

Limitations in Activities of Daily Living Among Spanish Women Diagnosed With Endometriosis

Mario Lozano-Lozano, Antonio Mundo-López, Ainhoa P. San-Sebastian, Noelia Galiano-Castillo, Carolina Fernandez-Lao, Irene Cantarero-Villanueva, Manuel Arroyo-Morales, Olga Ocón-Hernández, Francisco Artacho-Cordón

Importance: Understanding the impact of endometriosis symptoms on patients' activities of daily living (ADLs) is a priority to establish effective and personalized intervention programs.

Objective: To explore limitations in ADLs and instrumental ADLs (IADLs) and their association with pelvic pain (PP), chronic fatigue, and pain-catastrophizing thoughts among women with endometriosis.

Design: Cross-sectional study.

Setting: Spain.

Participants: Two hundred thirty women with endometriosis.

Outcomes and Measures: Information regarding performance of ADLs (Barthel Index) and IADLs (Lawton–Brody questionnaire), PP intensity (Numeric Rating Scale), chronic fatigue (Piper Fatigue Scale), and pain-catastrophizing thoughts (Pain Catastrophizing Scale) was gathered. Multivariate regression analyses were created, and mediating effects of fatigue and pain-catastrophizing thoughts on the association between PP and ADL and IADL limitations were assessed.

Results: The prevalence of limitations in at least one ADL and one IADL was 22.6% (95% confidence interval [CI] [17.2, 28.1]) and 39.1% (95% CI [32.8, 45.5]), respectively. Limitations in bowel continence, housework, shopping, and meal preparation were reported most frequently. Women reporting severe PP showed higher risk for ADL (odds ratio [OR] = 3.33, 95% CI [1.10, 10.10]) and IADL (OR = 7.99, 95% CI [2.86, 22.34]) limitations. Chronic fatigue and pain-catastrophizing thoughts were also positively related to ADL–IADL limitations, showing a mediating effect on the association between PP and ADL–IADL limitations.

Conclusions and Relevance: This study reveals the widespread presence of difficulties in ADL–IADL performance among women with endometriosis, with some symptoms underlying these difficulties in occupational performance. This study points to the need for cost-effective occupational therapy interventions for affected women.

What This Article Adds: This research shows that the occupational performance of women with endometriosis is frequently impaired; therefore, the effectiveness of occupational therapy interventions should be addressed in the near future.

Endometriosis, a common condition among women characterized by the growth of endometrium-like tissue outside of the uterus, is a chronic, painful, and inflammatory disease (As-Sanie et al., 2019); it has an estimated prevalence of up to 15% among women of reproductive age and up to 50% among women with infertility problems (Soliman et al., 2019). Of relevance, endometriosis mainly affects premenopausal women, which has a huge socioeconomic impact. The estimated annual economic burden can reach \$119 billion in the United States because of direct costs, such as hospitalization and medication; indirect costs, including workplace absenteeism and presenteeism (Soliman et al., 2017); and time lost completing household chores (Soliman et al., 2018).

The main and most incapacitating symptom of endometriosis is pain (including pelvic pain [PP], dysmenorrhea, dyspareunia, and back pain; Rush & Misajon, 2018). Because pain is often accompanied by a delay in diagnosis

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(Soliman et al., 2018) and other symptoms associated with the disease (e.g., reduced mobility, bloating, fatigue), endometriosis often leads to the development of psychological changes (Márki et al., 2017); social and relationship problems; lower quality of life (Nnoaham et al., 2011); and decreased vitality, energy, and time for activities (Young et al., 2015). All these symptoms, reported by most women throughout the course of the disease, could affect all occupational domains, as reported by some authors (e.g., Fagervold et al., 2009). However, the impact of endometriosis on the occupational performance of activities of daily living (ADLs) has been poorly addressed.

Unlike other chronic conditions in which symptoms are related to ADL dysfunction (Cheong et al., 2019), no research has reported on the impact of endometriosis symptoms on ADLs. Thus, the aim of the current study was to explore the presence of difficulties in the performance of ADLs and instrumental activities of daily living (IADLs) among women diagnosed with endometriosis. Moreover, we were interested in identifying potential factors related to these ADL and IADL limitations.

Method

Study Population

In this cross-sectional study, we recruited 230 women with a clinical diagnosis of endometriosis from all regions of Spain from January to July 2019. Gynecologists and Spanish associations of patients with endometriosis helped during the recruitment process through advertisements of the study in their social networks. Interested women were invited to participate in the study, informed about the nature and objectives of the study, and asked to read and sign the informed consent.

Inclusion criteria included attending a gynecological visit with any of the participating gynecologists, belonging to any of the Spanish associations of patients with endometriosis, having a clinical diagnosis of endometriosis, and having the ability (and availability) to use an electronic device with an Internet connection (i.e., computer, tablet, or mobile phone). Exclusion criteria included being younger than age 18 yr, living in a country other than Spain, and being a non-Spanish speaker.

This study was approved by the Research Ethics Committee of Granada (Comité de Ética de la Investigación Biomédica de la Provincia de Granada; No. 1733-N-18).

ADL and IADL Assessment

ADLs were assessed with the Barthel Index (Bernaola-Sagardui, 2018; Mahoney & Barthel, 1965). It has shown good reliability and validity, with a Cronbach's α coefficient $>.70$ (Bernaola-Sagardui, 2018).

The Lawton-Brody questionnaire was used for IADL evaluation (Lawton & Brody, 1969). It has shown excellent reliability and validity, with a Cronbach's α coefficient of $.94$ (Vergara et al., 2012).

For both assessments, *ADL and IADL limitation* was defined as difficulty with or need for assistance to carry out activities.

Evaluation of Pain, Fatigue, and Pain-Related Catastrophizing Thoughts

Pain intensity was assessed with the Numeric Rating Scale (Boonstra et al., 2016). This 11-point Likert scale (0 = *no pain*; 10 = *unbearable pain*) is an internationally validated scale, is a quick self-administered instrument with which to obtain information, and has been shown to be one of the best single-item methods to estimate pain intensity in women with endometriosis (Bourdel et al., 2015). Women were asked to report intensity of current pelvic pain, last week pelvic pain (lwPP), dysmenorrhea, dyspareunia, dyschezia, and dysuria. Pain severity was categorized as mild (0–3), moderate (4–7), and severe (8–10), as reported elsewhere (Boonstra et al., 2016).

Chronic fatigue was assessed with the Piper Fatigue Scale (PFS; [Cantarero-Villanueva et al., 2014](#); [Piper et al., 1998](#)). The PFS is a validated 22-item tool with high reliability and validity (Cronbach's $\alpha = .86$) ranging from 0 to 10. Participants were divided into two groups according to the clinically significant fatigue criteria: nonfatigued (≤ 3.9) or fatigued (≥ 4 ; [O'Regan & Hegarty, 2017](#); [Piper et al., 1998](#)).

Pain-related catastrophizing thoughts were assessed with the Pain Catastrophizing Scale (PCS; [García Campayo et al., 2008](#); [Sullivan et al., 1995](#)), a 13-item, validated, self-report instrument with adequate reliability (Cronbach's $\alpha = .79$). Scores range from 0 to 52, with higher scores representing higher levels of catastrophizing thoughts.

Covariates

Sociodemographic information (age, civil status, schooling, residence, and job status) and gynecological characteristics (number of children, severity of premenstrual syndrome [PMS], type of endometriosis, and time since its diagnosis) were recorded.

Statistical Analysis

Continuous variables were summarized as means, standard deviations, and quartiles, whereas categorical variables were expressed as the number and percentage of women in each category. Associations among pain, fatigue, and catastrophizing thoughts in ADL and IADL limitations were accomplished through bivariate and multivariate unconditional logistic regression analyses adjusted for potential confounders (age, schooling, civil status, number of surgeries, type of endometriosis diagnosis, time since diagnosis, number of children, and severity of PMS). Additional multivariate models adjusted for lwPP intensity were conducted. Statistical significance was set at .05. IBM SPSS Statistics (Version 23) was used for statistical analyses, and figures were created with GraphPad Prism (Version 5.0; GraphPad Software, San Diego, CA). The mediation effect of fatigue and pain-catastrophizing thoughts on the relationship between pain and ADL and IADL limitations was assessed with the macro PROCESS for IBM SPSS Statistics ([Hayes, 2017](#)). Associations were considered significant when zero was not located within the confidence intervals (CIs).

Results

Participants

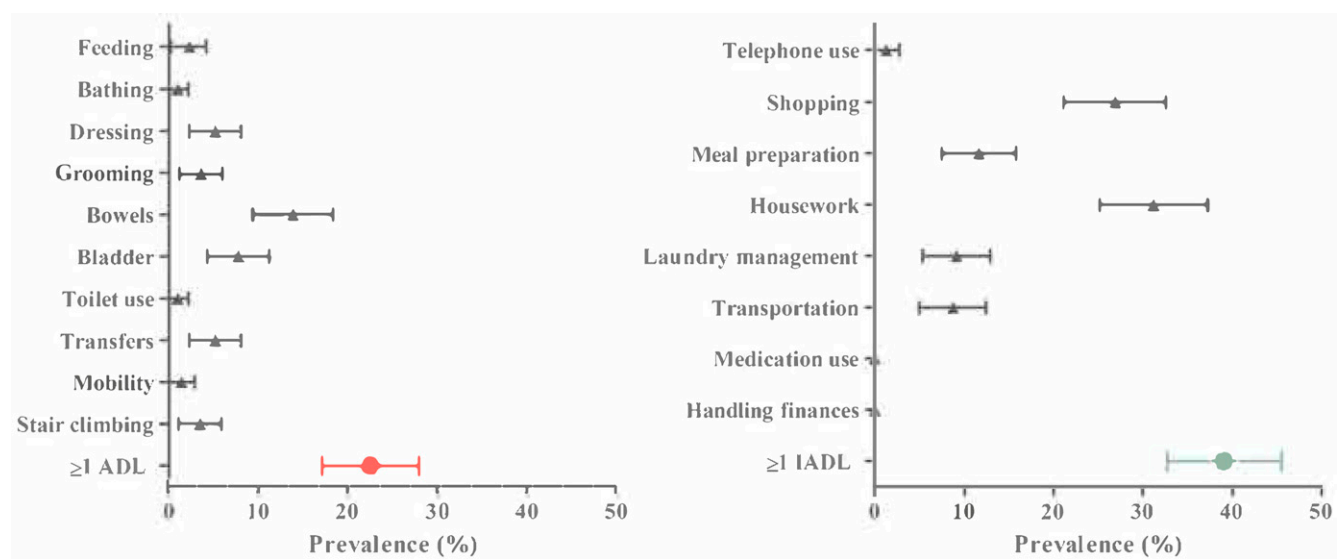
Regarding characteristics of the study population, the mean age was 36.7 yr ($SD = 5.2$), and the majority of women held a university degree and worked outside the home; in addition, of the 230 women, 30 (13.0%) were on sick leave, and 26 (11.3%) had loss of work because of endometriosis symptoms. Only 68 women (29.6%) had children, and the majority of women reported experiencing moderate to severe PMS. Concerning endometriosis history, two-thirds had a laparoscopic diagnosis of endometriosis, and the mean time since endometriosis diagnosis until study recruitment was 5.0 yr ($SD = 5.3$). Moderate to severe lwPP was reported by 176 women (76.5%), whereas chronic fatigue was observed in 196 women (85.2%). The mean PCS score was 27.9 ($SD = 13.7$). Intensity of self-reported pain ranged from a mean of 3.0 ($SD = 3.2$) for women with dysuria to 7.9 ($SD = 2.3$) for women with dysmenorrhea.

ADL and IADL Limitations and Influence of Endometriosis-Related Symptoms

As shown in [Figure 1](#), the prevalence of limitations in at least one ADL and IADL was 22.6% (95% CI [17.2, 28.1]) and 39.1% (95% CI [32.8, 45.5]), respectively. Limitations related to bowel and bladder continence (among ADLs) and related to housework, shopping, and meal preparation (among IADLs) were the most prevalent. The overall prevalence of limitations in any ADL was 45.7% (95% CI [39.2, 52.1]; data not shown in figure).

[Figure 2](#) shows self-reported intensities of endometriosis-related pain, chronic fatigue, and pain-catastrophizing thoughts according to the presence of limitations in any ADLs or IADLs. Thus, higher intensity of any type of pain and

Figure 1. Prevalence of ADL and IADL limitations.



Note. Error bars represent the 95% confidence interval of the prevalence. ADLs = activities of daily living; IADLs = instrumental activities of daily living. Circles and triangles represent the prevalence of areas of limitation in the study sample.

higher scores for fatigue and pain-catastrophizing thoughts were found among women with limitations in at least one ADL or IADL. Logistic models adjusted for potential confounders revealed a positive trend between lwPP severity and the risk of limitations in ADLs and IADLs (Table 1). Similar models were sequentially created considering other types of pain, reaching similar results (data not shown). Moreover, increased risk for ADL and IADL limitations was observed among patients with fatigue in fully adjusted models (the latter almost reaching statistical significance). Moreover, PCS scores were identified as being related to higher risk for ADL limitations.

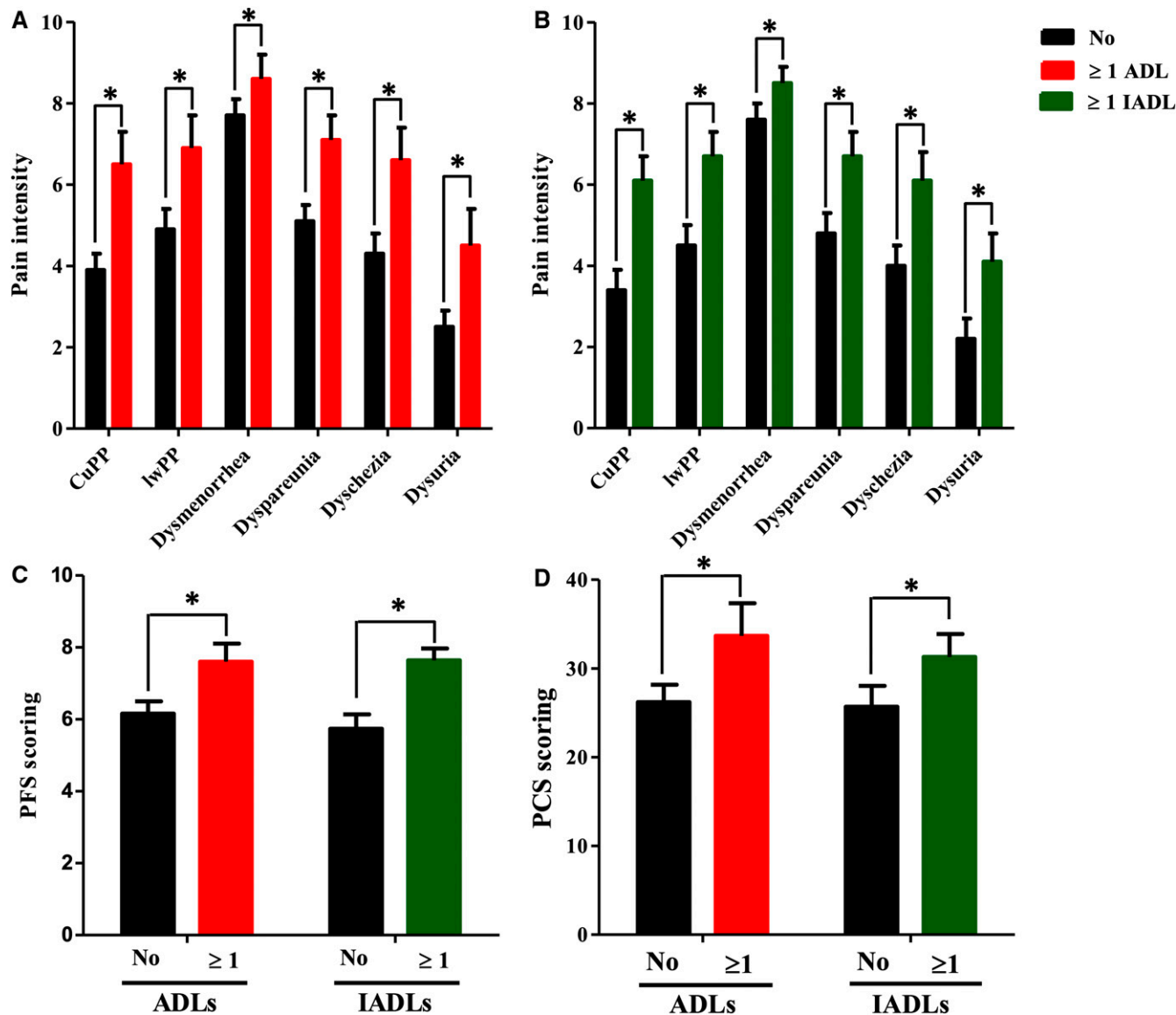
Figure 3 represents the mediating effects of chronic fatigue and catastrophizing thoughts in the relationship between lwPP and ADL and IADL limitations. As shown, the influence of pain severity on ADL performance was partially explained through the presence of chronic fatigue (indirect effect ranging from .03 to .11; $p < .05$). A similar significant indirect effect of catastrophizing thoughts was found in the relationship between lwPP and ADL limitations, and between lwPP and total ADL limitations (.02 and .03, respectively; $p < .05$), but not for IADL limitations.

Discussion

This study offers the first evidence regarding the high prevalence of difficulties in the performance of ADLs and IADLs among women with endometriosis. We found difficulties in at least one ADL and IADL among nearly 50% of the participating women, with IADLs being affected the most frequently. Moreover, we identified that lwPP, fatigue, and pain-catastrophizing thoughts influenced these ADL and IADL limitations.

Difficulties in the performance of ADLs and IADLs were frequently reported among women with endometriosis, especially those women with more complex, energy-consuming IADLs. Despite being an initial study, our findings are in accordance with research suggesting that endometriosis-related PP is severe enough to lead to the development of psychosocial alterations; moreover, it can also lead to decreased vitality, energy, and time for activities, all of which negatively affect occupational performance (Márki et al., 2017). Considering patients experiencing chronic pain, our

Figure 2. Associations between ADL and IADL limitations and (A) pain in ADLs, (B) pain in IADLs, (C) chronic fatigue, and (D) pain-catastrophizing thoughts.



Note. Error bars represent the 95% confidence interval of the mean. ADLs = activities of daily living; CuPP = current pelvic pain; IADLs = instrumental activities of daily living; IwPP = last week pelvic pain; PCS = Pain Catastrophizing Scale; PFS = Piper Fatigue Scale. * $p < .05$.

findings are in line with a systematic review that found a limitation prevalence of 36.7% and 54.6% for ADLs and IADLs, respectively, among adults with cancer (Neo et al., 2017).

Moreover, considering another study with older adults that showed lower prevalence rates than our results—17.13% and 35.75% of participants reported limitations in at least one ADL and IADL, respectively (Ćwirlej-Sozańska et al., 2019)—our results highlight the impact of a “benign” disease on the daily life of patients who are affected

Table 1. Relationships Between ADL and IADL Limitations and Pelvic Pain, Chronic Fatigue, and Pain-Catastrophizing Thoughts

Variable	Adjusted Analysis ^a			Adjusted Analysis ^b		
	OR	95% CI	p	OR	95% CI	p
ADLs						
lwPP						
Moderate (4–7)	1.30	[0.45, 3.71]	.630			
Severe (8–10)	3.33	[1.10, 10.10]	.034			
Chronic fatigue ^c	4.65	[1.29, 16.71]	.019	3.69	[0.98, 13.97]	.054
PCS score	1.04	[1.01, 1.07]	.007	1.03	[1.00, 1.07]	.024
IADLs						
lwPP						
Moderate (4–7)	2.58	[1.05, 6.35]	.040			
Severe (8–10)	7.99	[2.86, 22.34]	<.001			
Chronic fatigue ^c	5.49	[2.08, 14.54]	.001	3.59	[1.32, 9.80]	.013
PCS score	1.02	[1.00, 1.05]	.092	1.01	[0.99, 1.04]	.389
ADLs + IADLs						
lwPP						
Moderate (4–7)	2.11	[0.92, 4.86]	.078			
Severe (8–10)	6.96	[2.60, 18.60]	<.001			
Chronic fatigue ^c	4.74	[1.99, 11.28]	<.001	3.29	[1.33, 8.13]	.010
PCS score	1.03	[1.00, 1.05]	.022	1.02	[0.99, 1.05]	.119

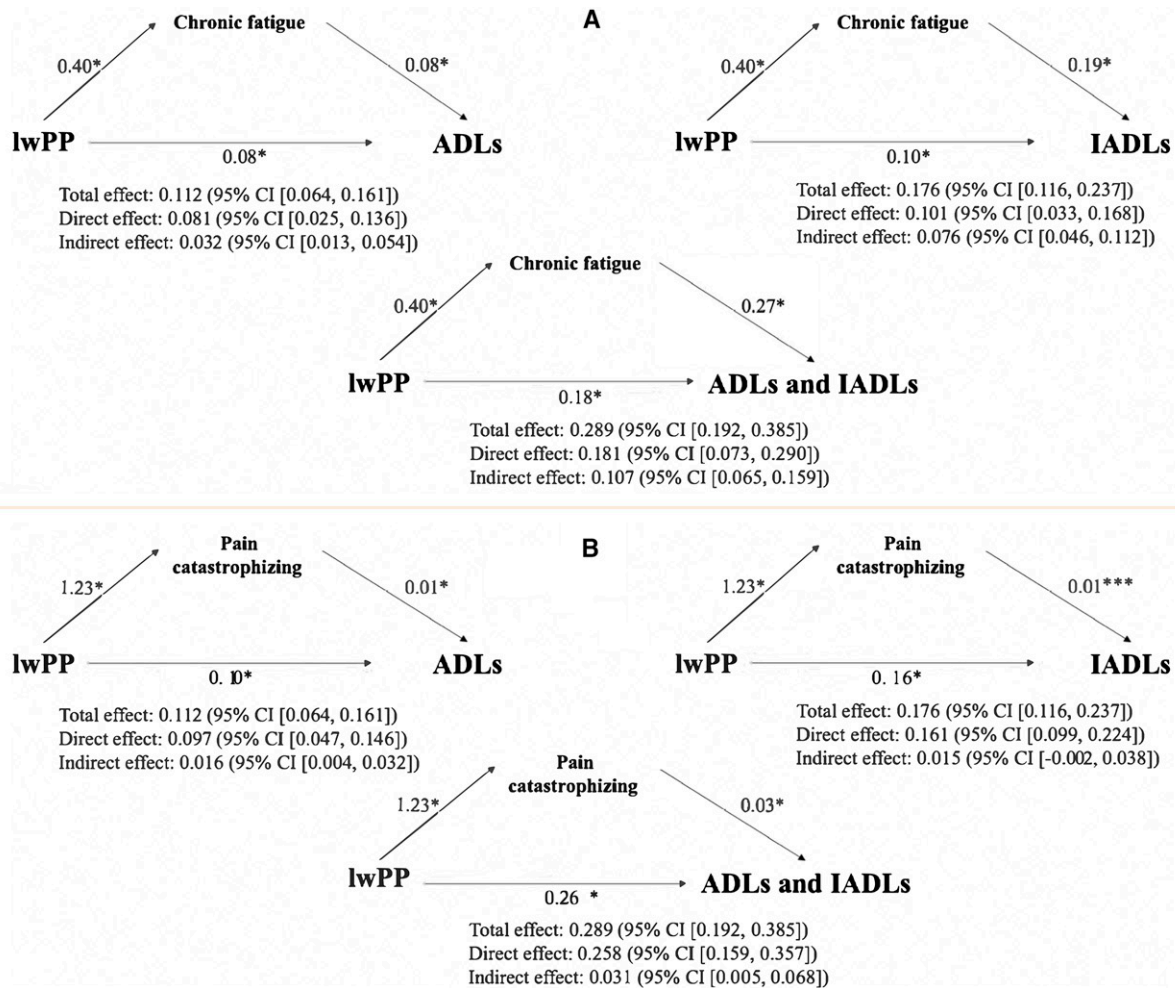
Note. Associations with a $p < .05$ are in **boldface**. ADLs = activities of daily living; CI = confidence interval; IADLs = instrumental activities of daily living; lwPP = last week pelvic pain (average intensity); OR = odds ratio; PCS = Pain Catastrophizing Scale.
^aAdjusted for age (years), schooling, civil status, number of surgeries, type of diagnosis, time since diagnosis, number of children, and premenstrual syndrome severity. ^bAdditionally adjusted for lwPP. ^cAssessed with the Piper Fatigue Scale.

(Mehedintu et al., 2014). Because women with endometriosis are usually old enough to be in the workforce, and because the economic burden of people with some ADL and IADL limitations is higher than for those without limitations (Chen et al., 2019; Kabiri et al., 2018), it is plausible that deterioration in occupational performance may lead to increased socioeconomic burden for this population of women.

Our results indicate lower occupational performance among women with higher levels of PP and fatigue, suggesting that these endometriosis-related symptoms might underlie the functional impairment observed in these patients. This hypothesis is partially supported by previous literature reporting that an important mediator of disability among women is body pain (Fowler-Brown et al., 2013). Similarly, another study showed that multimorbidity-related pain was responsible for approximately one-fifth of the occupational performance impairment in community-dwelling adults (Peng et al., 2020). Charalambous et al. (2019) also identified pain and fatigue as mediators between cancer diagnosis and the reduction of quality of life and physical performance. In accordance with our results, they also suggested that fatigue could mediate the relationship between pain and quality of life in this population.

In our study, we also showed that pain-catastrophizing thoughts may play a relevant role as a mediator in the relationship between pain and occupational impairment. However, the exact underlying mechanisms by which symptoms correlate with one another are not yet fully understood (Finnegan-John et al., 2013; Santos Salas et al., 2016; Wilkie & Ezenwa, 2012). Nevertheless, although our cross-sectional design hampers the elucidation of causal effects, our results indicate that the integral management of these symptoms through the development of effective multimodal

Figure 3. Mediation effect of (A) chronic fatigue and (B) pain-catastrophizing thoughts on the association between self-reported intensity of pain and ADL and IADL limitations.



Note. ADLs = activities of daily living; CI = confidence interval; IADLs = instrumental activities of daily living; lwPP = last week pelvic pain. * $p < .05$; *** $p < .001$.

interventions for women with endometriosis might improve their occupational performance, thereby decreasing their economic burden.

Limitations

Despite the large number of participants and the use of validated scales, which allow a precise characterization of the outcomes, this study has certain limitations. The cross-sectional design hampered the elucidation of causal effects, given that the temporality of endometriosis-related symptoms and occupational performance cannot be definitively established. Moreover, the clinical staging of endometriosis could not be considered because many women reported


that they did not know the different endometriosis stages. Finally, because data were mainly collected with self-reported questionnaires, an information bias could have been introduced.

Implications for Occupational Therapy Practice

The results of this study have the following implications for occupational therapy practice:

- Women with endometriosis present with complications in occupational performance in both ADLs and IADLs.
- Understanding these difficulties is a priority for the development of effective multimodal interventions that include occupational therapy to improve women's occupational performance.
- A multimodal occupational therapy intervention can reduce the economic burden related to endometriosis.
- Interventions could include equipment and environmental adaptation and energy conservation or relaxation techniques to improve endometriosis-related symptoms and difficulties in performing ADLs and IADLs.

Conclusion

To our knowledge, this study constitutes the first evidence of the widespread presence of ADL and IADL limitations among women with endometriosis. In addition, we identified potential factors related to these ADL and IADL limitations. Thus, although future research with longitudinal designs needs to be performed to confirm our findings, the results highlight the need for integral intervention approaches in the management of endometriosis-related symptoms. These interventions may have a positive effect on women's occupational performance and, in turn, may lead to a considerable decrease in the annual economic burden of endometriosis. 

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Mario Lozano-Lozano, PhD, is Postdoctoral Researcher, Instituto de Investigación Biosanitaria ibs. Granada; Occupational Therapist Researcher, “Cuidate” Support Unit for Oncology Patients, Sport and Health University Research Institute; and Associate Professor, Department of Physiotherapy, University of Granada, Granada, Spain; mlozano@ugr.es

Antonio Mundo-López, PhD, is Postdoctoral Researcher, Instituto de Investigación Biosanitaria ibs. Granada, University of Granada, Granada, Spain, and Psychologist, Clinic Psychology Center Alarcón, Granada, Spain.

Ainhoa P. San-Sebastian, BsC, is Occupational Therapist, Department of Radiology and Physical Medicine, University of Granada, Granada, Spain.

Noelia Galiano-Castillo, PhD, is Professor, Instituto de Investigación Biosanitaria ibs. Granada; Physiotherapist Researcher, “Cuidate” Support Unit for Oncology Patients, Sport and Health University Research Institute; and Professor, Department of Physiotherapy, University of Granada, Granada, Spain.

Carolina Fernández-Lao, PhD, is Researcher, Instituto de Investigación Biosanitaria ibs. Granada; Physiotherapist Researcher, “Cuidate” Support Unit for Oncology Patients, Sport and Health University Research Institute; and Professor, Department of Physiotherapy, University of Granada, Granada, Spain.

Irene Cantarero-Villanueva, PhD, is Researcher, Instituto de Investigación Biosanitaria ibs. Granada; Physiotherapist Researcher, “Cuidate” Support Unit for Oncology Patients, Sport and Health University Research Institute; and Professor, Department of Physiotherapy, University of Granada, Granada, Spain.

Manuel Arroyo-Morales, PhD, MD, is Researcher, Instituto de Investigación Biosanitaria ibs. Granada; Physiotherapist Researcher, “Cuidate” Support Unit for Oncology Patients, Sport and Health University Research Institute; and Professor, Department of Physiotherapy, University of Granada, Granada, Spain.

Olga Ocón-Hernández, PhD, MD, is Researcher, Instituto de Investigación Biosanitaria ibs. Granada, University of Granada, Granada, Spain, and Doctor, Gynaecology and Obstetrics Unit, San Cecilio University Hospital, Granada, Spain.

Francisco Artacho-Cordón, PhD, is Researcher, Instituto de Investigación Biosanitaria ibs. Granada; Physiotherapist Researcher, “Cuidate” Support Unit for Oncology Patients, Sport and Health University Research Institute; and Professor, Department of Radiology and Physical Medicine, University of Granada, Granada, Spain, and Centro de Investigación Biomédica en Red, Epidemiology and Public Health, Madrid, Spain.

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