

1 **Assessing the experience of dyspareunia in the endometriosis population: the Subjective**
2 **Impact of Dyspareunia Inventory (SIDI)**

3

4 **Running title:** The Subjective Impact of Dyspareunia Inventory

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19 **Abstract**

20 **Study question:** Is the Subjective Impact of Dyspareunia Inventory (SIDI) a reliable tool to
21 examine the experience of dyspareunia in the context of endometriosis?

22 **Summary answer:** In this study, the SIDI showed good structural and psychometric properties, and
23 can be used as a reliable questionnaire to assess the impact of endometriosis-related dyspareunia on
24 multiple dimensions, such as sexuality and intimate relationships.

25 **What is known already:** In the endometriosis population, dyspareunia has a tremendous negative
26 impact on psychological health, overall sexual function, and couple relationships. However, there is
27 a paucity of tools that can be effectively used in either research or clinical practice to assess the
28 subjective components of the dyspareunia experience, including coping strategies to deal with the
29 pain.

30 **Study design, size, duration:** In this cross-sectional study, the validity of the SIDI was examined
31 considering the responses provided by 638 participants with endometriosis and dyspareunia, who
32 participated in an online survey conducted between 8 November and 21 December 2021.
33 Participants were recruited using snowball sampling that involved posting the invitation to
34 participate in the study on the social media of a patient association.

35 **Participants/materials, setting, methods:** Participants were women aged ≥ 18 with clinical or
36 surgical diagnosis of endometriosis. The SIDI measures the subjective impact of dyspareunia and is
37 composed of 16 items focused on the frequency of dyspareunia-related experiences in the last six
38 months, rated on a 5-point Likert scale. Sexuality was assessed using the Female Sexual Function
39 Index. Psychological health was measured using the Hospital Anxiety and Depression Scale and the
40 Rosenberg Self-Esteem Scale. Sociodemographic and endometriosis-related information was
41 collected using a researcher-made questionnaire. Statistical significance was set at $P < .05$.

42 **Main results and the role of chance:** Factor analysis revealed that the SIDI has a 4-factor structure
43 and allows for examining the impact of dyspareunia in terms of Sexual Concerns (factor 1),
44 Relationship Concerns (factor 2), Partner Support (factor 3), and Endurance of pain (factor 4). The

45 SIDI showed good structural and psychometric properties (including internal consistency), was
46 associated with sexual function and psychological health, and was able to discriminate between
47 participants with and without sexual dysfunction.

48 **Limitations, reasons for caution:** Reasons for caution are related to the risk of self-selection bias
49 depending on the study population and recruitment strategy. Moreover, all the information provided
50 by the participants were self-report, which may have affected the accuracy of the data collected,
51 especially with regards to endometriosis-specific information.

52 **Wider implications of the findings:** This study may provide a new brief tool that can be used by
53 clinicians and researchers to assess the impact of dyspareunia from a multidimensional perspective
54 and considering subjective aspects that can be usefully integrated with information about pain
55 severity, timing, and localization.

56 **Study funding/competing interest(s):** None.

57 **Trial registration number:** N/A.

58

59 **Keywords:** dyspareunia; endometriosis; psychological health; sexual function; subjective impact

60 **Introduction**

61 Endometriosis is a chronic gynaecological disease due to the growth of endometrial tissue outside
62 the uterine cavity, with consequent ectopic implants that cause an inflammatory condition (Agarwal
63 *et al.*, 2019; Schneider *et al.*, 2020). The estimated prevalence of endometriosis is approximately
64 10% of women (i.e., people assigned female at birth) of reproductive age (Zondervan *et al.*, 2020).
65 Endometriosis may manifest itself without symptoms, but in most instances it is associated with
66 different forms of pelvic pain (e.g., chronic pain, dysmenorrhea, dyspareunia, dyschezia, dysuria)
67 and subfertility (Agarwal *et al.*, 2019).

68 The negative impact of endometriosis on women's mental health and quality life has been
69 widely demonstrated (Wang *et al.*, 2021). Endometriosis-related pelvic pain is associated with
70 anxiety/depressive symptoms and low self-esteem, with a remarkable negative impact on intimate
71 relationships (De Graaff *et al.*, 2013; Facchin *et al.*, 2020, 2021a,b). In this regard, dyspareunia
72 plays an important role, also considering that it may affect up to 79% of young women with
73 endometriosis, including adolescents (Schneider *et al.*, 2020). Moreover, endometriosis is one of the
74 most important causes of deep dyspareunia, which is associated with deep penetration and is
75 experienced as pain inside the vagina or in the pelvic region (Shum *et al.*, 2018).

76 There is a growing body of interesting research investigating pain during intercourse in
77 women with endometriosis (Bernays *et al.*, 2020; Shum *et al.*, 2018; Wahl *et al.*, 2021; Witzeman *et*
78 *al.*, 2020). Quantitative studies mostly focused on the impact of dyspareunia on women' sexual
79 function and sexual quality of life. In a study by Bernays *et al.* (2020), endometriosis-related
80 dyspareunia was associated with a higher probability of no sexual activity (OR 2.42, 95% CI 1.26,
81 4.63), but the reduced frequency of intercourse was not compensated by other types of sexual
82 activities (such as petting and foreplay), although all the participants considered sexuality as an
83 important component of quality of life. Other authors demonstrated that dyspareunia is
84 independently associated with impaired sexual quality of life as measured using one of the six
85 modular parts of the Endometriosis Health Profile (EHP-30) (see Agarwal *et al.*, 2020; Shum *et al.*,

86 2018; van Poll *et al.*, 2020), which is a well-known validated endometriosis-specific tool to evaluate
87 multiple aspects of women's quality of life. This specific EHP-30 subscale is composed of 5 items
88 assessing pain during intercourse, worries about having intercourse and avoidance of sex due to
89 pain, sense of guilt about not wanting intercourse, and feelings of frustration for not enjoying
90 intercourse (Jones *et al.*, 2001, 2006).

91 The most widely used sexual function questionnaires, such as the Female Sexual Function
92 Index (Rosen *et al.*, 2000) or the Female Sexual Distress Scale-Revised (FSDS-R; Derogatis *et al.*,
93 2008), cannot capture the specificities of sexuality in the context of endometriosis. The EHP-30
94 remains a useful and reliable disease-specific questionnaire to assess quality of life in women with
95 endometriosis (including sexual quality of life), but the evidence provided by qualitative studies
96 contributed to highlight the complexity of women's subjective experience of dyspareunia (see the
97 recent systematic review by Facchin *et al.*, 2021a).

98 In this regard, women with endometriosis use a variety of coping strategies to deal with
99 dyspareunia that involve not only avoiding or interrupting intercourse, but also enduring the pain in
100 silence (especially among women who are seeking pregnancy), or finding unpainful sexual options,
101 such as non-penetrative sexual activities, or other positions during intercourse (Denny, 2004; Denny
102 and Mann, 2007; Facchin *et al.*, 2018; Fauconnier *et al.*, 2013; Moradi *et al.*, 2014; Rea *et al.*,
103 2020). Moreover, dyspareunia negatively affects self-esteem and sense of femininity, and is
104 associated with feelings of being different, or even flawed and insignificant as a person (Facchin *et*
105 *al.*, 2018; Hållstam *et al.*, 2018; Wahl *et al.*, 2021). The negative psychological impact of
106 dyspareunia is also linked to the tremendous consequences of dyspareunia on women's intimate
107 relationships, in terms of sexual dissatisfaction and concerns, sense of guilt and inadequacy towards
108 the partner, and couple conflicts (Facchin *et al.*, 2020, 2021a,b; Matías-González *et al.*, 2021). The
109 scenario is even worse when women with endometriosis receive poor support from their partner,
110 who may tend to minimize their pain, or to accuse them to use pain as an excuse for avoiding sex
111 (Matías-González *et al.*, 2021; Moradi *et al.*, 2014; Namazi *et al.*, 2021).

112 Given these premises, and considering the paucity of endometriosis-specific instruments for
113 assessing sexual pain, the current study was conducted to: (1) develop a new tool for assessing the
114 subjective impact of dyspareunia (i.e., the Subjective Impact of Dyspareunia Inventory; SIDI) in the
115 endometriosis population and examine its structural and psychometric properties; (2) provide new
116 evidence on the association between dyspareunia-related subjective factors (other than pain
117 severity) on sexual function and psychological health in the context of endometriosis.

118 **Materials and Methods**

119 **Study setting and population**

120 Data collection was performed through an online survey hosted on Qualtrics (Qualtrcis Ltd.), as
121 done in previous endometriosis studies (Facchin *et al.*, 2021b). The research, including the
122 development of the SIDI, was conducted in collaboration with the largest Italian **endometriosis**
123 patient association, Associazione Progetto Endometriosi (APE [Endometriosis Project
124 Association]). Participant recruitment was carried out by APE using a snowballing sampling
125 procedure that involved inviting women via Facebook and newsletters. A direct link to the online
126 survey was provided to facilitate women's access. Data were collected between 8 November and 21
127 December 2021. **The online survey was anonymous; complete information regarding all aspects of**
128 **the research, including the estimated response time calculated by Qualtrics (i.e., 20 minutes), was**
129 **reported on a separate downloadable pdf file and women were allowed to participate in the study**
130 **only after providing their electronic informed consent (anonymously). The participants who denied**
131 **their consent by clicking on "I do not give my consent" were automatically directed by the system**
132 **to the end of the survey.**

133 **Anonymity was guaranteed by multiple factors: first, participants were recruited by APE**
134 **volunteers, who also sent the invitation to participate in the study through newsletters, without**
135 **sharing the list of contacts with the research team; second, the research team did not disclose the**

136 data to APE volunteers; third, the large sample size further contributed to eliminate the risk of
137 identifying participants.

138 In this study, we included women with clinically or surgically diagnosed endometriosis who
139 reported experiencing dyspareunia in the last six months. Exclusion criteria were: (a) age < 18
140 years, (b) pregnancy, (c) spontaneous menopause (i.e., not due to endometriosis treatment), (d)
141 never sexually active, (e) incomplete responses or non-response to the SIDI.

142 **The development of the Subjective Impact of Dyspareunia Inventory**

143 The development of the SIDI involved two phases. First, we carefully examined the existing body
144 of research on the impact of dyspareunia in women with endometriosis, with a specific focus on
145 qualitative studies, which are concerned with women's subjective experience (Facchin *et al.*,
146 2021a). This literature review led to a more comprehensive understanding of the negative
147 consequences of dyspareunia on women's lives, including coping strategies to deal with pain during
148 sex (e.g., avoiding or interrupting intercourse, enduring pain, trying different position) and women's
149 feelings towards their partner (e.g., sense of inadequacy, sense of guilt). Second, relevant items
150 were pooled by two researchers (FF and DD) and were subsequently reviewed to evaluate content
151 validity by an expert panel composed of gynaecologists, a sexologist, a psychologist, and two
152 women with endometriosis who were current or past members of APE. Following this review (see
153 Supplemental Table 1), a new item focused on women's sexual desire was included, whereas two
154 items were removed and condensed in a single item that was deemed closer to the subjective
155 experience of women with endometriosis. The final questionnaire was composed of 16 items and
156 respondents were asked to rate on a 5-point Likert scale (1 = never; 5 = always) how often they
157 experienced the specific dyspareunia-related situation described in each item (considering the last
158 six months). **The SIDI was developed in Italian and then translated into English by the authors in a
159 non-systematic fashion, and without using back translation. The English version of the SIDI is
160 provided as supplementary material (see Appendix 1).**

161 **Other measures**

162 *Sociodemographic and medical data.* A researcher-made questionnaire was used to collect
163 sociodemographic data and medical information (such as type of diagnosis, type of lesions,
164 endometriosis stage, infertility, hormonal therapy, surgical interventions). The severity of pelvic
165 pain (dyspareunia, chronic pelvic pain, dysmenorrhea, dyschezia, dysuria) was assessed using a
166 numerical rating scale (NRS) from 0 = “no pain at all” to 10 = “the worst imaginable pain”).
167 Participants were also asked to indicate whether they experienced introital dyspareunia, deep
168 dyspareunia, or both.

169 *Sexual function.* A well-known questionnaire was used to assess sexual function in
170 participants with dyspareunia who reported having a current sexual partner: the Female Sexual
171 Function Index (FSFI; Rosen *et al.*, 2000; validation of the Italian version by Filocamo *et al.*, 2014).
172 The FSFI is composed of 19 items and measures six sexual function dimensions (desire, arousal,
173 lubrication, orgasm, pain, and satisfaction). The global score ranges from 2 to 36 (with higher
174 scores indicating better sexual function) and allows for discriminating between premenopausal
175 women with vs. without sexual dysfunction considering the 26.55 threshold (Wiegel *et al.*, 2005).
176 In this study, Cronbach’s alpha ranged from 0.90 for satisfaction to 0.97 for the FSFI global score.

177 *Psychological health.* Symptoms of anxiety and depression were assessed in all the
178 participants using the Hospital Anxiety and Depression Scale (HADS; Costantini *et al.*, 1999;
179 Zigmond and Snaith, 1983), a 14-item questionnaire composed of two 7-item subscales for anxiety
180 (HADS-Anxiety) and depression (HADS-Depression), with frequency of symptoms scored on a 0-3
181 scale (with higher scores indicating poorer psychological health). **A total score (HADS-Total) can**
182 **also be calculated as the sum of all items.** In this study, the values of Cronbach’s alpha were 0.82
183 for HADS-Anxiety, 0.78 for HADS-Depression, **and 0.88 for HADS-Total.** Self-esteem was
184 measured using the Rosenberg Self-Esteem Scale (RSES; Prezza *et al.*, 1997; Rosenberg, 1965), a
185 10-item scale with responses scored on a 4-point Likert scale (0 = “strongly disagree”, 3 = “strongly

186 agree”; the higher the score, the higher the level of self-esteem). Cronbach’s alpha for the RSES
187 was 0.90.

188 **Statistical Analyses**

189 Statistical analyses were performed using the SPSS software, version 25 (IBM corporation).

190 Descriptive statistics were reported as mean \pm standard deviation. Before conducting our main
191 analyses, we examined the distribution of continuous variables considering skewness and kurtosis.

192 As done in other studies, values of asymmetry and kurtosis between -2 and +2 were considered
193 acceptable for normal distribution (Bonanomi *et al.*, 2021).

194 Factor analysis was performed to examine the structural and psychometric properties of the
195 SIDI, choosing the principal axis method for factor extraction with Promax rotations. We evaluated
196 the Kaiser-Mayer-Olkin measure of sampling adequacy, Bartlett’s test of sphericity, and factor
197 loadings. Cronbach’s alpha was calculated to examine the internal consistency of the items within
198 each factor. To assess *convergent validity* (i.e., the extent to which a measure of a construct is
199 actually correlated with other measures of a similar construct; Westen and Rosenthal, 2003), we
200 examined the correlations between the SIDI factor scores and the FSFI (one of the most widely used
201 sexual function questionnaires, with a validated Italian version), because we anticipated that a
202 greater subjective impact of dyspareunia should be significantly associated with poorer sexual
203 function. Correlations with the HADS and RSES scores were considered to examine *concurrent*
204 *validity* (i.e., the extent to which the measure of a construct correlates with a validated measure of
205 the same or a presumably related construct assessed within the same time frame; Frey, 2018),
206 because the extant literature has demonstrated that dyspareunia is associated with psychological
207 health (Facchin *et al.*, 2021a). In this regard, we hypothesized that a higher subjective impact of
208 dyspareunia should be significantly correlated with greater symptoms of anxiety/depression and
209 lower self-esteem. These analyses were performed using Pearson correlation.

210 Comparisons between participants with vs. without sexual dysfunction (considering the
211 FSFI threshold) were performed using univariate and multivariate analysis of variance, controlling
212 for the effects of potential confounders (age, infertility, dyspareunia severity, chronic pelvic pain).
213 These analyses were conducted to evaluate whether the SIDI was able to discriminate between
214 women with and without sexual dysfunction.

215 As done in other endometriosis studies (Arion *et al.*, 2020; Shum *et al.*, 2018), sample size
216 was determined considering the indications provided by Schönbrodt and Perugini (2013), who
217 reported that approximately 250 participants are necessary to obtain stable and valid estimates of
218 correlation coefficients in observational studies. Therefore, we decided that the minimum required
219 sample size should be 250 and we planned to interrupt data collection after five days without new
220 responses from additional participants. With regards to factor analysis, we also considered that, as a
221 rule of thumb, there is need for 10-15 participants per item (Barbaranelli, 2007). Statistical
222 significance was set at $P < .05$. Missing data were not replaced, and in this article we report the
223 exact number of respondents for each variable.

224 **Ethical approval**

225 This cross-sectional study was approved by the Ethics Commission for Research in Psychology
226 (CERPS), Department of Psychology, Catholic University of the Sacred Heart, Milan (protocol
227 number: 83-21; approval date: 29 October 2021).

228 **Results**

229 **Participant Characteristics**

230 Of the 1,027 women who accessed the online survey, 784 (76%) responded to the question related
231 to the presence of dyspareunia. Of these, 638 (81%) were included in this study because they
232 reported dyspareunia and completed the SIDI (a study flow diagram with specific reasons for
233 participant exclusion is presented in Figure 1). Interestingly, of the 15 women who were excluded
234 because they never had sexual intercourse, the majority (11 [73%]) reported that this was due to

235 endometriosis. The characteristics of the study population are reported in Table 1. Participants' age
236 was 36.1 ± 6.9 . Most of them (575 [90%]) had a sexual partner and were in a relationship (295
237 [46%]) or married (259 [41%]). Only 10 participants (2%) were in a homosexual relationship. Most
238 participants (473 [74%]) had a clinical diagnosis of endometriosis. Rectovaginal endometriosis was
239 reported by 376 (59%) participants, 456 (72%) participants had ovarian endometriosis, 416 (65%)
240 had adenomyosis, and 338 (53%) reported other types of endometriosis such as peritoneal, bladder,
241 bowel, parametrial or ureteral endometriosis (most participants reported multiple forms of
242 endometriosis, with or without adenomyosis). The descriptive statistics of the validated
243 questionnaires used in this study (FSFI, HADS, RSES) are also presented in Table 1.

244 **Initial validation of the SIDI**

245 The descriptive statistics of the SIDI (for each item) are reported in Table 2. The values of
246 asymmetry and kurtosis were in the pre-planned acceptable range for normal distribution for all
247 items. Items 8, 9, 10 and 11 were then reversed for subsequent analyses. Factor analysis was
248 conducted using the "eigenvalues greater than 1" criterion, which led to the extraction of four latent
249 factors with 69% of explained variance (see Table 3a). Bartlett's test was significant (Chi-square =
250 5349.56, $P < .001$) and the Kaiser-Mayer-Olkin measure of sampling adequacy was 0.87, which
251 indicated that the correlation matrix had good factoriability. Internal consistency was also very good
252 (see the values of Cronbach's alpha reported in Table 3a). The four factors were named *Sexual*
253 *Concerns* (factor 1), *Relationship Concerns* (factor 2), *Partner Support* (factor 3), *Endurance*
254 (factor 4). The highest inter-correlations were found between factor 1 and 2 (.653), whereas the
255 other factors showed moderate correlations (between .187 and .468). The scoring system (see
256 Appendix 2) involved calculating scores for each domain (the mean of the items of each factor) and
257 a total score (the sum of the four domain scores). Higher scores indicate a greater subjective impact
258 of dyspareunia. For the SIDI full scale, Cronbach's alpha was 0.87, which confirms the reliability of

259 the questionnaire. Descriptive statistics for each SIDI factor and full scale score are reported in
260 Table 3b.

261 A second set of analyses aimed at evaluating concurrent and convergent validity by
262 examining the correlations between the SIDI scores and three questionnaires with validated Italian
263 versions assessing sexual function (FSFI), symptoms of anxiety/depression (HADS), and self-
264 esteem (RSES). These analyses (see Table 4a and Table 4b) showed that the SIDI scores were
265 significantly correlated with all the FSFI domains and total score (convergent validity), as well as
266 with the HADS subscales and total score, and the RSES (concurrent validity).

267 **SIDI and sexual dysfunction**

268 The association between the subjective impact of dyspareunia and sexual dysfunction was further
269 explored using multivariate and univariate analysis of variance. Specifically, we compared the SIDI
270 scores in participants with vs. without sexual dysfunction, controlling for the effects of potential
271 confounders (age, infertility, chronic pelvic pain severity, dyspareunia severity). Of the 524
272 participants with dyspareunia who reported having a current sexual partner and completed the FSFI,
273 429 (82%) had sexual dysfunction. As shown in Table 5, the subjective impact of dyspareunia
274 (considering the four domains) was different in participants with vs. without sexual dysfunction
275 (Wilk's $\Lambda = .765$, $F[4,514] = 39.387$, $P < 0.001$, $\eta^2_p = .235$). Specifically, participants with sexual
276 dysfunction reported greater sexual and relationship concerns, poorer partner support, and higher
277 endurance than participants without sexual dysfunction ($P_s < 0.001$). The overall subjective impact
278 of dyspareunia (SIDI total score) was also greater in participants with sexual dysfunction ($F[1,517]$
279 $= 99.951$, $P < 0.001$, $\eta^2_p = .162$).

280 **Discussion**

281 Dyspareunia is a major clinical problem in women with endometriosis, whose subjective experience
282 of sexual pain is disease-specific, as it has been clearly demonstrated by qualitative research (e.g.,
283 Fauconnier *et al.*, 2013; Márki *et al.*, 2022; Namazi *et al.*, 2021; Roomaney and Kagee, 2018; Wahl

284 *et al.*, 2021). However, there is a paucity of endometriosis-specific instruments aimed at assessing
285 dyspareunia in this population, especially considering the importance of focusing on subjective
286 components of living with endometriosis-related dyspareunia, besides pain severity and
287 localization. In this study, we developed and examined the statistical properties of the SIDI, a new
288 questionnaire aimed at assessing the subjective impact of dyspareunia in women with endometriosis
289 from a multidimensional perspective. The analyses conducted showed that the SIDI has a 4-factor
290 structure and can be considered a reliable tool to examine women's sexual concerns (factor 1),
291 relationship concerns (factor 2), partner support (factor 3), and endurance of pain (factor 4) in
292 relation to dyspareunia. This conclusion is based on the good factoriability of the scale, the values
293 of Cronbach's alpha, and the statistical tests conducted to evaluate convergent and concurrent
294 validity.

295 The SIDI was developed following a systematic literature review (Facchin *et al.*, 2021a) and
296 – most importantly – was reviewed by an expert panel that included women with endometriosis
297 who volunteered from a patient association. The importance of examining endometriosis-related
298 pain (including dyspareunia) with a specific focus on women's subjective experience has been
299 highlighted by several authors (see Wahl *et al.*, 2021). Fauconnier *et al.* (2018) used women's
300 verbal descriptions of their own pain symptoms to develop a 21-item questionnaire aimed at
301 measuring endometriosis painful symptoms, including dyspareunia. This interesting and useful
302 questionnaire is focused on women's pain perceptions (e.g., deep internal pain, pain in certain
303 positions), rather than on the subjective impact of pain. Indeed, exploring the variability in women's
304 perceptions of dyspareunia – localization and timing (for instance, introital and/or deep
305 dyspareunia, positional dyspareunia, dyspareunia during and/or after intercourse, dyspareunia at
306 orgasm) is essential, also to rule out potentially associated conditions such as pelvic floor
307 dysfunction and provoked vestibulodynia (Wahl *et al.*, 2021). However, researching the subjective
308 impact of dyspareunia (and assessing it in clinical practice) involves considering multiple
309 dimensions related to sexuality, intimacy, and dysfunctional coping strategies such as enduring the

310 pain, that are captured by the multidimensional nature of the SIDI. In addition, the fourth subscale
311 (*Endurance*) may provide useful information by discriminating between enduring sexual pain
312 without saying anything (i.e., to “suffer in silence”; see Denny and Mann, 2007, p. 191), which is
313 often associated with pregnancy seeking (Facchin *et al.*, 2021a), and enduring the pain so as not to
314 let the partner down, which is more specific.

315 In our study, the SIDI was able to differentiate participants with vs. without sexual
316 dysfunction (see also the values of η^2_p indicating good effect sizes). These results are interesting not
317 only because they confirmed the validity of the questionnaire, but also because they further clarified
318 the strong association between dyspareunia-related issues and sexual function in women with
319 endometriosis. The correlations between the SIDI, the HADS, and the RSES (such that a greater
320 impact of dyspareunia was associated with symptoms of anxiety and depression, and poorer self-
321 esteem) are also interesting from either a statistical or a clinical perspective. On the one hand, these
322 results showed the validity of the questionnaire (i.e., concurrent validity). On the other hand, they
323 confirmed that sexuality and psychological health are intertwined, such that poor sexuality due to
324 endometriosis-related dyspareunia is associated with impaired psychological wellbeing.

325 **Limitations and reasons for caution**

326 Our study presents multiple strengths related to the sample size (i.e., it is one of the largest studies
327 on sexuality and dyspareunia in women with endometriosis) and the novelty value of the findings.
328 However, there are some limitations that should be acknowledged since they represent reasons for
329 caution when interpreting our results. From a methodological perspective, the cross-sectional
330 (rather than longitudinal) nature of our study did not allow to assess test-retest reliability, as done
331 for other important sexual function questionnaires such as the FSFI (Rosen *et al.*, 2000). Moreover,
332 our data were self-report (as it has been underlined in other endometriosis studies using a similar
333 methodology; e.g., Sullivan-Myers *et al.*, 2021), which might have led to unprecise information,
334 especially with regards to medical data such as type of diagnosis, form and stage of endometriosis,

335 hormonal treatment (although in our analyses they were not used to test specific hypotheses). In
336 addition, self-selection bias should be considered as a consequence of our recruitment strategy, as
337 previously underlined in studies with a similar methodology (Facchin *et al.*, 2021b): the study
338 population was entirely composed of voluntary participants from an online patient-association
339 community, which might have led to the inclusion of participants with particularly severe forms of
340 endometriosis and greater symptoms, including dyspareunia. Although this study was not
341 specifically focused on the prevalence of dyspareunia and sexual dysfunction in women with
342 endometriosis, the high rates reported in this article should be interpreted with caution. **The length**
343 **of the survey should also be considered as a limitation, although information about the response**
344 **time estimated by Qualtrics was provided in the pdf file that participants had to read before giving**
345 **their consent and completing the survey. We speculate that tiredness may have led a remarkable**
346 **percentage of women to abandon the study (see the flowchart reported in Figure 1). Significant**
347 **inconsistencies in participants' responses were not detected, also considering that the reliability of**
348 **the SIDI was confirmed by the good values of Cronbach's alpha.**

349 **Wider implications of the findings**

350 In this study, we provided an initial validation of the SIDI and we demonstrated that it can be a
351 reliable tool to measure the multidimensional subjective impact of dyspareunia in women with
352 endometriosis. Further research is needed to corroborate the validity of our findings and to clarify,
353 for instance, whether the SIDI can be effectively used in populations other than women with
354 endometriosis, including women with vulvodynia and other conditions associated with dyspareunia.
355 **It should be noted that the SIDI was translated from Italian into English by the authors without**
356 **using a systematic approach, including back translation. Therefore, future translations of the SIDI**
357 **are encouraged, especially in the context of studies aimed at validating the questionnaire. Cultural**
358 **specificities should be taken into account when translating and using the SIDI, also considering that**
359 **sexuality is a sensitive topic.**

360 In the context of endometriosis, the SIDI may be used to clarify the complex association
361 between dyspareunia and infertility. In this regard, there is evidence that superficial dyspareunia
362 (rather than deep dyspareunia) is associated with infertility concerns in women with the disease
363 (Wahl *et al.*, 2020). Moreover, the SIDI can be used in clinical practice with endometriosis patients
364 to assess the subjective impact of dyspareunia on important life domains such as sexuality and
365 intimate relationships. The individual items of the SIDI also allow for exploring a variety of
366 important aspects of the lived experience of dyspareunia, including coping strategies (i.e., how
367 women deal with dyspareunia individually and with their partner). This is very useful clinical
368 information that can be used to develop personalized treatment strategies focused on patients'
369 specific characteristics and needs. A comprehensive assessment of patients' sexuality may be
370 conducted by integrating the data collected using the SIDI with additional, important information
371 about dyspareunia severity, timing and localization, and with other validated sexual function
372 questionnaires.

373 Although the patient-doctor relationship is not directly affected by dyspareunia, it would be
374 also important to understand whether our endometriosis patients discussed sexual issues with
375 healthcare professionals, along with the quality of this experience (e.g., whether they felt supported
376 and understood). In fact, there is evidence that both patients and doctors may be reluctant or even
377 embarrassed to discuss sexual issues (Facchin *et al.*, 2021a; Witzeman *et al.*, 2020). In this regard,
378 the use of a brief questionnaire like the SIDI may facilitate disclosure.

379 **Conclusions**

380 Assessing sexuality in the context of endometriosis is vital, due to the remarkable impact of the
381 disease on this important life domain. Poor sexuality compromises overall quality of life and
382 psychological health, and sexual issues deserve great attention in clinical practice with these
383 patients. The interconnection between sexual and relational concerns, and psychological health
384 should be addressed using a multidisciplinary approach that should necessarily include

385 psychosexual counselling. Reaching pleasure through penetrative sex should not be seen as a
386 “sexual standard”, and a good clinical practice entails helping women with endometriosis find
387 personalized strategies to enjoy a satisfying, pain-free sexuality.

388

389 **Author’s roles**

390 All the authors provided substantial contribution to study conception and design (including the
391 development of the SIDI). FF coordinated the whole research project (supervised by PV),
392 performed statistical analyses, and wrote the article. The data were collected by AF, on behalf of the
393 Endometriosis Project Association (APE). GB, LB, DD, and PV also contributed to data
394 interpretation, drafted the article and revised it for important intellectual content. The final version
395 of the article was read and approved by all authors.

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402 **Conflicts of interest**

403 Annalisa Frassinetti is the President of APE-Odv (Associazione Progetto Endometriosi-
404 Organizzazione di volontariato [Endometriosis Project Association-Volunteer Organisation), the
405 largest non profit endometriosis patient association in Italy. The other authors have no conflicts of
406 interest.

407 **Data availability statement**

408 The data underlying this article will be shared on reasonable request to the corresponding author.

409 **The Italian version of the SIDI is also available from the corresponding author.**

410

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- 524

525 **Table 1. Characteristics of the study population**

Sociodemographic data (N = 638)		
Age in years (M ± SD)		36.1 ± 6.9
Relationship status (N [%])	In a relationship	295 (46)
	Married	259 (41)
	Separated/divorced	12 (2)
	Single	72 (11)
Sexual partner (N [%])	Yes	575 (90)
	No	63 (10)
Level of education (N [%])	Postgraduate	114 (18)
	Graduate	212 (33)
	High school	273 (43)
	Middle school	39 (6)
Employment status (N [%])	Homemaker	40 (6)
	Unemployed	74 (12)
	Full-time job	332 (52)
	Part-time job	136 (21)
	Working student	24 (4)
	Student	32 (5)
Children (N [%])	Yes	178 (28)
	No	460 (72)
Country of origin (N [%])	Italy	624 (98)
	Other European countries	8 (1)
	Non-European countries	6 (1)
Medical data (N = 638)		
Type of diagnosis	Laparoscopic surgery	165 (26)
	Clinical diagnosis	473 (74)
Age at diagnosis (in years) (M ± SD)		28.8 ± 6.4
Time since diagnosis (in years) (M ± SD)		7.3 ± 6.3
Rectovaginal endometriosis (N [%])		376 (59)
Ovarian endometriosis (N [%])		456 (72)
Adenomyosis (N [%])		416 (65)
Peritoneal, bladder, bowel, parametrial or ureteral endometriosis (N [%])		338 (53)
Endometriosis stage (Asrm) (N [%])	Stage I	34 (5)
	Stage II	47 (7)
	Stage III	78 (12)
	Stage IV	262 (41)

	Not known	217 (34)
Surgical interventions (N [%])	Yes	431 (68)
	No	207 (32)
Hormonal therapy (N [%])	Yes	432 (68)
	No	206 (32)
Infertility (N [%])	Yes	263 (41)
	No	375 (59)
Type of dyspareunia (N [%])	Deep dyspareunia	232 (36)
	Introital dyspareunia	109 (17)
	Both	297 (47)
Severity of dyspareunia (M \pm SD)		6.4 \pm 2.2
Severity of chronic pelvic pain (M \pm SD)		5.5 \pm 2.8
Severity of dysmenorrhea (M \pm SD)		6.2 \pm 3.4
Severity of dyschezia (M \pm SD)		4.7 \pm 3.3
Severity of dysuria (M \pm SD)		2.5 \pm 2.9
Sexuality (N = 524)		
FSFI (M \pm SD)	Desire	2.8 \pm 1.3
	Arousal	3.0 \pm 1.7
	Lubrication	3.1 \pm 1.8
	Orgasm	3.2 \pm 1.9
	Satisfaction	3.4 \pm 1.6
	Pain	2.5 \pm 1.7
	FSFI-Total	17.9 \pm 8.6
Psychological health (N = 572)		
HADS (M \pm SD)	HADS-Anxiety	11.1 \pm 4.4
	HADS-Depression	9.9 \pm 4.2
	HADS-Total	20.9 \pm 7.9
RSES (M \pm SD)		16.8 \pm 6.3

526

527

528 **Table 2. SIDI descriptive statistics for each item (N = 638)**

Item	M	SD	Asymmetry	Kurtosis
1-I had to interrupt intercourse due to pain	2.90	1.15	-0.02	-0.70
2-I avoided intercourses due to pain	3.19	1.17	-0.39	-0.62
3-I lost sexual desire due to pain	3.36	1.20	-0.48	-0.57
4-I experienced fear of having pain during intercourse	3.95	1.04	-0.88	0.27
5-During intercourse, I could not relax due to fear of pain	3.60	1.08	-0.52	-0.28
6-During intercourse, I endured pain without saying anything	3.04	1.18	-0.29	-0.79
7-During intercourse, I endured pain so as not to let my partner down	2.94	1.25	-0.16	-1.03
*8-I felt understood and supported by my partner regarding the pain I experience during intercourse	3.95	1.16	-0.86	-0.21
*9-When I felt pain during intercourse, my partner and I tried together to find less painful positions	3.92	1.13	-0.91	0.05
*10-When I felt pain during intercourse, I still sought pleasure through other non-penetrative sexual activities	2.97	1.25	-0.07	-0.95
*11-I felt free to talk to my partner about the pain I experience during intercourse	3.98	1.15	-0.87	-0.25
12-I have been worried about what my partner may think of me due to my pain during intercourse	3.20	1.41	-0.29	-1.17
13-I felt guilty towards my partner for my pain during intercourse	3.51	1.29	-0.61	-0.65
14-I felt dissatisfied with my sex life due to pain during intercourse	3.76	1.12	-0.71	-0.14
15-I have been worried that pain during intercourse may have a negative impact on my love life	3.70	1.14	-0.73	-0.07
16-I felt wrong about how I experience sexuality due to pain during intercourse	3.42	1.30	-0.47	-0.81

529 *Original items.

530

531 **Table 3a. Eigenvalues, factor loadings, Cronbach's alphas (N = 638)**

Item	Factors			
	1	2	3	4
1-I had to interrupt intercourse due to pain	0.62			
2-I avoided intercourses due to pain	0.90			
3-I lost sexual desire due to pain	0.84			
4-I experienced fear of having pain during intercourse	0.75			
5-During intercourse, I could not relax due to fear of pain	0.77			
6-During intercourse, I endured pain without saying anything				0.92
7-During intercourse, I endured pain so as not to let my partner down				0.84
*8-I felt understood and supported by my partner regarding the pain I experience during intercourse			0.81	
*9-When I felt pain during intercourse, my partner and I tried together to find less painful positions			0.77	
*10-When I felt pain during intercourse, I still sought pleasure through other non-penetrative sexual activities			0.32	
*11-I felt free to talk to my partner about the pain I experience during intercourse			0.79	
12-I have been worried about what my partner may think of me due to my pain during intercourse		0.85		
13-I felt guilty towards my partner for my pain during intercourse		0.90		
14-I felt dissatisfied with my sex life due to pain during intercourse	0.56			
15-I have been worried that pain during intercourse may have a negative impact on my love life		0.59		
16-I felt wrong about how I experience sexuality due to pain during intercourse		0.55		
Eigenvalues	5.98	2.45	1.55	1.07
Cronbach's alpha	0.88	0.86	0.75	0.87

532 *Reversed items.

533 **Table 3b. Descriptive statistics for SIDI factors and full scale score (N = 638)**

	M ± SD	Asymmetry	Kurtosis
Sexual Concerns	3.46 ± 0.89	-0.43	-0.45
Relationships Concerns	3.46 ± 1.08	-0.41	-0.62
Partner Support	2.29 ± 0.89	0.73	0.12
Endurance	2.99 ± 1.15	-0.20	-0.89
SIDI-Total	12.20 ± 2.82	-0.26	-0.48

534

535

536 **Table 4a. Correlations between SIDI and FSFI (N = 524)**

SIDI	FSFI						
	Desire	Arousal	Lubrication	Orgasm	Satisfaction	Pain	FSFI-Total
Sexual Concerns	-.472**	-.561**	-.574**	-.490**	-.600**	-.673**	-.658**
Relationship Concerns	-.309**	-.344**	-.346**	-.284**	-.396**	-.443**	-.413**
Partner Support	-.149**	-.289**	-.161**	-.320**	-.317**	-.091*	-.263**
Endurance	-.157**	-.213**	-.163**	-.162**	-.195**	-.230**	-.218**
SIDI-Total	-.381**	-.486**	-.434**	-.427**	-.519**	-.511**	-.539**

537 ** $P \leq 0.001$ 538 * $P < 0.05$

539

540 **Table 4b. Correlations between SIDI, HADS, and RSES (N = 638)**

SIDI	HADS			RSES
	HADS-A	HADS-D	HADs-Total	
Sexual Concerns	.232**	.276**	.277**	-.226**
Relationship Concerns	.268**	.308**	.315**	-.343**
Partner Support	.092*	.218**	.168**	-.142**
Endurance	.171**	.154**	.178**	-.153**
SIDI-Total	.274**	.336**	.333**	-.310**

541 ** $P \leq 0.001$ 542 * $P < 0.05$

543

544

545 **Table 5. SIDI and sexual dysfunction (N = 524)**

SIDI (M ± SD)	With sexual dysfunction (N = 429)	Without sexual dysfunction (N = 95)
Sexual Concerns	3.65 ± 0.77	2.42 ± 0.76
Relationship Concerns	3.62 ± 1.02	2.57 ± 1.06
Partner Support	2.25 ± 0.81	1.87 ± 0.69
Endurance	3.10 ± 1.13	2.27 ± 1.05
SIDI-Total	12.61 ± 2.44	9.12 ± 2.57

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547