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Abstract

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

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

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

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

Keywords: Endometriosis, Improving care, Qualitative research, Patient involvement.

INTRODUCTION

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

MATERIALS AND METHODS

Setting

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

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

Participants

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

Collected data

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

Analysis

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

RESULTS

Characteristics of patients

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

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

Patients' ideas to improve endometriosis care

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

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

1. Improving caregivers' knowledge and recognition of the disease

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

2. Stopping medical violence

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

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

3. Improving some qualities of caregivers

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

4. Making caregivers more available

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

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

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

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

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

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

7. Providing a better organization and coordination

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

8. Improving therapeutic care

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

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

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

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

10. Improving society’s awareness and recognition of disease

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

11. Reducing the financial impact of the disease on patients' lives

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

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

12. Providing more support to patients

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

13. Facilitating reconciliation between work life and endometriosis

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

14. Promoting patient involvement in care

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

DISCUSSION

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

In the literature, very few studies have involved patients in identifying specific ideas to change the care of endometriosis. First, a German study evaluated supporting and inhibiting factors when coping with endometriosis from the patients' perspectives among 115 women by asking them "What has been 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 trengths. 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

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

CONCLUSIONS

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

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Authors' contributions: VTT and PR generated the idea. VTT, CR and PR created the methodology. IP, CR, ED, VTT and PR collected the data. IP performed data cleaning and randomization of data. SG, MK, CG, MG and VTT contributed to the analysis and interpretation of data. SG and ED performed the presentation of the results. SG, MK, VTT, ZGB and MV contributed to the writing of the manuscript. SG, MK, CR, ED, IP, ZGB, MV, MG, CM, PR and VTT agree with manuscript results and conclusions.

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

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

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

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