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1 **Patients' perspectives on how to improve endometriosis care: a large qualitative study**
2 **within the ComPaRe-Endometriosis e-cohort**

3
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27 **Abstract**

28 **Background:** Endometriosis is a chronic gynecological condition that affects about 10% of women of
29 reproductive age. Despite its prevalence, diagnosis is often delayed, misdiagnosis is common, and
30 treatment options are poor. This study aimed at capturing ideas to improve endometriosis care from
31 the patients' perspectives.

32 **Methods:** We analyzed cross-sectional data from 1,000 adult patients in ComPaRe-Endometriosis (a
33 French prospective e-cohort focused on endometriosis) who answered to the open-ended question:
34 "If you had a magic wand, what would you change about your health care?". The free-text responses
35 were analyzed by qualitative thematic analysis using an inductive approach.

36 **Results:** Patients had a mean age of 34.1 years (SD = 8.1); 56% and 42% had stage IV disease or deep
37 endometriosis, respectively. They elicited 2,487 ideas to improve the management of endometriosis,
38 which were categorized into 61 areas of improvement, further grouped into 14 themes. The top five
39 areas of improvement were mentioned by >10% of the patients and were to 1) train caregivers to
40 develop their knowledge on the disease, 2) provide better management of daily pain and pain attacks,
41 3) take patient-reported symptoms seriously, 4) standardize diagnostic processes to improve early
42 detection, and 5) have caregivers listen more to the patients.

43
44 **Conclusions:** We identified 61 areas for improvement in endometriosis care. These results reflect
45 patients' expectations in terms of management of their disease and will be useful to design a better
46 global care for endometriosis from the patients' perspectives.

47
48 **Keywords:** Endometriosis, Improving care, Qualitative research, Patient involvement.

49

50

51 INTRODUCTION

52

53 Endometriosis is an inflammatory condition in which endometrium-like tissue develops outside of the
54 uterus ¹. Symptoms can include severe pelvic pain, dysmenorrhea, deep dyspareunia, dysuria,
55 dyschezia, fatigue, and infertility. Adenomyosis, a disease in which endometrium-like tissue is located
56 within the myometrium, often coexists with endometriosis ². It is estimated that endometriosis affects
57 approximately 10% of women of childbearing age ³. Despite its prevalence, a mean diagnostic delay of
58 7 years was described between the onset of symptoms and diagnosis of the disease ⁴. Unfortunately,
59 diagnostic and therapeutic options remain limited ⁵ and many women live with unresolved pain due
60 to endometriosis and its consequences (physical, mental health, quality of life, sexual life, social
61 relationships, work)⁶⁻¹⁰. The trivialization of symptoms and the misperception of the disease by the
62 medical profession have been described as contributing to the delay in diagnosis and poor quality of
63 care ¹¹⁻¹³. About half of the women with endometriosis reported being dissatisfied with their care ^{14,15}.
64 It is deemed urgent to rethink endometriosis care with a more comprehensive and patient-centered
65 approach ¹⁶. The perspectives of patients with endometriosis have rarely been included in studies that
66 focus on improving care. In this study, we aimed to assess patients' ideas for improving the care of
67 people with endometriosis.

68

69 MATERIALS AND METHODS

70 Setting

71 This citizen science study was nested within the ComPaRe cohort (*Communauté de Patients pour la*
72 *Recherche*), an ongoing e-cohort of patients with chronic diseases. ComPaRe participants are French-
73 speaking adults with one or more chronic diseases, defined as diseases requiring care for at least 6
74 months, who are followed-up through online questionnaires allowing the collection of patient-
75 reported outcome measurements (PROMs) and patient-reported experience measurements (PREMs).
76 ComPaRe was launched in January 2017 and recruitment is still ongoing. Within ComPaRe, a sub-

77 cohort focused on endometriosis, “ComPaRe-Endometriosis”, was launched in November 2018 and
78 included about 9,000 patients with endometriosis in October 2019 (i.e., date of data extraction for
79 analysis). Participants are recruited by several complementary methods: invitation by the researchers
80 and physicians involved in ComPaRe, patient associations, media campaigns including television and
81 radio, and through social media. Participants give electronic consent before participating in the e-
82 cohort. The cohort was approved by the Institutional Review Board of the Hôtel-Dieu Hospital in Paris
83 (IRB: 0008367) and the National Commission for Data Protection and Privacy (CNIL: 916397). More
84 details on this cohort model have been described elsewhere ¹⁷.

85

86 **Participants**

87 We selected a random sample of 1,000 patients among the 9,000 participants from ComPaRe-
88 Endometriosis who had completed both the baseline endometriosis questionnaire and the general
89 questionnaires collecting data on socio-demographic characteristics, reproductive health, and an
90 open-ended question related to their ideas to improve care. This sample size was chosen to be large
91 enough to provide a rich overall understanding of the phenomenon under study and to strike a balance
92 between a sufficiently large number of patients and ideas, and the time for qualitative analysis ^{18,19}.

93

94 **Collected data**

95 Participants are regularly invited by e-mail to answer online questionnaires on the ComPaRe secured
96 internet platform. In addition to socio-demographic data (e.g., age, biological sex, place of residence)
97 collected at baseline, we used self-reported data on patients’ endometriosis stage (I-IV) and type
98 (superficial, endometrioma, deep), and on their pregnancy history. We also used their answer to the
99 open-ended question: “If you had a magic wand, what would you change in your health care?”. This
100 question was inspired by the miracle question used in the solution-focused brief therapy, which
101 encourages people to focus on possibilities rather than problems ²⁰, and by a study that aimed at
102 identifying HIV patients’ propositions to reduce their treatment burden in Sub-Saharan Africa ²¹.

103

104 **Analysis**

105 The free-text responses to the open-ended question were analyzed by qualitative thematic analysis.
106 First, one investigator (SG) read all the responses, identified patient ideas in the raw data, and classified
107 them by similarity into areas of improvement (i.e., codes) with the method described by Yin RK in the
108 “disassembling step” of qualitative data analysis ²². This initial classification was based on the results
109 of a previous analysis of the same open-ended question in a previous study aimed at identifying areas
110 of improvement for the care of patients with chronic diseases ²³. In addition to codes adapted from
111 the previous study, new codes were created as needed. The creation of new codes was systematically
112 discussed with two investigators (VTT and MK). Coding both referred to explicit statements in the data,
113 such as the mention of the term "pain", and to a more latent level, such as the implicit mention of pain
114 ²⁴. Second, the analysis was triangulated with the help of two patients with endometriosis (CG and
115 MG). During recorded meetings, they independently analyzed a random selection of 10% of the data,
116 blinded from the researchers' coding. They then discussed with two investigators (SG and VTT) how
117 the codebook could be improved. Finally, three investigators (SG, VTT and MK) organized the final
118 codes into broader themes (e.g., “improving caregivers' knowledge and recognition of the disease”)
119 through an inductive method to facilitate the presentation of the results.

120

121 **RESULTS**

122 **Characteristics of patients**

123 Among the 1,000 included patients, 685 (68.5%) reported a diagnosis of endometriosis, 37 (3.7%) a
124 diagnosis of adenomyosis, and 278 (27.8%) declared diagnosis of both diseases. One third of
125 participants (n=342, 34.2%) reported their endometriosis stage; more than half were stage IV (severe
126 disease). Of the 707 patients (70.7%) who reported their endometriosis type(s), deep endometriosis
127 was the most prevalent (n=452), followed by endometrioma (n=310). Participants' mean age at
128 inclusion was 34.1 years (SD=8.1) and about one third (n=287, 28.7%) reported at least one co-

129 morbidity (1 or more additional chronic illnesses). Almost all participants lived in France (n=975, 97.5%)
130 and they were distributed evenly between urban and rural areas, defined as cities with more or less
131 than 10,000 inhabitants (52.1% vs. 45.4%). More details on the patient characteristics are presented
132 in **Table 1**.

133

134 **Patients' ideas to improve endometriosis care**

135 We collected 2,487 ideas for improving endometriosis care, which were coded into 61 areas of
136 improvement and 14 broad themes, presented in **Figure 1** and in **Appendix 1**. The ten areas of
137 improvement most frequently elicited by patients are presented in **Table 2**. The 14 broad themes are
138 described below.

139

140 The first 4 themes described concern ideas about how the disease management can be improved by
141 caregivers. In total, these 4 themes represent 1,016 ideas out of 2,487.

142

143 *1. Improving caregivers' knowledge and recognition of the disease*

144 This theme included 5 areas of improvement with a total of 414 ideas related to 1) better training
145 caregivers on the disease, 2) providing more explanation about the disease to patients, 3) having the
146 disease better recognized by doctors, 4) stop believing that it is normal to suffer during menstruation,
147 and 5) developing research on endometriosis. Regarding the need for more training for caregivers
148 (elicited by 194 (19.4%) patients), this encompassed both gynecologists and general practitioners.
149 Patients wanted this training both to increase caregivers' knowledge and to train more specialists.

150

151 *2. Stopping medical violence*

152 This theme contained 7 areas of improvement with a total of 256 ideas related to 1) taking patient-
153 reported symptoms seriously, 2) stopping telling patients that their pain is psychological or stress-
154 related, 3) not judging patients, 4) stopping patronizing patients, 5) ending gender-biased care, 6)

155 ensuring that there is no more physical and emotional abuse in care, and 7) guaranteeing patient
156 intimacy.

157

158 *3. Improving some qualities of caregivers*

159 This theme included 4 areas of improvement with a total of 230 ideas related to 1) making caregivers
160 listen more to patients, 2) increasing their empathy towards patients, 3) making them more proactive
161 in providing information, initiating follow-up and monitoring, and 4) training them in interpersonal
162 skills. The area “making caregivers listen more to patients” was mentioned by 138 patients (13.8%).
163 The patients explained that they wanted to be listened to by caregivers about their pain, their needs,
164 or without specifying, but simply to be listened to.

165

166 *4. Making caregivers more available*

167 This theme gathered 5 areas of improvement with a total of 116 ideas related to 1) decreasing waiting
168 times for appointments and medical exams, 2) reducing the workload of caregivers so that they have
169 more time for each patient, 3) proposing longer doctor's consultations, 4) making it possible to
170 communicate with doctors outside of consultations, and 5) reducing time spent in the waiting room.
171 The area “decreasing the waiting times for appointments and medical exams” was mentioned by 75
172 patients (7.5%). Patients reported waiting times of up to 1 year for an appointment.

173

174 *5. Improving the management of some symptoms or care specific to endometriosis*

175 This theme grouped 4 areas of improvement with a total of 248 ideas related to 1) improving the
176 management of daily pain and pain crises, 2) enhancing the management of infertility, 3) integrating
177 the management of sexual problems into care, and 4) reducing the number of painful examinations
178 and ensuring better pain management during these examinations. The area “improving the
179 management of pain” was mentioned by 184 patients (18.4%). The patients proposed several options

180 to better manage their pain, such as better recognition of the intensity of their pain by physicians,
181 easier access to pain centers, relief through effective treatments, and the help of alternative medicine.

182

183 *6. Ensuring an early diagnosis with an adapted process and support*

184 This theme encompassed 4 areas of improvement with a total of 219 ideas related to 1) creating a
185 better framed diagnostic process for early diagnosis, 2) proposing relevant medical exams for
186 diagnosis, 3) improving the diagnosis announcement with empathy and appropriate support, and 4)
187 initiating screening for earlier detection. The area “creating a better framed diagnostic process” was
188 mentioned by 141 patients (14.1%). The patients explained that they had experienced a very long delay
189 in diagnosis and that a better diagnostic process was much-needed to reduce these delays.

190

191 *7. Providing a better organization and coordination*

192 This theme included 8 areas of improvement with a total of 208 ideas related to 1) developing a more
193 multidisciplinary approach in care, 2) creating a unique multidisciplinary and specialized endometriosis
194 care center, 3) providing more frequent and better organized medical follow-up, 4) developing a more
195 holistic approach in care, 5) strengthening coordination and communication between doctors, 6)
196 planning for a referral doctor to centralize and coordinate follow-up, 7) creating an optimal care
197 pathway, and 8) strengthening the shared medical record system.

198

199 *8. Improving therapeutic care*

200 This theme grouped 3 areas of improvement with a total of 164 ideas pertaining to 1) proposing more
201 alternative medicine and self-management options, 2) developing drugs with fewer side effects, and
202 3) avoiding surgery as much as possible. The area “proposing more alternative medicine and self-
203 management options” was mentioned by 85 patients (8.5%). The patients indicated that they wanted
204 to use these methods to treat their endometriosis (i.e., pain and other symptoms of the disease). Some
205 of them wanted non-drug therapies to avoid drug side effects. Patients mentioned treatments such as

206 balneotherapy, spa treatments, massages, adapted sports, or a special endometriosis diet. They
207 wanted access to this type of care to be easier, less expensive, and for doctors to be more open to
208 these alternative methods and offer them as part of their treatment.

209

210 *9. Improving the access or referral to endometriosis-specific care*

211 This theme encompassed 5 areas of improvement with a total of 161 ideas covering 1) helping patients
212 in accessing a doctor with expertise in the disease and with human qualities, 2) making endometriosis
213 care geographically accessible, 3) improving the process of accessing medical services specialized in
214 endometriosis, 4) referring the patient more quickly to an expert colleague in case of doubt, and 5)
215 creating a directory of doctors specializing in the disease. The area “providing help in accessing an
216 expert doctor” was mentioned by 88 patients (8.8%). The patients mentioned their difficulties in
217 finding a “good doctor”, which they defined as a doctor who knows their disease and has interpersonal
218 skills. They would have liked to know who to turn to at the beginning of their illness.

219

220 *10. Improving society’s awareness and recognition of disease*

221 This theme included 4 areas of improvement with a total of 132 ideas related to 1) improving the public
222 recognition of the disease, 2) recognizing endometriosis as a chronic disease, a long-term disabling
223 condition, or a disability by the social security administration, 3) raising awareness among the general
224 public, and 4) providing more information on research results.

225

226 *11. Reducing the financial impact of the disease on patients’ lives*

227 This theme contained 2 areas of improvement with a total of 109 ideas related to 1) reimbursing
228 certain medicines, care acts, and care-related transportation, and 2) ceasing medical fees exceeding
229 reimbursement levels. The first area was mentioned by 96 patients (9.6%). The patients explained that
230 the disease was very expensive for them and wanted the reimbursement of their drugs (certain non-

231 reimbursed pills, analgesics, dietary supplements...), alternative medicine, psychological follow-up,
232 and transportation costs to attend a medical appointment for instance.

233

234 *12. Providing more support to patients*

235 This theme included 4 areas of improvement with a total of 104 ideas related to 1) integrating
236 psychosocial support into endometriosis care, 2) increasing guidance and support to patients to make
237 them feel less alone or lost with the disease, 3) giving patients the opportunity to participate in patient
238 discussion groups, and 4) involving their partner or family in care.

239

240 *13. Facilitating reconciliation between work life and endometriosis*

241 This theme grouped 3 areas of improvement with a total of 85 ideas related to 1) adjusting work and
242 creating specific leaves of absence, 2) recognizing the disease in the work sphere, and 3) facilitating
243 reconciliation of work life and medical follow-up of the disease.

244

245 *14. Promoting patient involvement in care*

246 This theme gathered 3 areas with a total of 41 ideas related to 1) sharing decision-making in care, 2)
247 taking into account the patients' expertise, and 3) personalizing care on a case-by-case basis.

248

249 **DISCUSSION**

250 We involved 1,000 patients with endometriosis in proposing ideas to improve their care and identified
251 61 areas of improvement to enhance endometriosis care.

252

253 In the literature, very few studies have involved patients in identifying specific ideas to change the care
254 of endometriosis. First, a German study evaluated supporting and inhibiting factors when coping with
255 endometriosis from the patients' perspectives among 115 women by asking them "What has been
256 lacking in the management of this disorder and what could be improved?"²⁵. The results revealed that

257 the main areas for improvement were the performance of health system professionals (n=56),
258 treatment (n=53), and information (n=33). These results were consistent with the areas identified in
259 the present work. This study also highlighted the fact that doctors were not sufficiently informed about
260 the disease, which led to symptoms of endometriosis not being recognized quickly and patients not
261 taken seriously. Second, a survey study among members of the US Endometriosis Association explored
262 patients' experience of diagnosis ²⁶. Almost two thirds of respondents consulted three or more
263 physicians before being diagnosed. During this diagnosis process, 63% were told by at least one doctor
264 that nothing was wrong and 59.6% said they were not taken seriously by their doctors. Finally, the
265 Endometriosis Priority Setting Partnership (PSP) involved patients, people who support them, and
266 clinicians in defining top 10 priorities for endometriosis research in Ireland and the United Kingdom ²⁷.
267 While our study was not centered on research priorities to improve endometriosis care, it is interesting
268 to note that participants in our study mentioned almost all of the 10 areas identified in the PSP project.
269 The most frequently cited areas in our study were those related to the education of healthcare
270 professionals, improving the diagnosis of endometriosis, and pain management.

271
272 We identified several differences and similarities in comparison to the study on patients' ideas to
273 improve the management of chronic conditions conducted in ComPaRe ²³. In both studies, patients
274 wanted more listening from care professionals and requested care to be more affordable. However,
275 some areas were more often reported in our endometriosis study. For patients with chronic conditions
276 in general, improving the diagnosis process was a priority for only 3.8%, while this area of improvement
277 was mentioned 141 times (14.1%) among endometriosis patients. Similarly, pain management was a
278 priority for a higher proportion of patients with endometriosis (18.4%) than for those with any chronic
279 disease (4.1%). In the study on chronic diseases, 5.9% of people requested more training for healthcare
280 professionals to improve their knowledge of specific conditions or treatments, while for
281 endometriosis, this area was mentioned 194 times (19.4%). Finally, in our analyses, we considered the
282 responses of women with adenomyosis exclusively, but they were not presented separately in the

283 results because they did not differ from the ideas of those with endometriosis or both conditions.
284 Another study also found a high level of agreement about needs among people with endometriosis
285 and/or adenomyosis ²⁸. It might be possible that women with adenomyosis have other unmet and
286 specific needs, but our study cannot determine this, in part because there were so few of these
287 participants (n=37).

288

289 This study has several strengths. First, we used data collected in a prospective cohort study of a large
290 sample of women with endometriosis with diverse profiles in terms of age, city of residence
291 (rural/urban), and life course with the disease. The participants provided many suggestions to improve
292 endometriosis care, in total 2,487 ideas which represents more than two per patient. Second, we used
293 the methodology of a previous study that has already yielded informative results (12). Third, the results
294 were reviewed by two investigators and two patients, which reduced potential interviewer's
295 preconceived ideas on the analysis ²⁹. Fourth, the involvement of patients in the research and data
296 analysis is innovative and brought a real advantage for this type of qualitative study. These
297 partnerships enable the implementation of patient-centered research and can better ensure that
298 research integrates the voice of the patients involved ³⁰. In addition, the role of patients in improving
299 their care is increasingly important ³¹. The perspective of patients with endometriosis should be taken
300 into account in the development of health and social policies to improve the management of
301 endometriosis.

302

303 This study has also weaknesses. First, interpretation of patients' responses was prone to subjectivity.
304 For instance, when women say they want "to be listened to by caregivers", it may be difficult to tease
305 out whether they are referring to the quality of caregivers' listening or whether they want to be heard
306 and taken seriously by caregivers. Moreover, participants could have other chronic diseases in addition
307 to their endometriosis, since 28.7% women declared comorbidities. Since the open-ended question
308 that we used was not endometriosis-specific, we cannot rule out that the presence of comorbidities in

309 some participants may have influenced some of the findings, although most of the ideas proposed by
310 the women mentioned endometriosis. Finally, the transferability of our findings to other settings may
311 not always be possible because some ideas are linked to the specificities of the French healthcare
312 model (e.g. universal health coverage, institutional polycentrism)³². Furthermore, the population of
313 our study is likely not representative of the endometriosis patient population. As with other online
314 studies ³³, our results likely reflect a large proportion of individuals with higher-education levels.
315 Regarding self-reported stages and types of endometriosis, the study population may also be particular
316 in terms of disease severity. Finally, the ideas most often mentioned were not necessarily those that
317 participants "wanted" most, but those that came to mind most clearly. Therefore, this work reflects
318 patients' general ideas for the improvement of endometriosis care rather than their identified
319 priorities for care improvement.

320

321 **CONCLUSIONS**

322

323 In this citizen science study, we involved a large sample of endometriosis patients to determine how
324 to improve endometriosis care. Through many ideas from patients, we identified a total of 61 areas
325 for improving endometriosis care classified into 14 themes. These results reflect patients' expectations
326 in terms of management of their disease and will be useful to design a better global care for
327 endometriosis from the patients' perspectives.

328

329

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339
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341 CR, ED, VTT and PR collected the data. IP performed data cleaning and randomization of data. SG, MK,
342 CG, MG and VTT contributed to the analysis and interpretation of data. SG and ED performed the
343 presentation of the results. SG, MK, VTT, ZGB and MV contributed to the writing of the manuscript.
344 SG, MK, CR, ED, IP, ZGB, MV, MG, CM, PR and VTT agree with manuscript results and conclusions.

345
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353
354 **Ethics approval and consent to participate:** ComPaRe was approved by the Institutional Review Board
355 of Hôtel-Dieu Hospital, Paris (IRB: 0008367) and the National Commission for Data Protection and
356 Privacy (CNIL: 916397). This study methods and procedures were conducted in accordance with the
357 Declaration of Helsinki or comparable ethical standards. All the participants provided written informed
358 consent to participate and were all adults over the age of 18.

359
360 **Consent for publication:** Patients who participated in the analyses of this study consent to publication.

361

362 **Availability of data and materials:** All data collected for the study, including individual participant data
363 and a data dictionary is available for research purposes, under the rules of the ComPaRe e-cohort
364 (<https://compare.aphp.fr/>)

365

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