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Illness Experiences of Chilean Women With Sjögren's Syndrome: The Patient Perspective

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Objective. Sjögren's syndrome (SS) challenges everyday functioning and well-being. The aim of this study was to structure and summarize the life experiences of Chilean women with SS in an integrated model.

Methods. Interviews from a previous study yielded 75 experiences of living with SS. A sample of 30 women with SS sorted these experiences by content and rated their level of agreement with each experience. A hierarchical cluster analysis was used to structure the experiences of the participants with SS in a comprehensive overview. A team-based consensus analysis was used to define the number of clusters. The level of agreement was examined with Wilcoxon's signed rank test.

Results. Ten clusters were identified and grouped into 6 main categories: symptoms (clusters: mucosal dryness and related symptoms), social environment, emotion management (clusters: fears and sadness), information (clusters: uncertainty and lack of knowledge), coping strategy (clusters: resilience and self-care), and health staff relationship. The clusters that describe the more common experiences among patients were resilience, self-care, uncertainty, lack of knowledge, health staff relationship, and mucosal dryness.

Conclusion. This study provided an integrated and structured overview of disease experiences comprising both biomedical and psychosocial aspects as being of vital importance for the health of patients with SS. The overview can be used to get a quick impression of disease experiences that are important for an individual patient, in a therapeutic goal setting, and in the construction and evaluation of medical and nonmedical interventions or education.

INTRODUCTION

Sjögren's syndrome (SS) is a chronic systemic autoimmune disease that mainly affects the exocrine (salivary and lacrimal) glands in the form of a lymphocytic infiltrate (1). Key symptoms are dry eyes and dry mouth (2), and this dryness, along with systemic features, pain, and fatigue can progressively affect daily life (3). People with SS encounter a series of transformations in their daily activities, and considering these aspects is important to develop a clinical approach focused on patients' welfare. This study examined illness experiences that are conceptualized as the means and ways in which individuals and social groups perceive, conceive, and respond to a specific episode of disease (4). The concept of experience is defined according to a phenomenologic approach: the interpretation or meaning that each participant attributes to a life event influences the cognitive, emotional, and behavioral aspects in relation to that event (5). For the purpose of this study, illness experience is defined as a cognitive-emotional and behavioral response as a result of the interpretation of illness phenomena. Examples are feelings of loneliness as a consequence of perceived social rejection when living with stigmatized disease, or changes in family roles as a consequence of symptoms of the disease.

Illness experiences have commonly been investigated under the label health-related quality of life (HRQoL), which refers to limitations faced in different areas (biologic, psychological, and social) resulting from pathology or an accident (6) such as reductions in well-being and functioning (7,8). Assessments of HRQoL are used to evaluate the results of health interventions and treatments, understand the burden of a particular disease, identify health inequities, distribute health care resources, and support epidemiologic studies (9). Patients with SS have lower HRQoL than the general or healthy population; specifically, physical and mental functioning components of HRQoL are reduced (10,11), and the prevalence

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SIGNIFICANCE & INNOVATIONS

- Concept mapping provided a comprehensive and structured overview of illness experiences of women with Sjögren's syndrome.
- Most participants agreed with having experiences relating to resilience, self-care, uncertainty, lack of knowledge, health staff relationship, and mucosal dryness.
- The overview serves as an input guiding interviews supporting communication and the quality of the doctor-patient relationship.

of mood disorders is higher, which is associated with symptom burden and disability (12).

These findings using generic HRQoL measures highlight the importance of evaluating and knowing how patients with SS live their illness, make sense of it, and respond to the adversities of their disease. Illness experiences of SS include more facets than measured with generic HRQoL instruments. Illness experiences specific for SS have been indicated in qualitative and quantitative studies. Patients with SS apparently have little understanding of their disease, which could be due to the large variety of symptoms in this disease (11). When assessing their health condition, patients consider somatic experiences that are unique for SS, such as dryness and related psychological, functional, and social consequences, which probably influence the overall interpretation of the disease that they experience. The psychological response to SS is related to loss of health but also to a lack of knowledge of the disease and problems within social interaction (13). In interviews, patients reported experiencing feelings of sadness, abandonment, and powerlessness and difficulties in maintaining social relationships, while social support is fundamental to maintaining activities and sustaining social networks (13). Results from these interviews are considered a basis for the comprehensive description that the current study aims to provide.

The first aim of the current study was to structure and summarize the individual life experiences of Chilean women with SS in an integrated model using a concept mapping method. Based on previous research, the expectation was that multiple life domains would be influenced by SS, especially illness experiences, psychological responses, and social interaction (13), and that efforts to manage the disease would be part of the life experiences of patients (14). Moreover, we aimed to determine the degree of agreement with the experiences of illness among patients with SS by using a checklist including all identified experiences.

MATERIALS AND METHODS

Ethics approval and participants. The ethics committee of the Faculty of Dentistry at the University of Chile approved the research proposal (May 2017). All participants provided written informed consent. Participants were recruited through the treating doctors at the University of Chile Clinical Hospital and through a Facebook message by the national association of patients with SS. Interested participants could send an email to register. This process resulted in 30 women with SS who wanted to participate. The inclusion criteria were women age 18 to 70 years with a medically confirmed diagnosis of SS by a rheumatologist of the University of Chile Clinical Hospital and based on American–European Consensus Group criteria (15). Exclusion criteria were pregnancy, untreated other chronic conditions, being an inpatient, mental disorders, and having an acute phase of SS. The sample was heterogeneous in terms of disease characteristics and consisted of 30 women with SS without distinguishing between primary and secondary SS. The women experienced different symptoms and glandular or systemic signs of the disease. The sociodemographic characteristics of the participants are shown in Table 1.

Procedure. This study employed a concept mapping design (16) to structure qualitative content obtained from semistructured interviews in a previous study that examined experiences about the disease in 19 women with SS, medically confirmed by a rheumatologist (13). From an original set of 129 experiences derived from the interviews, a representative set of 75 experiences was selected by a group comprising researchers, clinicians, and a patient representative. The experiences were selected to represent an encompassing variety of experiences. Similar experiences were combined, and a statement involving multiple experiences was split into single experiences, with a decision that the experience should neither be ambiguous or abstract nor too specific. The research group discussed until consensus was reached about selected experiences.

The concept mapping technique consisted of 3 steps. First, in a session at the Faculty of Dentistry, participants individually sorted 75 cards with experiences about SS (card-sorting task) by categorizing them into piles using similarity of content as a criterion. The participants gave each pile a label that could be used by the researchers to interpret the sorting. One member of the research team was present during the task with each participant. Second,

Table 1. Characteristics of the sample (n = 30)*

Characteristic	Value
Age, years	52.23 ± 10.6 (29–74)
Diagnosis duration, years	6.9 ± 6.0 (<1–30)
Symptom duration, years	10.9 ± 6.6 (1–31)
Symptom duration before diagnosis, years	3.4 (3.0)
Marital status, no. (%)	
Married or cohabiting	17 (56.7)
Divorced	6 (20.0)
Widowed	1 (3.3)
Single	6 (20.0)
Highest level of education, no. (%)	
Primary	1 (3.3)
Incomplete secondary	1 (3.3)
Complete secondary	10 (33.3)
Technical-professional	10 (33.3)
Incomplete university	1 (3.3)
Complete university	4 (13.3)
Postgraduate	3 (10.0)

* Values are the mean ± SD (range) unless indicated otherwise.

to classify and structure the experiences that were sorted by the participants, a hierarchical cluster analysis was performed using a statistical software program (SPSS). Finally, a team-based consensus analysis consisting of 1 patient, 2 psychologists, 2 dentists, and 1 dentistry student examined and discussed the hierarchical cluster analysis results and decided on the number of clusters.

Using a checklist of 75 experiences with SS, the participants in this study indicated their level of agreement related to each experience included in the card-sorting task on a 4-point Likert rating (agree, mildly agree, mildly disagree, and disagree). In addition to the card-sorting and the level of agreement tasks, the participating women completed demographic questions.

Statistical analysis. IBM SPSS software, version 22 for Windows, was used for all analyses. Descriptive statistics were obtained to describe the sociodemographic variables (age, diagnosis, symptom duration, marital status, and education level). Hierarchical cluster analysis (Ward's method, squared Euclidian distances) was used to analyze the experiences that were individually sorted by the participants during the card-sorting task according to the similarity of meaning. In cluster analysis, the cells of the input matrix of experiences comprised the number of times that 2 experiences were not sorted in the same pile. The number of clusters was set, guided by the dendrogram and agglomeration schedule produced by the statistical software, showing which experiences were being combined at each stage of the hierarchical clustering process. The main criterion to decide on the number of clusters was that the clusters should reflect distinct components of experiences.

To analyze the level of agreement, a nonparametric statistical test for 1 sample (Wilcoxon's signed rank test) was used to compare the response of the participants with the median (2.5) response possibility. A P value less than 0.05 was considered to indicate statistical significance. Statistical significance of an item indicates that there was agreement among patients reflecting a common or uncommon experience. Based on the number of significant items in each cluster, the agreement percentage of each cluster was calculated. The median was derived to describe the agreement of the participants with the items.

RESULTS

Concept analysis. Figure 1 shows a schematic overview of the outcome of hierarchical cluster analysis, grouping the 75 experiences of having SS. The experiences included in the clusters

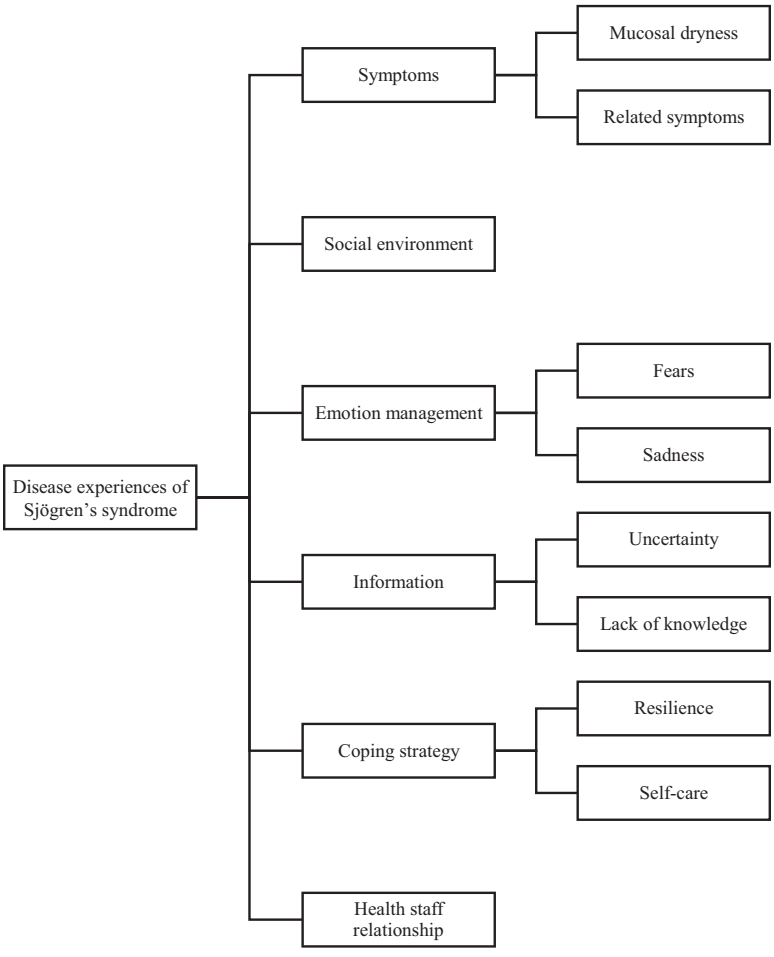

Figure 1. Schematic overview of the outcome of hierarchical cluster analysis grouping 75 experiences of having Sjögren's syndrome.

Table 2. Level of agreement with experiences, organized into 10 clusters, of patients with Sjögren's syndrome (SS)*

Cluster (% agreement) and experiences	Median	*P*
Mucosal dryness (73%)		
5. There is tooth loss or tooth damage by the dry mouth.	2	0.0788
7. The oral mucosa and the lips stick and become irritated.	1	0.0007
9. I feel a sensation of burning or sensitive oral mucosa.	1.5	0.0206
16. Eyes become red and sore by lack of tears.	1	0.0000
72. You cannot eat without drinking.	1	0.0007
53. Patients do not recognize dry mouth as a symptom of a disease.	1	0.0003
58. We do not recognize dry eyes as a symptom of a disease.	1	0.0009
49. It is difficult to talk clearly and for a long time.	1	0.0114
57. It is difficult to have a job that involves talking.	2	0.0009
26. The sense of taste is lost or decreased.	1	0.5774
75. The sense of smell is lost or decreased.	3	0.6728
Related symptoms (67%)		
4. There is deterioration of the physical appearance.	2	0.1419
36. There is weakness, tiredness, and permanent apathy. The energy does not last long.	1	0.0000
59. Avoid doing everyday tasks such as housework or shopping.	2	0.5012
17. The quality of sleep is poor.	1	0.0000
24. The disease gets worse because of daily stress.	1	0.0020
8. My mood changes according to my symptoms.	1	0.0009
Social environment (44%)		
23. Relationship break-up due to physical problems.	2.5	0.6310
28. The understanding of the partner is essential to maintain the relationship.	1	0.0000
32. Sexual intercourse is avoided because of the vaginal dryness, body ache, or dry mouth.	2	0.4840
12. The SS disease draws attention of the family and causes concern in the family.	2	0.1240
38. The family minimizes the illness of the patient.	2	0.0462
40. Social roles (mother, housewife, wife) are affected.	2	0.9913
43. The social environment is unwelcoming for SS sufferers and does not consider the limitations of the disease.	1.5	0.0475
70. The social environment does not either know or understand the disease.	1	0.0000
52. Physical difficulties (pain, fatigue, dry mouth) cause a withdrawal from social network.	3	0.4614
Fear (50%)		
62. I feel embarrassed for the state of my mouth.	2	0.8020
68. I am afraid of losing teeth because of dry mouth.	1	0.0004
11. I am afraid of possible blindness because of SS.	2	0.1438
27. I am afraid that the drugs can cause other diseases.	1	0.0001
Sadness (50%)		
34. The inability to cry with tears can lead to a nervous breakdown or depression.	3.5	0.0319
45. I prefer to avoid speaking about sad issues to avoid crying.	4	0.0062
31. I feel sadness, but I cannot cry with tears.	3	0.1783
2. An intense muscle contraction (neck, face, shoulders) happens when you cannot cry.	3	0.0896
33. Emotions like sadness, blame, rage, and resentment may be the cause of SS.	2	0.6867
39. I feel sadness for having an irreversible and complex disease.	2.5	0.7453
Uncertainty (80%)		
29. Before arriving at the diagnosis of SS, one visits a lot of doctors.	1	0.0003
48. The patient is able to actively participate in the diagnosis and treatment.	1	0.0000
37. The SS diagnosis is uncertain and provisional.	2	0.1641
60. The SS diagnosis can be a relief, as it ends the uncertainty of not having a diagnosis.	1	0.0002
61. There is uncertainty in the face of future events (complications).	1	0.0000
Lack of knowledge (78%)		
35. SS is a hereditary disease; it is part of our body.	3	0.5178
50. Past sad or traumatic experiences may initiate SS.	2.5	0.4193
3. SS is a disease whose name is hard to read, write, and pronounce.	1	0.0001
18. I had never heard about SS.	1	0.0259
65. I do not understand what the disease is about.	3.5	0.0376
54. The symptoms of SS are common with other diseases.	1.5	0.0053
56. The symptoms of SS appear many years before the diagnosis.	1	0.0000
73. Confusion when facing unexpected symptoms.	1	0.0001
30. It is necessary to search for additional information, either on the internet or in books.	1	0.0000
Resilience (83%)		
19. It is better to accept that you have to live with SS because there are worse diseases.	1	0.1214
66. It is better not to think about what could happen. Whatever has to happen, let it happen.	1	0.0012
47. The faith in God helps to face the disease.	1	0.0000
51. The disease is an opportunity for personal growth.	1	0.0218

(Continued)

Table 2. *(Cont'd)*

Cluster (% agreement) and experiences	Median	*P*
46. I try to maintain a normal life despite the symptoms.	1	0.0000
67. Being calm and in a good mood helps for a better health status.	1	0.0000
Self-care (83%)		
13. Herbs and natural foods are part of the self-care.	1	0.0000
64. Alternative medicine (Reiki, acupuncture, apitherapy, and so on) helps to control the symptoms.	1	0.0028
15. Taking self-care measures (diet, relaxation, following medical advice) is very helpful.	1	0.0000
14. I abandon the treatment when it causes unpleasant symptoms.	2	0.7878
25. If the medicine puts my health at risk, I stop taking it.	2	0.0152
21. The symptoms are the same, with or without treatment.	3	0.0443
Health staff relationship (77%)		
10. This disease implies spending a lot of money.	1	0.0016
41. It is exhausting to go to the doctor again and again, to complete health checks, and to face bureaucratic procedures.	1	0.0004
1. The doctors have little time to spend with patients.	1	0.0016
22. It is extremely difficult to get an appointment with the doctor when it is required.	1	0.0019
6. You must fully trust in the decisions and instructions of the rheumatologist.	1	0.0084
63. It is comforting for the patient that the doctor considers the human side of the patient.	1	0.0000
74. I drop out of treatment because it is impossible to get an appointment for medical check-up.	3.5	0.0376
44. Even the physicians from other medical specialties do not know much about SS.	1	0.0001
55. Doctors do not provide sufficient and clear information to guide the patient.	1	0.0081
42. I fear being admonished by the physician for not following the instructions.	2	0.5808
69. Physicians do not consider expectations, fears, and preferences of patients.	1.5	0.0595
71. Some limitations of the medical care are the responsibility of the institution and not of the doctors.	1	0.0010
20. The doctors think that other diseases are more important than SS.	2	0.0607

* Shown are the cluster name, the percentage of subjects agreeing with a cluster, the experiences (numbered 1–75), the median agreement (lower scores reflect higher agreement), and whether the agreement or disagreement significantly deviates from neutral. Scores of 1 to 4 reflect agree, mildly agree, mildly disagree, and disagree, respectively.

are shown in Table 2. Supplementary Figure 1, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.24256/abstract, shows the dendrogram of the grouped experiences.

The team-based consensus analysis determined that the number of clusters was set to 10. Increasing the number of clusters from 10 to 11 divided the cluster self-care into 2 clusters: deciding for oneself about abandoning pharmacologic treatment (items 14, 25, and 21) and deciding for oneself about complementary therapies (items 13, 64, and 15). Although the division was evident, both clusters contained items clearly reflecting the fact that the patients wanted to manage care related to SS themselves; therefore, there was no need to further divide these clusters. Increasing the number of clusters to 12 also divided the cluster health staff relationship into 2 different clusters: not directly related to physician care (items 10 and 41) and directly related to physician care (items 1 to 20). Because both clusters had the same items concerning health staff, this cluster was not split.

Decreasing the number of clusters from 10 to 6 indicated a solution combining 4 pairs of clusters into overarching categories (Figure 1). The items included in the clusters are shown in Table 2. The clusters mucosal dryness and related symptoms both involved symptoms. Mucosal dryness is a primary symptom of SS, and its management is different from other, more generic symptoms, such as fatigue or sleep disturbance. Also the pairs of clusters fear and sadness, uncertainty and lack of knowledge, and resilience and self-care. could be combined into overarching categories (Figure 1). We decided to maintain these separate clusters. Although both fear and sadness are emotions, they are distinct emotions. Sadness is an important issue in patients with SS because of the difficulty and the pain of crying without tears. Both uncertainty and lack of knowledge are related to information about SS; nevertheless, uncertainty is a feeling, while lack of knowledge is a cognition that could cause someone to feel uncertain. While both resilience and self-care are means to cope with the consequences of the disease, resilience concerns the cognitive and positive reappraisal of the disease, and self-care involves behavioral management of SS. Thus, the experiences of having SS comprise on the highest-order level 6 domains, of which 4 include 2 lower-order clusters each.

Level of agreement with experiences. Patients indicated their level of agreement with the 75 experiences associated with the illness. The median of the patients' responses (agree, mildly agree, mildly disagree, and disagree) to the 75 illness experiences and the agreement percentage of each cluster are shown in Table 2. These experiences are arranged according to membership in one of the higher-order dimensions obtained and shown in Figure 1. Significance (*P* value), obtained through statistical analysis with Wilcoxon's signed rank test, established whether the pattern in the answer options indicated agreement (is significantly lower than 2.5)

or disagreement (is significantly higher than 2.5) with the experience. The score distributions of the level of agreement with the 75 experiences at the 10 clusters are shown in Table 2. For 52 experiences of illness, the agreement or disagreement of the participants deviated from neutral, which corresponds to 69.3% of the total of illness experiences analyzed. Clusters that describe the more common experiences among patients are resilience, self-care, uncertainty, lack of knowledge, health staff relationship, mucosal dryness (Figure 2). Other clusters, especially sadness, are less common. A large range of scores indicating individual differences in the level of agreement with experiences were especially observed for lack of knowledge and self-care and, to a lesser extent, for mucosal dryness, related symptoms, and resilience.

Experiences related to oral mucosa (items 7, 9) are common, while experiences related to teeth (item 5), sense of smell (item 75), and taste (item 26) are particular to each patient. Many of the experiences on coping with SS are common, except the idea that other diseases are worse (item 19). Similar to options to care about oneself, most experiences related to being active on self-care are common. Patients agree that the diagnosis process generates uncertainty, but they disagree on whether a diagnosis is uncertain and provisional. Most of the participants agree on a lack of knowledge related to SS, both on social and medical environment, while there is no agreement on the origin or cause of SS. There is an agreement on how the functioning of the health care center influences the adherence to treatment. About the patient–health provider relationship, there is agreement on the importance of considering the human side of the patient and the need to trust in medical decisions.

DISCUSSION

The main aim of the current study was to structure and summarize the life experiences of Chilean women with SS in an integrated model. Ten clusters were identified that were arranged in 6 main categories: symptoms, social environment, emotion management, information, coping strategy, and health staff relationship. Some clusters of experiences were more common to the broad group of patients than others.

The participants in this study recognized many illness experiences, and several clinical characteristics of the disease and its psychological and social repercussions appear to constitute a relatively homogeneous experience. Interviewees shared the experience that they do not recognize, at an initial stage, the symptoms of dryness as part of a disease. Evidently, dry mouth may be interpreted as an irrelevant or transient symptom that could be explained by a variety of circumstances, such as anxiety or aging instead of an autoimmune disease. The lack of consideration of oral dryness as a disease symptom may mean that medical professionals are not consulted. This delay is relevant, because symptoms of dryness are a core symptom of the disease (15–19). The fear of losing teeth, another illness experience with high concordance, is related to objective aspects, such as the decrease in salivary flow that occurs in SS (20–24); however, for interviewees, this fear does not necessarily come

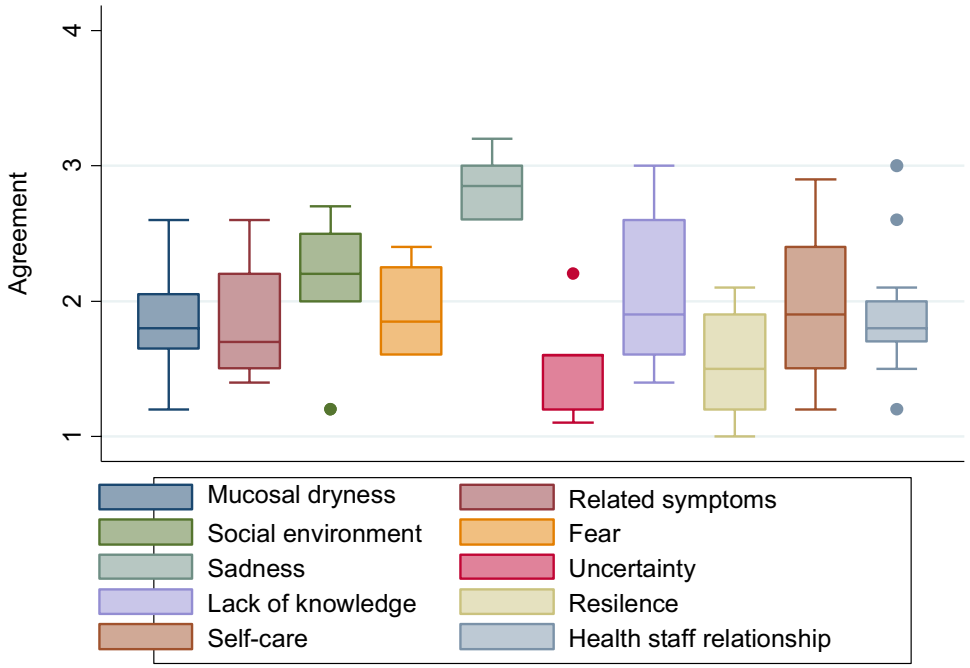

Figure 2. Box-and-whisker plot showing the level of agreement related to each experience of illness. The lowest possible score is 1 (agree) and the highest possible score is 4 (disagree). A wider range (indicated by the whiskers) indicates greater variability in agreement levels. Outliers are represented by dots.

from direct experience with professionals but rather from information they receive through the internet (13).

Chronic fatigue and poor sleep quality are other highly shared experiences that are widely supported by the literature (25,26) and that affect HRQoL (10,26). Both experiences are linked to the perception of a lack of understanding and devaluation of experience by others, a phenomenon described as invalidation (27). It is related to reduced physical health (28) and to low social support, which also constitutes a risk factor that affects HRQoL (23,24,29,30).

Difficulty in managing sadness due to lack of tears affects few women, although it is perceived as relevant. Difficulty in crying does not involve physical or psychological problems; our findings contradicts literature, which observes that the lack of tears hampers the recognition and expression of emotions (31).

A particular finding of this study was the lack of information represented by the experiences of uncertainty and lack of awareness regarding SS. The limited recognition of the disease by the community could contribute to patients not knowing what to expect or how to react. Also the difficulty in pronouncing the Swedish name "Sjögren" by Spanish speakers may contribute to the lack of information. In addition, the nonspecific symptomatology of the clinical picture may lead to a delay in disease diagnosis, which may have implications for health. The time course before diagnosis is generally long (3.4 years on average), which is consistent with the findings reported in the literature for this disease (32). Uncertainty and lack of awareness are characteristics of SS. This finding is consistent with a previous study showing that the uncertainty and strangeness experienced by patients with SS are phenomena that impact daily life (13).

Patients accept and try to give positive value to their disease, trusting their faith in God and mixing feelings of acceptance and resignation. In general, patients give great value to self-care strategies that are not part of conventional medical treatment, such as relaxation, alternative medicine, or the use of herbs. Psychological interventions, such as stress management or relaxation therapies, have been reported as being effective as complementary therapies in other chronic rheumatic diseases, improving clinical indicators, such as pain and functional disability (33).

One of the experiences about which patients agreed relates to their relationship with doctors and other professionals (dentists, nurses, kinesiologists, etc.), with a demand for attention that emphasizes the relational rather than the technical. A collaborative relationship between the patient and health providers, which includes effective communication and patient satisfaction, is relevant for patient adherence to treatment (34,35). The emergence of this domain in the current study and the observation of some negative experiences with the health care system, shows that there is room for improvement and emphasizes the need to incorporate the relationship with the health system as a relevant variable in the pursuit of well-being for patients. Such demand is frequent, as reported by several studies (36,37); therefore, it should be a priority consideration in the clinical field.

To the extent that the clusters of symptoms, information, and health staff relationship can be classified under illness experiences, emotion management under psychological responses, social environment under social interaction, and coping strategy under efforts to manage the disease, our findings are close to previously found categorizations of experiences with SS (13,14). Illness experiences related to symptoms and social environment are to a certain extent reflected in the dimensions of some scales of HRQoL, such as the Short Form 36 health questionnaire (38,39), and emotion management and coping strategy are reflected in generic coping measures. However, the current overview yields experiences that are more specific for SS. Moreover, other domains, such as information and health staff relationship, that emerged in this study have not been identified in prior HRQoL studies, although they are important areas of illness experiences that may influence disease management and general life satisfaction (32).

The biopsychosocial model of illness highlights the patient's subjective experience as an essential contribution to accurate diagnosis, health outcomes, and in general, the care of people (40). The findings of this study show that there is diversity in experiences that is fundamental to understanding the behaviors involved in facing a disease, as well as the possibility of having a satisfactory life, which includes the acceptance and proper management of SS. The identification of the most and least common domains with their respective illness experiences is in line with the biopsychosocial approach and provides elements that strengthen this perspective and are useful for the clinical approach to treating patients with SS. As the results show, the disease involves a series of phenomena not only involving the somatic experience or the psychological response, but actually is the combination of different levels of human experience, confirming the ongoing relevance of Engel's biopsychosocial model of illness (40).

A strength of our study is that the perspective of patients was consistently applied. This design allowed a description beyond the subjective interpretation of researchers, because patients instead of researchers categorized the experiences in meaningful constructs. A distinguishing feature of our study was also that not only outcomes of the disease per se but also mediator variables that influence outcomes were included in the set of illness experiences.

A limitation of this study relates to the generalizability of findings. First, only women participated. Some findings about illness experience may be related to the female sex. Second, more unique experiences, such as those associated with specific systemic manifestations, were not represented in this study. They can, however, severely reduce the quality of life and require attention in clinical practice. Third, how much the findings generalize beyond patients from a Latin American country is unclear. A larger sample size is needed to increase the external validity by including the more unique experiences of patients with SS. From a statistical point of view, a sample size of 10–20 people has been suggested to be a workable number for a card-sorting task (16) and as few as 25–30 participants will likely yield results similar to those of several

hundred, provided these participants are representative of actual users and are familiar with the domain being considered (41).

Notably, this study used as a starting point the uniqueness of patients instead of generic components of the disease. Therefore, this study provides a valuable description of the disease for the purposes of the clinical care of patients with SS, since the findings can be used as input to guide interviews and help improve both communication and the quality of the doctor-patient relationship. There is a great need for education of health care professionals and the public about this disease. We hope this research will increase awareness of SS and enhance personalized assessment and treatment. Future research should examine intercultural aspects of the findings and investigate which SS experiences are more specific for a culture and which are more general. The current structured overview of illness experiences can be used in research, assessment, therapeutic goal setting, the construction of interventions aimed to improve quality of life, and the evaluation of medical and nonmedical interventions or education.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Rojas-Alcayaga had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Herrera, Espinoza, Geenen, Rojas-Alcayaga.

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Analysis and interpretation of data. Herrera, Espinoza, Wurmann, Leiva, Geenen, Rojas-Alcayaga.

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