

Quality of life in patients with Sjögren's syndrome: habits and practices in Iberoamerica. A perspective from the administration

Calidad de vida en pacientes con síndrome de Sjögren: hábitos y prácticas en Iberoamérica. Una perspectiva desde la administración

De León-Sigg, Inés Angélica^a & Pérez-Veyna, Oscar^b

^a Universidad Autónoma de Zacatecas • 7218-2024 • 0000-0002-9897-3219 • 994261

^b Universidad Autónoma de Zacatecas • GPF-5672-2022 • 0000-0001-5371-6676 • 120243

CONAHCYT classification:

Area: Social Sciences

Field: Administration and Business

Discipline: Administration and management

Sub-discipline: Administration of the fields of education, health, sports agronomy arts and humanities

<https://doi.org/10.35429/JAF.2024.11.28.1.13>

Article History:

Received: January 13, 2024

Accepted: December 31, 2024

* [\[inesangelica.deleonsigg@unizacatecas.edu.mx\]](mailto:inesangelica.deleonsigg@unizacatecas.edu.mx)

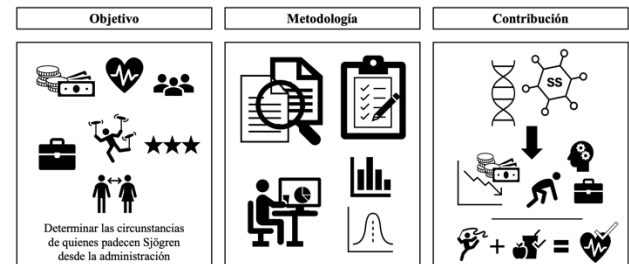
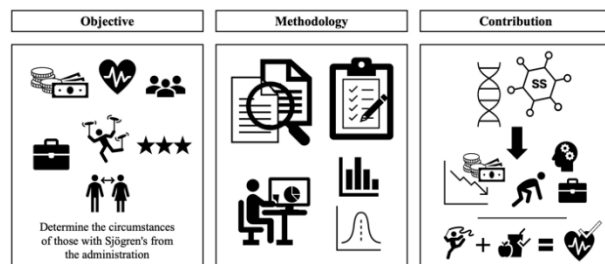


Abstract

Objective: Determine the circumstances (labor, social, economic, emotional, physical) that accompany patients diagnosed with Sjögren's Syndrome from the perspective of administration and with a gender focus. The above in the context of Ibero-America and for a period that includes the first 20 years of the 21st century. **Methodology:** Theoretical review of articles related to Sjögren's Syndrome, quality of life in its health, economy and work dimensions, and legislative initiatives on rare diseases. A questionnaire was applied based on those already validated on Quality of Life, the responses were analyzed with SPSS, Excel, StatGraphics. **Results:** The disease affects job stability, economic stability, social relationships and decreases physical and mental health. Adaptations are required in the work environment. The financial costs are high if it does not have health insurance. Routine exercise and diet generate a perception of reduced symptoms to continue with a normal productive life.

Resumen

Objetivo: Determinar las circunstancias (laborales, sociales, económicas, emocionales, físicas) que acompañan a los pacientes diagnosticados con Síndrome de Sjögren desde la perspectiva de la administración y con enfoque de género. Lo anterior en el contexto de Iberoamérica y para un período que comprende los primeros 20 años del siglo XXI. **Metodología:** Revisión teórica de artículos relacionados con Síndrome de Sjögren, calidad de vida en sus dimensiones salud, economía y trabajo, e iniciativas legislativas sobre enfermedades raras. Se aplicó un cuestionario basado en los ya validados sobre Calidad de Vida, las respuestas se analizaron con SPSS, Excel, StatGraphics. **Resultados:** La enfermedad afecta la estabilidad laboral, económica, relaciones sociales y disminuye la salud física y mental. Se requieren adaptaciones en el ambiente laboral. Los costos económicos son elevados si no se cuenta con seguro médico. Ejercicio rutinario y dieta genera una percepción de síntomas reducidos para continuar con una vida productiva normal.



Sjögren's Syndrome, Quality of Life, Administration

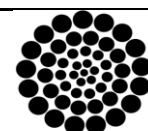
Síndrome de Sjögren, Calidad de Vida, Administración

Citation: De León-Sigg, Inés Angélica & Pérez-Veyna, Oscar. [2024]. Quality of life in patients with Sjögren's syndrome: habits and practices in Iberoamerica. A perspective from the administration. Journal of Administration and Finance. 11[28]-1-13: e11128113.



ISSN 2410-342X/© 2009 The Author[s]. Published by ECORFAN-Mexico, S.C. for its Holding Bolivia on behalf of Journal of Administration and Finance. This is an open access article under the CC BY-NC-ND license [<http://creativecommons.org/licenses/by-nc-nd/4.0/>]

Peer Review under the responsibility of the Scientific Committee MARVID® - in contribution to the scientific, technological and innovation Peer Review Process by training Human Resources for the continuity in the Critical Analysis of International Research.



RENIECYT
Registro Nacional de Instituciones y
Empresas Científicas y Tecnológicas

1702902 **CONAHCYT**

Introduction

The human resource within organisations has gone from being just an element capable of performing tasks to being a vital element, capable of driving change, innovation and long-term success, but it is still important to go beyond that to venture into specific aspects of people, as determining elements of organisations; in other words, the organisation-person interaction, but of the latter, particularly their health condition and the organisation's response to this circumstance (Richter et al., 2010; University of Vigo, 2001). This document seeks to raise the visibility of people suffering from rare diseases, specifically Sjögren's Syndrome (SS), who are of productive age but who, due to their condition, find it necessary to reduce their workload or even leave their job, which has repercussions on their economic, social and family situation and further degrades their physical and mental health.

As a hypothesis, H_0 was proposed: the diagnosis of SS in people of working age in Ibero-America implies a change in the work context, which could jeopardise the continuity of work, with the inherent economic, family and emotional consequences.

First, we talk about SS and how it affects the female population, and then we explain the Quality of Life (QoL) and its dimensions, as well as its effect on these dimensions due to SS and especially on productivity. It is important to know what is being done in Mexico with regard to this type of illness and how its politicians deal with it, so, as a fourth point, public policies in the field of health are discussed.

Subsequently, the methodology developed for this research is described, followed by the results, the conclusions of the study and the references that provided the basis for this information.

Sjögren's syndrome

SS is a chronic autoimmune disease that causes dryness of the mucous membranes, some internal organs and the nervous system (Povoas Barsottini et al., 2023).

In addition to dryness, its main symptoms are fatigue and musculoskeletal pain; in some cases, it facilitates the development of lymphomas (Anaya, 2017; Thorlacius et al., 2023; Thurtle et al., 2024; Zhong et al., 2022).

It is a disease that mainly attacks women, in ratios of 9 and up to 19 women to one man (Diez Morrondo et al., 2010; Ladino et al., 2015; Sorlí et al., 2009; Stefanski et al., 2017; Thorlacius et al., 2023). It has an incidence between 7 and 43 patients per 100,000 globally (Arellano Aguilar et al., 2016; Reyes Jaraba et al., 2022); with a prevalence between 0.03% and 4.6% worldwide (Fernández-Ávila et al., 2020); there is no exact number due to the different criteria used for its classification, which depend on the standards of each country, the study design and the population in which the study is being conducted (Reyes Jaraba et al., 2022).

Symptoms degrade the quality of life of patients due to pain, fatigue, joint inflammation, dry eyes and possible complications that may arise (Hernández-Molina, 2017; Papageorgiou et al., 2015; Povoas Barsottini et al., 2023; Ramos-Casals, 2021); it causes low work productivity, leaving the patient at risk of losing their job or resorting to part-time work (Allen et al., 2012), affecting the patient's economy due to a decrease in income, in addition to the costs of doctors, medicines and laboratory studies.

Quality of life

QoL depends on both objective and subjective factors, as it has to do with how the person feels, how satisfied they feel their physiological, work, economic, affective needs, expectations, their goals and even their emotions and concerns (Medvedev & Landhuis, 2018; Cummins, 1998, cited by Perea, 2018; Rodríguez & García, 2005; WHO, 2012), i.e. QoL is made up of several dimensions and there is a strong relationship with the happiness that the individual perceives (Medvedev & Landhuis, 2018).

When it comes to health, the quality of life will depend on the pain, disability and autonomy that the person has, whether physical or emotional (Fernández-López et al., 2010).

On the other hand, relationships at work, the type of work, job satisfaction, the recognition given by the organisation, remuneration and opportunities for growth are all related to the quality of working life (Chiavenato, 2017; Granados, 2011). When the person is affected in any of the dimensions of the QoL, the others will also be affected in some way.

In the workplace, physical and mental health, as well as the relationship in the family environment, can influence the worker's productivity (González Baltazar et al., 2007). Autoimmune diseases, such as SS, can be a cause of absenteeism and presenteeism, resulting in poor performance that has consequences for both the organisation and the worker (Shultz & Becker, cited by Mungaray Lagarda & Ramírez Urquidy, 2007). Symptoms such as fatigue, depression or pain can cause work disability or even sick leave (Westhoff et al., 2012), which is a problem in socio-economic development (Pan American Health Organization [PAHO], 2020).

Public health policies

If we add to all this the fact that, according to data from the Public Policy Research Centre of the Mexican Institute for Competitiveness (IMCO, 2024), women in Mexico have only 46% participation in the formal economy, compared to 77% participation by men, with a wage gap of 35% less than that of men; On the other hand, their participation in the informal sector is higher, with 55% compared to 49% for men; although women's participation in the informal sector is higher, it is a sector where they lack benefits, health services and legal uncertainty.

Another relevant situation is the little attention given to these diseases by the Mexican government; only in June 2023 did the Mexican government accept the International Classification of Diseases (ICD) (SEGOB, 2023; WHO, 2024), before which date only 20 rare diseases were recognised (Consejo de Salubridad General [CSG], 2018), so it is to be assumed that the more than 7,000 rare diseases existing globally (Orphanet, 2012; Secretaría de Salud, 2019) are already accepted in Mexico.

Similarly, law initiatives presented by Mexican deputies only focus on treatments or diagnoses, on the recognition of certain diseases, or on the costs they generate (Espinoza Cárdenas, 2020; Flores-Suárez, 2019; Hernández Pérez, 2022; Madrigal Sánchez, 2016; Romo Cuellar, 2022), but not in public policies that stimulate research leading to accurate diagnoses, appropriate medicines, education and awareness-raising on the treatment of people suffering from rare diseases (Peña Castillo, 2023).

Methodology

The hypothesis (Ho) was posed: The diagnosis of SS in people of working age in Latin America implies a change in their context motivated by their condition (age, sex, diet, physical activity, genetics) and by the expression of symptoms that can range from the change of work activities to the attention of the patient.

From the point of view of the Administration, this is observed as a vacuum in terms of the regulation of labour relations that could begin to be filled if it is understood that these circumstances (mainly labour) are related to a legislative work that should aim to fill this vacuum in the national context.

In order to initiate this work, empirical and theoretically supported contributions are required to channel and initiate the repair of the vacuum. Otherwise, Mexicans diagnosed with SS will remain in the shadows of oblivion and will continue to live in conditions far removed from the principles established in the Political Constitution of the United Mexican States in relation to health and the right to work.

One way that is considered favourable for people with SS is diet and physical activity, which seem to influence the evolution of health, attenuating the symptoms caused by the condition. This could be feasible provided that legislation is in place to guarantee the adequacy of physical spaces and the reconsideration of the workload, which will have an impact on the social, economic and emotional aspects of people diagnosed with SS.

On the other hand, the fact that in organisational studies the relevance of the individual condition and circumstances is overlooked seems to be a theoretical gap that can begin to be filled, starting with work that begins with the effort to dimension the physical and labour implications derived from SS, even starting from the personal circumstance.

In order to generate empirical evidence and provide information that would facilitate the testing of the hypothesis put forward, qualitative research was carried out on documents related to rare diseases, autoimmune diseases, SS and how they affect the quality of life of those who suffer from them, in their health, economic, social and, especially, occupational dimensions.

Different questionnaires on QoL assessment proposed in the literature were analysed; those focused on assessing and controlling disease manifestations were eliminated because the results are more related to medical use; questionnaires without free access or without a Spanish version and not self-administered were not considered. We looked for questionnaires that integrated the greatest number of QoL dimensions and that dealt with productivity and health; they had a smaller number of questions so as not to be tiring for respondents. The questionnaires considered were SF-36 and WPAI-GH.

SF-36. Self-administered questionnaire of 36 questions, assesses the eight dimensions (Table 1). It uses a 5-point scale; high scores indicate favourable responses (Institut Hospital del Mar d'Investigacions Mèdiques [IMIM], 2000).

Box 1

Table 1

The dimensions of the SF-36 questionnaire and their meaning. Information based on IMIM (2000)

Dimension	Meaning
Physical Function	Extent to which health limits physical activities
Physical Role	Extent to which physical health interferes with work and other daily activities
Body Pain	Intensity of pain and its effect on regular work
General Health Vitality	Perception of health Energy and vitality in the face of fatigue and exhaustion
Social Role	Extent to which health problems interfere with social life
Emotional Role	Extent to which emotional problems interfere with work and activities
Mental Health	Mental health in general

WPAI-GH. A questionnaire that assesses the effect of health problems on work activities, ability to work and overall productivity; it measures presenteeism, absenteeism and deficiencies in unpaid activities (Zhang et al., 2010). Table 2 shows the different dimensions and their meaning.

Box 2

Table 2

The different dimensions of the WPAI-GH questionnaire and their meaning. Information based on Reilly Associates (2021)

Dimension	Meaning
Absenteeism	Time lost from work due to ill health
Presenteeism	Impairment while working due to ill health
Loss of Productivity	General work disability due to health
Deterioration of Activity	Impairment of activity due to ill health

In addition, questions were developed about the demographics of the participants, based on the National Survey of Demographic Dynamics (ENADID) of the National Institute of Statistics, Geography and Informatics (INEGI, 2018); as well as questions that respond to the dimensions of CV that the aforementioned questionnaires do not include, such as the economy, employment situation, the effects of the disease and the environment.

The questionnaire was administered online using Google Forms. The link was shared with the Spanish Sjögren's Syndrome Association (AESS) for their support in applying the questionnaire to the population in Spain and to partners in other countries. Research physicians in Central and South America and Mexican physicians were contacted. The link to the questionnaire was shared via email to all participants, who in turn shared it with their respective patients. The questionnaire was online from 15 May 2023 until there were no more responses on 30 June 2023. Microsoft Excel 365, SPSS v.21 and Statgraphics Centurion 18 were used for the analysis.

Results

A total of 130 responses were obtained from the questionnaire, of which 95% were female and 5% male. Ages ranged from 21 to 70 years old.

Participants were residents of Argentina, Chile, Colombia, Ecuador, Spain, Guatemala, Mexico, Paraguay, Puerto Rico, Dominican Republic and Venezuela; the majority of respondents were of Spanish nationality (75%), followed by Argentinian nationality (6%), Mexican nationality (5%) and other nationalities in a lower percentage.

Of the total number of participants, 63.85% stated that they were working at the time of answering the questionnaire. Of those who were not working, 9.3% were unemployed and looking for work and 2.33% had a disability that prevented them from working.

Of the symptoms that SS causes, the symptoms that the respondents suffer most from are dry eyes and dry mouth, with percentages of 96% and 93% respectively. 90.4% reported being affected by SS in their work activities; 26.5% of them moderately, 45.8% quite a lot and 18.1% completely (Figure 1). 91.54% have joint problems and 39.22% suffer from exhaustion or tiredness, as well as mental fog.

Of those who mentioned having modified their diet after being diagnosed with SS, 56.76% reported feeling better, while of those who reported having included exercise in their routine, 69.57% reported feeling better.

Box 3

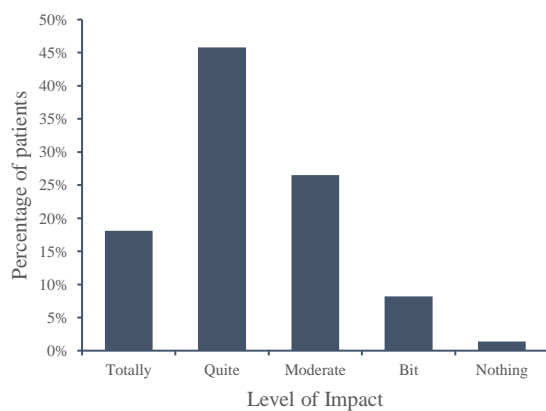


Figure 1
Affect of SS on working life

Source: Own elaboration

Regarding the expenses related to the disease, the participants responded with an approximation of what they spend monthly on medicines, medical consultations, studies or laboratory analyses, hospitalisation due to the disease and the trips they have to make for the aforementioned concepts. It is necessary to clarify that the answers given by the participants correspond to the currencies of the respective countries of residence, so the different currencies were converted into Mexican pesos, considering their exchange rate on 6 August 2023, in order to homogenise the values.

Box 4

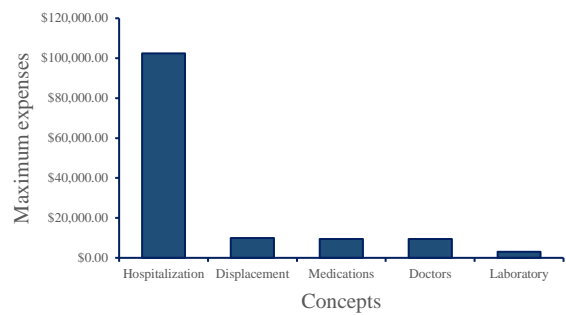


Figure 2
Maximum expenses due to SS

Source: Own elaboration

It was observed that the maximum monthly amount for medicines and medical consultations is \$9,390.00 pesos for both cases, and \$3,000.00 pesos for laboratory expenses; in addition, six respondents answered that they had incurred hospital expenses due to the disease, where the maximum expense was \$102,420.00 pesos and the minimum was \$3,414.00 pesos per month, as shown in Graph 2. It is important to remember that most of the respondents live in Spain, a country where SS is a disease that is on the list of diseases for which a permanent disability pension can be claimed (Disability Information Service [SID], 2023).

In relation to diet, 85.4% of respondents responded that they had changed their diet and of these, 56.8% reported feeling improvement; the percentage of those who responded that they had included exercise in their daily routine was 70.8%, of whom 69.6% reported feeling improvement as a result.

Responses to the SF-36 and WPAI-GH questionnaires were handled according to the scores and coding described in the respective manuals (Alonso, 2003; Reilly et al., 1993), with a Cronbach's alpha reliability statistic of 0.611. On average, the WPAI-GH questionnaire showed that 58% of respondents felt Activity Impairment due to health impairment; 39% showed Presenteeism, 27% showed Absenteeism and Loss of Work Productivity and 26% showed Work Disability (Figure 3).

Box 5

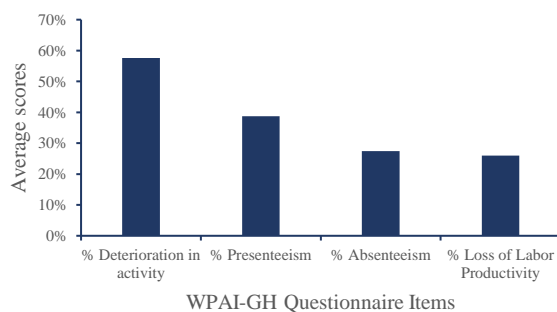


Figure 3

Mean scores of the WPAI-GH questionnaire

Source: Own elaboration

Regarding the result of the SF-36 questionnaire, the average score for health as a limiting factor in physical activities (Physical Function) was 60.65, the degree to which physical health interferes with work and other physical activities (Physical Role) was 5.77 points, the intensity of pain and its effect on usual work (Bodily Pain) was 35.7 points, the perception of health (General Health) was 28 points, the energy and vitality in the face of tiredness and exhaustion (Vitality) was 26 points, the degree to which health problems interfere with social life (Social Role) was 44 points, the degree to which emotional problems interfere with work and activities (Emotional Role) was 5.5 points, and the overall Mental Health of respondents was 53 points. It is important to note that Spain, with 103 responses, is the country that allows for a detailed review of its responses, showing the highest percentage for Physical Function with 60.24 points and the lowest score for Physical Role (Graph 4).

Box 6

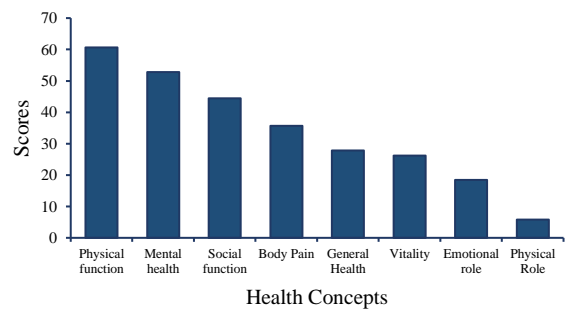


Figure 4

Mean scores of the SF-36 questionnaire

Source: Own elaboration

Other questions included in the questionnaire have to do with the need to condition the physical work area, the relocation of the work area or the reduction of the workload and the discrimination suffered in the work space and its relationship with the symptoms that SS causes and that have been documented in the literature; the Chi-square test showed that symptoms such as dry eyes and allowed us to prove that cognitive and mental problems present a greater association with respect to discrimination ($P\text{-value} \leq 0.05$); the correlation matrix shows that fatigue, circulation and joint problems, mental fog and diseases of the pancreas and liver have an influence on the need for physical work space conditioning ($P\text{-value} \leq 0.05$); while muscular, emotional and pulmonary problems have an effect on workload (Table 3).

Box 7

Table 3

Significance of the correlation between symptoms of HS and the need for changes in work and personal aspects

Symptoms (Need for refurbishment of physical space)	Titling out the physical workspace (P-value)	Relocation within the workspace (P-value)	Reduction of the workload (P-value)	Discrimination (P-value)	Fitting out the physical space in the home (P-value)
Oral dryness	0.119	0.010	0.051	0.017	0.649
Ocular dryness	0.264	0.60	0.489	0.017	0.240
Genital dryness	0.193	0.052	0.188	0.030	0.465
Lung disease	0.121	0.721	0.037	0.789	0.248
Pancreatic disease	0.022	0.048	0.240	0.399	0.955
Liver disease	0.035	0.352	0.186	0.677	0.484
Circulation problems	0.036	0.034	0.580	0.615	0.211
Joint problems	0.037	0.324	0.645	0.441	0.037
Muscle problems	0.527	0.391	0.019	0.619	0.646
Emotional	0.008	0.024	0.014	0.019	0.640
Headaches	0.000	0.053	0.537	0.611	0.001
Fatigue / tiredness	0.022	0.540	0.254	0.042	0.520
Mental fog	0.015	0.210	0.209	0.993	0.746
Cognitive problems	0.349	0.772	0.146	0.013	0.212
Mental disorders	0.796	0.671	0.988	0.008	0.302

Source: Own elaboration

When comparing the questionnaires, statistically significant correlations were found between absenteeism and seven of the health concepts; the only concept where no correlation was found was Physical Role. Presenteeism and Loss of Work Productivity showed no statistically significant relationship with the eight health concepts (P-value > 0.05). Activity Impairment due to health showed a significant correlation (P-value ≤ 0.05) with all health concepts except Emotional Role (Table 4).

Box 8

Table 4

Pearson's Correlation Test for SF-36 and WPAI-GH questionnaire results (p-value)

SF-36 n WPAI	Physical Function	Mental health	Physical Role	Dolor Corporal	General Health	Vitalidad	Social function	Emotional roll
Absenteeism	0.010	0.005	0.306	0.001	0.037	0.031	0.001	0.012
Presenteeism	0.195	0.334	0.791	0.180	0.227	0.065	0.050	0.144
Loss of labour productivity	0.827	0.681	0.232	0.803	0.509	0.334	0.768	0.990
Deterioration of Activity	0.000	0.009	0.015	0.000	0.003	0.000	0.001	0.114

Source: Own elaboration

To determine whether there is a correlation between the results of the SF-36 questionnaire (Physical Function, Physical Role, Body Pain, General Health, Vitality, Social Function, Emotional Role and Mental Health) and the results of the WPAI-GH questionnaire (Absenteeism, Presenteeism, Loss of Work Productivity and Activity Impairment), Pearson's correlation test was carried out, considering only those responses to the WPAI-GH questionnaire that correspond to patients who mentioned that they were working at the time of its application; these responses correspond to 83 of the 130 received.

An additional step towards the exhaustive use of the information consisted of a Canonical Correlation Analysis (CCA), in order to jointly analyse all the variables of both instruments (SF-36 and WPAI-GH). The dimensions of the SF-36 questionnaire (Table 1) were considered as items for set 1 and the dimensions of the WPAI-GH (Table 2) for set 2. The results provided four linear functions (Table 5), however, only linear combination 1 is significant (P-Value ≤ 0.05).

Box 9

Table 5

Canonical correlations

Number	Eigenvalor	Canonical Correlation	Wilks' Lambda	Chi-Square	G.L.	Value-P
1	0.402796	0.634662	0.426214	57.5649	32	0.0037
2	0.206936	0.454902	0.713683	22.7689	21	0.3564
3	0.0612274	0.247442	0.899906	7.11892	12	0.8497
4	0.0414019	0.203475	0.958598	2.85413	5	0.7225

Source: Own elaboration

Figure 5 shows more clearly the correlation between the variables of the SF-36 and WPAI-GH questionnaires, which formed the linear function 1.

Box 10

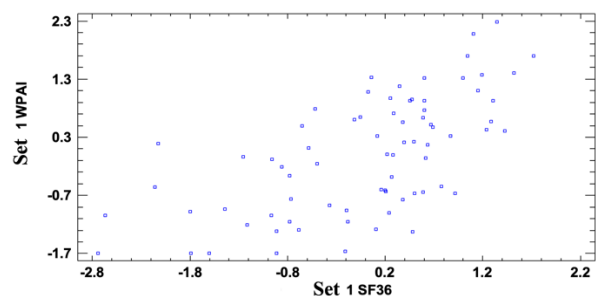


Figure 5

Graph of canonical variables

Source: Own elaboration

The first set of the linear combination is:

-0.180316*Physical Function - 0.173707*Physical Role - 0.434014 *Body Pain + 0.0280773*General Health - 0.488742 *Vitality + 0.0332032*Social Function + 0.0592606*Emotional Role - 0.0169062*Mental Health, which correspond to the SF-36 variables; the second set of variables (WPAI-GH) was **0.0889311*% work time lost due to health (Absenteeism) + 0.70153*% impairment while working due to health (Presenteeism) - 0.857266*% General work disability due to health (Loss of Work Productivity) + 0.928902*% activity impairment due to health (Activity Impairment)**. From the reading of the CCA, it is evident the multivariate relationship that is evident from the perspective allowed by the instruments used.

Conclusions

After carrying out this research, the opinion of the interviewees on how they consider that their condition as patients diagnosed with SS affects their sphere of work in the sense of requiring relocation of the work space and its refurbishment was recorded. Evidence was found that non-attendance at work, motivated by the deterioration of physical activity, has repercussions in the weakening of social, family and trade union relations.

The results also showed that the patients who had the highest monthly expenses were those who needed hospitalisation, paying more than 100,000 pesos in one month. It should be remembered that SS exposes patients to easily contracting infections, and that their condition is complicated to the point of requiring hospitalisation.

In relation to the emotional aspect, a highly significant correlation was found with absenteeism and simultaneously a highly significant correlation between cognitive problems and mental disorders, as well as with emotional illnesses associated with discrimination.

As for the physical component, bodily pain, general health, vitality and social function were found to be significantly correlated with absenteeism.

In this sense, it would be necessary to consider progressive changes in the laws of Health, ISSSTE, IMSS and IMSS-Bienestar, etc., Federal Labour Law, so that public and private organisations take into consideration the particular circumstances of workers diagnosed with SS. It is therefore proposed to incorporate the collective treatment of absenteeism and deterioration of activity in the work environment into the current regulations; in the family environment, the way to deal with both expressions (absenteeism and deterioration of activity) should correspond to family values in order to keep the social function active.

Another recommendation includes the need to design actions that can subsequently lead to a public policy that addresses the emotional component of people of working age, regardless of gender; such actions should be undertaken first of all on the basis of the full identification of symptoms by medical specialists who, in parallel, work with staff close to the legislative function.

It is important, on the one hand, that the person makes the organisation in which he or she works aware of his or her condition as an SS patient, and in advancing the legislative issue, it should go in the direction of the design and actions in the organisations that facilitate the conditioning of the physical work space; these actions that can be designed will result in reducing common expressions such as headaches or tiredness of the person.

The results described above for the context of Mexico should be considered with reservations due to the composition of the sample; however, from the perspective of management studies, it can be established that there would be two tasks to be fulfilled: the first would have to do with generating, from the Mexican health system, greater interest in the creation of an information system that, as in the case of Spain, specifically seeks to capture and facilitate the analysis of the information that accounts for the evolution of the condition in the national context. On the other hand, from a legislative point of view, although important progress has been made recently in the recognition of the number of illnesses that can cause absenteeism from work, it will be necessary to continue systematising evidence in relation to SS statistics in Mexico.

At the workplace level and with the help of the government, it is important that companies adopt a culture of inclusion, recognising the skills and abilities of workers with chronic diseases and supporting them in the flexibility or adaptation of their work space, which could be cheaper for the company and for the government itself by avoiding a major public health problem if these workers were to lose their jobs.

It has become clear from the composition of the sample that, as documented, the proportion of women is much higher than that of men affected by SS; consequently, the gender focus of this research has really shown that comments and reflections should naturally be considered with a much greater bias in favour of women.

In relation to the complementary objectives, it was found that the social relations that are expressed in a strong association with absenteeism can be a factor in improving the condition of patients with SS, in the sense of designing actions within organisations that facilitate the comprehensive understanding of patients and avoid, at all costs, acts of discrimination from within the same organisation or from co-workers themselves.

From the results obtained, it is concluded that patients who have made a dietary change by virtue of their condition as patients with SS, is actually a factor that helps in the perception that participants tend to improve their condition for that reason. A further step in this direction would be to investigate in detail by gender and age group which diet should make the best contribution to coping with SS complications and also the cost of the diet for low socio-economic levels in a high percentage of the Mexican population. It is very likely that in Mexico, the so-called social programmes should include a category for people diagnosed with SS, and from this, that they can count on specific support that allows them to modify their personal and family environment.

In the same way it occurred and with the same frequency of response from patients who do or incorporate physical exercise into their daily routine, that this activity contributes to a better condition.

In this sense, in the case of diet and exercise, it will be necessary to continue with research to design specific routines according to age group, sex, physical condition and diet, in order to investigate the interaction of both factors in the improvement of the circumstances of patients with SS.

In accordance with the above, the objectives set were fully achieved thanks to the collaboration achieved through the Internet network.

As has been seen, the results provided evidence of the importance of nutrition and physical activity as ways of coping. Although both are important according to the interviewees, the fact is that it is important to generate interest from the health institutions so that, once a person is diagnosed with SS, the relevant provisions can be made without having to go to the extreme of wanting to make improvements when these should probably have been made beforehand.

The objectives were set with the aim that after a theoretical-methodological development, evidence would be obtained that would allow, through the dissemination of results in academic-scientific publications, the positioning of the issue among those who propose actions that are then the object of local and federal legislation to become Public Policies. At the same time, from the labour and health spheres, Mexico can achieve, within a peremptory period of time, legislation that contributes to the consideration of people diagnosed with SS, in the sense of guaranteeing access to employment options, equal opportunities and income, and social mobility.

Likewise, this work seeks in some way to raise the voice for the inclusion of people suffering from diseases considered rare, as is the case of SS, in society and, consequently, in the labour and educational spheres so that they can maintain decent jobs, access to health systems, adequate education, eradicate their stigmatisation, and thus reduce the tendency towards impoverishment and the degradation of their CV; challenges that several international organisations are fighting for ([National Organization for Rare Disorders \[NORD\], 2022](#); [Rare Diseases International \[RDI\], 2023](#)).

The data and the processing that has been carried out provide empirical evidence to conclude that the working hypothesis is NOT REJECTED.

This implies that, in effect, the context of people with SS changes from the manifestation of symptoms; therefore, it is necessary to consistently take up the idea of seeking information in Mexico, in order to contrast whether what has been found so far, with a sample heavily made up of Spanish citizens, is different or whether there are similarities with a broader sample of Mexicans with SS. This is seen as an immediate strategy to be able to clearly discern what is happening with the affected Mexican population.

In the meantime, the publication of the information obtained is considered important, with the often-mentioned considerations of the sample, but without overlooking the fact that it is necessary to make progress in the particular context of Mexico.

Also, the evidence in favour of not rejecting the hypothesis are the results of the implications for the health and social relations of people with SS, above all due to the lack of culture in terms of understanding the circumstances and adaptations in the family and work context.

The above are elements that are exposed so that once they come to light, they can be taken up by those interested and responsible for institutions and legislative bodies that initiate the process of paying attention to this type of patients (SS) and what derives from it; that is, considerations for workers, students and people in general who, under the protection of the state, must have protection and social and occupational security.

Statements

The authors declare that the approach and development of the research was their own responsibility and that the analyses carried out are consistent with the postulates underlying the evidence in terms of satisfying the assumptions that make it valid.

Conflict of interest

The authors declare that they have no conflicts of interest. They have no known competing financial interests or personal relationships that might have appeared to influence the article reported in this paper.

10. Authors' contributions

Pérez Veyna, Oscar: Contributed to conceptualisation and study design, questionnaire design, data analysis and interpretation, drafting and critical revision of the manuscript, final approval.

De León Sigg, Inés Angélica: Contributed to study design, literature search, data selection, data analysis and interpretation, drafting of the manuscript, final approval.

All authors have read and accepted the published version of the manuscript.

Availability of data and materials

The data obtained in this research can be consulted at <https://drive.google.com/drive/folders/1Wbe-De19XFb0qY-UnP4f7x2UQuFDyhsU?usp=sharing>

Funding

No funding was received for this study.

Acknowledgements

We would like to thank the Spanish Sjögren's Syndrome Association for their support in distributing the survey among their members; we would also like to thank Dr. Oscar Flores, Dr. Juan Carlos Ramírez, Dr. Francisco Merayo and Dr. Katia Ramírez for distributing the questionnaire in Mexico; and Dr. Jairo Cajamarca from Colombia and Dr. Urbano Solís from Ecuador for distributing the questionnaire in their respective countries.

Abbreviations

AESS Spanish Sjögren's Syndrome Association

CIE International Classification of Diseases

Article

CV	Quality of Life
IMCO	Mexican Institute for Competitiveness
IMSS	Mexican Social Security Institute
ISSSTE	Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado (Institute of Security and Social Services of the State Workers)
SF-36	Short-Form
SS	Sjögren's síndrome
WPAI-GH	Work Productivity and Activity Impairment Questionnaire - General Health

References

Background

Richter, K. D., Acker, J., Scholz, F., & Niklewski, G. (2010). [Health promotion and work: Prevention of shift work disorders in companies](#). *EPMA Journal*, 1(4), 611–618.

Universida de Vigo. (2001). Carta de Ottawa para la promoción de la salud. *Salud Publica Educ Salud*, 1(1).

Basics

Allen, H., Bunn, W. B., & Naim, A. B. (2012). [The Self-Reported Health and Productivity Burden of Autoimmune Disorders at a Major Self-Insured Employer](#). *Journal of Occupational & Environmental Medicine*, 54(9), 1049–1063.

Anaya, J.-M. (2017). ¿Qué es el Síndrome de Sjögren y por qué es importante? En *Síndrome de Sjögren* (2a ed., pp. 18–26). Universidad del Rosario.

Arellano Aguilar, G., Magaña Reyes, J., Gutiérrez Velazco, J. L., & Domínguez Carrillo, L. G. (2016). Síndrome de Sjögren. Revisión con un caso ilustrativo. *Acta Médica Grupo Ángeles*, 14(2), 90–100.

Chiavenato, I. (2017). *Comportamiento Organizacional. La dinámica del éxito en las organizaciones*. McGraw-Hill.

ISSN: 2410-342X
RENIECYT-CONAHCYT: 1702902
ECORFAN® All rights reserved.

Diez Morrondo, C., Lema Gontad, J. M., Álvarez Rivas, N., Atanes Sandoval, A., De Toro Santos, F. J., Pinto Tasende, J. A., & Galdo, F. (2010). [Aspectos actuales del síndrome de Sjögren: Etiopatogenia, manifestaciones clínicas, diagnóstico y tratamiento](#). *Seminarios de la Fundación Española de Reumatología*, 11(2), 70–76.

Fernández-Ávila, D. G., Rincón-Riaño, D. N., Bernal-Macías, S., Gutiérrez Dávila, J. M., & Rosselli, D. (2020). [Prevalencia y características demográficas del síndrome de Sjögren en Colombia, según información del Sistema Integral de Información de la Protección Social](#). *Reumatología Clínica*, 16(4), 286–289.

Fernández-López, J. A., Fernández-Fidalgo, M., & Cieza, A. (2010). [Los conceptos de calidad de vida, salud y bienestar analizados desde la perspectiva de la Clasificación Internacional del Funcionamiento \(CIF\)](#). *Revista Española de Salud Pública*, 84(2).

González Baltazar, R., Hidalgo Santacruz, G., & Salazar Estrada, J. G. (2007). Calidad de vida en el trabajo: Un término de moda con problemas de concepción. *Psicología y Salud*, 17(1), 115–123.

Granados, I. (2011). [Calidad de vida laboral: Historia, dimensiones y beneficios](#). *Revista de Investigación en Psicología*, 14(2), 271–276.

Hernández-Molina, G. (2017). Criterios de clasificación diagnóstica. En *Síndrome de Sjögren* (2a ed., pp. 547–558). Universidad del Rosario.

IMIM. (2000). Manual de puntuación de la versión española del Cuestionario de Salud SF-36. Unitat de Recerca en Serveis Sanitaris.

INEGI. (2018). Encuesta Nacional de la Dinámica Demográfica 2018. Subsistema de Información Demográfica y Social.

Ladino, R. M., Gasitulli, O. A., & Campos, M. X. (2015). [Síndrome de Sjögren. Caso clínico](#). *Revista Chilena de Pediatría*, 86(1), 47–51.

Medvedev, O. N., & Landhuis, C. E. (2018). [Exploring constructs of well-being, happiness and quality of life](#). *PeerJ*, 6, e4903.

De León-Sigg, Inés Angélica & Pérez-Veyna, Oscar. [2024]. Quality of life in patients with Sjögren's syndrome: habits and practices in Iberoamerica. A perspective from the administration. *Journal of Administration and Finance*. 11[28]-1-13: e11128113. DOI: <https://doi.org/10.35429/JAF.2024.11.28.1.13>

Article

- Mungaray Lagarda, A., & Ramírez Urquidy, M. (2007). Capital humano y productividad en microempresas. *Investigación Económica*, LXVI(260), 81–115.
- OPS. (2020). *Economía de las ENT*. Organización Pabamericana de la Salud.
- Papageorgiou, A., Voulgarelis, M., & Tzioufas, A. G. (2015). *Clinical picture, outcome and predictive factors of lymphoma in Sjögren syndrome*. *Autoimmunity Reviews*, 14(7), 641–649.
- Perea, R. (2018). Educación para la Salud y Calidad de Vida. Diaz de Santos.
- Povoas Barsottini, O. G., Moraes De Moraes, M. P., Almeida Fraiman, P. H., Rocha Marussi, V. H., Silva De Souza, A. W., Braga Neto, P., & Spitz, M. (2023). *Sjogren's syndrome: A neurological perspective*. *Arquivos de Neuro-Psiquiatria*, 81(12), 1077–1083.
- Ramos-Casals, M. (2021). *Sociedad Española de Medicina Interna [Sitio Web]*. El ABC de las enfermedades autoinmunes sistémicas (EAS).
- Reilly Associates. (2021, febrero). WPAI Translations. Reilly Associates.
- Reilly, M. C., Zbrozek, A. S., & Dukes, E. M. (1993). *The Validity and Reproducibility of a Work Productivity and Activity Impairment Instrument: Pharmacoeconomics*, 4(5), 353–365.
- Reyes Jaraba, C. A., Pájaro Galvis, N. E., Vergara Serpa, O. V., Conquett Huertas, J. Y., Echenique Torres, O. D., Cortina Gutiérrez, A., Serna Otero, D. A., & Zapata Cerpa, D. C. (2022). *Síndrome de Sjögren: Epidemiología y manifestaciones clínicas*. *Revista Colombiana de Reumatología*, 29(4), 310–324.
- Rodríguez, N., & García, M. (2005). *La noción de Calidad de Vida desde diversas perspectivas*. *Revista de Investigación*, 49–68.
- Sorlí, J. V., Ejarque Doménech, I., Valderrama Zurián, F. J., Martín Gutiérrez, V., Mingarro Castillo, M., García-Ribes, M., & Ortiz Uriarte, R. (2009). *Síndrome de Sjögren*. *Atención Primaria*, 41(7), 417–419.
- Stefanski, A.-L., Tomiak, C., Pleyer, U., Dietrich, T., Burmester, G. R., & Dörner, T. (2017). *The Diagnosis and Treatment of Sjögren's Syndrome*. *Deutsches Ärzteblatt International*.
- Thorlacius, G. E., Björk, A., & Wahren-Herlenius, M. (2023). *Genetics and epigenetics of primary Sjögren syndrome: Implications for future therapies*. *Nature Reviews Rheumatology*, 19(5), 288–306.
- Thurtle, E., Grosjean, A., Steenackers, M., Strege, K., Barcelos, G., & Goswami, P. (2024). *Epidemiology of Sjögren's: A Systematic Literature Review*. *Rheumatology and Therapy*, 11(1), 1–17.
- Westhoff, G., Dorner, T., & Zink, A. (2012). *Fatigue and depression predict physician visits and work disability in women with primary Sjogren's syndrome: Results from a cohort study*. *Rheumatology*, 51(2), 262–269.
- WHO. (2012). *WHOQOL User Manual*.
- Zhang, W., Bansback, N., Boonen, A., Young, A., Singh, A., & Anis, A. H. (2010). *Validity of the work productivity and activity impairment questionnaire—General health version in patients with rheumatoid arthritis*. *Arthritis Research & Therapy*, 12(5), R177.
- Zhong, H., Liu, S., Wang, Y., Xu, D., Li, M., Zhao, Y., & Zeng, X. (2022). *Primary Sjögren's syndrome is associated with increased risk of malignancies besides lymphoma: A systematic review and meta-analysis*. *Autoimmunity Reviews*, 21(5), 103084.

Support

Alonso, J. (2003). Cuestionario de Salud SF-36 (versión 2). Instituto Municipal de Investigación Médica.

CSG. (2018, junio 14). Lista actualizada de las enfermedades que se han determinado como raras en México 2018. Consejo de Salubridad General.

Espinoza Cárdenas, J. M. (2020, marzo 12). [Iniciativa que reforma y adiciona los artículos 513 de la Ley Federal del Trabajo y 3° de la Ley General de Salud, a cargo del diputado Juan Martín Espinoza Cárdenas, del grupo parlamentario de Movimiento Ciudadano.](#) Sistema de Información Legislativa de la Secretaría de Gobernación.

Flores-Suárez, R. (2019, octubre 17). [Iniciativa que adiciona diversas disposiciones de la Ley General de Salud, suscrita por el diputado Ricardo Flores Suárez e integrantes del grupo parlamentario del PAN.](#) Sistema de Información Legislativa de la Secretaría de Gobernación.

Hernández Pérez, M. E. (2022, noviembre 23). [Iniciativa que adiciona diversas disposiciones de la Ley General de Salud, en materia de acreditación de establecimientos de atención y tratamiento a enfermedades raras, a cargo de la diputada María Eugenia Hernández Pérez e integrantes de los grupos parlamentarios de Morena, de PT y del PVEM.](#) Sistema de Información Legislativa de la Secretaría de Gobernación.

IMCO. (2024, marzo 5). [DATOS Y PROPUESTAS POR LA IGUALDAD.](#) Centro de Investigación en Política Pública.

Madrigal Sánchez, A. (2016, abril 19). [Que reforma el Artículo 159 de la Ley General de Salud, a cargo de la diputada Araceli Madrigal Sánchez, del grupo parlamentario del PRD.](#) Sistema de Información Legislativa de la Secretaría de Gobernación.

NORD. (2022, marzo 3). [Navigating Diversity, Equity and Inclusion in Rare Disease Nonprofits.](#) National Organization for Rare Disorders.

Orphanet. (2012). [Acerca de las enfermedades raras.](#) Portal de información de enfermedades raras y medicamentos huérfanos.

Peña Castillo, D. (2023, julio 6). [Cómo construir políticas públicas para enfermedades raras.](#) FEMEXER.

RDI. (2023). [Inclusión y Derechos Humanos.](#) Rare Diseases International.

Romo Cuellar, M. E. (2022, marzo 28). [Iniciativa con proyecto de decreto en materia de salud, por el que se reforma el Artículo 61 de la Ley General de Salud, suscrita por la diputada Martha Estela Romo Cuéllar, integrante del grupo parlamentario del Partido Acción Nacional.](#) Sistema de Información Legislativa de la Secretaría de Gobernación.

Secretaría de Salud. (2019, marzo 1). [¿Qué son las enfermedades raras?](#) Secretaría de Salud.

SEGOB. (2023, junio 29). [ACUERDO por el que se reconocen las enfermedades raras incorporadas en la Clasificación Internacional de Enfermedades emitida por la Organización Mundial de la Salud.](#) Diario Oficial de la Federación.

SID. (2023, enero 23). [Estas son las enfermedades que dan derecho a pensión por incapacidad permanente.](#) Servicio de Información sobre Discapacidad.

WHO. (2024, enero). [ICD-11 for Mortality and Morbidity Statistics.](#) International Classification of Diseases 11th Revision.