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RESEARCH PAPER

ALEXITHYMIA AND LONELINESS IN WOMEN WITH ENDOMETRIOSIS. TESTING THE FACTORIAL STRUCTURE OF THE ITALIAN ENDOMETRIOSIS HEALTH PROFILE (EHP-30) AND A MEDIATION MODEL

Francesca Gioia, Anna Parola, Valentina Boursier

Abstract

Objective: Endometriosis is a pathological condition characterized by endometrial-like tissue outside the uterus, chronic inflammatory reaction, and pelvic pain that dramatically decrease women's health-related quality of life (HRQoL). Furthermore, this invisible and difficultly diagnosable disease might lead women to experience alexithymia, loneliness, and consequent impairment of perceived quality of life. Firstly, the present study aimed at validating the Italian EHP-30 version which is the most used specific questionnaire for HRQoL measurement. Secondly, the present study aimed at exploring the still understudied relationship between alexithymia and HRQoL in endometriosis conditions, evaluating the mediating role of perceived loneliness.

Method: A total of 435 women with endometriosis (mean age=35.75 years) have been involved. All items were loaded on their own factors.

Results: The measure showed good internal consistency (Cronbach's α ranged between 0.60-0.95 for core and 0.74-0.94 for modular parts). The Italian EHP-30 is a psychometrically valid measure of HRQoL with endometriosis. The tested mediation model provided adequate goodness-of-fit indices ($\chi 2$ (51) = 206.071; $p < 0.001$; RMSEA = 0.084; 90%CI: 0.072, 0.096, CFI = .933, SRMR= 0.058), showing that alexithymia only indirectly affected women's perceived HRQoL, via the mediating effect of feelings of loneliness.

Conclusions: The current study highlighted the pivotal role of perceived loneliness in directly affecting women's quality of life and mediating the effect of the alexithymic experiences.

Key words: women, endometriosis, quality of life, validation, italian

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Introduction

Endometriosis is a benign pathological condition characterized by endometrial-like tissue outside the uterus (such as on the pelvic peritoneum, ovaries, rectovaginal septum, and rarely on the diaphragm, pleura, and pericardium), which induced chronic inflammatory reaction and pelvic pain, (Bianco et al., 2021; Giudice, 2010; Luisi et al., 2009). This chronic, frequently progressive, and relapsing disease is one of the most spread gynecologic conditions reported by women of reproductive age, especially Caucasian women (Bougie et al., 2019; Maiorana et al., 2012; Nogueira-Silva et al., 2015). Indeed, despite difficulties in estimation and asymptomatic conditions (Cramer & Missmer, 2002; Morassutto et al., 2016), it is thought that approximately 200 million women suffer from endometriosis worldwide (Endometriosis Worldwide March, 2021). In Italy, 10-15% of reproductive-age women are affected by endometriosis, for a total of at least 3 million patients (Migliaretti et al., 2012; Ministero della Salute, 2021).

The pain symptoms typically associated with endometriosis are dysmenorrhea, dyspareunia, dysuria, and dyschezia, deeply affecting women's physical, mental, and social wellbeing (Maiorana et al., 2012; Nogueira-Silva et al., 2015). In addition, the strictly related infertility and abnormal bleeding generally led to psychological stress, low self-esteem, depression, and feelings of loneliness and frustration (Jia et al., 2012; Jones et al., 2001; Nogueira-Silva et al., 2015). Furthermore, endometriosis has been found in association with other gynecological and systemic comorbidities, such as immune (i.e., asthma, rheumatoid arthritis, psoriasis, and multiple sclerosis), inflammatory (bowel inflammatory disease and Crohn's disease), and psychiatric disorders (depression and anxiety) (Chen et al., 2021; Kvaskoff et al., 2015; Surrey et al., 2018; Vannuccini et al., 2018). Finally, as Bianco et al. (2021) and Lazzeri et al. (2015) suggested, women affected by endometriosis often experience problems in their self-care, work productivity, social, sexual, and emotional daily life. Overall, the endometriosis diagnosis dramatically decreases women's health-related quality of life (HRQoL) (Bourdel et al., 2019; Chen et al., 2021; Facchin et al., 2017; Jia et al., 2012; Jones et al., 2001; Maiorana et al., 2012).

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Quality of life, loneliness, and alexithymia in women with endometriosis

The HRQoL has been defined as a multidimensional and dynamic concept, including physical, psychological, and social issues related to a disease or its treatment (Jia et al., 2012; Nogueira-Silva et al., 2015; Verket et al., 2018). Over the last decades, the assessment of HRQoL has been increasingly involved in clinical studies and routine clinical management, using patient-reported outcome measures (Jia et al., 2012; Verket et al., 2018). However, despite a generic HRQoL measure might be spent with patients affected by a variety of conditions, disease-specific instruments might point out important aspects of certain conditions inaccessible by generic instruments (Verket et al., 2018). In this regard, Nogueira-Silva et al. (2015) highlighted that for an optimal approach to endometriosis, the women's subjective assessment of perceived quality of life represents a crucial issue and a growing concern, increasingly underlined by both health professionals and patients (Bourdel et al., 2019). As largely reported, several experiences dramatically impact the HRQoL of women with endometriosis, including pain, more perceived stress, many psychological symptoms of anxiety and depression, and impairment of intimate and social relationships with experienced loneliness and social isolation (Culley et al., 2013; Della Corte et al., 2020; Mor & Efrati, 2021; Rush & Misajon, 2018). Accordingly, in a recent qualitative study, Cole et al. (2021, p. 171) described endometriosis as "the most lonely condition I can imagine", using a participant's words. Indeed, women with endometriosis often reported a lack of social support, other people's doubt concerning the severity of their disease, difficulties to disclose their condition and symptoms because of embarrassment or a fear of not being understood or believed (Culley et al., 2013; Rush & Misajon, 2018). The invisibility of endometriosis seems to lead to experiences of loneliness and isolation (Culley et al., 2013; Karavadra et al., 2019; Rush & Misajon, 2018) and the health professionals' delay in diagnosis and treatment of endometriosis might enhance perceived social isolation (Cole et al., 2021; Mor & Efrati, 2021; Shoebotham & Coulson, 2016; Young et al., 2020), concerns, worries, anxiety, self-blame, and financial and relationship difficulties, impairing women's perceived HRQoL (Ballard et al., 2006; Culley et al., 2013; Nnoaham et al., 2011; Seear, 2009). In addition, difficulties to identify, label, and describe feelings that have been found more likely related to interpersonal problems and loneliness (Qualter et al., 2009), might impact on women's perceived HRQoL as well.

Alexithymia represents a subclinical experience of lacking emotional awareness and consists of difficulty identifying and describing feelings and externally oriented thinking with negative consequences in emotion regulation (Luminet & Zamariola, 2018). Individuals who experience alexithymia and impaired capacity to describe and share their own feelings are more likely to report interpersonal problems, poor intimate communication and social support networks, and feel lonely and disconnected from others (Conti et al., 2023; Qualter et al., 2009; Vanheule et al., 2007). Experiences of alexithymia have been observed in several chronic somatic diseases in which physical pain represents a core symptom (Aaron et al., 2019); nevertheless, studies in the endometriosis field (in which physical pain represents one of the main symptoms) are still limited (Cavaggioni et al., 2014; Kalfas et al., 2022; Melis et al., 2014). In this regard, the inability to recognize feelings might lead to increased somatization or serve as a defense mechanism against mental and physical pain (Aaron et al., 2019; Bailey & Henry, 2007; Di Tella & Castelli, 2016). Therefore, as Melis et al. (2014) stated, alexithymic experiences are related to low general health and physical health, but further evidence is still needed.

Therefore, the present study firstly aimed at evaluating the psychometric properties and validating the Italian version of the Endometriosis Health Profile-30 (EHP-30; Jones et al., 2001), an ad-hoc developed specific endometriosis scale recommended by the American Society for Reproductive Medicine (ASRM) and the European Society of Human Reproduction and Embryology (Nogueira-Silva et al., 2015; Vincent et al., 2010), in Italian women diagnosed with endometriosis. The EHP-30 was developed starting from interviews of patients with endometriosis (Jones et al., 2001) and it is made up of two parts: a core questionnaire that consists of 30 items and that is applicable to all women with endometriosis, relating to five dimensions (pain, control and powerlessness, emotions, social support, and self-image), and a modular questionnaire that is not applicable to all women (such as for those who have no children) and that includes 23-item with six subscales (work life, relationship with children, sexual intercourse, medical profession, treatment, and infertility). Response categories are rated on a five-point Likert scale (0–4) and each EHP-30 scale is translated into a scoring system ranging from 0-100, by which 0 represents the best possible health status and 100 the worst possible health status. The EHP-30 has been validated in many languages (i.e., Dutch, Chinese, Iranian and Portuguese) and Maiorana et al. (2012) evaluated some psychometric properties of the Italian version of EHP-30, suggesting that this measure might represent a useful and effective alternative to the generic HRQoL instruments, such as the SF-36. However, an Italian validation of EHP-30 is still lacking.

Secondly, the present study aimed at exploring the still understudied relationship between alexithymia and HRQoL in endometriosis conditions, evaluating the mediating role of perceived loneliness. Indeed, previous findings widely described the endometriosis conditions as experiences of loneliness and social isolation (Cole et al., 2021; Mor & Efrati, 2021; Shoebotham & Coulson, 2016; Young et al., 2020), in which women often feel not being understood or believed. Furthermore, previous studies highlighted the association between loneliness and alexithymia in chronic conditions (Conti et al., 2023; Qualter et al., 2009; Vanheule et al., 2007). More specifically, as Conti et al. (2023) highlighted, a direct association between alexithymia and loneliness has been reported, since alexithymia might lead to people's difficult intimate communication, consequent poor social support, and feelings of disconnection from others and isolation. Furthermore, considering the common experiences of loneliness among women with endometriosis (Cole et al., 2021; Culley et al., 2013; Rush & Misajon, 2018), they might reasonably mediate the relationship between alexithymia and women's perceived HRQoL. However, only a few studies focused on the alexithymic experiences in women with endometriosis (Cavaggioni et al., 2014; Kalfas et al., 2022; Melis et al., 2014); whereas, to our knowledge, no studies explored the direct and indirect effects of alexithymia and loneliness on the HRQoL in endometriosis conditions.

Table 1. *Core questionnaire: item descriptive statistics and CFA*

	Descriptive statistics				CFA					
	Mean	*SD*	Skewness	Kurtosis	Pain(λ)	Control and powerless(λ)	Emotional well-being(λ)	Social support(λ)	Self-image(λ)	R^2
Item 1	2.97	1.258	-0.153	-1.009	0.84*					0.71
Item 2	3.2	1.23	-0.347	-0.868	0.91*					0.83
Item 3	3.37	1.305	-0.521	-0.822	0.93*					0.86
Item 4	2.92	1.358	-0.045	-1.221	0.77*					0.59
Item 5	3.26	1.294	-0.417	-0.911	0.90*					0.80
Item 6	3.41	1.244	-0.556	-0.627	0.93*					0.87
Item 7	2.6	1.297	0.19	-1.152		0.63*				0.39
Item 8	3.34	1.325	-0.486	-0.911		0.79*				0.63
Item 9	3.61	1.31	-0.722	-0.588		0.86*				0.74
Item 10	3.44	1.282	-0.56	-0.728		0.95*				0.90
Item 11	2.96	1.33	-0.119	-1.131		0.74*				0.54
Item 12	3.25	1.201	-0.128	-0.86		0.74*				0.55
Item 13	3.41	1.394	-0.363	-1.166		0.87*				0.76
Item 14	3.53	1.388	-0.527	-1.006		0.84*				0.70
Item 15	3.87	1.249	-0.782	-0.563		0.45*				0.09
Item 16	3.37	1.375	-0.257	-1.172		0.86*				0.74
Item 17	2.77	1.376	0.173	-1.188		0.81*				0.66
Item 18	2.75	1.277	0.251	-0.978			0.81*			0.65
Item 19	3.76	1.183	-0.764	-0.29			0.88*			0.78
Item 20	3.51	1.186	-0.509	-0.649			0.85*			0.73
Item 21	3.91	1.097	-0.793	-0.186			0.86*			0.74
Item 22	3.68	1.154	-0.578	-0.576			0.89*			0.80
Item 23	2.3	1.245	0.648	-0.642			0.53*			0.28
Item 24	3.35	1.282	-0.306	-0.921				0.43*		0.09
Item 25	3.92	1.247	-0.952	-0.203				0.63*		0.40
Item 26	3.79	1.303	-0.828	-0.454				0.84*		0.71
Item 27	3.22	1.328	-0.273	-1.047				0.78*		0.62
Item 28	3.43	1.412	-0.377	-1.155					0.87*	0.76
Item 29	3.59	1.286	-0.525	-0.816					0.86*	0.74
Item 30	3.14	1.293	-0.106	-1.038					0.83*	0.68

Note. SD= standard deviation; CFA = confirmatory factor analysis; λ = factor loading. * $p < .001$.

Methods

Participants and procedure

A total of 435 women, aged between 19 and 55 years (mean age = 35.75 years; SD = 6.72), responded to an online survey. A snowball sampling method was adopted to recruit participants through advertisements in Italian Internet communities, forums, and other online groups (via social media platforms, such as Facebook) of women with endometriosis, and the groups' members were asked for dissemination in their turn. A website link was contained in the call for participation in the online study. Before completing the questionnaire, all of the participants were informed about the research aims, scopes, and the measures to be used in generating the data. Participation was voluntary, and confidentiality and anonymity were assured. The participants could withdraw from the study at any time. The study was approved by the University Research Ethics Committee and was conducted according to the ethical guidelines for psychological research established by the Italian Psychological Association (AIP).

Measure

Sociodemographic Information. Information was collected about age, educational level, being employed, being a mother, and years of delayed diagnosis.

Endometriosis Health Profile-30 (EHP-30; Jones et al., 2001). Participants were asked to complete the Italian version of the core (30 items) and modular (23 items) questionnaires of the EHP-30 (Jones et al., 2001). The scale comprises a total of 53 items rated on a five-point-Likert scale, from 0 (*never*) to 4 (*always*) and evaluates the women's perceived health-related quality of life with endometriosis. The translation of the questionnaire followed the standard guidelines for translating questionnaires (Van de Vijver & Hambleton, 1996). Two native Italian-speaking clinical researchers translated the items. Later, the translation has been reviewed by Italian-speaking experts in clinical research. Then, the

Table 2. *Modular questionnaire: item descriptive statistics and CFA*

	Descriptive statistics				CFA						
	Mean	*SD*	Skewness	Kurtosis	Work(λ)	Relationship with child/children(λ)	Sexual intercourse(λ)	Feelings about medical profession(λ)	Feelings about treatment(λ)	Feelings about infertility(λ)	R^2
Item 1	2.7	1.165	0.064	-0.902	0.92*						0.85
Item 2	2.64	1.161	0.054	-0.966	0.95*						0.90
Item 3	3.01	1.34	-0.117	-1.141	0.91*						0.83
Item 4	2.76	1.547	0.194	-1.472	0.91*						0.82
Item 5	3.21	1.405	-0.261	-1.181	0.92*						0.86
Item 1	2.87	1.21	-0.022	-0.912		0.87*					0.76
Item 2	2.83	1.165	-0.093	-0.903		0.99*					0.90
Item 1	3.42	1.286	-0.282	-1.041			0.95*				0.90
Item 2	3.43	1.301	-0.464	-0.834			0.97*				0.95
Item 3	3.23	1.221	-0.419	-0.696			0.96*				0.91
Item 4	3.5	1.555	-0.564	-1.213			0.98*				0.97
Item 5	3.64	1.442	-0.66	-0.948			0.99*				0.98
Item 1	2.51	1.268	0.328	-0.984				0.94*			0.88
Item 2	2.1	1.259	0.88	-0.367				0.95*			0.91
Item 3	3.61	1.407	-0.603	-0.961				0.95*			0.90
Item 4	2.39	1.421	0.611	-0.95				0.92*			0.85
Item 1	2.99	1.31	0.055	-1.06					0.88*		0.78
Item 2	3.39	1.318	-0.351	-0.964					0.94*		0.89
Item 3	3.39	1.38	-0.328	-1.156					0.93*		0.86
Item 1	4.8	0.446	-2.096	3.832						0.99*	0.90
Item 2	4.32	1.181	-1.638	1.584						0.99*	0.99
Item 3	4.29	1.099	-1.652	2.198						0.99*	0.99
Item 4	3.08	1.523	-0.117	-1.439						0.97*	0.96

Note. SD= standard deviation; CFA = confirmatory factor analysis; λ = factor loading. * $p < .001$.

back-translation has been performed by a professional bilingual translator involved in the previous step of translation. A comparison between the back-translated and original versions of the questionnaire has been conducted by Italian and English-speaking natives.

Toronto Alexithymia Scale-20 (TAS-20; Bressi et al., 1996; for the original English version Bagby et al., 1994). The TAS-20 is rated on a 5-point Likert-type scale, and responses range from 1 (*strongly disagree*) to 5 (*strongly agree*). The TAS-20 has a three-factor structure: difficulty in identifying feelings (assessing the ability to identify own feelings and to distinguish between feelings and bodily sensations of emotional arousal; e.g., "*I am often confused about what emotion I am feeling*"); difficulty in describing feelings (the inability to communicate his own feelings to other people; e.g., "*It is difficult for me to find the right words for my feelings*"); and the externally oriented thinking (e.g., "*I prefer to analyze problems rather than just describe them*"). The TAS-20 showed good internal consistency (α = 0.81).

Italian Loneliness Scale (ILS; Zammuner, 2008). The ILS is a 20-item self-report scale rated on a 4-point Likert scale, from 1 (*never*) to 4 (*always*) that evaluates perceived loneliness. The measure included three subscales: emotional loneliness focused on

Table 3. *Core questionnaire: item-total correlation*

Dimension	Item-total correlation
Pain (α = 0.95; *n* = 435)	
Item 1	0.77
Item 2	0.86
Item 3	0.86
Item 4	0.70
Item 5	0.84
Item 6	0.87
Item 7	0.61
Item 8	0.76
Item 9	0.82
Item 10	0.88
Item 11	0.66
Control and powerlessness (α = 0.87; *n* = 435)	
Item 12	0.67
Item 13	0.82
Item 14	0.77
Item 15	0.40
Item 16	0.80
Item 17	0.72
Emotional well-being (α = 0.86; *n* = 435)	
Item 18	0.63
Item 19	0.71
Item 20	0.69
Item 21	0.74
Item 22	0.75
Item 23	0.46
Social Support (α = 0.60; *n* = 435)	
Item 24	0.42
Item 25	0.49
Item 26	0.54
Item 27	0.46
Self-image (α = 0.79; *n* = 435)	
Item 28	0.71
Item 29	0.72
Item 30	0.49

Table 4. *Modular questionnaire: item-total correlation*

Dimension	Item-total correlation
Work (α = 0.87; *n* = 327)	
Item 1	0.68
Item 2	0.73
Item 3	0.69
Item 4	0.66
Item 5	0.73
Relationship with child/ children (α = 0.77; *n* = 136)	
Item 1	0.63
Item 2	0.63
Sexual intercourse (α = 0.92; *n* = 265)	
Item 1	0.73
Item 2	0.83
Item 3	0.78
Item 4	0.81
Item 5	0.86
Feelings about medical profession (α = 0.81; *n* = 272)	
Item 1	0.67
Item 2	0.70
Item 3	0.57
Item 4	0.62
Feelings about treatment (α = 0.74; *n* = 312)	
Item 1	0.51
Item 2	0.63
Item 3	0.57
Feelings about infertility (α = 0.75; *n* = 59)	
Item 1	0.43
Item 2	0.71
Item 3	0.79
Item 4	0.46

emotional abandonment and missing companionship (e.g., "*I experience a general sense of emptiness*"); social loneliness assessing feelings of sociability and of having significant relationships (e.g., "*There are many people whom I can count on completely*"); and general loneliness focused on feelings of isolation (e.g., "*I feel isolated from others*"). In light of the high Pearson's r correlations among the ILS factors (0.683, $p < 0.001$ between emotional and social loneliness; 0.862, $p < 0.001$ between emotional and general loneliness; 0.742, $p < 0.001$ between social and general loneliness), a total score was generated that included emotional, social, and general loneliness, which showed a good internal consistency (α = 0.71).

Data analysis

All the analyses were run in Mplus 8.0. Firstly, an Exploratory Factor Analysis has been conducted on the 30-items of the EHP-30 with the weight least square adjusted for mean and variance (WLSMV) estimator and geomin rotated solution. Secondly, the Confirmatory Factor Analysis (CFA), applying the WLSMV estimator, has been performed to assess the structural validity of five first-order factors of the core questionnaire of EHP-30 and the six first-order factors of the modular questionnaire. Thirdly, the five first-order factors of the core questionnaire were specified as indicators of independent second-order factors. The procedure was performed following the recommendation of EFA and CFA use (Schmitt, 2011).

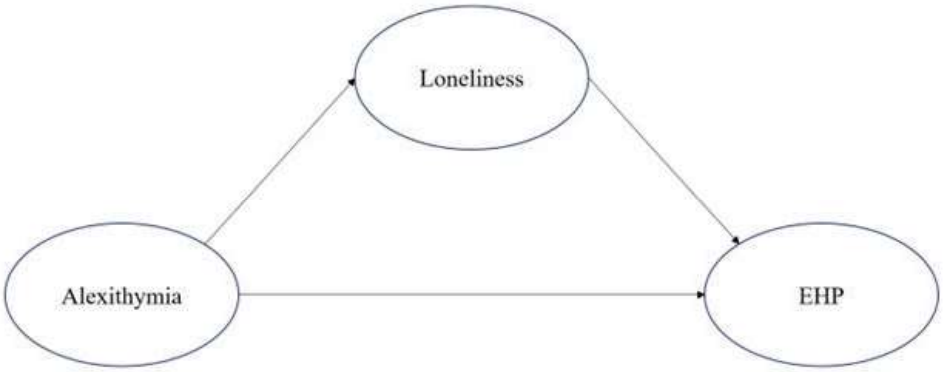
Factorial validity was assessed by several fit indexes, including the comparative fit index (CFI), the Tucker-Lewis index (TLI), and the root mean square error of approximation (RMSEA). The following criteria were used as cutoffs for satisfactory fit: the CFI and the TLI

Table 5. *Descriptive statistics of eleven dimensions of the endometriosis health profile-30 core and modular Italian questionnaires*

Domain	*n*	Mean	SD	median	25th percentile	75th percentile
Core questionnaire						
Pain	435	49	4.24	49	46	52
Control and powerlessness	435	24.5	0.71	24.5	24	25
Emotional well-being	435	27.5	0.71	27.5	27	28
Social Support	435	16.50	0.71	16.50	16	17
Self-image	435	13.50	2.12	13.50	12	15
Modular questionnaire						
Work	327	11.5	4.95	11.5	8	15
Relationship with child/ children	136	6	1.41	6	5	7
Sexual intercourse	265	20.5	6.36	20.5	16	25
Feelings about medical profession	272	5.5	2.12	5.5	4	7
Feelings about treatment	312	9.5	4.95	9.5	6	13
Feelings about infertility	59	19.5	0.71	19.5	19	20

Note. SD= standard deviation

Figure 1. *Tested mediation model*



Note. EHP = Endometriosis Health Profile

value approximately 0.90 or above (Medsker et al., 1994), and RMSEA approximately 0.08 or less (Byrne, 2013). Finally, the inter-correlation and Cronbach's α values for the five dimensions, and the global scale were computed using Pearson's test.

Concerning the mediation analysis, preliminarily, the Pearson correlation coefficient (r) was computed to evaluate the relationship between TAS, ILS, and EHP dimensions. The mediation model (SEM) with latent variables was used using a two-step approach. First, a predictor-only model was specified: TAS (X) predicts EHP (Y). Second, a mediation model was specified: TAS (X) was regressed on EHP (Y) through ILS (M). The goodness of the model was evaluated by using the following goodness of fit indices: χ^2, RMSEA, CFI, and SRMR. The following cut-off criteria were chosen to evaluate the goodness of fit: (a) statistical non-significance of the χ^2, (b) an RMSEA lower than 0.08, (c) a CFI higher than 0.90, and (d) an SRMR lower than 0.08 (Brown, 2015; Hu & Bentler, 1999; Hoyle, 2012).

Considering the score distribution of the measured variables, the maximum likelihood (ML) estimator was used. All the reported regression coefficients were standardized (β). The internal consistencies were evaluated by computing Cronbach's alpha (α).

Results

All the participants reported that they have received a diagnosis of endometriosis, and 46.4% reported infertility problems. Furthermore, 14.9% were single, 31.3% had children, 75.2% were employed, and there was a mean of 8.56 years of delayed diagnosis.

Exploratory Factor Analysis

The Kaiser-Meyer-Olkin measure confirmed the sampling adequacy for the analysis (KMO = .94), and Bartlett's test of sphericity χ^2 (435) = 9403.397, $p <$ 0.001, indicated that the correlations between the items were sufficiently large for EFA. The analysis showed that five components had eigenvalues above Kaiser's criterion of 1 and, in combination, explained 65.69%

of the variance. The five-component structure was also confirmed by Cattell's scree test (Cattell, 1966).

This structure showed a very good fit, χ^2 (295) = 1007.968, CFI = 0.975; TLI = 0.963; RMSEA = 0.075. Each item loaded adequately on the right component and no cross-loadings emerged.

Confirmatory Factor Analysis

Different models were computed with CFA. The first tested model considered five first-order latent variables of the core questionnaire (Pain, Control and powerlessness, Emotional well-being, Social Support, Self-image) and the six first-order latent variables of the modular questionnaire (Work, Relationship with child/children, Sexual intercourse, Feelings about medical profession, Feelings about treatment, Feelings about infertility). This model showed a very good fit, χ^2 (1270) = 3076.625, CFI = 0.981; TLI = 0.979; RMSEA = 0.057. All factor loadings were above 0.60 except for the factor loading of items 15 and 24, respectively 0.45 and 0.43 (Tab. 2-3).

A second-order CFA was tested where a second-order dimension, i.e., *Health-Related Quality of Life with Endometriosis* (HRQoL-E), loaded on the five first-order dimensions of the core questionnaire (pain, control and powerlessness, emotional well-being, social support, self-image). This model showed a very good fit, χ^2 (1299) = 3107.247, CFI = 0.981; TLI=0.979; RMSEA = 0.057. Loadings of the second-order dimension on the first-order dimensions ranged between .51 and .86, indicating that a global score of HRQoL-E might be reliably computed and used.

The Cronbach's α for each scale confirmed the reliability of the measure (Tab.3). Reliability indices revealed an acceptable consistency of each scale, as well as of the overall dimension of HRQoL-E (α = 0.94).

Descriptive statistics

Concerning the core questionnaire, high data completeness (100% in all core dimensions) by the 435 participants was found. As regards the modular questionnaire, the number of women who responded to each dimension depended on personal circumstances, as not all the dimensions could be applied to all patients (i.e., 'work' could not be applied to unemployed participants). Therefore, data completeness varied between 327 women in the 'work' dimension and 59 in the 'feelings about infertility' dimension. The descriptive statistics for the dimensions included in the EHP-30 are shown in **table 5**. As regards the core questionnaire, the 'pain' dimension showed the highest average score (49) and therefore the most negative impact on the quality of life. In addition, the 'self-image' dimension showed the lowest average score (13.5). In the modular questionnaire, the 'sexual intercourse' dimension showed the highest average score (20.5) and the most important negative impact on quality of life, whereas 'feelings about the medical profession' showed the lowest values (5.5) (**table 5**).

Mediation model

Bivariate correlations between all variables have been performed. Significant positive correlations were observed between loneliness and EHP (r = 0.479; p < 0.001) and loneliness and alexithymia (r = 0.119; p < 0.05). On the contrary, alexithymia did not co-occur with EHP.

The hypothesized model (see **figure 1**) provides adequate goodness-of-fit indices: χ^2 (51) = 206.071; p < 0.001; RMSEA = 0.084; 90%CI: 0.072-0.096, CFI = 0.933, SRMR= 0.058. The results showed that TAS was positively associated with ILS (β = 0.121, SE = 0.056, p = 0.031) and ILS was positively associated with EHP (β = 0.580, SE = 0.045, p < 0.001). No direct effect between TAS and EHP was found. The covariate "delayed diagnosis" was positively associated with EHP (β = 0.141, SE = 0.045, p < 0.001). The indirect effect was statistically significant (β = 0.70, SE = 0.33, p < 0.033, 90%CI: 0.007-0.131).

Discussion

Endometriosis is a gynecological condition that is largely associated with a variety of symptoms and dramatically affects women's quality of life. Previous research used both generic and endometriosis-specific instruments to evaluate the impact of this condition on patients' health-related quality of life (Bourdel et al., 2019; Jones et al., 2001). Overall, the generic measures might not gather information about the potentially important areas of well-being and functioning for women with endometriosis, leading to a decreased quality of life (Jones et al., 2001; Verket et al., 2018). On the contrary, the EHP-30 dimensions seem to reflect the many areas of well-being that are affected by endometriosis (i.e., pain, emotions, self-image) (Jones et al., 2001).

The present study firstly involved the psychometric assessment of the Italian version of the EHP-30. Previously, Maiorana et al. (2012) evaluated some psychometric properties of the Italian version of EHP-30, highlighting weak validity and reliability, likely due to the EHP-30 translation into Italian. Nevertheless, they showed that EHP-30 appeared more appropriate than generic tools to assess the quality of life of women with endometriosis. Therefore, consistently with the aims of the present study, the psychometric properties of the Italian version of the EHP-30 have been tested. The CFA confirmed the five-dimension structure of the core questionnaire and the six-dimension structure of the modular questionnaire of EHP-30, supporting their use also in the Italian context. Moreover, according to the findings of the original version, as well as North American, Iranian, and Portuguese versions (Jenkinson et al., 2008; Jones et al., 2001; Nogueira-Silva et al., 2015; Nojomi et al., 2011), the CFA also indicated that a total score (HRQoL-E) can be computed and used to assess the perceived quality of life of women suffering for endometriosis. The Cronbach's α values indicated that the internal consistency was satisfactory for both its dimensions and the total score.

In previous studies, the 'control and powerless' dimension showed a severe and negative impact on the quality of life of women with endometriosis (Chauvet et al., 2017; Grundström et al., 2020; Jones et al., 2001). Differently, in the present study, endometriosis-related pain appeared as the most invalidating factor affecting women's quality of life, confirming the impairment of patients' physical, mental, and social wellbeing (Maiorana et al., 2012; Nogueira-Silva et al., 2015). Similarly, among the modular dimensions, the 'sexual intercourse' dimension seemed to impact women's quality of life highly and negatively. However, in line with previous findings (Chauvet et al., 2017; Jones et al., 2001; Nogueira-Silva et al., 2015; Nojomi et

al., 2011), also concerns regarding possible infertility played an important role in determining the patients' well-being. Likely, the young age of the present sample could impact the pivotal centrality that sexual life and motherhood seemed to have.

After the EHP-30 validation analyses, the present study aimed at exploring the direct and indirect effects of alexithymia and loneliness experiences on the quality of life of women with endometriosis. Indeed, as aforementioned, previous findings showed the association between alexithymia and loneliness experiences in chronic conditions (Conti et al., 2023; Qualter et al., 2009; Vanheule et al., 2007) and the effects of feeling of loneliness and social isolation on the HRQoL in endometriosis conditions (Cole et al., 2021; Mor & Efrati, 2021; Shoebotham & Coulson, 2016; Young et al., 2020). However, to our knowledge, no studies explored the relation among these factors.

Previous findings showed a significant and positive relation between alexithymia and feelings of loneliness, underlining that highly alexithymic people are more likely report poorer perceived social support, fewer close relationships, and more feelings of disconnection from others and loneliness (Frye-Cox & Hesse, 2013; Hesse & Floyd, 2011; Humphreys et al., 2009). Indeed, reduced capacity to talk about, describe, understand, and recognize personal and others' emotions might hinder interpersonal relationships and lead to interpersonal problems and isolation that make difficult the creation of key relationships for the individuals' well-being (Conti et al., 2023; Qualter et al., 2009). Furthermore, in other chronic diseases, alexithymic experiences make it difficult to distinguish between feelings and bodily sensations and describing own emotions (Aaron et al., 2019; Di Tella & Castelli, 2016). Similarly, in the present study, endometriosis patients with difficulties understanding, recognizing, and talking about their emotions might feel lonelier, not understood, or not believed due to the 'invisible disease' (Karavadra et al., 2019).

Interestingly, in the current study, alexithymia did not directly affect the HRQoL in endometriosis conditions. Previous evidence largely highlighted the association between alexithymia and poorer HRQoL in various medical statuses (Di Tella & Castelli, 2016; Iglesias-Rey et al., 2012; Martino et al., 2020; Mattila et al., 2009), but no studies focused on the relation of alexithymia with endometriosis patients' perceived quality of life. Different interpretations of the current lack of direct effect of alexithymia on participants' quality of life are possible. Firstly, as previously conceptualized (Helmes et al., 2008; Parker et al., 1998; Tang et al., 2020; Taylor & Bagby, 2013), alexithymia, in association with defense mechanisms, might represent a coping style against affective stressful situations, including chronic medical illness. Secondly, alexithymia might represent a secondary phenomenon and, inversely to the currently tested model, poor HRQoL in endometriosis conditions might predispose to alexithymia as a defensive state reaction, resulting from prolonged distress caused by poorer health (Mattila et al., 2009; Wise et al., 1990). As Melis et al. (2014) stated, the emotion-related difficulties in endometriosis patients might be explained as an adaptive strategy to a chronic illness. Certainly, further studies focused on this relationship are needed.

According to previous findings (Cole et al., 2021; Mor & Efrati, 2021; Shoebotham & Coulson, 2016; Young et al., 2020), in the present study perceived loneliness is crucial in the experience of women with endometriosis, strongly and negatively impacting on their perceived HRQoL (Culley et al., 2013; Nnoaham et al., 2011). Indeed, women with endometriosis have been found to be reluctant to disclose their condition to others as they often feel embarrassed, disbelieved, and misunderstood, experiencing loneliness as a result of social isolation (Culley et al., 2013; Rush & Misajon, 2018). In this regard, the lack of understanding by familiar individuals and health professionals might lead women to feel more isolated and lonelier with their experience, overwhelmed and powerless facing their condition (Hållstam et al., 2018; Seear, 2009). As previously reported, receiving an endometriosis diagnosis might have some benefits, such as relief from social and work responsibilities, a language to discuss and disclose the problem, the access to assistance in pain management and treatment (Ballard et al., 2006; Seear, 2009), whereas the invisibility of the endometriosis (Karavadra et al., 2019), the related concerns, worries, anxiety, self-blame, financial and relationship difficulties attributable to delays in diagnosis and negative experiences with the medical assistance reduced the women's perceived HRQoL (Ballard et al., 2006; Culley et al., 2013; Nnoaham et al., 2011; Seear, 2009). The present findings confirmed the influence of the delayed diagnosis on the women's perceived quality of life in endometriosis conditions.

Overall, the tested mediation model demonstrated that alexithymia was only indirectly associated with lower quality of life in women with endometriosis, highlighting the pivotal role of perceived loneliness in directly affecting their HRQoL and mediating the effect of the alexithymic experiences. It is possible that endometriosis patients' difficulties in describing, understanding, and recognizing their emotions increased the feelings of being lonely, isolated, likely disbelieved and not understood, which in turn leads to pooper perceived endometriosis-related quality of life.

Limitations

Although the current study contributed to the literature by testing the psychometric properties of the Italian EHP-30, some limitations need to be addressed. Firstly, the present study used a self-report survey with its well-known potential method biases concerning the misunderstanding of measures' purposes and social-desirability bias (Rosenman et al., 2011). Secondly, the problematic recruitment of women with endometriosis is a well-known challenge in the endometriosis research field (Grundström et al., 2020). Indeed, several studies recruited participants in referral centers which might lead to select study groups with an over representation of women with severe symptoms (Chauvet et al., 2017; Grundström et al., 2020; Nogueira-Silva et al., 2015; Nojomi et al., 2011; Verket et al., 2018). On the contrary, the present study recruited participants through an online survey. On the one hand, this sampling method allowed to involve a large number of women with different degrees of symptom severity but, on the other hand, it might be affected by potential weaknesses, such as low representativeness and unclear answering instructions (Evans & Mathur, 2005). Finally, the present study explored only a small number of variables in relation to the complexity of the relationship between endometriosis and women's condition-related experiences, leaving aside the evaluation of the Italian EHP-30 criterion validity. Therefore, future studies should evaluate convergent and discriminant validity, using SF-36 (Ware & Sherbourne, 1992) or other widespread measures. Furthermore, future studies need to evaluate the relationship between the EHP-30

and other demographic information and constructs, such as marital status, having children, self-esteem (Christian, 1993; Facchin et al., 2017), mood and anxiety disorders in association with the alexithymia (Cavaggioni et al., 2014; Melis et al., 2014). For these reasons the representativity of the sample was lacking and the generalizability of the results might be limited. Concerning the still understudied role of alexithymia in endometriosis conditions, the cross-sectional design of the present study cannot consider the possible bidirectional nature of the relationship between alexithymia and HRQoL. Indeed, according to Mattila et al. (2009), alexithymic experiences might predispose to poorer quality of life or, inversely, poor HRQoL and prolonged suffering and stressful situations might impair the capacity to recognize, describe, and understand emotions. Further and longitudinal findings are needed.

Conclusions

The present findings demonstrated that the Italian EHP-30 is a psychometrically valid measure of the health-related quality of life with endometriosis. In this regard, the adequate internal reliability of the EHP-30 as well as of its dimensions further contributed to support the adequacy of the instrument. The results of this study show that the EHP-30 can be reliably used by the researcher and health professionals in the Italian context for further studies and interventions. Indeed, the endometriosis-specific nature of EHP-30 might allow health professionals to monitor the perceived quality of life of suffering women. As Jones et al. (2001) previously stated, it is pivotal to evaluate from the patients' perspective whether treatments and interventions are affecting and enhancing their health-related quality of life. According to Hållstam et al. (2018), severe chronic pain and endometriosis represent a complex bio-psychosocial issue and its understanding by health professionals might be considered the first step to improving meetings and care for women who suffer from this condition. The EHP-30 application in various healthcare settings might provide new important information that traditional and global clinical measures of outcome did not provide.

Furthermore, the present study provides new findings about the relationship among alexithymia, loneliness, and HRQoL in endometriosis conditions. More specifically, according to Conti et al. (2023), the capacity to express and communicate emotions to others is pivotal to effective social interactions and interpersonal understanding, allowing individuals to ensure adequate social relationships and reduce feelings of loneliness. Women with endometriosis seem to largely suffer due to their 'invisible disease' (Karavadra et al., 2019) that forces them into conditions of isolation and loneliness that dramatically impact their quality of life (Cole et al., 2021; Mor & Efrati, 2021; Shoebotham & Coulson, 2016; Young et al., 2020).

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