

# Sex and Gender Interactions in the Lives of Patients with Spondyloarthritis in Spain: A Quantitative-qualitative Study

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**ABSTRACT. Objective.** To illustrate the experiences and contextual support perceived by men and women with spondyloarthritis (SpA) in relation to their demanding productive and reproductive roles.

**Methods.** A quantitative-qualitative study of 96 men and 54 women with SpA was conducted at the Alicante University General Hospital, in a Spanish Mediterranean city, from March 2013 to February 2014. Descriptive and qualitative content analyses compared working lives and family/partner relationships of male and female patients.

**Results.** Working life: both women (55.6%) and men (51.04%) were similarly affected, but women had worse disease activity (5.4 vs 4.0,  $p = 0.01$ ) and less antitumor necrosis factor- $\alpha$  therapy (56.7% vs 77.6%,  $p < 0.05$ ). Different patterns were found by gender: women mostly practiced presenteeism whereas men practiced absenteeism, women took antiinflammatories prior to work and men after work, employers suggested more frequently the beneficial actions for men, and some women withdrew permanently from the labor market. Family/partner relationships: women were more affected (57.4%) than men (41.7%), with worse results for diagnostic delay (11.2 vs 6.4 yrs,  $p = 0.02$ ), disease activity (5.8 vs 3.6,  $p < 0.001$ ), and physical function (5.2 vs 3.8,  $p = 0.02$ ). Gender role conflicts emerged, with women developing strategies to face compulsory housework whereas men avoided them; women regretted neglecting their children and men not sharing leisure activities with them.

**Conclusion.** Our study highlights the vital complexity in which patients with SpA are immersed, especially for women in a country where a mix of new and traditional gender roles coexist. Awareness of its existence is crucial when professionals strive to provide healthcare focused on their well-being in addition to medical therapy. (First Release July 1 2017; J Rheumatol 2017; 44:1429–35; doi:10.3899/jrheum.170128)

## Key Indexing Terms:

SPONDYLOARTHROPATHY

GENDER ROLES

GENDER BIAS

The term *spondyloarthritis* (SpA) describes a heterogeneous group of diseases characterized by early onset in the second or third decades of life<sup>1</sup>, a time when men and women are subject to high demands for participation in productive and reproductive life. It has been shown that both sexes experience a considerable diagnostic delay, which worsens their prognosis, and that this is greater in women<sup>2,3</sup>. As a

result, access to anti-tumor necrosis factor- $\alpha$  (anti-TNF- $\alpha$ ) treatment, which has been shown to decrease disease activity and hinder damage, is also delayed<sup>4</sup>.

SpA severely restricts physical function and quality of life<sup>5</sup> because of pain and stiffness<sup>6</sup>. Although data are available on sex-related differences in SpA regarding diagnosis, course of the disease, and costs because of work days lost<sup>7,8</sup>, aspects of importance to patients have received little research attention<sup>9</sup>. In particular, there is little understanding of how sex and gender can heavily affect the lives of people with SpA, which would help physicians to better tailor treatment to the needs of women and men according to the social identity they are assigned. This would entail considering sex-related differences to treat people who are affected differently by SpA and responding to the unequal gender expectations and demands of productive and reproductive roles, in accordance with the different social value attributed to men and women<sup>10</sup>.

The aim of our study of a group of patients with SpA attending the rheumatology department at a public hospital was to illustrate the experiences and contextual support perceived by men and women in relation to their demanding productive and reproductive roles.

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## MATERIALS AND METHODS

**Study design and participants.** A cross-sectional study of 150 patients with SpA (54 women and 96 men) who attended the Department of Rheumatology at the Alicante University General Hospital, in Spain, was designed to yield quantitative and qualitative information. It was developed from March 2013 to February 2014, after excluding 3 men and 1 woman because of recall bias, and another woman who refused to participate.

**Data collection.** Semistructured interviews were conducted to obtain the following quantitative data: age, occupational social class (manual or non-manual)<sup>11</sup>, diagnostic delay, disease duration, anti-TNF- $\alpha$  treatment (yes/no), disease activity assessed using the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) questionnaire (score: 0 = no activity to 10 = worst result), and physical function as measured by the Bath Ankylosing Spondylitis Functional Index (BASFI) questionnaire (score: 0 = best function to 10 = worst function)<sup>12</sup>. For both the BASDAI and the BASFI questionnaires, a score of  $\geq 4$  was considered severe.

Qualitative information was obtained by asking about productive and reproductive roles using the following structure: Do you think that having SpA has had a significant effect on your working life? On your family relationships? On your relationship with your partner? How?

Three trained interviewers conducted the face-to-face interviews that lasted from 30–75 min. The interviews were held at the hospital to minimize patient travel, and the venue was arranged in such a way as to provide a relaxed atmosphere.

**Data analysis.** A descriptive analysis of the above-mentioned data was performed to compare sex-related differences in patients with SpA, using means and 95% CI for continuous variables, and frequencies and percentages for dichotomous variables. A comparative analysis of the continuous variables, which proved to be nonparametric, was performed by means of the Mann-Whitney U test and of the dichotomous variables using the chi-square test. A *p* value of  $< 0.05$  was considered statistically significant. Statistical analyses were performed using SPSS 15.0 software.

A qualitative content analysis was conducted of the texts of the responses according to Neundorff<sup>13</sup>. Using a manifest analysis approach, the content of the texts was searched to inductively generate categories about the patients' productive and reproductive environment. After reading the texts, the first units of meaning were identified by MBB. Subsequently, the entire texts were read and reread by MBB, MTRC, and LJH, who then held several discussions to determine the final codes and categories. Each patient was identified as a "Man" and a consecutive number, and the same for "Woman".

**Ethical approval and consent.** The ethics committee of medical research (CEIC) of the Alicante University General Hospital approved this study (Ref. CEIC PI2010/09). Before participating in the interviews, the subjects gave their verbal and signed informed consent, and confidentiality of all information was guaranteed.

## RESULTS

### Effect on Work

We found 55.6% of women and 51.04% of men with SpA reported that the disease had affected their working life, and sex-related differences were observed in disease activity and treatment received (Table 1). Two themes emerged regarding the main work-related differences and similarities between women and men (Table 2).

**1. Dealing with working conditions.** Three categories emerged of work-related actions taken by participants in response to their disease (22.9% of men and 25.9% of women):

**1.1. Job transfers and support from colleagues.** Transfers to posts within the same company that entailed less physical effort or stress were frequent in men and rare in women. This strategy was only facilitated for 1 woman in the health sector

(Man 1 and Woman 1). In addition, participants of both sexes acknowledged receiving support from work colleagues (Man 2 and Woman 2).

**1.2. Concealing limitations to avoid dismissal (presenteeism), and delegating to others (absenteeism).** Presenteeism refers to the phenomenon whereby patients conceal their illness from employers to avoid dismissal, and go to work despite knowing that they will be unable to do their jobs and will perform fewer tasks. Presenteeism was observed in both sexes. Among the women, this primarily occurred in the feminized sector of cleaning, a major area of the informal economy. Self-employed women also practiced presenteeism, since they generally ran their businesses alone and had no one to whom they could delegate; further, when the situation became untenable, their businesses foundered (Man 3 and Woman 3). In contrast, the usual practice of self-employed men was absenteeism, because their businesses had a stronger structure than those of their female counterparts and thus they were able to delegate their tasks to business partners or employees (Man 4) and take sick leave.

**1.3. Medicalization.** Participants reported that non-steroidal antiinflammatories (NSAID) and anti-TNF- $\alpha$  drugs represented a necessary resource that enabled them to work. In particular, they reported that the latter were essential since they facilitated a normal working life. The time when participants consumed NSAID varied by sex; men took them after work in oral presentations (Man 5), whereas women took them before going to work, and also used injectable formats (Woman 1 and Woman 4).

**2. Work transition.** Two categories emerged for changes in participants' working lives (31.3% of men and 31.5% of women), according to the person responsible for originating these changes:

**2.1. Patients and employers agree (and do not agree) on changes.** Changes included registering as unemployed, permanent sick leave, and dismissal. Both men and women reported reaching agreements with their employers to terminate their contracts to be eligible to receive unemployment benefits (Man 6 and Woman 5; Table 2). However, although some companies suggested permanent sick leave for some men, none did so for women (Man 7). In addition, because of a perception of their fragility, women were the main targets of dismissal decisions taken unilaterally by some companies (Man 8 and Woman 6).

**2.2. Changes instigated by patients because of an untenable work situation.** Repeated sick leave was one of the largest effects on participants' working lives, disrupting the normal course of their work and creating fear of dismissal. They developed behavior to avoid sick leave (Man 9 and Woman 7), although ultimately, this disruption could be final, obliging them to stop working. Men and women adopted different strategies after stopping work. Some men changed occupations when they found another job that entailed less physical effort or stress. Conversely, some women withdrew

Table 1. Effect on work, and family and partner relationships according to sociodemographic and clinical characteristics of women and men with spondyloarthritis. Values are n (%) unless otherwise specified.

Variables	Effect on Work		p	Effect on Family and Partner Relationships		
	Women, n = 30	Men, n = 49		Women, n = 31	Men, n = 40	p
Diagnostic delay, yrs, mean (95% CI)	12.8 (7.9–17.8)	8.4 (5.9–10.9)	0.1	11.2 (7.2–15.2)	6.4 (4.2–8.6)	<b>0.02</b>
Disease duration, yrs, mean (95% CI)	19.6 (13.6–25.6)	21.5 (17.5–25.5)	0.6	19.1 (13.7–24.5)	18.4 (14.2–22.6)	0.8
BASFI, 0–10, mean (95% CI)	4.4 (3.4–5.4)	4.6 (3.8–5.4)	0.7	5.2 (4.3–6.1)	3.8 (2.9–4.6)	<b>0.02</b>
BASDAI, 0–10, mean (95% CI)	5.4 (4.6–6.3)	4 (3.4–4.6)	<b>0.01</b>	5.8 (4.9–6.6)	3.6 (2.9–4.3)	<b>&lt; 0.001</b>
Receiving anti-TNF- $\alpha$ therapy	17 (56.7)	38 (77.6)	<b>&lt; 0.05</b>	19 (61.3)	31 (77.5)	0.1
Current age, yrs, mean (95% CI)	48.2 (43–53.4)	52.0 (48.4–55.5)	0.2	50.6 (45.7–55.4)	48.7 (44.5–52.8)	0.5
< 30 yrs	3 (10)	1 (2)	0.1	2 (6.5)	2 (5)	0.7
30–39 yrs	9 (30)	10 (20.4)	0.3	7 (22.6)	9 (22.5)	0.9
40–49 yrs	3 (10)	12 (24.5)	0.1	4 (12.9)	13 (32.5)	0.06
50–59 yrs	7 (23.3)	10 (20.4)	0.7	9 (29)	5 (12.5)	0.08
60–64 yrs	2 (6.7)	8 (16.3)	0.2	4 (12.9)	4 (10)	0.7
$\geq$ 65 yrs	6 (20)	8 (16.3)	0.6	5 (16.1)	7 (17.5)	0.8
Social class: manual	18 (60)	38 (77.6)	0.09	14 (56)*	21 (60)**	0.7
Non-manual	12 (40)	11 (22.4)	0.09	11 (44)*	14 (40)**	0.7

\* Only 25 working women said their family and partner relationships were affected. \*\* Only 35 working men said their family and partner relationships were affected. Significant data are in bold face. BASFI: Bath Ankylosing Spondylitis Functional Index; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; anti-TNF- $\alpha$ : anti-tumor necrosis factor- $\alpha$ .

permanently from the labor market in favor of a less hostile environment, such as the home (Man 10 and Woman 8).

### Effect on Family and Partner Relationships

Family and partner relationships were affected in 57.4% of women and 41.7% of men. Table 1 shows sex-related differences regarding disease activity, physical function, and diagnostic delay. Several themes emerged in relation to coping with changes arising from conflicts in the performance of gender roles caused by SpA symptoms (Table 3):

1. *Family transition.* Pain, fatigue, and loss of physical function heavily affected family life (30.2% of men and 29.6% of women), prompting changes in relationships. In this case, 2 categories emerged:

1.1. Mood and isolation from family and partner. One consequence of the symptoms was a change in character in both sexes, influencing other family members, including the partner. Feelings were also reported of loneliness, whether sought or unsought, lack of understanding, and disability (Man 11 and Woman 9).

1.2. Problems in sexual relations and loss of partner. Symptoms even affected sexual relations (Man 12 and Woman 10), which in addition or not to the change in character in both sexes occasionally resulted in separation (Man 13 and Woman 11). Further, the early and insidious onset of disease prevented 1 man and 1 woman from achieving their family project of having a partner and the children they intended to have (Man 14 and Woman 12).

2. *Response to post-SpA gender conflict: coping with reproductive roles.* Housework and child care were affected in 12.5% of men and 29.6% of women. One category concerning limitations emerged, according to the domestic tasks performed.

2.1. Rethinking limitations: taking responsibility versus willful blindness. Despite their incapacity, the women adopted strategies to enable them to perform housework, which was seen as their obligation (Woman 10). Men reported limitations in performing specific tasks such as painting, shopping, and taking out the rubbish, activities that they stopped doing because of their symptoms (Man 15).

Most women expressed regret about their limitations with regard to child care (Woman 13), whereas this aspect was only mentioned by 3 men in their 30s (Man 11), and most men reported being concerned instead about loss of leisure time spent with children (Man 16).

### DISCUSSION

Our findings show that the physical fragility caused by SpA in combination with the framework of femininity and masculinity prompted changes in symptomatic patients because it forced them to create appropriate working and family care conditions. In a country in transition to a dual-earner family model, men and women with SpA were obliged to reconstruct their lives, changing the way they fulfilled their productive and reproductive roles, identifying their limitations, and renegotiating new roles within the family and at work.

Table 2. Challenges reported by women and men with SpA related to their productive roles in coping with the disease.

Categories	Codes	Examples of Responses
Theme 1: Dealing with working conditions		
Job transfers	Common in men	"I used to install air conditioning, but had to give it up due to physical difficulty and I transferred to the workshop." Man 1, age: 57 y/o, DD: 20 yrs, BASDAI: 2.7, BASFI: 5.7. Bilateral sacroiliitis IV/IV, cervical and lumbar fusion and severe hip involvement. Permanent sick leave, previously: Air conditioning mechanic.
	Rare in women (only 1 female nurse)	"They try to assign me to services, like Pediatrics, if they can." Woman 1, age: 48 y/o, DD: 4 yrs, BASDAI: 9.9, BASFI: 6.9. Peripheral SpA. Normal radiograph and MRI. Nurse.
Support from colleagues	Help from colleagues	"At work, I lifted very heavy objects with a partner, but I couldn't do it anymore and dropped them, putting him in danger; my partner supported me and didn't let on to the bosses." Man 2, age: 79 y/o, DD: 53 yrs, BASDAI: 4.2, BASFI: 7.5. Bilateral sacroiliitis IV/IV, syndesmophyte in lumbar spine and heel enthesitis. Permanent sick leave, previously: Mechanic in the iron and steel sector. "Especially when I'm on call, I see that I have to do something and I'm in pain. I don't take sick leave because it's just been for a day or two and I've solved the problem by changing my days with colleagues." Woman 2, age: 27 y/o, DD: 3 yrs, BASDAI: 8.3, BASFI: 1.2. Bilateral sacroiliitis III/IV. Gynecology fellow.
Concealing limitations to avoid dismissal	Presenteeism	"The disease played a role in my dismissal. I didn't take sick leave, but my productivity dropped and I had to go for numerous tests. When they needed to fire someone, I was the first in line." Man 3, age: 45 y/o, DD: 11 yrs, BASDAI: 0.1, BASFI: 0.1. MRI with sacroiliac edema. Unemployed, previously: Computer work. "I know that I'm not capable of working at the moment. I have to sit down and put my feet up; if it wasn't my own business, I wouldn't be able to work, no one would put up with this situation." Woman 3, age: 51 y/o, DD: 8 yrs, BASDAI: 4.7, BASFI: 7.8. Ultrasound with heels enthesitis. Bakery owner.
Delegating to others	Absenteeism	"I'm self-employed. When I have an outbreak I have to ask for help or go home [his business partner is understanding]." Man 4, age: 53 y/o, DD: 37 yrs, BASDAI: 3.0, BASFI: 4.7. Bilateral sacroiliitis IV/IV and peripheral affection. Construction company owner.
Medicalization	After work in men	"Despite the pain, I've continued working. I felt awful after a day at work, so I would take painkillers and go to bed, and the next day I was fine again." Man 5, age: 61 y/o, DD: 21 yrs, BASDAI: 4.1, BASFI: 3. Bilateral sacroiliitis IV/IV, severe hip involvement, syndesmophytes in lumbar spine, and cervical spine fusion. Permanent sick leave, previously: Elevator technician.
	Prior to work in women	"If it wasn't that I love my job, I wouldn't be able to do it. I don't know where I get my strength from. I inject myself before going to work." Woman 1, age: 48 y/o, DD: 4 yrs, BASDAI: 9.9, BASFI: 6.9. Peripheral SpA. Normal radiograph and MRI. Nurse. "I never took a day off work; they did not have any problem with me. I stuffed myself with aspirin and went to work. With the uveitis, I inserted catheters wearing sunglasses [for photophobia]." Woman 4, age: 61 y/o, DD: 41 yrs, BASDAI: 6.1, BASFI: 6.4. Bilateral sacroiliitis III/IV. Nurse.
Theme 2: Work transition		
Agreements and disagreements between patients and employers		
	Registering as unemployed	"I was a heavy machinery mechanic. The situation became untenable and we agreed on dismissal. I returned 2 years later, but couldn't continue and had to leave." Man 6, age: 49 y/o, DD: 20 yrs, BASDAI: 5.3, BASFI: 7.6. Bilateral sacroiliitis IV/IV and syndesmophytes in cervical spine. Unemployed, previously: Mechanic in the iron and steel sector. "I was very limited and took a lot of sick leave, so we agreed on dismissal because I couldn't continue to take sick leave." Woman 5, age: 32 y/o, DD: 19 yrs, BASDAI: 2.3, BASFI: 3.2. Bilateral sacroiliitis III/IV. Unemployed, previously: Supermarket worker.
	Agreements on permanent sick leave	"They didn't make any problems for me at work. Under the circumstances, the doctor at work advised me [to] apply for a disability pension." Man 7, age: 70 y/o, DD: 35 yrs, BASDAI: 4.6, BASFI: 9.5. Bilateral sacroiliitis IV/IV, severe hip involvement, syndesmophytes in cervical and lumbar spine. Retired, previously: Copper rolling mill operator.
	Dismissal by employers	"After being on sick leave for 18 months, my case was reviewed by the medical board, I returned to work and they fired me." Man 8, age: 63 y/o, DD: 18 yrs, BASDAI: 4.2, BASFI: 3.6. Bilateral sacroiliitis III/IV and syndesmophytes in lumbar spine. Retired and previously: mechanic. "The crisis coincided with my sick leave, and I was fired." Woman 6, age: 54 y/o, DD: 24 yrs, BASDAI: 8.1, BASFI: 7.8. MRI with sacroiliac edema. Unemployed dressmaker.



Table 2. Continued.

Categories	Codes	Examples of Responses
Prioritizing work over self-care	Fear of temporary sick leave	“I took sick leave even though I was afraid of being fired.” Man 9, age: 36 y/o, DD: 15 yrs, BASDAI: 5.2, BASFI: 6.9. Bilateral sacroiliitis III/IV and lumbar squaring. Unemployed shelf stacker. “I try not to go to the doctor to avoid being admitted to hospital [She is frightened of sick leave because of hospital admissions due to biological infections].” Woman 7, age: 27 y/o, DD: 5 yrs, BASDAI: 5.6, BASFI: 4.6. Bilateral sacroiliitis II/IV and peripheral affection. Caregiver at a nursery.
	Stopping work	“I used to be a form worker, but changed jobs because it became too physically demanding for me.” Man 10, age: 68 y/o, DD: 40 yrs, BASDAI: 4.5, BASFI: 3.9. Bilateral sacroiliitis III/IV and lumbar fusion. Retired, previously: Caretaker. “It’s affected my work in the sense that I didn’t feel well but I did my job... I couldn’t leave the girls alone and my husband was doing well at work, so I left.” Woman 8, age: 38 y/o, DD: 12 yrs, BASDAI: 4.2, BASFI: 5.4. Bilateral sacroiliitis III/IV. Homemaker, previously: Supermarket worker.

SpA: spondyloarthritis; y/o: years old; DD: disease duration; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; BASFI: Bath Ankylosing Spondylitis Functional Index; MRI: magnetic resonance imaging.

In southern European countries, work and family demands are associated with poorer health, mainly in women<sup>14</sup>, and this effect has been intensified by an economic crisis that has led to worse working conditions and minimal support for public policies aimed at achieving a work-life balance in Spain<sup>15</sup>. People with SpA are thus obliged to balance work demands with the limitations caused by SpA. Further, women especially must also cope with reproductive demands. Perhaps for this reason, women reported self-medicating with NSAID before going to work, whereas men did so after work. There is a lack of information of the existence of a possible gender pattern, although some evidence exists of a relationship between work and greater self-medication in women<sup>16</sup>.

We found that women were more liable to practice presenteeism, the underlying cause of which is the job insecurity — temporary contracts, poor labor relations, lack of social insurance — that mainly affects women<sup>17</sup>. Such was the case of domestic workers. In addition, self-employed workers who had no substitutes practiced presenteeism more than other workers<sup>18</sup>, and this group coincided with self-employed women, but not with their male counterparts, who were able to delegate to others because their businesses were larger and more consolidated. Besides the possibility of dismissal, the consequences of presenteeism include economic costs, lost productivity, subsequent temporary sick leave, and worse future health<sup>19,20,21</sup>, possibly because of stress caused by the interaction between SpA and unfavorable working conditions.

A similar gender pattern emerged from participants’ responses regarding dismissal. Probably some of our participants failed to tell employers and colleagues about their disease because of the employment implications, which is clear from other actions they took to hide their condition such as the presenteeism; hiding of diseases has been reported previously<sup>22</sup> and could restrict beneficial actions such as work flexibility<sup>23</sup>. In our study, some male respondents and

1 female nurse reported that employers allowed them to transfer to a less stressful post. In addition, some of the men’s employers suggested that they took permanent sick leave, whereas the women were dismissed, which suggests the lower value placed on women’s work. Respondents of both sexes also reported that support from their colleagues helped them, and it has been shown that the absence of such support is associated with the risk of work withdrawal<sup>24</sup>.

When the measures taken to cope with the demands of paid work were insufficient or nonexistent, job retention became untenable and some participants reached an agreement with their employers to be dismissed, while others simply gave up. Some of the men interviewed changed their occupation once they found another, while some women withdrew from the labor market and did not seek other work, entailing the social and economic losses that have been documented elsewhere<sup>25</sup>. Deeply rooted gender roles in Spanish society enable men to meet social expectations that they will support their families and leave one job for another, whereas women are more likely to make reproductive work a priority over paid work, especially when the former entails child care and their experience of the latter is negative<sup>26</sup>.

We did not find a different gender pattern regarding the effect of SpA on family and partner relationships and sexual relations, but participants reported that symptoms prompted changes in character which in some cases led to separation and divorce. An interaction emerged between physical and emotional damage, consistent with the findings of other studies on SpA, and this exerted an effect on relationships and sexuality<sup>27,28,29</sup>. Women reported more limitations than men in carrying out the tasks assigned according to their gender role; however, despite their incapacity they developed strategies to perform tasks such as housecleaning. In contrast, men stopped performing the tasks they had carried out prior to the onset of SpA, such as shopping or gardening, results that have also been found in other musculoskeletal diseases<sup>30</sup>.

Table 3. Challenges reported by women and men with SpA related to their reproductive roles in coping with the disease.

Categories	Codes	Examples of Responses
Theme 1: Family transition		
Mood and isolation from family and partner	Mood swings change relationships	“I took it out on her [his wife], everything has an effect. It was too much for both of us.” Man 11, age: 39 y/o, DD: 9 yrs, BASDAI: 7.1, BASFI: 3.9. Normal radiograph, heel enthesitis. “I am anxious, nervous; I am very touchy around my family and my partner. My head thinks I can do something, but my body says no.” Woman 9, age: 46 y/o, DD: 1 yrs, BASDAI: 5.9, BASFI: 3.7. Normal radiograph, ultrasound with heel enthesitis.
Problems in sexual relations and loss of partner	Loss of sexual relations	“Difficulties with mobility affect sexual relations.” Man 12, age: 68 y/o, DD: 6 yrs, BASDAI: 0.3, BASFI: 1. Bilateral sacroiliitis III/IV and syndesmophytes in lumbar spine. “In sexual relations, because I get very tired and my hips hurt.” Woman 10, age: 51 y/o, DD: 23 yrs, BASDAI: 7.8, BASFI: 6.2. Bilateral sacroiliitis II/IV and peripheral affection.
	Separation from partner	“We coped badly, and I left, partly because of this [referring to a change in character].” Man 13, age: 43 y/o, DD: 7 yrs, BASDAI: 2, BASFI: 3.9. Unilateral sacroiliitis III/IV. “I left because of that, because it was impossible in bed [sexual relations].” Woman 11, age: 66 y/o, DD: 58 yrs, BASDAI: 5.3, BASFI: 6.3. Bilateral sacroiliitis II/IV and peripheral affection.
	Loss of family project of having a partner and children	“I’m single; the pain doesn’t allow me to maintain a relationship because it limits me.” Man 14, age: 44 y/o, DD: 22 yrs, BASDAI: 2, BASFI: 5. Bilateral sacroiliitis III/IV and knee and heel enthesitis. “The disease has prevented me from having a partner.” Woman 12, age: 66 y/o, DD: 39 yrs, BASDAI: 6.3, BASFI: 8.1. Syndesmophytes in cervical spine.
Theme 2: Response to post-SpA gender conflict		
Rethinking limitations	Taking responsibility	“To put my shoes on, to wash up, to pick things up; I cannot do a thorough clean... because it hurts. I manage; I have switched to cleaning products in smaller containers so that I can pick them up...” Woman 10, age: 51 y/o, DD: 23 yrs, BASDAI: 7.8, BASFI: 6.2. Bilateral sacroiliitis II/IV and peripheral affection. “I could not be 100% with my children. I knew I had to do things, but I could not.” Woman 13, age: 55 y/o, DD: 35 yrs, BASDAI: 3, BASFI: 0.2. Bilateral sacroiliitis III/IV and lumbar squaring.
	Turning a blind eye	“I’m limited as regards [to] domestic activities such as painting or lifting heavy objects.” Man 15, age: 60 y/o, DD: 9 yrs, BASDAI: 5.8, BASFI: 6.8. Bilateral sacroiliitis IV/IV and syndesmophytes in cervical spine. “I could not play with my children. I hurt everywhere they touched me.” Man 16, age: 65 y/o, DD: 35 yrs, BASDAI: 3.9, BASFI: 4.7. Bilateral sacroiliitis IV/IV and lumbar fusion.
	Feelings of incapacity with children	“I’m limited in the care I can provide for my children.” Man 11, age: 39 y/o, DD: 9 yrs, BASDAI: 7.1, BASFI: 3.9. Normal radiograph, heel enthesitis.

SpA: spondyloarthritis; y/o: years old; DD: disease duration; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; BASFI: Bath Ankylosing Spondylitis Functional Index.

With regard to children, women expressed regret at their inability to care for them, while most men regretted being unable to participate in leisure activities with them. Nevertheless, some middle-aged men expressed concern about their inability to care for their children, in line with the development observed in Spain of a new model of fatherhood in which young Spanish fathers assume equal responsibility for child care<sup>15</sup>. Aside from this new model of fatherhood, most of the women with SpA had to cope with their disease in a social context characterized by gender inequalities, obliging them to tackle daily obligatory domestic tasks combined with a poor work-life balance, increasing their workload and exacerbating their poor health.

Our study presented both advantages and limitations. Our sample was representative of the SpA population in terms of sex. Participants presented a range of conditions, degrees of severity, duration of illness, treatments, and ages, and represented not only traditional gender roles but also new ones.

Recall bias is a challenge in this disease because of the long delay in diagnosis, especially in women. However, their rheumatology visits are perceived positively by patients; at the same time they are more aware than ever of their disease, which may have helped reduce recall bias. The qualitative methodology was not intended to yield results suitable for extrapolation. However, in sociocultural contexts similar to that of Spain, with a public health system and specialists authorized to prescribe independently, the results may be transferable. It is possible that the participants held a view different from those who did not respond regarding their gender role issues.

From a gender perspective, good professional practice should pay particular attention to the effect of contextual factors such as family support and employment structure on important aspects of patients’ lives.

The principles proposed by the Canadian Institute for Work and Health<sup>31</sup> can serve as a basis for research on the

help these contextual factors can provide. It is surprising that the women received less anti-TNF- $\alpha$  treatment, despite their greater disease activity. This finding, together with the reports by some women of taking antiinflammatories prior to going to work, suggests the existence of gender bias in healthcare. Such bias could be prevented by taking into account whether medications are prescribed according to some clinical signs, such as radiological damage, instead of the different symptoms of SpA in each sex, and the interaction of these with everyday tasks and gender roles socially established.

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