

REVIEW ARTICLE

CHALLENGES OF PATIENT- CENTRED COMMUNICATION IN ENDOMETRIOSIS: A SYSTEMATIC REVIEW

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ABSTRACT

Patient-centred communication is healthcare professionals' (HCPs) emotional understanding of a patient's experience which manifests in their communication with patients. HCPs tend to focus more on administrating treatment and often providing personalised communication gets side-lined. In offering care to endometriosis patients, a lack of understanding of patients' experiences, emotions, and mental health, will result in communication that tend to lack humility, compassion, and respect. Resulting in patients with feelings of vulnerability and anxiety during consultations. This review examines the gaps in the research on the challenges healthcare professionals face while offering patient-centred communication with endometriosis patients. Using Google Scholar, Web of Science, and Scopus, the researchers reviewed literature published from 2000 to 2022 on providing patient-centred communication during consultation. Based on full-text availability, the researchers were able to retrieve 227 peer-reviewed papers. Fifteen articles addressing patient-centred communication were chosen based on the inclusion and exclusion criteria. A thematic approach was used to classify prevalent themes that constitute significant challenges for HCPs. Six emerging themes were identified: 1) medical knowledge, 2) authority/control, 3) acknowledging patients' perspectives and empathy, 4) healthcare professionals' emotional exhaustion, 5) healthcare professionals' uncertainty and 6) patients' shame. The review provides healthcare professionals with information on challenges faced by HCPs in balancing disease-centric communication while prioritising patient-centred communication for endometriosis patients. Significant research gaps were discovered through the systematic review, which can be used to assist researchers in identifying key study areas for future research.

Keywords: Endometriosis, healthcare professionals, endometriosis patients, systematic review, patient-centred communication, health consultation

INTRODUCTION

Endometriosis commonly affects women of reproductive age, which can have an adverse effect on every aspect of a woman's life¹. Women with endometriosis usually suffer from painful periods, excessive bleeding, infertility, constipation, diarrhoea, and ongoing fatigue^{2,3}. Regardless of the severity of the disease, endometriosis can take up to eight years to diagnose⁴. Patients seek the advice of their healthcare professionals (HCPs), who sometimes are unable to communicate effectively with patients. This may explain the delay in receiving a diagnosis⁵. Therefore, this review aims to fill the gap by looking at the empirical data on healthcare professionals' challenges when providing patient-centred communication to endometriosis patients.

Patient-Centered Communication

Patient-centred communication enables HCPs to provide care that is in line with patients' values, needs, and preferences, as well as their involvement in making decisions about their care⁶. In other words, patient-centred communication is a deep understanding of a patient's pain and a desire to alleviate it⁷. Healthcare professionals that continuously use patient-centred techniques, such as

acknowledging and exploring the patient's feelings and identifying the patient's coping methods, notice that their patients can manage some of the challenges related to pain, such as endometriosis^{8,9,7,10,5}. Several studies^{8,11,12} show that focusing on patients' needs can help reduce pain and anxiety while improving overall patient treatment quality.

METHOD

This review aims to synthesise existing literature on the challenges that healthcare professionals (HCPs) face when practising patient-centred communication. In this review, the focus will be on research related to women's reproductive health issues, such as endometriosis. A systematic literature review was conducted on Three electronic databases—Google Scholar, Web of Science, and Scopus. These three databases were selected for the consistent high citation score across all areas, with Google Scholar (93%-96%), Scopus (35%-77%), and Web of Science (27%-73%)¹³.

As shown in Figure 1, the four phases of review conducted in this study is based on the recommendation by Pollard, Bransback and Bryan¹⁴. Following Pollard's guidance, a thorough search was made for relevant titles, abstracts,

and keywords to achieve the objectives of this review. Keywords entered were endometriosis, healthcare professionals, endometriosis patients, patient-centred communication, and health consultation. Based on the references in each article, the search engine was used at random to look for peer-reviewed articles published in English. For database searches, the inclusion criteria were (a) articles that matched the keywords, (b) the availability of full-text articles, and (c) articles written in English-. Each researcher independently entered the data for each article into an excel spreadsheet. The papers assigned to them were double-checked by a

second reviewer. The following section further discusses the four phases of review employed in this study.

Phase 1: Identification

The publication search covered all publications published in the last two decades from 2000 to 2022. The keywords entered resulted in a large number of papers (n=227); hence, an advanced search was conducted by identifying eligible publications using the inclusion and exclusion criteria. The inclusion and exclusion criteria are shown below in Table 1.

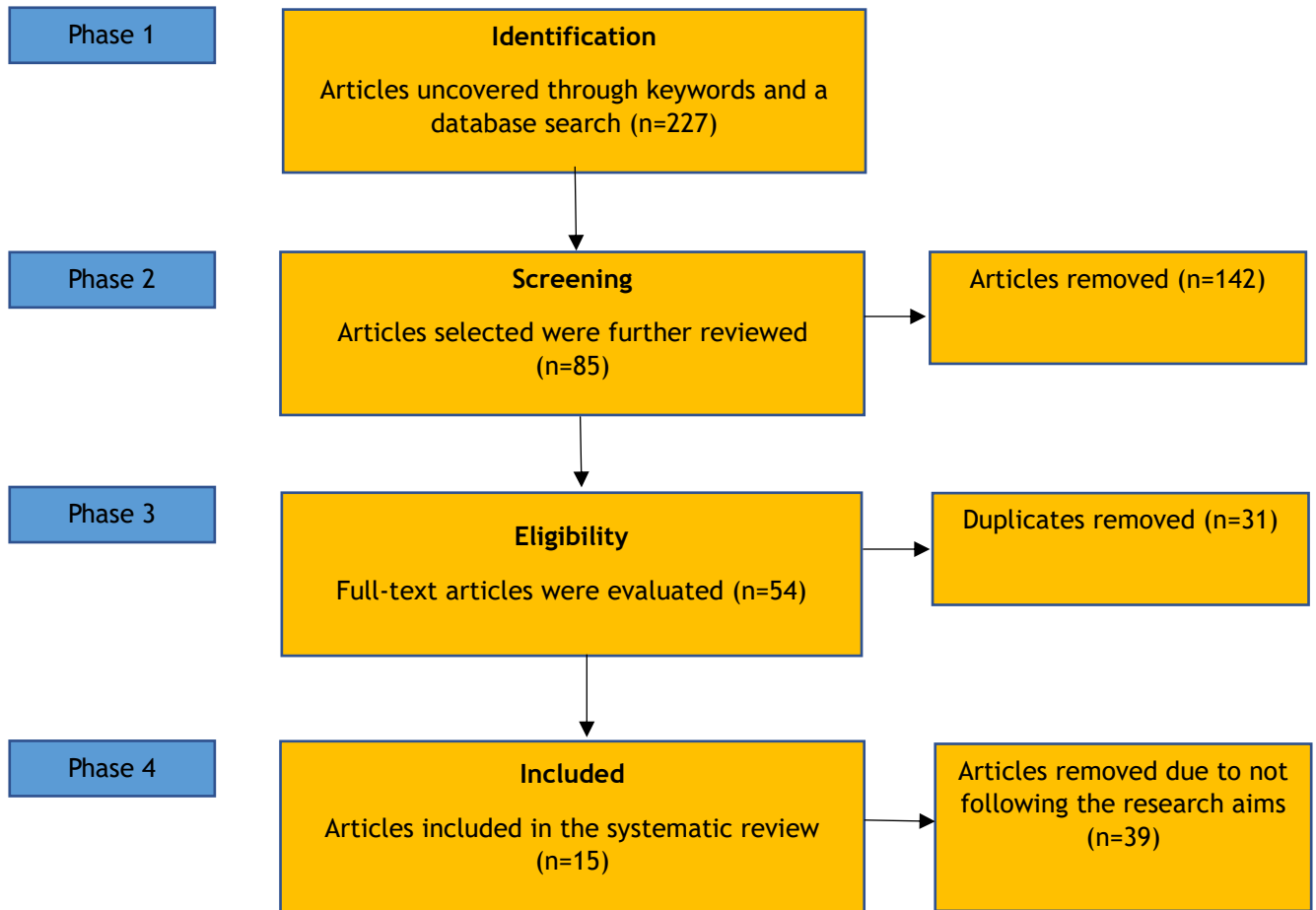


Figure 1: The four phases of the review¹⁴

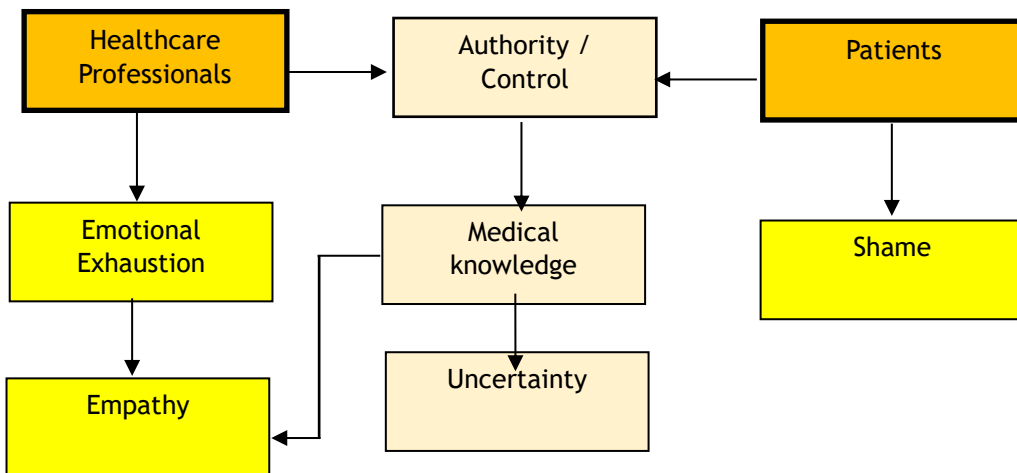


Figure 2: Themes associated with HCPs and patients.

Table 1: Inclusion and Exclusion Criteria for Article Selection

Inclusion	Exclusion
1. Research related articles, dissertations and complete research on doctors, medical specialists and patients.	1. Studies on nurses, midwives, and complementary and alternative medicine practitioners.
2. Reported patients' attitudes or opinions toward consultation with HCPs in a qualitative, quantitative or mixed-mode method.	2. Studies that were not written about healthcare.
3. Reported HCPs' attitudes or opinions toward patient-centred communication in a qualitative, quantitative or mixed-mode method.	3. Research that did not use data from patients and healthcare experiences.
4. Patients or HCPs' communication challenges encountered by HCPs in patient-centred communication during the consultation.	4. Review articles.
5. Focuses on general health and reproductive health issues such as endometriosis.	5. Studies specifically on male reproductive health issues.

Since the study aims to investigate the theoretical and methodological perspective of prior research on patient-centered communication and based on the inclusion and exclusion criteria, the identified articles for review included qualitative, quantitative or mixed-mode method research on patients' attitudes or opinions about consultation with HCPs and HCPs' attitudes or opinions toward patient- communication.

Phase 2: Screening

The articles selected were further reviewed by screening the title and abstract for relevance in this study (n=85). The remaining papers (n=142) were excluded for the following reasons: i) studies that were not written about healthcare, ii) research that did not use data from patients and healthcare experiences and iii) literature review articles were eliminated; however, reference lists of all review articles that discussed patients and HCPs' perspectives on patient-centred communication were checked to ensure that all possibly qualifying articles were included.

Phase 3: Eligibility

Extensive literature reviews of the selected qualitative and mixed-method articles (n=54): will be reported separately and were classified into two types 1) Patients who reported communication challenges encountered by HCPs in patient-centred communication during consultation and 2) HCPs who reported communication challenges in patient-centred communication during consultation. A total of 31 duplicated articles were excluded from this phase.

Phase 4: Inclusion

In the final stage, articles selected in phases 1, 2 and 3 were reviewed, and 15 (n=15) empirical studies were chosen and reviewed to form the foundation of knowledge and research for this paper. Manual analysis was conducted by carefully reading each of the selected articles. The remaining (n=39) articles were excluded as it did not fulfil the research aims. The researchers evaluated the articles critically for quality. Any disparity in quality was then investigated further. To fulfil the aims of identifying the challenges of patient-centred communication in medical settings with endometriosis patients, the final set of 15 research articles was carefully examined, and the purpose of the study and the research methodologies were recorded.

Based on the inclusion and exclusion criteria, Table 2 lists all selected studies, authors, publication dates, titles, subjects, and methods. The articles selected were synthesised using descriptive synthesis analysis. Some of the themes selected from the review indicated both HCPs and patients tend to have similar challenges in patient-centred communication, as depicted in Figure 2. The subthemes of the review were assigned to the six selected prominent themes indicated in Table 2. Repetitive subthemes were eliminated, whereas emerging subthemes were merged and incorporated into the selected themes. Furthermore, the six-step theme analysis was utilized in this review to facilitate the development of a well-organized summary¹⁵. The process consists of six steps: 1) familiarisation; 2) generation of codes; 3) development of themes; 4) examination of possible themes; 5) establishment and classification of themes; and 6) generation of final themes.

Table 2: Studies selected for inclusion

Author, date of publication	Title	Theme	Subject	Method
Kenny et al., (2004)	Constructions of chronic pain in doctor-patient relationships: bridging the communication chasm.	1.Authority/control 2.Healthcare professional's Emotional exhaustion	Chronic pain patients and Healthcare professionals	Qualitative
Ballard et al., (2006)	What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis.	1.Healthcare professional's uncertainty 2.Patients' shame	Pelvic pain patients.	Qualitative
Markovic et al.,(2008)	Endurance and contest: women's narratives of endometriosis.	1.Authority/control	Endometriosis patients	Qualitative
Fauconnier et al., (2013)	Comparison of patient-and physician-based descriptions of symptoms of endometriosis: a qualitative study.	1.Medical knowledge	Healthcare professionals and Endometriosis patients	Qualitative
Moradi et al., (2014)	Impact of endometriosis on women's lives: a qualitative study.	1.Medical knowledge	Endometriosis patients	Qualitative
Grundström et al., (2016)	"A challenge"-healthcare professionals' experiences when meeting women with symptoms that might indicate endometriosis.	1.Acknowledging patients perspectives and empathy	Healthcare professionals	Qualitative
Bullo, (2018)	Exploring disempowerment in women's accounts of endometriosis experiences. Discourse & Communication.	1.Medical Knowledge 2.Acknowledging patients' perspectives and empathy 3.Healthcare professional's uncertainty	Endometriosis patients	Mixed-mode
Rowe et al., (2019)	Improving clinical care for women with endometriosis: qualitative analysis of women's and health professionals' views.	1.Healthcare professional's emotional exhaustion 2.Healthcare Professional's uncertainty	Endometriosis patients and Healthcare professionals	Qualitative
Young et al., (2019)	Do mad people get endo or does endo make you mad?": Clinicians' discursive constructions of Medicine and women with endometriosis.	1.Medical knowledge 2.Authority/control 3.Acknowledging patients' perspectives and empathy	Healthcare professionals	Qualitative
Westeneng, (2019)	" I didn't need to know that!": the regulation of women with endometriosis.	1.Patients' shame	Endometriosis patients	Qualitative
Wang et al., (2020)	Do physicians' attitudes towards patient-centered	1.Authority/control	Healthcare professionals	Quantitative

	communication promote physicians' intention and behavior of involving patients in medical decisions?			
Witzeman et al., (2020)	Patient-physician interactions regarding dyspareunia with endometriosis: Online survey results.	1. Patients' shame	Endometriosis patients	Quantitative
Dixon et al., (2021)	Navigating possible endometriosis in primary care: a qualitative study of GP perspectives.	1. Healthcare professionals uncertainty	Healthcare professionals	Qualitative
Armour et al., (2021)	Menstrual health literacy and management strategies in young women in Australia: a National Online Survey of young women aged 13-25 Years.	1. Patients' Shame	Adolescence	Quantitative
Laub, (2021)	"Allow us to show them the pain by squeezing their hand": The study of pain communication and the diagnostic delay of endometriosis.	1. Acknowledging patients' perspectives and empathy	Endometriosis patients	Mixed-mode

RESULTS

This review employed the six-step thematic analysis to help create a structured summary¹⁵. Following the six steps, the review employed a data-driven method reliant on the themes identified within the papers rather than imposing a predetermined coding framework¹⁵. Each element of the thematic scheme was compared to the data and examined to determine whether the themes could stand alone, require integration with another element, or be removed.

The selected articles were thoroughly read four times by the researchers, who then recorded their initial impressions, thoughts, and text interpretation. By engaging in a process of reading four times, the researchers would be able to participate actively and analytically in the data development. The selected themes were then evaluated carefully and reorganised as indicated in Figure 2. Six major themes emerged from the review on patient-centred communication in healthcare: 1) medical knowledge, 2) authority/control, 3) acknowledging patients' perspective and empathy, 4) healthcare professionals' emotional exhaustion, 5) healthcare professionals' uncertainty and 6) patients' shame. Each theme was addressed and approved by all of the researchers.

Challenges in Patient-Centred Communication

The review synthesis found that the communication challenges faced by patients and HCPs resulted in difficulty in practising patient-centred communication. Patients and HCPs frequently sense the need to discuss and control

the dialogue, particularly when it comes to period pain and endometriosis. According to the studies reviewed, this is attributed to HCPs' inability to determine the signs and symptoms of endometriosis. Patients, in turn, may be unable or unwilling to communicate about period discomfort due to the taboo on discussing menstrual health²⁵.

Medical Knowledge vs Patients' Experience

At present, medical knowledge is given more credibility than women's knowledge of their bodies¹⁶. By discounting what women know about their bodies, HCPs seemed to doubt the "accuracy" of the women's stories¹⁶. Endometriosis patients, in contrast to HCPs, have a deeper grasp of pain because it is experienced as "severe," "incapacitating," "debilitating," and "growing worse with time." which can be difficult to quantify by HCPs¹⁷. One of the primary sources of frustration for endometriosis patients is HCPs' perceived normalisation or trivialisation of pain¹⁰. Many negative patients' experiences involved health professionals who refuse to listen to patients' concerns, who do not have time to respond to patients' questions and consider the symptoms experienced as 'normal' and 'not serious'³. The underlying source of dispute between HCPs and chronic pain patients was the debate over whether the origin of the pain was physical or psychological¹⁶.

Authority/control

The review conducted indicates that medical knowledge tends to impose authority by disregarding women's knowledge of their bodies as irrelevant because HCPs can "infer from patient

behaviour as to how it's [endometriosis] impacting them."¹⁶. According to patients, diagnostic delays were caused by inadequate communication between patients and HCPs¹⁸. However, women with greater bargaining power—primarily those with higher education and jobs in the healthcare industry—were more inclined to support patient-centred treatment and challenge healthcare professionals who dismissed their symptoms¹⁸. Typically, consultations begin with a struggle to establish the ground rules for HCPs-patient engagement⁹. These exchanges involve power and control over who must listen attentively, which can be intimidating for patients who wish to be heard.

Implementing patient-centred communication in medical decisions makings is complex due to patients' reliance on HCPs' authority and some HCPs' belief that they are more knowledgeable than their patients⁶. According to HCPs, patients frequently lack the medical literacy required to form an informed opinion about what is most important to their health. Asian cultures, particularly the Chinese, are more collectivistic and commonly lead to HCPs making judgements about patients' healthcare instead of Western cultural norms that emphasise personal rights⁶.

Acknowledging Patients' Perspectives and Empathy

Another challenge faced by HCPs, according to the review, is acknowledging the patient's perspective on the disease and demonstrating empathy. HCPs need to make an effort to comprehend patient's circumstances to determine the type of assistance a patient requires¹⁹. Understanding endometriosis patients' perspectives requires looking into their feelings, ideas, concerns, and experiences regarding the impact of the illness and what patients expect from their healthcare professionals¹⁰. In reality, patients often describe "*medical gaslighting*" as a recurring phenomenon during consultations. HCPs offer ultimatum treatment with little empathy and dismiss patients from the practice when there is no improvement²⁰. By acknowledging patients, HCPs increase the likelihood that the encounter will be corroborated in that patients will trust their HCPs¹⁹. By disregarding women's experience, HCPs ignore a significant component that will help address the intricacies of endometriosis¹⁶.

Healthcare Professionals' Emotional Exhaustion

According to the review, emotional exhaustion has been identified as one of the significant obstacles to patient-centred communication because HCPs believe they are not obligated to provide psychosocial care⁵. On the other hand, patients' frustration level increases when they do not respond to treatments or painkillers⁵. This may include endometriosis patients who do not adhere to their treatment plan. However, many HCPs find it challenging to communicate their concerns and listen intently because they are

themselves experiencing emotional exhaustion. This is reported in a study on four HCPs who expressed the following, "*I've decided to stop treating people who have chronic, unexplained pain. I'm no longer interested in people who never improve. I refer on as soon as I know what I'm dealing with*"⁹. Similarly, normalising discomfort due to exhaustion without thoroughly investigating the issue may be interpreted as obstructing the patient's feelings⁹.

Healthcare Professionals' Uncertainty

Suffering is difficult to explain and quantify; hence, endometriosis patients often endure pain in silence, which hinders patient-centred communication with HCP¹⁰. One of the studies reviewed indicates endometriosis patients' reluctance to express their concerns to healthcare professionals, as doing so can pose potential adverse effects of long-term medication use and the knowledge that endometriosis may impede fertility⁵. The combination of HCPs normalising pain and women's lack of understanding about "normal period pain" prompted many patients to question their experiences of the symptoms, with the majority believing at times they were "*going crazy*" or that the pain was "*all in their head*"²¹. Uncertainty is prevalent with HCPs when encountering patients with symptoms that were not previously evaluated or identified²². This suggests various potential reasons for the patient's symptoms and possible diagnosis. Before additional diagnosis (including endometriosis) could be considered, assessing, and ruling out potential period discomforts was necessary.

Patients' Shame

The final challenge to patient-centred communication is patients' feelings of shame. As the pain increased, it is known that patients were less likely to believe their periods were "normal," but due to shame this did not translate into formal health-seeking behaviours, such as consulting their HCPs. This may be attributed to the commonly held perception that menstruation symptoms are a fundamental part of female life, no matter how severe. This notion has been maintained over time²³. The idea that women's emotions should be kept in check, even in the face of the unpleasant challenges they experience due to endometriosis, can make patient-centred communication challenging²⁴. Endometriosis patients have been known to keep their condition a secret out of shame and to avoid looking helpless and unable to handle what they believed to be normal, if painful, periods²¹. Besides that, patients are often embarrassed to approach their health professional about their pain, and most agreed that having their HCPs initiate the conversation would have made them feel more at ease²⁵.

DISCUSSION

The review produced extensive data from a variety of perspectives and it is clear that endometriosis patients believe that HCPs do not understand them^{1,16}. Patients fear what might be wrong with them and find it hard to explain why they cannot attain a good quality of life^{23,24}. Therefore, consulting patients is vital to foster a favourable environment for patient-centred communication. Creating patient-centred communication can be challenging because the more the doctor rejects the patient's visual manifestations of pain, the more difficult it is to establish satisfactory patient-centered communication. Patients who receive a cold reception from their HCPs will either become their own "health professionals" or seek alternative ways of healing. Therefore, there is considerably more at stake in these consultations than the right diagnosis, which may explain why HCPs and patients continue to engage in exhausting interactions that leave them physically and mentally drained.

This review of patients' and healthcare professionals' issues regarding endometriosis care reveals a consensus on the challenges and solutions of patient-centred communication. Endometriosis patients have a right to healthcare that is essentially centred on them as whole people rather than just as reproductive individuals¹⁶. There is also evidence that patient-centred communication, characterised by persistence, respect, and knowledge, can improve endometriosis patients' health-related quality of life.

CONCLUSION

To develop a harmonious relationship between HCPs and patients, the reviewed articles made it evident that the challenges of patient-centred communication must be examined. This review shows that endometriosis consultations can be complex, and treatments are not always effective. Both patients and HCPs reported a sense of helplessness that led to dissatisfaction, making patient-centred communication challenging to practise.

This review also draws two crucial conclusions. First, practising patient-centred communication with endometriosis patients can be difficult due to the illness' enigmatic nature. Second, normalising and dismissing patients' ordeal without fully addressing the patient's concerns risks undermining patient-centred communication and suppressing the patient's emotions. Current studies address some of the most common patient-centred communication challenges, but a thorough investigation would be required to improve our understanding of patient-centered communication.

Ethical Statement

This is a systematic review article; therefore, clearance from the ethical committee is not required to publish it.

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