are presented in bold. ^b*n* = 73. Analysis did not include sexually inactive cases (*n* = 17) and menopausal women (*n* = 8). ^c*n* = 90. Analysis did not include menopausal women (*n* = 8).

identified in 85.2% of respondents (*n* = 69/81, median = 18.90, IQR = 8.45).

Sexual functioning, sexual distress, and menopausal status

Stratifications based on menstrual status indicated that postmenopausal women with SS had significantly poorer sexual function (total FSFI score) than premenopausal women with SS. Analysis of FSFI subdomains revealed that postmenopausal women with SS had significant reductions in desire, lubrication, and satisfaction and experienced significantly more pain during vaginal penetration or intercourse than premenopausal women with SS (all *P* < .05). No significant differences were found between the groups on the orgasm or arousal subdomain (*P* > .05; Table 2). Point biserial correlations identified a significant association between menopausal status and sexual function (*r* = -0.351, *P* = .002; Table S1). According to the total FSDS cutoff score of 11, 87.8% (86/98) of women with SS in this sample regularly experienced high levels of emotional distress in regard to their sexual lives. Between-group analyses (*n* = 90) demonstrated no significant differences to suggest that total FSDS score was influenced by menopausal status (*P* > .05; Table 2). Point biserial correlations between menopausal status and sexual distress were not significant (*P* > .05; Table S1).

Parameters associated with sexual function (FSFI score)

Associations among psychosocial and interpersonal parameters, disease parameters, and sexual function were explored (Table 3). Poorer sexual function, as indicated by a lower total FSFI score, was significantly associated with decreases in B-IPQ personal control and increases in the following: age; vaginal dryness; ProFaD mental fatigue; CERQ self-blame, rumination, and catastrophizing; B-IPQ consequences, identity, and total score; WHYMPI negative responses; and MMQ relationship dissatisfaction. Higher self-rated sexual functioning was significantly associated with increases in CERQ positive reappraisal and perspective, as well as WHYMPI solicitous responses, distracting responses, and total score (all *P* < .05).

All variables that significantly correlated with sexual function were entered into the regression model. Analyses revealed that less vaginal dryness, more CERQ positive reappraisal, and less CERQ catastrophizing were significantly associated with higher self-rated sexual functioning, accounting for 42.0% of

the variance in total FSFI scores ($R^2 = 0.420$, $F_{3,72} = 17.394$, $P < .001$; Table 4).

Parameters associated with sexual distress (FSDS score)

Associations among psychosocial and interpersonal parameters, disease parameters, and sexual distress were explored (Table 3). Sexual distress, as indicated by a higher total FSDS score, was significantly associated with decreases in B-IPQ personal control and treatment control and with increases in the following: vaginal dryness; ProFaD mental fatigue; CERQ self-blame, rumination, and catastrophizing; B-IPQ consequences, identity, illness concern, emotional representation, and total score; WHYMPI negative responses; and MMQ relationship dissatisfaction. Lower self-rated sexual distress was significantly associated with increases in CERQ positive reappraisal and perspective, as well as WHYMPI solicitous responses, distracting responses, and total score (all *P* < .05).

The results of the regression analyses indicated that 4 variables explained 63.1% of the variance in total FSDS scores ($R^2 = 0.631$, $F_{5,83} = 28.376$, $P < .001$). The variables that were significantly associated with higher sexual distress (higher total FSDS score) were higher CERQ rumination, lower CERQ perspective, less WHYMPI distracting responses, and higher B-IPQ identity (Table 5).

Discussion

This study explored associations between various psychosocial and interpersonal variables and sexual function and sexual distress for women with SS. Previous research investigating sexual functioning for women with SS typically identified a high prevalence of clinical-level sexual dysfunction in its samples,^{10,13,43} which was also the case in this study. In our sample, we identified a higher prevalence of vaginal dryness, although this was marginally higher in this sample than in prior investigations with women with SS.^{10,13} We found that increases in severity of vaginal dryness were significantly associated with poorer sexual function, as reported previously.^{10,42} Results from the regression analyses indicated that vaginal dryness was significantly associated with reductions in sexual function for women with SS. To our knowledge, no previous research has included vaginal dryness as a predictor variable in similar analyses for this population group. However, this association has been identified for healthy women^{44,45} and women with systemic

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,

Table 4. Regression analysis between FSFI scores and psychosocial, interpersonal, and disease parameters for women with Sjögren’s syndrome (n = 81).^a

	Sexual functioning: FSFI					
	Model 1			Model 14		
	B	SE	β	B	SE	β
Age, y	−0.071	0.052	−0.151			
VAS: vaginal dryness	−0.594	0.306	−0.240	−0.689	0.231	−0.278**
ProFaD: mental fatigue	0.057	0.493	0.015			
CERQ						
Self-blame	0.032	0.242	0.021			
Rumination	−0.351	0.279	−0.164			
Positive reappraisal	0.539	0.227	0.327*	0.530	0.170	0.322**
Perspective	−0.140	0.255	−0.079			
Catastrophizing	−0.563	0.274	−0.292*	−0.534	0.198	−0.277**
B-IPQ						
Consequences	−0.166	0.637	−0.043			
Personal control	−0.443	0.386	−0.158			
Identity	−0.350	0.599	−0.098			
Total	0.189	0.129	0.293			
MMQ total	0.042	0.066	0.103			
WHYMPI						
Negative responses	−0.506	0.945	−0.083			
Solicitous responses ^b	—	—	—			
Distracting responses	0.587	1.151	0.116			
Total	0.252	1.916	0.034			
R ² (adjusted R ²)	0.505 (0.371)***			0.420 (0.396)***		
F	3.762			17.394		

Abbreviations: B-IPQ, Brief Illness Perceptions Questionnaire; CERQ, Cognitive Emotion Regulation Questionnaire; 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. ^aParticipants who did not have sexual intercourse in the last 3 months were excluded (n = 17). ^bDashes indicate the first variable deemed least significant in the backwards regression model. *P < .05. **P < .01. ***P < .001.

Table 5. Regression analysis between FSDS scores and psychosocial, interpersonal, and disease parameters for women with Sjögren’s syndrome (N = 98).

	Sexual distress: FSDS					
	Model 1			Model 14		
	B	SE	β	B	SE	β
VAS: vaginal dryness	0.492	0.442	0.098			
ProFaD: mental fatigue	−0.741	0.706	−0.094			
CERQ						
Self-blame	0.486	0.342	0.158			
Rumination	2.098	0.412	0.513***	2.161	0.335	0.528***
Positive reappraisal	−0.417	0.344	−0.126			
Perspective	−0.618	0.402	−0.171	−0.922	0.254	−0.255***
Catastrophizing	0.109	0.409	0.028			
B-IPQ						
Consequences	−0.020	1.007	−0.003			
Personal control	1.257	0.692	0.228			
Treatment control	0.713	0.713	0.144			
Identity	2.094	0.972	0.295*	1.093	0.507	0.154*
Illness concern	0.798	0.804	0.134			
Emotional representation	1.439	0.775	0.239			
Total	−0.836	0.445	−0.627			
MMQ total	0.050	0.096	0.061			
WHYMPI						
Negative responses	0.488	1.076	0.039			
Solicitous responses	1.129	1.176	0.129			
Distracting responses	−2.112	1.105	−0.210	−1.515	0.718	−0.150*
Total ^a	—	—	—			
R ² (adjusted R ²)	0.674 (0.590)***			0.631 (0.609)***		
F	8.034			28.376		

Abbreviations: B-IPQ, Brief Illness Perceptions Questionnaire; CERQ, Cognitive Emotion Regulation Questionnaire; FSDS, Female Sexual Distress Scale; MMQ, Maudsley Marital Questionnaire; ProFaD, Profile of Fatigue and Discomfort; VAS, visual analog scale; WHYMPI, West Haven–Yale Multidimensional Pain Inventory. ^aDashes indicate the first variable deemed least significant in the backwards regression model. *P < .05. ***P < .001.

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

Supplementary material is available at *The Journal of Sexual Medicine* online.

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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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