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3	A woman's worth: the psychological impact of beliefs about motherhood, female identity and
4	infertility on childless women with endometriosis
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# 27 Abstract

29	In this study, we examined whether beliefs regarding motherhood, female identity, and infertility
30	affected the psychological health of 127 childless endometriosis patients. Anxiety and depression
31	were measured using the Hospital Anxiety and Depression Scale (HADS), while self-esteem was
32	assessed using the Rosenberg Self-Esteem Scale (RSES). A set of six Likert type items (1 = "Not at
33	all"; 5 = "To a very great extent") was developed to explore women's beliefs. Women who were
34	more likely to believe that childless and infertile women were less appreciated by others reported
35	poorer psychological health. Patients' beliefs should be explored during psychological counseling.
36	Dysfunctional beliefs about female identity, especially as regards others' perceptions, should be
37	restructured to improve patients' psychological health.

40 Keywords: Endometriosis, female identity, psychological health, self-esteem, women's beliefs
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#### 44 Introduction

Endometriosis is a chronic, inflammatory, gynecologic disease that affects approximately 6 45 to 10% of reproductive-aged women (Bulletti et al. 2010; Kuznetsov et al. 2017) and is associated 46 47 with subfertility (Vercellini et al. 2014). Several studies demonstrated that endometriosis has a negative impact on women's psychological health and quality of life, especially due to the presence 48 of pelvic pain symptoms (see the reviews by Culley et al. 2013; Gambadauro et al. 2019; Laganà et 49 al. 2017; Pope et al. 2015). However, endometriosis has a complex nature and research has 50 indicated that the psychological impact of the disease is associated with a variety of factors, such as 51 personality (Facchin et al. 2016), emotion regulation (Márki et al. 2017), coping styles (Eriksen et 52 al. 2008), and self-concept (Facchin et al. 2017). Uncertainty characterizes the subjective 53 54 experience of these patients, because the course of the disease is cyclical and unpredictable (Denny 55 2009). Almost all women with endometriosis have to deal with initial biographical disruption caused by the diagnosis, which may entail restructuring individual and couple projects for the 56 future, especially as regards planning for and having children (Culley et al. 2017; Gilmour et al. 57 58 2008; Hudson et al. 2016; Roomaney and Kagee 2016, 2018).

Infertility, defined as inability to conceive after 12 months of unprotected intercourse (Vitale 59 et al. 2017), is reported by 30 to 50% of endometriosis patients (Bulletti et al. 2010). This condition 60 may play an important role in the pathogenesis of mood and anxiety disorders in these women, but 61 in the context of endometriosis existing evidence is poor and inconclusive (Gambadauro et al. 62 2019). In a recent qualitative study, Facchin et al. (2018) highlighted that not only actual infertility, 63 but also "anticipated" infertility (i.e., being aware of the risk of having infertility in the future) was 64 associated with negative psychological outcomes in endometriosis patients. Specifically, women 65 with the worst mental health conditions (anxiety and depression) were extremely worried about not 66 becoming a mother, with negative effects on their female identity, to the point of seeing themselves 67 as "half a woman", and thus flawed. 68

69 These findings are consistent with those from studies of infertile patients. For instance, 70 Galhardo et al. (2011) demonstrated that, in the context of infertility (regardless of its cause), impaired mental health-depression, in particular-is associated with negative psychological 71 72 processes such as self-judgment and shame deriving from patients' and especially women's belief of being incomplete, damaged, and thus not meeting others' expectations. These patients tend to 73 perceive themselves as seen by the others as someone flawed and inferior. The authors interestingly 74 reminded the impact of social messages (to which individuals are exposed since childhood and 75 adolescence) underlying the importance of becoming a parent, and especially a mother, as a central 76 component of female identity. 77

In the context of endometriosis, the psychological processes and personal beliefs that may 78 79 lead to anxiety and depression remain underexplored, especially in relation to infertility. In order to 80 provide further insight into this issue, we conducted the current study to investigate whether the psychological health (anxiety, depression, and self-esteem) of childless endometriosis patients, who 81 experience either anticipated or diagnosed infertility, may be influenced by their beliefs about the 82 importance of motherhood for female identity, and their ideas about the way childless women (in 83 general) and infertile women (specifically) are perceived by others. We expected negative 84 psychological outcomes in women who (i) perceived motherhood as a fundamental component of 85 women's identity and fulfillment and (ii) believed that women without children (overall), as well as 86 87 infertile women were negatively viewed by others.

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# 89 Materials and methods

These data were derived from a larger study on the psychological impact of endometriosis
conducted between 2016 and 2018 in a tertiary endometriosis referral center located in Northern
Italy and approved by the competent Institutional Review Board (registration number #1018/2016,
approval date May 24, 2016). Initial participants were 190 consecutively recruited women with
surgical or current clinical diagnosis of endometriosis (Nisenblat et al. 2016). These participants

matched our inclusion criteria (i.e., diagnosis of endometriosis, age ≥ 18, fluency in Italian).
Menopausal women, as well as women diagnosed with mental or physical illness other than
endometriosis (such as for instance sexually transmitted, gastrointestinal, urologic, orthopedic,
rheumatologic, and autoimmune disease), obstructive uropathy, bowel stenosis, and genital
malformations, were excluded from the study. All participants were extensively informed about
research aims and procedures, and returned signed consent form. Of the original 190 participants,
127 (67%) did not have children and were included in this study.

Demographic and clinical data (including presence of pain symptoms and diagnosed 102 103 infertility, i.e., inability to conceive after 12 months of unprotected sexual activity) were collected using a structured interview or retrieved from medical records. Mental health (i.e., anxiety and 104 105 depression) was assessed using the Hospital Anxiety and Depression Scale (HADS; Costantini et al. 106 1999; Zigmond and Snaith 1983), a validated questionnaire composed of 14 items assessing the frequency of anxiety (HADS-A) and depression symptoms (HADS-D) on a 0-3 scale, with a full-107 scale score (HADS-Total)  $\geq$  15 indicating clinically relevant conditions. This cut-off was 108 109 effectively used in previous studies to identify distressed vs. non-distressed endometriosis patients (Facchin et al. 2018). Self-esteem was measured using the Rosenberg Self-Esteem Scale (RSES; 110 Prezza et al. 1997; Rosenberg, 1989), a well-known standardized questionnaire, whose 10 items-111 with responses scored on a 0-3 scale (0 = Strongly disagree; 3 = Strongly agree, or vice-versa)—are 112 113 summed to obtain a total score (higher scores indicate greater self-esteem). In this study, both 114 questionnaires showed good internal consistency, with Cronbach's  $\alpha$  ranging from 0.82 for the RSES and 0.87 for the HADS. 115

In order to explore women's beliefs regarding motherhood, female identity, and infertility we developed a set of questions in collaboration with volunteers of an Italian endometriosis patient association [REMOVED FOR BLIND REVIEW]. The questionnaire was preliminary tested on a pilot sample of 30 women. The final questionnaire was composed of six items, with responses scored on a 1-5 Likert scale (1 = "Not at all"; 5 = "To a very great extent"). These items were: "To what extent do you think that: (A) Having children is very important in a woman's life; (B) Having
children would be/have been very important for your personal fulfillment; (C) A childless woman is
less socially appreciated than a woman with children; (D) Infertility may negatively affect the way a
woman is seen by others; (E) Infertility may negatively affect the way a woman is seen by her
partner; (F) Based on your idea of femininity, being a mother is a fundamental component of being
a woman?".

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#### 128 Statistical analyses

129 We used the software SPSS (Statistical Package for Social Sciences, SPSS Inc., Chicago, IL, USA) version 22 to perform our statistical analyses. In this article, we report continuous variables as mean 130 131 ± standard deviation, and categorical variables as frequencies. Preliminary analyses aimed at 132 examining psychological health and personal beliefs in childless endometriosis patients with vs. without diagnosed infertility. Chi square, Mann-Whitney or T-tests were used as appropriate. 133 Then, before conducting our main analyses, we summarized the information provided by the 134 six items related to women's beliefs using principal component analysis, which allowed to avoid 135 multicollinearity problems. This procedure led to the extraction of two composite variables or 136 components (KMO test = .69, Bartlett's test of sphericity = 277.08, Ps < .001), with a total variance 137 explained of 71%. Component-1 summarized the information provided by items A, B, F, with an 138 eigenvalue of 2.5 and component loadings ranging from 0.84 for item F to 0.89 for item B. This 139 140 component measured participants' beliefs about the relation between motherhood and women's identity and fulfillment. Component-2 summarized the information provided by the remaining three 141 items (C, D, E), with an eigenvalue of 1.79 and component loadings ranging from 0.64 for item E 142 and 0.83 for item D. This second component measured women's beliefs regarding others' 143 perceptions of childless women in general, as well as of infertile women. 144

We used a multiple hierarchical regression approach to examine the impact of these twocomponents (entered in regression step 3) on women's psychological health (anxiety, depression,

and self-esteem), controlling for the effects of age and intimate relationship status (step 1), presence of pelvic pain symptoms (yes/no) and diagnosed infertility (step 2). Moreover, because we wanted to further understand what kind of beliefs had the most relevant impact on women's psychological health, we compared patients who reported clinically relevant anxiety and depression symptoms (HADS-Total  $\geq$  15) with those who reported HADS-Total < 15 on each of the six items using Mann-Whitney test. In this article, these two subgroups of patients were named "clinically distressed" and "non-distressed", respectively.

Significant tests were conducted at P < 0.05. As regards power analysis, we used Cohen's indications (Cohen 1992), according to which our sample was sufficiently large to detect a medium effect size ( $f^2 = .15$ ) for the *F* test of the multiple  $R^2$  at *Power* = 0.80.

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## 158 Results

Participants were 127 endometriosis patients aged 19-51 years  $(35.4 \pm 7.4)$ . Most participants were 159 in an intimate relationship (91 [72%]) and had secondary education or more (114 [90%]). Infertility 160 was diagnosed in 42 participants (33%). Only 13 participants (10%) were currently undergoing or 161 underwent IVF. Pelvic pain symptoms were reported by 62 participants (49%). Considering the 162 whole sample, we found that a relevant number of participants (52 [41%]) was clinically distressed, 163 with HADS-Total  $\geq$  15 (HADS-A: 7.5 ± 3.8; HADS-D: 5.9 ± 3.5; HADS-Total: 13.4 ± 6.7). Self-164 esteem values ranged from 17 to 40 (RSES:  $31.8 \pm 4.7$ ). The distribution of women's responses to 165 166 the six items is represented in Figure 1.

The characteristics of participants with vs. without diagnosed infertility are reported in Table 1. We did not find any significant group difference regarding anxiety, depression, and self-esteem (Ps > 0.05). Mann-Whitney test revealed that infertile participants were more likely to believe that having children would be important for their personal fulfillment (item B, P = 0.045), but surprisingly they were less likely to believe that infertility may negatively affect the way a woman is seen by her partner (item E, P = 0.001).

#### 173 Women's beliefs and psychological health

The multiple hierarchical regressions conducted, whose significant findings are extensively reported 174 in Table 2, showed statistically significant results only for Component-2, which was associated with 175 greater anxiety (HADS-A), depression (HADS-D), and worse overall psychological health (HADS-176 Total), as well as with poorer self-esteem (RSES). In other words, participants who were more 177 likely to believe that the fact of being childless (both in general and specifically related to 178 infertility) could negatively affect others' perceptions displayed poorer psychological conditions. 179 Considering the  $\Delta R^2$  values reported in Table 2, it is worth underlining that the introduction of the 180 two components in regression step 3 led to a 12% increase in the amount of variance explained by 181 the model when depression (HADS-D) was the dependent variable. The presence of pain symptoms 182 predicted greater anxiety (HADS-A), poorer overall psychological health (HADS-Total), and lower 183 self-esteem (RSES), but did not have any effect on depression (HADS-D; P > 0.05). 184

Subsequent Mann-Whitney tests revealed that clinically distressed (vs. non-distressed) participants were more likely to believe that a childless woman is less socially appreciated compared to a woman with children (item C, P = 0.025) and that the inability to conceive may negatively affect the way a woman is seen by others (item E, P = 0.016).

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#### 190 Discussion

The primary aim of this study was to examine whether childless endometriosis patients' 191 192 beliefs about motherhood and female identity, and regarding others' perceptions of childless (in general) and infertile women, could affect their psychological health (anxiety, depression, self-193 esteem). We found that endometriosis participants who were more likely to believe that the fact of 194 not having children (either related or unrelated to infertility) could negatively influence the way 195 women are seen by others (Component-2), reported worse mental health (especially depression) and 196 poorer self-esteem. More specifically, clinically distressed patients (with HADS-Total  $\geq$  15) tended 197 to believe that childless women are less socially appreciated than women with children, and that 198

infertility could negatively influence the way women are seen by others. Our findings suggest that
clinically distressed women were particularly worried about the fact of being perceived as inferior
and defective by others. This psychological situation was referred to by the literature as *external shame*, i.e., feelings of shame deriving from perceptions of being considered by others as
inadequate and flawed (Matos and Pinto-Gouveia 2010). There is evidence that external shame is a
direct predictor of infertility-related distress (Galhardo et al. 2013) and depression (Galhardo et al.
2011), although no previous research has addressed this issue in the context of endometriosis.

The importance of women's beliefs was also underlined by findings of our preliminary 206 207 analyses, revealing that endometriosis participants with diagnosed infertility (vs. women without diagnosed infertility) were more likely to consider the fact of having children as important for their 208 209 own fulfillment. Although we did not find any significant group difference with regard to anxiety, 210 depression, and self-esteem, this type of belief may represent a risk factor for impaired psychological health in this subgroup of infertile endometriosis patients, because people's 211 subjective experience of infertility may partly depend on the importance attributed to having 212 213 children (Galhardo et al. 2016). The more individuals consider parenthood as a major life goal, the higher is the risk of experiencing feelings of failure and defeat, which can be associated with 214 215 depressive symptoms (Galhardo et al. 2013, 2016; Gilbert 2006).

Although these psychological processes have been explored in the context of infertility, no 216 previous studies of endometriosis patients investigated the association between women's beliefs and 217 218 psychological health outcomes. Most research focused on the predictive role of pelvic pain in the onset of anxiety and depressive symptoms (Facchin et al. 2015; Lorençatto et al. 2006; Vannuccini 219 et al. 2018). In this regard, our study confirms the relation between presence of pelvic pain and 220 impaired psychological health, and adds to the extant literature by showing that pelvic pain is also 221 associated with lower self-esteem (as reported in Table 2). Indeed, successful pain treatment is 222 fundamental if we want to improve the psychological conditions of these patients. However, an 223 increasing number of studies highlighted the complex nature of endometriosis, specifying that the 224

225 psychological impact of the disease is the result of the non-linear combination of multiple factors, as reminded by Gambadauro et al. (2019). The current study adds to the literature by demonstrating 226 that endometriosis patients' beliefs may influence their psychological response to the condition. 227 228 Our findings may also provide useful ideas for future endometriosis studies. For instance, we believe that investigating the psychological impact of endometriosis by comparing women with 229 the disease to women without the disease should no longer be considered as a fruitful research 230 avenue, as suggested by the unresolved heterogeneity in the findings provided by this type of 231 research (Gambadauro et al. 2019). Endometriosis manifests itself with remarkable variability 232 related to multiple biopsychosocial variables, and for this reason we need to identify and investigate 233 sources of vulnerability (and resilience) for specific subgroups of patients. For instance, the role of 234 235 endometriosis-related infertility (either diagnosed or anticipated) deserves further attention, as well 236 as the impact of the disease on childless young women. There is evidence that these patients may feel stressed and pressured by doctors, who recommend to try to conceive as soon as possible to 237 avoid future problems (Facchin et al. 2018). In this regard, qualitative studies may be particularly 238 useful for in-depth investigation of women's subjective illness experience. 239 Indeed, our findings should be considered as preliminary due to several methodological 240

limitations, such as the fact that we did not use validated measures to explore women's beliefs. 241 Moreover, our questionnaire allowed to see whether women's beliefs were in line with social 242 messages that emphasize the importance of being a mother for female identity, as well as for others' 243 244 perceptions of a woman's value. We did not ask questions regarding, for instance, possible advantages and opportunities of being childless, which may have led to a partial description of a 245 more complex scenario. Social and cultural variables should also be examined, since they may play 246 an important role in the construction of individuals' beliefs and feelings of shame (which is a 247 'social' emotion) and stigma, and future studies should investigate their effects on women's 248 reactions to endometriosis. 249

## 251 Conclusions

Based on our results, the psychological health of women who live with a medical condition related 252 to infertility can be influenced by the belief that women without children are less appreciated than 253 those who have children. Endometriosis patients with greater psychological pain seem to perceive 254 infertility as a social stigma. In this regard, our study may provide suggestions for clinical practice 255 by indicating that women's beliefs regarding the disease and its consequences (either on an 256 individual and a social/relational level) should be investigated during psychological counseling with 257 endometriosis patients. The psychological health of these women may be improved by helping them 258 explore and restructure dysfunctional beliefs about female identity, especially as regards ideas about 259 others' perceptions. A fruitful collaboration between clinicians and patient associations in terms of 260 school- and community-based prevention programs may contribute to reframe female identity as a 261 262 complex, multidimensional concept separated from motherhood, and childfree lifestyle (in general) as an option for women, rather than a defect. Indeed, the way in which these beliefs may enhance 263 the psychological burden of endometriosis deserves more research. 264

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#### 266 Declaration of conflicting interests

267 There are no conflicts of interest associated with this publication and there has been no financial268 support for this work.

269

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Variables		Infertility	No infertility	Р
		(N = 42)	(N = 85)	
Women's age $(M \pm SD)$		$39.8\pm5.5$	$33.2 \pm 7.3$	< 0.001
In a relationship (n [%])		39 (93)	52 (61)	< 0.001
Level of education	Level of education Secondary education or more		80 (94)	0.06
(n [%])	Middle/primary school	8 (19)	5 (6)	
Employed		39 (93)	75 (88)	0.26
Pain symptoms (n [%])		23 (55)	39 (46)	0.35
HADS $(M \pm SD)$	HADS-A	$7.8 \pm 3.4$	$7.3 \pm 4.0$	0.44
	HADS-D	$5.6 \pm 2.8$	$6.1 \pm 3.8$	0.49
	HADS-Total	$13.5\pm5.5$	$13.4 \pm 7.3$	0.93
RSES $(M \pm SD)$				
Items (median)	А	4.0	3.0	0.399
	В	4.0	3.0	0.045
	С	2.0	3.0	0.582
	D	2.5	3.0	0.496
	Е	2.0	3.0	0.001
	F	3.0	3.0	0.928

Table 1. Characteristics of childless endometriosis patients with vs. without diagnosed infertility

HADS (Hospital Anxiety and Depression Scale) HADS-A (Hospital Anxiety and Depression Scale-Anxiety) HADS-D (Hospital Anxiety and Depression Scale-Depression) HADS-Total (Hospital Anxiety and Depression Scale-Total)

RSES (Rosenberg Self-Esteem Scale)

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		Unstandardized coefficients		Standardized coefficients	Sig.	95%
Predictors		В	Std. Error	β	Р	Lower l
HADS-A	Pelvic pain symptoms	1.688	0.677	0.221	0.014	0.34
	Component-2	0.965	0.336	0.251	0.005	0.30
HADS-D	Component-2	1.226	0.294	0.352	< 0.001	0.64
HADS-Total	Pelvic pain symptoms	2.726	1.157	0.203	0.020	0.43
	Component-2	2.190	0.574	0.326	< 0.001	-2.5
RSES	Pelvic pain symptoms	-2.146	0.832	-0.229	0.011	-3.7
	Component-2	-1.193	0.413	-0.254	0.005	-2.0

Table 2. Hierarchical multiple regressions: significant effects and coefficients

\* *P* < 0.05

\*\*  $P \le 0.001$ 

HADS-A (Hospital Anxiety and Depression Scale-Anxiety)

HADS-D (Hospital Anxiety and Depression Scale-Depression)

HADS-Total (Hospital Anxiety and Depression-Total)

RSES (Rosenberg Self-Esteem Scale)

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