The hidden burden of fibromyalgia: exploring work impairment and quality of life in caregivers

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Abstract

Objective

Fibromyalgia (FM) syndrome is a chronic musculoskeletal disorder that profoundly impacts not only patients but also their informal caregivers, affecting their quality of life and work productivity. This study aims to investigate the impact of FM on the work productivity and quality of life of informal caregivers.

Methods

This cross-sectional study included FM patients who applied to our Physical Medicine and Rehabilitation clinic and their informal caregivers. FM was diagnosed using the revised 2016 American College of Rheumatology (ACR) criteria. A healthy control group and their cohabiting relatives were also included. FM patients completed the Revised Fibromyalgia Impact Questionnaire (FIQR), while caregivers and control group relatives completed the Work Productivity and Activity Impairment Questionnaire-General Health (WPAI-GH) and the World Health Organization Quality of Life Scale-Short Form (WHOQoL-BREF).

Results

The study included 68 FM caregivers and 68 control group relatives. WPAI scores revealed significant differences in presenteeism, overall work productivity loss, and activity impairment between FM caregivers and controls ($p<0.05$), though no difference in absenteeism was observed. WHOQoL-BREF scores showed significant reductions across all quality-of-life domains for FM caregivers compared to controls, with a notable correlation between the FIQR scores of FM patients and the social relationships domain of their caregivers ($p=0.026$, $r=-0.269$).

Conclusion

FM poses substantial burdens on both patients and their informal caregivers, reducing caregivers' work productivity and quality of life. Given the chronic nature of FM and the resulting long-term caregiving responsibilities, interventions that support both patients and caregivers, such as integrated healthcare and psychotherapy, may be beneficial. Further longitudinal studies are needed to examine these effects over time and support the development of comprehensive caregiver support strategies.

Key words

caregivers, fibromyalgia, quality of life, work impairment, work productivity

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Introduction

Fibromyalgia (FM) syndrome is a chronic musculoskeletal disorder characterised by widespread pain, affecting approximately 3% of the global population and 8.8% in Turkey (1, 2). FM primarily affects women aged 20 to 55 and is the third most common musculoskeletal pain condition after low back pain and osteoarthritis (2). Symptoms such as fatigue, sleep disturbances, and psychiatric disorders further complicate FM, negatively impacting patients' family life, work, and social interactions more severely than other chronic painful conditions (3-5).

FM not only burdens patients but also imposes significant functional and psychological challenges on their relatives, who often provide informal caregiving support (6, 7). These patients frequently rely on unpaid informal support from family members or friends to assist with daily tasks, as in many countries, formal caregiving support is unavailable due to the lack of recognition of FM as a qualifying condition. Informal caregivers assist with daily tasks such as personal care, meal preparation, household chores, and financial management. Studies report that FM patients frequently rely on family members, with caregiving demands often affecting the caregivers' own productivity and quality of life (8, 9). For instance, 86% of FM patients have difficulty performing household tasks, with 44% relying on family members, and 27% of caregivers altering their work activities due to caregiving responsibilities (10).

Chronic caregiving burdens affect employed caregivers by reducing work productivity, both through absenteeism and presenteeism (11). In FM, caregiving demands often fall on spouses or cohabitants, who may experience fatigue, burnout, and impaired work performance due to the strain (12).

Unlike other rheumatic diseases, FM lacks visible symptoms such as swelling, making it difficult for caregivers to validate the patient's pain (13). Additionally, unlike conditions such as stroke, dementia, and cancer, the absence of visible physical disability and less impaired cognitive functions in FM patients may lead to insufficient support from the external environment (14, 15). While social support systems are generally more active in most chronic illnesses, FM is often perceived as exaggerated by the patient or as a psychological disorder. This contributes to psychological distress and strained relationships between the caregiver and the patient (16).

Despite the significant caregiving burden associated with FM, the impact of FM on the work productivity of informal caregivers has not been thoroughly explored. This study aims to evaluate these impacts, highlighting the need for targeted interventions to support both FM patients and their caregivers.

Methods

Patients

Patients diagnosed with FM who applied to our Physical Medicine and Rehabilitation clinic and their caregivers, between June 2024 and November 2024, were included in the study. Patients were included regardless of whether they were newly diagnosed or had a previous diagnosis of FM. The revised 2016 American College of Rheumatology (ACR) criteria were used to diagnose FM (17).

The term 'caregiver' refers to an adult family member or trusted person who helps the patient perform activities of daily living. This person is a member of the patient's family and supports the care of the loved one without charge. Inclusion criteria for FM informal caregivers in the study were as follows: being in good health, aged between 18–65 years, living in the same household as the FM patient, and holding either full-time or part-time employment. A healthy control group of the same age range and similar gender was established. Close family members of the control group who lived in the same household and were employed either full-time or part-time were included as control group relatives.

The study protocol did not require any medical intervention. The study protocol was approved by Basaksehir Cam and Sakura City Hospital Ethics Committee with the decision number, 2023-645. Also, ClinicalTrials Identifier is NCT06357793. All the patients and their caregivers signed a written informed consent to participate in this study.

Power analysis and sample size calculation were conducted using G*Power version 3.1.9.7 software to determine the adequate sample size for the "t-test: the difference between two independent means". Based on a desired power of 0.95 [α (Type I error) =0.05 and β (Type II error) =0.05] and prior study (18), the effect size was set to d=0.69, yielding a total sample size of n=112. For this study, 66 individuals per group were planned. This calculation was designed to ensure sufficient statistical power to detect meaningful differences in the specific outcomes assessed in this study, such as work productivity loss and reductions in quality of life. The selected effect size of 0.69 reflects the magnitude of differences we aimed to observe.

Evaluation

FM patients, their caregivers, healthy controls, and their relatives were asked to complete a demographic information form. For FM patients, the duration and treatment history of FM were recorded. Additionally, the Revised Fibromyalgia Impact Questionnaire (FIQR) was completed by the FM patients. The Work Productivity and Activity Impairment Questionnaire-General Health (WPAI-GH) and the World Health Organisation Quality of Life Scale-Short Form (WHOQOL-BREF) were administered to the caregivers and control group relatives.

Questionnaires

1. Revised Fibromyalgia Impact Questionnaire (FIQR); FIQR is an assessment and evaluation instrument developed to measure FM patient status, progress, and outcomes. It consists of 21 items, and 11-point numerical rating scales (0-10) that investigate three main domains about the previous week. The Turkish version of the scale, whose validity and reliability studies were conducted by Ediz *et al.*, was used in the study (19).
2. Work Productivity and Activity Impairment Questionnaire - General Health (WPAI-GH): Participants responded to a set of six single-choice questions. The first question assesses the participant's current employment status. The second question asks about work hours lost due to health problems, the third question inquires about work hours lost due to other reasons, the fourth question requests total work hours, the fifth question examines the impact of health status on productivity, and the sixth question evaluates the effect of health status on normal daily activities outside of work. Questions two, three, and four are quantified in hours. The fifth question uses a global pain scale from 0 to 10 (0: "my health issues/caregiving responsibilities have no effect on my work" to 10: "my health issues/caregiving responsibilities completely prevent me from working"). The sixth question also uses a global pain scale from 0 to 10 (0: "my health issues/caregiving responsibilities have no effect on my daily activities" to 10: "my health issues/caregiving responsibilities completely prevent me from engaging in daily activities"). This questionnaire covers the previous seven days, excluding the day of evaluation. Responses are expressed as impairment percentages; higher numbers indicate greater impairment and reduced productivity (20). The validity and reliability of the Turkish version of this questionnaire were established by Bucak *et al.* (21).
3. World Health Organisation's Quality of Life-BREF (WHOQoL-BREF) scale: The WHOQoL-BREF consists of 26 questions, each scored between 1 and 5, covering physical health, psychological, social relations and environmental domains (22). The Turkish version of the WHOQOL-BREF underwent a validity and reliability assessment in 1999 (23). When the Turkish version is used (question 27 is included) the environmental domain score is called environment-TR. Scores for each domain are calculated separately, and the raw scores are then converted to a 0–100 scale. Higher scores indicate better QoL. The WHOQoL-BREF scale was chosen due to its frequent use in studies evaluating the quality of life of informal caregivers of chronic illnesses (24-26). This tool provides a comprehensive assessment by emphasising domains such as social relationships and environmental factors, making it particularly suitable for understanding the caregiving experience and its impact on work life.

Statistical analysis

The data obtained in the study were analysed using IBM SPSS 25.0 (Statistical Package for the Social Sciences). The normal distribution of parameters was assessed with the Shapiro-Wilk test. Data in the study are presented as percentages (%), mean ± standard deviation (SD), minimum, median, and maximum values. Comparisons between the two groups were performed using the Chi-square or Fisher's exact test for categorical variables and the Mann-Whitney U-test for parametric data. Pearson and Spearman's tests were used for correlation analyses. Statistical significance was set at $p<0.05$.

Results

Our study included 68 FM caregivers and 68 healthy controls. The demographic data of patients and controls are detailed in Table I. Among the demographic data of patients and controls, only body mass index (BMI) showed a statistically significant difference, with no statistically significant differences in other variables. Among FM patients, the mean FIQR score was 55.37±12.48, while the average duration since diagnosis was 3.91±4.26 years.

Of the patients, 26.5% had not received any treatment. The treatments received by the patients, listed from most to least common, included duloxetine, combined use of duloxetine with pregabalin, exercise, pregabalin alone, physiotherapy, and amitriptyline (41.2%, 10.3%, 10.3%, 7.4%, 2.9%, 1.9%, respectively) Table II.

The demographic data of FM patient caregivers and control group relatives are provided in Table III. No differences were observed in the demographic data between FM caregivers and control group relatives. A statistically signifi-

Table I. Demographic characteristics of participants.

Participants	FM patient	Healthy control	*p*-value
Total	68	68	
Gender			0.511
Male	4 (5.9%)	6 (8.8%)	
Female	64 (94.1%)	62 (91.2%)	
Age (mean±SD)	44.59 ± 6.32	42.82 ± 6.12	0.058
BMI (mean±SD)	27.70 ± 3.85	26.39 ± 3.43	**0.046***
Working type			0.356
Desk worker	23 (33,8%)	28 (41,2%)	
Physically active worker	17 (25%)	20 (29,4%)	
Not working/retired	28 (41,2%)	20 (29,4%)	
Educational status			0.075
Primary school	34 (50%)	21 (30,9%)	
High school	22 (32,4%)	31 (45,6%)	
University	12 (17,6%)	16 (23,5%)	
Marital status			0.154
Single	2 (2.9%)	0 (0.0)	
Married	66 (97.1%)	68 (100.0%)	
Smoking			0.271
No	43 (63.2%)	49 (72.1%)	
Yes	25 (36.8%)	19 (27.9%)	
Alcohol			0.382
No	60 (88.2%)	63 (92.6%)	
Yes	8 (11.8%)	5 (7.4%)	

$^*p<0.05$. BMI: Body Mass Index; SD: standard deviation; FM: fibromyalgia.

Table II. Treatment types and disease severity among FM patients.

FM treatment (count %)	No	18	26.5%
	Yes	50	73.5%
Type of treatment (count %)	No	18	26.5%
	Duloxetine	28	41.2%
	Pregabalin	5	7.4%
	Amitriptyline	1	1.5%
	Pregabalin + Duloxetine	7	10.3%
	Physical Therapy	2	2.9%
	Exercise	7	10.3%
FIQR (mean ± SD)	55.36 ± 12.47		
FM diagnosis time (year) (mean ± SD)	3.91 ± 4.26		

SD: standard deviation; FM: fibromyalgia; FIQR: Revised Fibromyalgia Impact Questionnaire.

cant difference was found in the daily working hours between FM caregivers and control group relatives (*p*=0.029). There were no significant differences between caregivers and control group relatives in terms of their total duration of employment (time since they began working) or the number of days they worked per week.

The WPAI and WHOQoL-BREF scores of FM caregivers and control group relatives were compared with the subscales displayed in Table IV. The WPAI-caregiver four subscales resulted: work time missed (absenteeism) 0.44% (SD 2.51), impairment while working (presenteeism) 15.15% (SD 24.59), overall work productivity loss (absenteeism + presenteeism) 15.32% (SD 24.81), and activity impairment 22.79% (SD 26.19). A statistically significant difference was detected in all comparisons except for WPAI work time missed (*p*<0.05).

There was a statistically significant difference in all domains evaluated by WHOQoL-BREF in FM caregivers compared to the control group relatives (*p*<0.05). A statistically significant negative correlation was found between the WHOQoL-BREF social relationships domain of FM caregivers and the FIQR scores of FM patients (*p*=0.026, r=-0.269) (Fig. 1). No statistical significance was found between FIQR scores and WPAI and other WHOQoL domains (*p*>0.05).

Discussion

Individuals who become ill or can no longer carry out daily activities require someone to assist them. Caregiving is typically provided by cohabiting spouses, children or friends, is unpaid, and often by already employed individuals. Upon reviewing the literature, interest in this topic is evident, with studies examining the relationship between caregiving for various disease groups and work productivity. The need for caregiving is common among individuals with general aging, cancer, dementia, lupus, stroke, disabilities, and chronic pain-causing musculoskeletal disorders (8, 11, 27). Considering that FM, similarly, imposes significant caregiving demands, we hypothesised that FM caregivers might experience a loss in workforce participation and productivity, prompting the planning of this study.

Demographic data were statistically evaluated to ensure no differences between the patient and healthy control groups. Among the FM patients included in the study, 94.1% were female. Literature similarly reports that 75-90% of FM patients are female (28). In our study, 58.8% of FM patients were employed. Despite cross-country variations, literature indicates that approximately 50% of FM patients are employed at the time of initial diagnosis (29). Up to 97% of FM patients are married, thus most informal caregivers, whose productivity and quality of life we analysed, were men (94%) and spouses (94%). Previous studies on informal FM caregivers, often focused on spouses, showed a 100% participation

Table III. Demographic characteristics of relatives of FM patients and controls.

Relatives	FM caregiver	Control relative	*p*-value
Total	68	68	
Relation			0.404
Partner	64 (94.1%)	66 (97.1%)	
Daughter/son	4 (5.9%)	2 (2.9%)	
Gender			0.145
Male	64 (94.1%)	59 (86.8%)	
Female	4 (5.9%)	9 (13.2%)	
Age mean±SD	45.57 ± 9.41	44.31 ± 6.35	0.094
BMI mean±SD	25.20 ± 2.01	25.81 ± 2.04	0.073
Working type			0.169
Desk worker	32 (47.1%)	40 (58.8%)	
Physically active worker	36 (52.9%)	28 (41.2%)	
Educational status			0.152
Primary school	26 (38.2%)	17 (25.0%)	
High school	25 (36.8%)	25 (36.8%)	
University	17 (25.0%)	26 (38.2%)	
Marital status			0.145
Single	6 (8.8%)	2 (2.9%)	
Married	62 (91.2%)	66 (97.1%)	
Smoking			0.226
No	35 (51.5%)	42 (61.8%)	
Yes	33 (48.5%)	26 (38.2%)	
Alcohol			0.259
No	59 (86.8%)	63 (92.6%)	
Yes	9 (13.2%)	5 (7.4%)	
Working duration (year)			
mean±SD	16.50 ± 11.38	19.46 ± 7.14	
(min/med/max)	0.00/16.50/40.00	6.00/20.00/37.00	0.055
Weekly work (day)			
mean±SD	5.38 ± 0.77	5.53 ± 0.66	
(min/med/max)	3.00/5.00/7.00	4.00/5.00/7.00	0.234
Daily work (hours)			
mean±SD	8.66 ± 1.82	9.53 ± 1.77	
(min/med/max)	4.00/8.00/12.00	8.00/8.00/12.00	**0.006***

BMI: body mass index; SD: standard deviation; FM: fibromyalgia.

rate, primarily men (16,30). Although our study did not require marriage as an inclusion criterion, the requirements of full or part-time employment and cohabitation led to predominantly male participation.

A statistically significant difference in BMI was observed between FM patients and the control group, supporting the idea that FM patients may lead a more sedentary lifestyle due to chronic pain. However, it should also be noted that high BMI may not solely result from sedentary but could also be influenced by systemic low-grade inflammation, disruptions in endocrine function, and alterations in opioid systems (31).

All relatives included in the study were employed full-time or part-time. The average daily working hours for FM caregivers were 8.5, while the control group averaged 9.5, with this difference being statistically significant. The WPAI evaluates absenteeism (missed work time), presenteeism (impaired productivity at work), and overall work productivity loss by combining these domains. While disease-specific WPAI versions offer tailored insights, the WPAI-GH is a broader tool addressing any physical or emotional issue (11). It has been widely used to assess productivity in healthy informal caregivers (32-34). Unlike previous studies on FM caregivers, which used de novo questionnaires focusing solely on absenteeism (9), our study is the first to assess absenteeism, presenteeism, and overall work impairment using an international scale.

In the previous study, work time missed among FM patient caregivers was found to be 0.75%, whereas, in our study, it was 0.44%, a similarly low rate in both studies. (9). By contrast, caregiving for cancer patients (33), was associated with 9.7% absenteeism, 12.8% for lupus (32), 9% for inflammatory bowel disease (IBD) (34), and 9% among caregivers of post-stroke patients with spasticity (35). One of the key findings in our study is that caregivers of FM patients experienced a 15% decrease in work productivity, a statistically significant difference compared to the control group relatives. Mazanec *et al.* reported a 15.4% impairment rate in caregivers of cancer patients (33). For IBD caregivers (34) and post-stroke caregivers (35) overall productivity loss was 21%, 27% respectively. It was found to be significantly higher than absenteeism.

Despite attending work, presenteeism was observed among FM caregivers. Since FM is not a condition that causes physical disability or bed dependency, it does not prevent caregivers from attending work. However, our study has demonstrated that caregiving responsibilities profoundly impact work productivity. Caregivers often face psychological burdens, such as the emotional strain of managing an invisible illness like FM, where symptoms are not visibly apparent, making validation of the patient's pain challenging. This emotional toll, combined with the demands of daily caregiving tasks, including personal care, household responsibilities, and medical coordination, contributes to mental fatigue and reduced productivity at work. The observed presenteeism underscores how caregiving responsibilities can impair caregivers' ability to focus and perform effectively, even when physically present at work. The WPAI measures impairments in daily living activities. These include activities that are not directly related to work. The results of both the presenteeism and the activity impairment, support the conclusion

Table IV. Work productivity and quality of life scores for FM caregivers and control relatives.

Group		FM caregiver mean ± SD (min/med/max)	Control relative mean ± SD (min/med/max)	*p*-value
WPAI-GH	Worktime miss	0.44±2.51 0.00/0.00/19.35	0.03±0.24 0.00/0.00/1.96	0.301
	Impairment of productivity while at work	15.15±24.59 0.00/0.00/80.00	6.91±15.48 0.00/0.00/70.00	**0.039***
	Overall loss of work productivity	15.32±24.81 0.00/0.00/83.87	6.93±15.50 0.00/0.00/70.00	**0.038***
	Impairment in activities of daily living	22.79±26.19 0.00/10.00/80.00	13.24±21.33 0.00/0.00/80.00	**0.020***
WHOQoL-BREF	General health	52.76±22.63 0.00/50.00/100.00	71.14±11.88 25.00/75.00/100.00	**<0.001***
	Physical	63.76±18.53 3.57/60.71/100.00	74.32±16.41 28.57/78.57/100.00	**<0.001***
	Psychological	63.17±15.93 29.17/62.50/100.00	70.04±9.37 37.50/70.83/83.33	**<0.001***
	Social relationships	62.62±19.50 16.67/66.67/100.00	72.43±12.74 33.33/75.00/91.67	**<0.001***
	Environment-TR	53.31±15.88 12.50/53.13/84.38	59.56±12.38 28.13/59.38/84.38	**0.007***

WPAI-GH: Work Productivity and Activity Impairment questionnaire-General Health; WHOQoL-BREF: World Health Organisation Quality of Life Scale-Short Form; SD: standard deviation; FM: fibromyalgia.

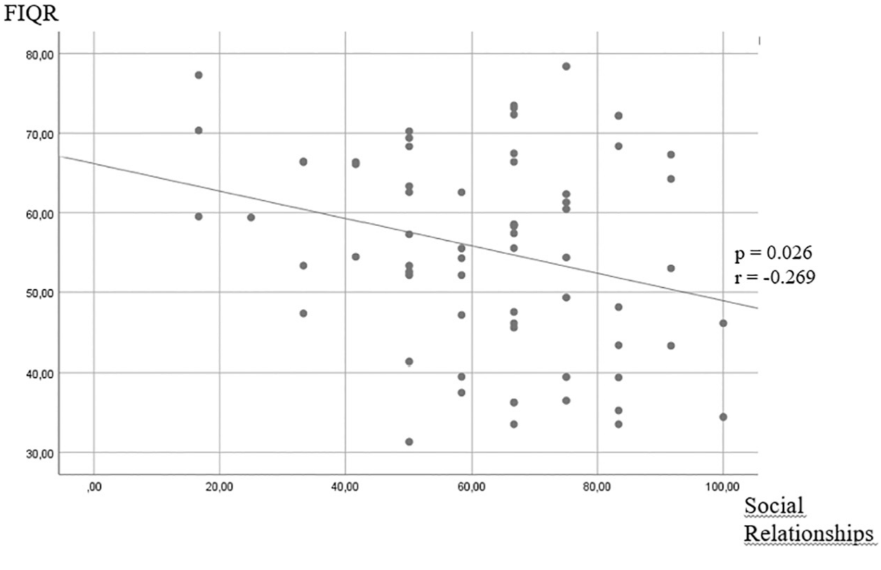

Fig. 1. FIQR correlation with WHOQoL-BREF social relationships.
This scatterplot illustrates the negative correlation between the Revised Fibromyalgia Impact Questionnaire (FIQR) scores and the social relationships domain scores of the WHOQoL-BREF for caregivers. The trend line indicates that higher FIQR scores, reflecting greater FM severity, are associated with lower social relationship scores, suggesting a decline in the caregivers' perceived quality of their social interactions.

that living with FM creates a heavy burden on the caregivers, affecting not only their professional life but also their overall well-being.

Studies on FM caregivers, particularly spouses, have increased recently (36-38). Research topics of interest include the impact of FM on daily activities, mood states, sexual relationships, and social interactions of spouses or relatives. In a recent systematic review by Goltzman *et al.* it was found that FM had an increased effect on depression, a moderate effect on worsening quality of life, and a low effect on sleep quality, sexual life and marital satisfaction (39). In the literature review, the SF-36 scale has generally been used to assess the quality of life of family members or caregivers of FM patients (18, 32, 37, 40). However, we could not find any study using the WHOQoL-BREF scale, as we did. Studies on the quality of life among informal caregivers of other chronic illnesses, such as cancer, cerebral palsy, and stroke, frequently used the WHOQoL-BREF scale (24-26). Research indicates that although SF-36 and WHOQoL measure some similar domains, they differ in specific areas emphasised by WHOQoL, particularly in social relationships and environmental factors (41). SF-36 focuses more prominently on specific health statuses. In our study, the inclusion criteria for family members required them to be healthy, leading to the conclusion that a scale like WHOQoL would be more appropriate than SF-36. The environmental domain of WHOQoL is one of the areas that SF-36 either neglects or places less emphasis on. WHOQoL provides a comprehensive approach by including environmental factors such as living conditions, safety, financial situation, and access to healthcare, which are precisely the areas we aimed to evaluate in terms of quality of life for FM patients' family members (42). In our study, WHOQoL's environmental domain was found to be significantly lower compared to the control group. Due to the absence of an environment domain in SF-36-based studies, no comparison could be made.We know that the domains of physical function (SF-36) and physical health (WHOQOL-BREF), mental health (SF 36) and psychological (WHOQOL-BREF), social function (SF-36) and social relationships (WHOQOL-BREF) are similar. As observed in most of the studies before, evaluation of the quality of life of the individual living with FM compared to control groups or the general population consistently demonstrates a moderate reduction in quality of life

(39). Tutoglu *et al.* and Celepkolu *et al.*, in their study using SF-36, found social function to be nonsignificant in a comparison between spouses and controls (18, 37).

In our study, while the domain of social relationships was found to differ significantly, the social relationships domain of caregivers of FM patients with high FIQ scores was also correlated with a lower value. This finding suggests that the psychological and emotional demands of caregiving, exacerbated by the severity of the patient's symptoms, may challenge caregivers' ability to maintain healthy social relationships. As demonstrated in the study by Cheong *et al.* (43), holistic protocols that include both patients and caregivers could be implemented across countries. These comprehensive treatments could involve pilot studies incorporating physiotherapy, psychotherapy sessions, art therapy, massage therapy, and social skills training. We believe that integrated healthcare models addressing the needs of both patients and caregivers could improve social relationship quality and enhance caregivers' overall well-being.

Our study had certain limitations. Among these was the need to highlight differences among participants and FM syndrome characteristics, as well as the requirement for analyses with a larger number of patients for subgroup assessments of WPAI and WHOQoL. The cross-sectional design of our study may also lead to potential biases arising from unmeasured variables, such as caregivers' personality traits or patient-caregiver dynamics. These factors could have influenced the observed outcomes and should be considered in future longitudinal studies to provide a more comprehensive understanding.

Conclusion

The findings of the study and referenced literature have shown that individuals living with and providing care for FM patients experience deterioration in both work life and quality of life. Considering the chronic nature and relatively early onset of FM, the obligation for spouses, partners, and relatives of these patients to provide long-term care presents a rather discouraging picture. Therefore, offering an integrative healthcare service that rehabilitates both the patient and their informal caregivers in the same session, as well as providing psychotherapy support for caregivers; could be considered among potential solutions. More extensive and prospective studies should be planned to support these recommendations.

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