

"I want to remain active": Women suffering from fibromyalgia strategies to conduct basic, instrumental, and advanced daily activities

"Quiero seguir en activo": Estrategias de mujeres que padecen fibromialgia para realizar actividades cotidianas básicas, instrumentales y avanzadas

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Fechas · Dates

Recibido: 13/06/2024

Aceptado: 10/01/2025

Publicado: 15/01/2025

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Abstract

Purpose: Fibromyalgia symptoms can significantly limit a person's ability to function and participate in daily activities, such as work. Exploring patients' perceptions of the impact of fibromyalgia symptoms on functionality can provide valuable insight into their coping strategies and needs to remain active. This study aims to describe the strategies and adaptations women with fibromyalgia use to carry out basic, instrumental, and advanced activities of daily living.

Methods: Qualitative study based on personal interviews with 25 women diagnosed with fibromyalgia. A thematic analysis was conducted following the classification of activities of daily living into basic (movement and moving around, personal hygiene and getting dressed), instrumental (cleaning, housekeeping, and shopping), and advanced (work).

Results: Due to the functional impact of symptoms in all activities of daily living, women with fibromyalgia introduced different compensatory strategies, support products, and modifications in the environment or task to increase their level of occupational competence. Introducing adaptations in the public space is a challenge, and work is a source of distress, either because it has disappeared or because of the effort to carry it out satisfactorily.

Conclusion: Healthcare professionals caring for women with fibromyalgia should recognize the impact of fibromyalgia on patients' functionality and employ strategies to improve their adaptation, as well as facilitate the assessment of sick leave.

Keywords: fibromyalgia, adaptations, limitations, activities of daily living, qualitative research, Spain.

Resumen

Objetivo: Los síntomas de la fibromialgia pueden limitar significativamente la capacidad de una persona para funcionar y participar en actividades cotidianas, como el trabajo. Explorar las percepciones de las pacientes sobre el impacto de los síntomas de la fibromialgia en su capacidad funcional puede aportar información valiosa sobre sus estrategias de afrontamiento y necesidades de permanecer activas. El objetivo de esta investigación es describir las estrategias y adaptaciones utilizadas por mujeres con fibromialgia para llevar a cabo las actividades básicas, instrumentales y avanzadas de la vida diaria.

Método: Estudio cualitativo basado en entrevistas personales a 25 mujeres diagnosticadas de fibromialgia. Se realizó un análisis temático siguiendo la clasificación de las actividades de la vida diaria en básicas (movimiento y desplazamiento, higiene personal y vestirse), instrumentales (limpieza, tareas domésticas y compras) y avanzadas (trabajo).

Resultados: Debido al impacto funcional de los síntomas en todas las actividades de la vida diaria, las mujeres con fibromialgia introdujeron diferentes estrategias compensatorias, productos de apoyo y modificaciones en el entorno o la tarea, para aumentar su nivel de competencia en el trabajo. Introducir adaptaciones en el espacio público es un reto y el trabajo una fuente de angustia, ya sea por su desaparición o por el esfuerzo que supone llevarlo a cabo satisfactoriamente.

Conclusiones: Los profesionales sanitarios que atienden a mujeres con fibromialgia deben reconocer el impacto de la fibromialgia en la funcionalidad de las pacientes y emplear estrategias para mejorar su adaptación, así como facilitar la valoración de la incapacidad laboral.

Palabras clave: Fibromialgia, Adaptaciones, Limitaciones, Actividades de la Vida Diaria, Investigación Cualitativa, España.

Resum

Objectiu: Els símptomes de la fibromiàlgia poden limitar significativament la capacitat d'una persona per a funcionar i participar en activitats quotidianes, com el treball. Explorar les percepcions de les pacients sobre l'impacte dels símptomes de la fibromiàlgia en la funcionalitat pot aportar informació valuosa sobre les seves estratègies d'afrontament i necessitats per a romandre actives. L'objectiu d'aquesta recerca és descriure les estratègies i adaptacions utilitzades per dones amb fibromiàlgia per a dur a terme les activitats bàsiques, instrumentals i avançades de la vida diària.

Mètode: Estudi qualitatiu basat en entrevistes personals a 25 dones diagnosticades de fibromiàlgia. Es va realitzar una anàlisi temàtica seguint la classificació de les activitats de la vida diària en bàsiques (moviment i desplaçament, higiene personal i vestir-se), instrumentals (neteja, tasques domèstiques i compres) i avançades (treball).

Resultats: A causa de l'impacte funcional dels símptomes en totes les activitats de la vida diària, les dones amb fibromiàlgia van introduir diferents estratègies compensatòries, productes de suport i modificacions en l'entorn o la tasca, per a augmentar el seu nivell de competència en el treball. Introduir adaptacions en l'espai públic és un repte i el treball una font d'angoixa, ja sigui per la seva desaparició o per l'esforç que suposa dur-lo a terme satisfactòriament.

Conclusions: Els/les professionals sanitaris/ries que atenen dones amb fibromiàlgia han de reconèixer l'impacte de la fibromiàlgia en la funcionalitat de les pacients i emprar estratègies per a millorar la seva adaptació, així com facilitar la valoració de la incapacitat laboral.

Paraules clau: Fibromiàlgia, Adaptacions, Limitacions, Activitats de la Vida Diària, Recerca Qualitativa, Espanya.

Introduction

Fibromyalgia syndrome (FMS) is a chronic health condition characterized by chronic widespread pain, fatigue, poor sleep quality, mood and memory disorders, and other cognitive symptoms⁽¹⁾. FMS has a worldwide average prevalence of 2.1%, and is more commonly diagnosed in women (4.3%) than in men (0.95%)⁽²⁾. In Spain, FMS represents between 10 and 20% of total rheumatology consultations, and the most affected age groups are those between 46 and 65 years of age⁽³⁾. This condition poses a significant socioeconomic challenge, impacting healthcare systems, societal resources, and the affected individuals. The disease severity directly correlates with the financial burden of treatment, underscoring the importance of timely intervention. A comprehensive understanding of the variables influencing FMS and its economic implications is imperative for mitigating this burden⁽⁴⁾.

FMS negatively impacts individuals' functionality and quality of life, with pain and fatigue influencing perceived function and physical performance in a subjective and individualized manner, affecting daily activities like housework and work⁽⁵⁾. Researchers have conducted numerous studies to better understand how FMS impacts the functionality and quality of life of those affected by the condition. People with FMS have lower functional performance than the general population due

to limitations in physical capacities, which seem to imply more significant limitations and decreased independence in performing activities, particularly in the workplace⁽⁶⁾. Also, women diagnosed with FMS experience more significant difficulties than healthy women of the same age in performing activities of daily living (ADLs), such as getting dressed, eating and personal hygiene, housekeeping, or shopping⁽⁷⁾. Thus, they may require more time or assistance to carry them out⁽⁸⁾.

Additionally, the limited physical capacity and an increased need for rest make it difficult for women with FMS to cope with daily physical, organisational, and psychosocial demands⁽⁹⁾, which negatively impacts different spheres of their life such as family, leisure environment⁽¹⁰⁾, or present obstacles to managing the demands of work and maintaining work function⁽¹¹⁾. Moreover, patients with FMS report being significantly impaired in a variety of roles and describe limitations in their relationships with other people and a poor ability to participate in social activities. For example, difficulties in completing household chores⁽¹²⁾, whereas they almost entirely did housework before their current health condition⁽¹³⁾. Therefore, patients describe strategies having flexibility at work, modifying their working space or the type of work they do⁽¹⁴⁾.

There are several qualitative studies on the experience of FMS⁽¹⁵⁾, patient routines⁽¹⁶⁾, or their ability to work⁽¹⁷⁾. Despite one study highlighting the importance of ADLs⁽¹⁸⁾, no studies have been identified that focus on all ADLs together and explore specific adaptations and/or solutions to develop these activities further. Increasing the knowledge base on the strategies adopted by people suffering from FMS to perform ADLs can help health professionals improve their recommendations. This study aimed to describe the strategies and adaptations used by women with FMS to continue to perform basic, instrumental, and advanced ADLs.

Methodology

A qualitative study was conducted in 2020, following a constructivist approach. Twenty-five semi-structured personal interviews were conducted with women diagnosed with FMS by a rheumatologist. Purposive sampling was employed to ensure a comprehensive and diverse representation of demographic variables among participants selected from two FMS associations and two Primary Health Care Centre in two regions of Spain (supplementary material 1). Each centre was invited to participate through contact with a key person who explained the purpose of the study to women with FMS. The gatekeepers provided the volunteer participants' contacts to the research team, who then contacted the FMS patients to arrange a place and time to conduct the interview.

Two authors (MP, CC) collected the data using in-depth face to face semi-structured personal interviews, following an interview guide of open questions designed by the research team. It included two thematic areas: symptomatology and occupational performance of the ADLs (supplementary material 2). The interviews were audio recorded after obtaining each participant's approval. The information was listened to, transcribed verbatim, and imported into the supporting software NVivo 11.

Analysis

Four authors (MP, DS, CC, EB) analysed the data sequentially and structurally using a thematic analysis following Clarke and Braun, and using the conceptual classification of ADLs into basic (movement/moving around, personal hygiene, getting dressed), instrumental (cleaning, housekeeping, and shopping) and advanced (paid work). The same authors read the data carefully and identified text fragments related to basic, instrumental, and advanced ADLs, which were coded deductively. They then open-coded these fragments by creating new codes summarising their meaning and organised the resulting code list into code families, which led to the creation of the subthemes presented in the results. All research team members discussed and agreed on the results, allowing triangulation of interpretations and ensuring analytic rigor.

Ethical considerations

The principles of the Declaration of Helsinki and the Belmont Report were respected in this study. Approval was obtained from the Ethics Committee of Hospital Universitari Arnau de Vilanova (Code CEIC-1999). The participants agreed to participate voluntarily and signed an informed consent form before the interviews were conducted and recorded digitally. Also, the study adhered to the COREQ (Consolidated Criteria for Reporting Qualitative Studies) guidelines for reporting qualitative studies, ensuring that the relevant aspects of the research were accurately documented.

Results

Results were organized under three main themes: basic, instrumental, and advanced ADLs, differentiating between limitations experienced by women with FMS in conducting ADLs and strategies and adaptations adopted to conduct ADLs.

The participants explained that the symptoms experienced, particularly pain, make it difficult for them to perform their ADLs. In a bidirectional cause-effect relationship, pain occurs both as a result of performing the activity and as a cause of the inability to perform it (such as going up or down the stairs or walking, etc.). Nonetheless, they described the pain that completely paralyzed their activity as only occurring occasionally.

"Pain doesn't let me live! I can't carry on with my life. It limits me greatly" (E14).

"What limits you is... constant pain" (E2)

"The terrible pains... It's that... look, not even the stairs/.../I couldn't even walk because of the pain, it was horrible" (E25)

Participants described a downward trend in their mobility since they began experiencing FMS symptoms. They described a transition from activity to inactivity and compared their current ability to the past.

"Well, before you used to bend down as if you were going to stretch, like when you go to the gym. And now you can't/.../It didn't use to be this way...before it was all continuous" (E3)

"I can't bend down, and so I say... well, I'll kneel and wipe this down here/.../I can't do that. And I used to do that. And now I don't" (E1)

Basic ADLs: movement and moving around, personal hygiene and getting dressed

Limitations experienced: 1) Movement and moving around: women explained that pain is caused by everyday movements requiring sustained effort, such as repetitive or maintaining the same posture. They described other types of functional limitations related to moving around, such as going up or down stairs, due to painful physical movements or their lack of balance. Furthermore, using means of transport causes them pain because they must remain in the same position for an extended time (Table 1); 2) Self-care: Participants described their difficulties with daily self-care activities due to the pain involved in specific movements, such as dressing, putting on shoes, and those involved in personal hygiene (taking a shower, drying their hair and combing, or using the toilet) and getting dressed. As a result, they felt that they had to decrease their expectations of physical self-care and appearance (Table 2):

"And your physical self comes second. Your physical appearance" (E3)

Strategies and adaptations: 1) Movement and moving around: they adapted their schedules to be able to carry out daily activities, dividing these activities into different parts of the day or week. One of the interviewees explained how she can adapt to the activity, although she finds it difficult to accept it. They also modified the activity or engaged in activities that did not cause fatigue and would try using other body parts to facilitate changes in posture or movements that involve more significant patient effort (Table 1); 2) Personal hygiene: participants reported using external adaptations such as handholds and non-slip flooring or even considered switching from a bathtub to a shower tray to adapt to their limitations in personal hygiene. If they were unable to perform certain personal hygiene activities -such as applying makeup, washing their hair, or cutting their nails- they would seek external assistance, such as going to a hairdresser or having someone else do it for them. To improve their hygiene and safety while performing these activities, they had to adapt to the facilities they had at home, such as using the shower instead of the bathtub, if they had one. In terms of clothing, they modified it for comfort (Table 2).

Table 1. Personal interviews with 25 women diagnosed with fibromyalgia. Textual quotes (verbatim): limitations and strategies for “Movement and moving around”.

Activity		Quotes (verbatim)
Limitations	Movement	Everyday movements
		"I can't move my hands; I can't handle them. Any friction causes me pain" (E16).
		Repetitive movements
		"Many. Sudden movements, above all. Repetitive movements too. And if you're cold... you can't maintain your posture"/.../When you're trying to get back to your place, you say is that my arm? or did they use a mannequin's arm? (laughs)/.../And you stay there I'm about to go down and I realise I can't. But you can't/ /same deal when it comes to bending down" (E3).
	Moving around	Going down the stairs
		"Going down the stairs. It's very hard for me. I can't do it. And if one day the lift breaks down, I'm left in the street waiting for the technician to come/.../Bending down and going up and down a staircase to do something... fatal too/.../The journey is unbearable for me. Because of the pain I have, I end up dying of pain" (E1).
		"If I have to go down 10 or 12 stairs, I have to do it backwards. Because I can't. Impossible" (E25).
Strategies		Going for a walk
		"Walking, going for a walk, then my back suffers greatly from it" (E4).
	Change of the activities	"I either change my activity or I go to the computer. And I'm sitting, or... Things that don't make me physically tired" (E3).
	Change the posture	"And when I try to change position, I have to support one leg with the other and leverage myself to change position. I have to lever myself up and then I say... one, two and three. And I change" (E3).

Table 2. Personal interviews with 25 women diagnosed with fibromyalgia. Textual quotes (verbatim): limitations and strategies for “Selfcare”.

Activity		Limitations, quotes (verbatim)	Strategy, quotes (verbatim)
Makeup			"The same as when you have your make-up done. [Refers to having her arm up and down]" (E1).
Hygiene	Nails	"And my nails... someone else must clip them"/.../ "I can't clip my toenails" (E1).	"I have to have it done" [she needs her nails clipped] (E1).
	Shower	"There are people who can't wash their hair/.../and people who can't take a shower. They need help /.../" (E1). "And before I used to reach my back -soaping myself in the shower with a sponge- And now I can't reach it /.../ Now I take a towel on both sides, and I get by " (E3). "In the shower, it's very difficult for me. I'm already very scared, I've fallen more than twice /.../ if you stumble you go straight to the floor. No reflexes..." (E8).	"I have a stick thing for my back, but yes, yes... it's hard for me/.../You do change things, a lot" - to scratch/ shower/.../I have put a handle in the bath and in the shower/.../If I didn't have a shower, I would have had to take the bathtub out/.../As I have a bath and shower at home, when I feel a bit agile I use the bath" (E1). "At home I have a shower tray" (E2). "In the bathroom I have a bathtub, and I have to change it to a shower tray because it is very difficult for me to get into the bathtub /.../ The only thing I have bought is for... under the bathtub so that I don't slip" (E3).
	Bath	"But I don't bathe, because I can't. I can't sit in the bathtub. Because when I've tried to take a relaxing bath, then I couldn't get up/.../But for sure, for sure, for sure. Because in the bathtub, I need to be sure to lift my foot, my leg to get in and out. When I feel insecure, when I see that I don't feel safe, that I might fall, I use the shower" (E1).	
	Hair	"I started to dry my hair and my arms fell to the sides /.../ I couldn't. I couldn't handle it. I couldn't cope with this.../.../I can't even put on a hair clip" -(E25).	And now I go to the hairdresser more often. Maybe just to wash my head and that's all" (E3).
	Toilet	"Using the toilet. That becomes very hard" (E3).	

Activity		Limitations, quotes (verbatim)	Strategy, quotes (verbatim)
Dressing	Type of shoes	"You don't dress the same. It's very important/.../It's not the same to wear a cute little heel as it is to wear a little thing like that.../.../The shoe, I've always worn heels like that. And now I have to wear them like this or nothing. Because I can't take a step/.../I just couldn't walk when I put them on" - the high heels -(E1). "It limits you a lot, in terms of putting on different shoes" (E4).	"I haven't had to change anything about my clothes and so on /.../ Shoes and so on, yes. I don't know if it's the same, I've had surgery on one foot, I had Morton's neuroma" (E2). "I had to wear high heels, be dressed up and all that /.../ I have changed to more comfortable, less flirtatious, more hippie" (E3).
	Putting on shoes	"When it comes to putting on my shoes. I notice that it's harder for me to put on shoes now than before" (E3).	

Instrumental ADLs: cleaning, housekeeping, and shopping

Limitations experienced: participants highlighted limitations in the domestic sphere (cleaning, housekeeping, and shopping) due to a lack of strength in legs and arms, limitations in the movements required for cleaning (such as bending down), and the consequences of the effort (pain -in arms, neck, hips-, and fatigue). Standing for long periods, cooking, cleaning the house, or doing the dishes may all result in fatigue, exhaustion, pain, and/or disability. Some participants felt unable to perform them and had to resign themselves because they could no longer do these activities, such as bending down or cleaning windows (Table 3).

Strategies and adaptations: The strategies they used to continue performing household chores included spending more time and splitting the effort; trying to find the most comfortable positions to perform the activities; relying on others, such as their partners, to carry out the actions they needed to; and trying to do so despite pain and exhaustion. Participants explained how lack of mobility caused by FMS led to changes in the movement patterns during the performance of IADLs at home; for example, trying to control and slow the movements when performing activities to avoid pain from sudden movements (Table 4).

The interviewees devised a few adaptations at home because of the difficulties encountered while cleaning activities. They introduced new objects into their daily lives or replaced some of them with others to facilitate these activities, such as pedal mops, household appliances such as dishwashers, food processors or smart pots, or steam cleaners, to make the tasks easier to perform. Adaptations also included the use of another object that aided in the execution of action (such as opening a jar with a cloth).

The participants reported that these modifications improved their ability to cook and clean. Those who could afford to use household appliances instead of doing the activity manually (e.g., washing the dishes) were grateful for the resource. In contrast, those who could not afford it emphasized its importance. They also stated that not using certain decorative items at home, such as carpets, could reduce their cleaning burden. The strategy for their daily shopping was to use a shopping trolley rather than carrying shopping bags.

Table 3. Personal interviews with 25 women diagnosed with fibromyalgia. Textual quotes (verbatim): limitations and strategies for “Cleaning, housekeeping, and shopping”.

Activity	Limitations: quotes (verbatim)	Strategy: quotes (verbatim)
Go shopping	"And always instead of going out in the morning to go shopping or anything else, to do a few errands, I just can't stand my soul" (E1).	"My strategy is my trolley [Uses the trolley to load better] /.../ Apart from this bag, and the other handbag. So, I've brought my trolley. Because no, otherwise I wouldn't be able to. My trolley is my companion" (E1).
Cooking	"[after cooking] I had such a pain in my hips that I couldn't even walk" (E1).	"Now I've bought one of those potato peelers that you squeeze out in circles like that/.../You go and find your own comfort/.../The Thermomix, the potato peeler, the floor scrubber" (E16). Well, now I've bought a potato cutter/.../I've also bought that potato cutter to make slices. Ah... the lettuce squeegee/.../ The steamer is the only thing I've bought because that's what it's for, to clean the tiles and all that" (E3). "But I also do...I bought a mop with steam. Because well, I had no strength in my legs and I couldn't walk/.../I couldn't scrub... I couldn't scrub. So I buy things to see how I feel" (E25). "Cans... Well, I open them. But I have a trick. I tap the lid all around and it's already open" (E2). "To open the jars I use a green scouring pad. And then that hooks and lets me open it better/.../To open cans, I have my own method- if her son and husband are not there- with the corkscrew that I bought" (E3).
Cutting	"I couldn't even sweep with the knife" (E22).	"I used to peel potatoes with a normal knife. And now I've had to buy one of those good ones" (E16).
Ironing	"The iron... fatal. Ouch, very bad. Very bad. When I iron, I don't let it pile up because my arms and neck hurt a lot. Because you have to use a bit of strength to iron" (E2).	

Activity	Limitations: quotes (verbatim)	Strategy: quotes (verbatim)
Cleaning dishes	"It's almost like you have no strength in your arms to squeeze" (E17). "And you have a lot that depends on you, and you can't/.../And everything becomes so difficult/.../Even doing the dishes becomes too hard..." (E25).	"Washer-dryer and dishwasher would be useful..../.../I have to wash with hot water. Cold water then hurts my fingers and everything/.../The dishwasher, especially, would be good for me. The dishes, the pots and pans, all that... it's hard for me. It's very hard for me" (E1). "Before, maybe I'd finish eating and I'd do the dishes. Well, I use the dishwasher more" (E3). "A basin, I can't even put it on top of the kitchen table" (E3).
Cleaning the house	"The daily life of cleaning the house, I also notice I get exhausted" (E3). "For example, this gesture, if I do it like this, as long as it's tolerable, I hold my shoulder, but of course when I'm finished, if I try to force myself more than I should, for example cleaning two panes of glass, so that we understand each other, then I pay for it in spades" (E4). "I mean, me wiping with the cloth and wringing it out, that gesture itself, well, it's really painful and (thinks) and my back, I can't bend down well, of course, it affects me... it limits me, it limits me a lot if..." (E16). "I drop the broom and I can't open a bottle of water" (E22). "So, I try to bend down, take out the pots and... I can't. I can't" (E1). "Cleaning windows...or the upper parts. The ceiling... Cleaning the kitchen and all this.... I can't/.../ Upper areas, glass and things like that, it's impossible" (E2). "If I try to spend time cleaning or anything like that... Bending down, trying to look for something or getting down on my knees, that's unthinkable now" (E4). "When housekeeping I feel very limited because I am a very active person and I like to... I am obsessive about cleaning, and I used to spend part of my life cleaning and now I don't, now I can't" (E16).	"I have a mop with a pedal" (E1). "I can't bend down and I say...Well, I'll kneel down and clean this down here" (E1). "The first thing the doctor told me is to clean under the furniture while sitting down, but not even sitting on the stool" (E17). "I already think about comfort. For example, carpets. I don't use carpets anymore because then I don't have to clean them" (E3).

Table 4. Personal interviews with 25 women diagnosed with fibromyalgia. Textual quotes (verbatim): strategies adopted to continue performing household activities.

Strategy	Quotes (verbatim)
Investing more time	"Look, today I'll do one thing and tomorrow I'll do something else" (E1).
Changing position	"I can't bend down and I say...Well, I'll kneel down and clean this down here" (E1). "The first thing the doctor told me is to clean under the furniture while sitting down, but not even sitting on the stool" (E17). "You look for a chair, you put the basin on the chair and then you go... stumbling around." (E3).
Delegating	"My husband has to do everything. And I can't handle the heavy things, I can't. Thank God my husband does it all for me. Thank God my husband does everything for me. Because I can't/.../When it comes to weight, a lot of weight is impossible" (E2). "Having to live with this mess makes me a bit upset, but my husband and my son are very understanding and don't say anything to me, they don't care if it's clean or not, but they won't clean it themselves, but they won't tell me to clean it either" (E14).
Persisting	"And day-to-day life?Well, you run your house as best you can" (E2). "Now first you bend down, bend your knees and then when you get up and say: mare meua(my god), now how do I get up" (E3). "If you force yourself a little bit, for example, cleaning, then 2-3 days later you are in bed" (E9). "It is clear to me that I will pay for the day I go too far" (E15). "I have cleaned the oven in my kitchen while crying in pain, sitting on the stool" (E17). "Today I'm going to clean as before, (forgets), but of course after a while you're all like puff...and you have to stop" (E22).
Renouncing	"Because I don't clean the kitchen and so on. But I don't do it. First I try" (E25).

Advanced ADLs: work

Limitations experienced: women stated that they had been very active in the past. Previous work requirements were strenuous and could include heavy lifting. Some participants linked their current complaints to experiences of overwork in the past. They explained that people with FMS frequently become aware of their limited situation as a result of constant physical demands at work, particularly in cleaning jobs. Furthermore, they were stressed because they felt restricted in their ability to perform at work. Being aware of their limitations at work caused frustration and made them feel inefficient in carrying out their responsibilities. Most participants reported that they were forced to leave their jobs because they could not bear the pain during the workday or because they were fired (Table 5).

Strategies and adaptations: The strategies and adaptations women used to continue working in their best conditions included sitting when they lost functional ability, changing joint postures or moving to avoid discomfort and/or pain, using external equipment like knee pads, avoiding breaks to prevent excessive movement, and avoiding overexertion. Those who continued to work reported having to adjust to meet work demands. For example, if they had to stand for a long time, they would need to sit down. If they spent time sitting, they would experience di-

fficulties getting up, so they used the strategy of moving around with the chair if it had wheels, instead of getting up or using knee pads to continue their work routine (Table 5).

Table 5. Personal interviews with 25 women diagnosed with fibromyalgia. Textual quotes (verbatim): limitations and strategies to work.

Limitations and strategy to work		Quotes (verbatim)
Limitation	Feeling exhausted at work	"I worked, I was very active /.../ I would come home without resting. Because I haven't been lazy. I have always been a hard worker since I was 12 years old" (E1). "Besides, I worked in a kindergarten kitchen, I made food for forty children, I took pots, I took this I used to say: I'm exhausted, I'm exhausted" (snorts)(E10). "At work, I felt exhausted at work, that's why I also realised it because I liked my job, but there came a time when physically" (E15). "It is normal that it is at work when you really notice it / / Of course, normally at work is where you notice it, because it is where you move around the most" (E25)
	Feeling stressed at work	"I was late for work, a lot of stress..." (E1). "Stress and work affected me a lot" (E7). "Stress, I had a stress on me... very strong /.../ I felt that my mental capacities were reduced, and it was influencing me at work" (E16).
	Not being capable	"I was very rough at work (laughs). It demanded a lot from me, the work was at a physical level and (blows) there came a time one day when I had an anxiety crisis and well, I exploded" (E17). "I want to comply, but I see that I can't make it in the morning, that I'm late" (E1).
	Feeling stressed at work	"I was late for work, a lot of stress..." (E1). "Stress and work affected me a lot" (E7). "Stress, I had a stress on me... very strong /.../ I felt that my mental capacities were reduced, and it was influencing me at work" (E16).
	Being forced to leave their jobs	"Horrible pains /.../ I couldn't bend down" (E1). "They kicked me out. They threw me out on the street. Nothing... I worked for 4 years without missing a day... and... I never took sick leave and... a month after being on sick leave, they sent me a letter telling me that... if I didn't go back to work, they would fire me. And I, as I was feeling unwell, I didn't go back. Of course, I didn't go back. And they threw me out on the street" (E2). "When I was working at the fairs is when I started to get the most pain. My shoulders, my arms..." (E9). "I also lost my job. The pains were deadly. I couldn't stand it. It was... it was everything. And I can stand the pain. But it was horrible /.../ At work, the pains were deadly" (E25).
Strategies	Sitting	"I started to feel bad, very tired and I had to sit down /.../ I say... you have to send me to the dole because, of course, because I can't... (E13)

Limitations and strategy to work	Quotes (verbatim)
Changing position	"When I work, yes [there are movements that bother her], because, even though my lower back hurts, I bend down well I bend my knees well and do what I have to do. You have to bend down with your knees bent. And if you bend down like that it's bad" (E2) "Well, as you can well look, I try to sit well, but if my leg hurts, I stretch it, I move it, since no one can see me behind the counter (laughs). If my right arm hurts a lot, I give the papers with my left arm / / I go around, depending on the side that hurts more or less, I put myself on one side or the other" (E4)
Use of Protective Gear	"Only when my knees attack a lot, then I use the knee pads" (E1).
Non-Stop Work Approach	"And there are times when I can't get up from my chair. I go there, I don't get up... so I turn back - in a work context - I start working at seven in the morning until three in the afternoon, and I can't stop. Because the moment I stop I can't go on" (E25)
Avoiding overexertion	"So, I'm afraid of overdoing it and getting those fainting spells I get. It's already happened to me three times or so, very recently too. And... before, I don't know if it would have happened to me, right?" (E3)

Those still working used strategies of not stopping, for example, not taking breaks or interrupting their activity during the day, as they explained that it was more difficult to resume their activity afterward, adapting their movements or avoiding movements that cause pain. They noted that, despite their localized pain, if the movements required by the work did not affect the same area, they did not cause pain. Therefore, they might fear "overdoing" the effort at work, which could have negative repercussions.

Consequences and challenges of work disability: women who had to stop working due to limitations described difficulties in obtaining work-related sick leave. They denounced the fact that there are disparities in obtaining disability to work with the same diagnosis and identified cases of people with FMS obtaining these benefits as exceptions. They explained that FMS is generally not considered a chronic or limiting disease. In this regard, women expressed abandonment and/or a lack of interest from medical personnel, implying that they do not believe in the seriousness of their health condition. This perception, in turn, created fear of not being heard and of not speaking up about what was happening to them (Table 6).

Table 6. Personal interviews with 25 women diagnosed with fibromyalgia. Textual quotes (verbatim): Consequences and challenges of work disability

Consequences and challenges of work disability		Quotes (verbatim)
Consequences	Difficulties in obtaining work incapacity	"The doctor would always tell me: don't suffer, I can't give you sick leave because this illness is not recognised - but as I have osteoarthritis - I can give you sick leave and when you are like this, come and I will give you sick leave" (E8). "I have been on sick leave for a year. Yes, because of fibromyalgia and everything that goes with it, psychologically and..." (E18) "No [work], I have an absolute disability" (E19) "I have been retired since 2003 due to absolute disability" (E20). "No, I don't work, I have a disability, I have a pension" (E22).
	Financial difficulties	"The troubles, the economy, you see that you can't make ends meet. You only get bills" "At the same time you need money" (E1).
	Abandonment of medical personnel	"You are there to work. Without even knowing what I had. And I still didn't know what I had. And they don't believe you. They don't believe you. Not even the doctors [Perceives lack of interest on the part of health personnel] Not even the doctors believe you" (E1). "But come on, you usually look good. That's why they want us to get to work" (E25).
	Regret for past decisions	"And it was a mistake I made there. Because it turns out that when I told my manager that it was because I hurt my shoulder taking out the box... he said to me: use a spray and it will be like nothing. No... that's nothing. Well, at that moment I should have said to that man: can you take me to the mutual insurance company? Please, I've hurt my shoulder, but I didn't fall.../.../So I went to the Social Security. But if I go to the mutual insurance, then today I would have a salary for the job I was doing. I can't do it anymore. I couldn't even do it now. But as I didn't do it like that... I didn't do it right, so I don't have anything" (E2).
Challenges	Good family support	"So, if I am fortunate enough to be married and have a child. And my husband works, and my son works, then it is not necessary for me to work" (E3). "Well, instead of doing 40 hours I'm going to ask if I can do 30, because at night when I arrive, I'm tired" (E24).
	Feeling unable to work	"I can't work. I can't. I can't.(E1) "Imagine being in a life where it wasn't like that [being able to afford not to work]. If I had no balls left but to work. Well then... I wouldn't be able to work" (E3)
	Trying to keep working	"It so happens that when employers hear fibromyalgia, they get scared/.../And they reject you a lot. You can never, ever, ever say that you have fibromyalgia. You will never find a job in your life" (E25). "You can't go to work they said, and I told them that I wanted to work, and I said: Don't give me sick leave. And they told me: you can't work, with these reports that I receive" (E19).
	Not finding a job again	"In the future I won't be able to work, and life... I think about lying down all day long and well.... /.../ The first thing that worries me is that I can't work. And the future, of course I worry about what is going to happen in the future" (E12).

Those unable to receive financial support expressed regret for past decisions, such as failing to visit the mutual fund when they should have to document the process and generate evidence. Participants were concerned by financial difficulties due to their inability to work. Those who did not need to work because they had adequate family support felt fortunate and reassured.

Participants who did not work were divided into three groups: those who felt unable to work, and those who wanted to keep working but were aware that their job performance had declined and/or felt unable to return to their jobs. A third group feared they would not find work because employers thought they would not perform well at their tasks and would be more costly to the company.

Discussion

Our qualitative study showed how women with FMS reported that coping strategies were multiple and individually adopted, considering the unstable and unpredictable course of FMS. Due to the functional impact of symptoms in all ADLs, women with FMS who participated in the study developed different compensatory strategies, support aids, and modifications of the environment or task to increase their level of occupational competence.

Occupational competence is highly affected in people with FMS⁽¹⁹⁾. Previous studies have shown that the functional impact of FMS is direct in all occupational areas (self-care, productivity, and leisure-free time)⁽²⁰⁾. For example, FMS patients performed worse in the assessment of manual dexterity and fine motor control compared to healthy women⁽²¹⁾. In this sense, women described themselves as clumsy and unstable. They showed greater participation in self-care activities, which correspond to the essential activities that cover the basic needs of hygiene food, and housekeeping.

While these strategies are presented naturally in the private space, introducing adaptations in the public space is a challenge. The flexibility that enables competent implementation must contend with the rigidity of the (work) system in which people with FMS are immersed. The attempt to normalize it encourages the development of strategies to make them invisible. Still, it must be borne in mind that the development of these strategies is a dynamic, unique process that must be assessed for each individual⁽¹⁹⁾. Work is a source of distress, either because of the inability to perform it or the effort involved in carrying it out satisfactorily⁽²²⁾. There are repeated absences from work and decreased productivity because the system and the work environment are not favourable to remaining active in the workplace⁽²³⁾.

In line with the results, people with FMS develop strategies (adapting the workplace, finding support in the workplace, control mechanisms, or regulating rest periods) that allow them to remain in productive activity⁽²⁴⁾. Productive work is associated with better physical and cognitive functioning in women with FMS, suggesting that keeping them employed may improve their health⁽²⁵⁾. Women in

productive work have shown higher levels of physical activity compared to women in reproductive work alone, except when they also participate in physical activity at home. It also appears to facilitate the movement of women with FMS toward a more active lifestyle^(25,26). Working women with FMS reported better health than nonworking women with FMS in terms of pain, fatigue, stiffness, depression, and health status despite being equally impaired in physical capacity⁽²⁷⁾.

On the other hand, both the reduction in labour participation and the difficulty in obtaining formal recognition of incapacity have a high economic impact, placing this group in a situation of vulnerability that is still unknown and unrecognized in many areas^(28,29). Being able to develop adaptive skills reflects a willingness to be active that departs from the myth that people with FMS are passive⁽³⁰⁾. This highlights the need for awareness programs at work to encourage the introduction of adaptations for workers with FMS.

Our qualitative study builds upon previous research on work ability in FMS^(31,32), and identified specific adaptations for the workplace and basic and instrumental activities, offering a more comprehensive perspective grounded in women's lived experiences with FMS. Also, following the trustworthiness criteria of Lincoln and Guba⁽³³⁾, credibility, dependability, confirmability, and transferability were enhanced. However, the study has some limitations. The sample consisted entirely of women belonging to patient associations, which may have influenced the fact that they are more active than those who do not belong to the group. Furthermore, leisure and exercise were not described as advanced ADLs, as they were not included in the interview script and did not emerge in all the interviews.

Despite these limitations, the findings of this study inform client-centered rehabilitation approaches and interventions to prevent premature retirement. The findings highlight the importance of involving companies' occupational health services, whether in-house or outsourced, in identifying and proposing workplace adaptations that address the specific needs of individuals with FMS. However, the formalization and implementation of these adaptations fall under the responsibility of the human resources departments or company management, emphasizing the need to establish effective communication channels among involved company departments and management.

Moreover, health professionals must have skills and knowledge to guide and help identify factors that may increase their symptoms, as well as contribute to creating modifications in their working conditions to help these people stay in the labour market⁽³⁰⁾. These results reinforce the fact that healthcare professionals should be educated on the approach to FMS, focusing more on promoting activities of daily living and psycho-emotional aspects, and avoid passive pain therapies. A qualitative synthesis on pain and FMS highlights that health professionals should discuss with each patient the strategies used and adopt an individualized, patient-centred approach to develop an effective treatment plan⁽³⁴⁾.

More knowledge is needed on how to adjust the working conditions of people with partial work capacity to benefit society and the individual and enable women with FMS to maintain their work roles⁽³⁵⁾. Future research, including the views of other

parties, such as employers or health professionals, could complement and contrast the information to help improve the acquisition of strategies and quality of life in patients with FMS.

In conclusion, women with FMS employ practices and strategies to normalize their activity due to their limitations during ADLs, such as delaying or postponing tasks, increased breaks and postural changes, the introduction of support products, energy-saving techniques, and role modification in both the private home and public workspace. Participants showed greater participation in self-care activities, while work is a source of distress, either because it has disappeared or because of the effort involved in carrying it out satisfactorily. This study contributes to the visibility of a problem that still needs greater social and professional recognition. Finally, this research represents the first instance in which specific strategies have been identified, potentially paving the way for recommendations that healthcare professionals can make.

Acknowledgments

We would like to thank all women who participated in the study.

Declarations

Ethical Approval

The article was conducted following the approval of the Ethics Committee of Hospital Universitari Arnau de Vilanova (Code CEIC-1999).

The participants agreed to participate voluntarily and signed an informed consent form before the interviews were conducted and recorded digitally.

Funding

No funds, grants, or other support was received. All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

The authors report there are no competing interests to declare.

Data and materials availability

The datasets generated and/or analysed during the current study are not publicly available because they are part of an ongoing PhD thesis, but they can be consulted through reasonable request to the corresponding author.

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Supplementary tables

Supplementary table 1. Socio-demographic characteristics of the participants.

Participant	Birth Year	Marital Status	Children (n)	Educational Level	Occupation	Work situation
E1	1955	Widow	2	Basic Education	Cleaner	Pensioner, unemployed since 2009
E2	1960	Married	2	Vocational training	Administrative	Unemployment
E3	1965	Married	1	Vocational training	Beautician	Unemployment
E4	1966	Lives with a partner	1	Vocational training	Administrative assistant	Working
E5	1959	Married	1	Graduate	Special education care	Early retirement due to illness
E6	1948	Married	2	Bachelor's degree	Housekeeper	Never employed
E7	1959	Married	2	Vocational training	University secretary	Retired
E8	1952	Married	1	Basic Education	Farmworker, caregiver	Retired
E9	1964	Single	0	Basic Education	Telemarketer	Working part-time
E10	1955	Married	2	Vocational training	She refers she works as a housewife	Recently at home
E11	1959	Single	1	Bachelor's degree and Vocational training	English teacher and has a mechatronics shop	NR
E12	1954	Single		Bachelor's degree	No reference	Working part-time
E13	1975	Married	2	Graduate	No reference	Working full time
E14	1952	Married	2	Bachelor's degree	No reference	Retired
E15	1962	Single	2	Basic Education	No reference	Working full time
E16	1961	Lives with a partner	0	Vocational training	No reference	Sick leave, chronic depression
E17	1961	Lives with a partner	2	Basic Education	No reference	Currently not working, permanent total disability due to fibromyalgia
E18	1976	Married	0	Vocational training	Staff member	One year sick leave, due to fibromyalgia
E19	1966	Married	1	Vocational training	Public-facing	Total disability
E20	1959	Single	1	Vocational training	No reference	Total disability, Retired
E21	1965	Married	1	Vocational training	Works with autistic people	Working
E22	1976	Single	0	Vocational training	No reference	Disability, pension
E23	1945	Married	2	Basic Education	Cleaning services	Retired
E24	1953	Married	2	Basic Education	No reference	Retired
E25	1956	Married	3	Basic Education	Services	Unemployed

NR = not reported

Supplementary table 2. Interview script.

TOPICS	QUESTIONS
Symptoms	How would you describe your early symptoms and how have they changed since you were diagnosed with fibromyalgia? Which of these symptoms limit you most in your usual activities? Have there been any changes from the beginning to the present day?
Treatment	Where were you diagnosed with fibromyalgia? What treatment was recommended? Did they suggest any specific place to go? Which one? What kind of therapies have you received?
Occupational performance	What activities do you do differently from what you used to do before the onset of symptoms? What are the most important activities for you? Are there any activities that you have stopped doing for good, and why? What activities or routines have you included in your life and which of them are related to the disease? Has anyone in your environment changed your usual activities? In what way? Have you made any changes in the distribution of the time you spend on any activity? Have you needed to buy any orthopedic products, which ones? Have you needed to adapt any objects that you usually use in order to continue doing a task? How? What changes do you think could help you to improve your quality of life?