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A COM-B and Theoretical Domains Framework Mapping of the Barriers and Facilitators to Effective Communication and Help-Seeking Among People With, or Seeking a Diagnosis Of, Endometriosis

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Endometriosis is a chronic condition in which tissue resembling the endometrium grows outside the womb, causing severe chronic pain. People with endometriosis report difficulty in help-seeking and communicating with healthcare professionals, contributing to diagnosis delays and ineffective management. The present study aimed to identify barriers and facilitators to effective communication using the Theoretical Domains Framework (TDF) and COM-B model to inform behavior change intervention development. This study was a qualitative semi-structured interview and open-ended survey design. Thematic Analysis was utilized to identify barriers and facilitators to effective communication which were mapped to the TDF and COM-B model. Four women aged 25 to 44 with a formal diagnosis of endometriosis participated in interviews. Thirty-three participants, aged 20–48 years, participated in the online survey, 21 of whom had a diagnosis of endometriosis (12 were currently seeking diagnosis). Five COM-B domains were identified: reflective motivation, social and physical opportunity, physical and psychological capability. Ten TDF domains were reflected in concerns surrounding dismissal, disempowerment, social norms, beliefs about consequences, cognitive resources, reinforcement, and environmental context and resources, among others. This is the first study to identify barriers and facilitators of effective communication and help-seeking in light of established behavioral change theory and frameworks for comprehensive intervention design. This provides a comprehensive explanation of challenges in help-seeking for endometriosis and represents the first step in the development of complex interventions to improve help-seeking and communication for people with endometriosis. Interventions targeting salient barriers will have greater potential to change behavior and improve outcomes.

Endometriosis is a chronic, debilitating disease, characterized by the abnormal presence and cyclical shedding of endometrial tissue outside of the uterus which provokes inflammatory reactions causing severe pain (Koninckx et al., 2021). The complexity of the condition and common misinterpretation of symptoms can lead to misdiagnoses and diagnosis delays of between seven to 12 years from symptom onset (Fabamwo & Agbara, 2018). Whilst the true prevalence of endometriosis is unknown due to its complexities, estimates suggest around one in ten women in the UK live with it, and approximately 200 million women globally have been diagnosed (Endometriosis, 2017; Sbaffi & King, 2020). Symptom presentation and severity varies from asymptomatic and unexplained infertility, to heavy and/or painful periods, chronic fatigue, and chronic pelvic pain, which has not only physical but also psychological and social impacts, such as low mood and work absenteeism (Kiesel & Sourouni, 2019).

Multiple challenges have been identified in the evidence-base surrounding effective management of endometriosis; alternative/complementary therapies such as acupuncture and psychological interventions promote reductions in pain, though efficacy evidence remains limited and therefore such interventions remain underutilized (Evans, Fernandez, Olive, Payne, & Mikocka-Walus, 2019). Similarly, the tendency for healthcare providers to retain a biomedical perspective whilst devising treatment plans, and the normalization of women's pain have also acted as barriers to women's help-seeking for appropriate and effective pain management. Indeed, people with endometriosis report negative experiences with healthcare professionals (HCPs), often in the form of trivializing or dismissing symptoms, which causes feelings of loneliness and alienation

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(As-Sanie et al. 2019; Grogan, Turley, & Cole, 2018). This consequently makes obtaining a diagnosis difficult; people with endometriosis may choose to avoid engaging with HCPs altogether (Mikesell & Bontempo, 2022).

Health care professionals' (HCPs) awareness and understanding of endometriosis has frequently been identified as a challenge. Indeed, women report the need to advocate for themselves and be their own doctor due to perceived lack of knowledge and apprehensive attitudes toward endometriosis (Young, Fisher, & Kirkman, 2020). Quibel, Puscasiu, Marpeau, and Roman (2013) found that less than half of HCPs were aware of the main symptoms of endometriosis whilst As-Sanie et al. (2019) further highlighted less than half of gynecologists considered early detection and diagnosis important due to the belief that symptoms would progress irrespective of diagnosis time due to a lack of effective treatments. Such attitudes may contribute to reduced likelihood of help-seeking and effective patient-provider communication along with delays in diagnosis and treatment. Moreover, whilst medical pain management may be effective for some, side effects often outweigh the minimal pain relief experienced (Leyland, Estes, Lessey, Advincula, & Taylor, 2021) which may result in reduced likelihood of help-seeking by those with endometriosis. Resultantly, there is a need to develop a thorough understanding of the needs, challenges, and facilitators surrounding help-seeking in endometriosis, in order to develop appropriate and effective strategies and interventions to address these.

Understanding factors predicting help-seeking and high quality communication is essential for the design of effective behavioral interventions. The Medical Research Council (MRC) framework provides comprehensive guidance for the development, evaluation and implementation of complex interventions to improve health. This emphasizes the need for a theory-informed understanding of determinants of behavior (Craig et al., 2008). The COM-B model is widely used to identify and understand determinants of **b**ehaviour through ***c**apabilities* (capacity to engage in behavior), ***o**pportunity* (environmental factors that influence behaviors) and ***m**otivation* (the willingness to change), which are further divided into six sub-domains capturing factors known to influence an individual's capacity to adopt new behaviors (Michie, van Stralen, & West, 2011). The Theoretical Domains Framework (Cane, O'Connor, & Michie, 2012) builds on this, rationalizing 33 psychological theories of behavior to provide a comprehensive framework for identifying determinants of behavior (e.g. help-seeking). The TDF clusters 14 groups of factors ("theoretical domains") which influence behavior, such as "knowledge" and "beliefs about consequences." Identifying the theoretical domains which act as barriers to help-seeking will facilitate the selection of appropriate behavior change techniques (BCTs) to implement in a behavioral intervention aimed at improving patient-provider communication and increasing the likelihood of help-seeking in people with endometriosis (Cane, Richardson, Johnston, Ladha, & Michie, 2015).

In line with this, as the first stage of developing an intervention to increase reporting, help-seeking, and management of endometriosis pain, the aim of this study was to identify enablers and barriers which motivated and prevented people with endometriosis to report and seek help for their symptoms. This will provide the foundation for the development of targeted behavioral interventions to support and empower patients with endometriosis to report symptoms and obtain effective, person-centered clinical care.

Methods

Design

A qualitative, open-ended survey design alongside qualitative interviews was utilized to elicit beliefs about perceived barriers and facilitators to help-seeking and effective communication and to identify areas for change (Hamilton & Finley, 2019).

Participants

Online posters were used to recruit participants via social media and a database of contacts that had previously participated in endometriosis research and agreed to be contacted about future research. Eligibility criteria were: aged 18 years or over, with experience of pain as a result of endometriosis and had or were in the process of obtaining a clinical diagnosis of endometriosis. The study aimed to recruit up to 40 participants to the open-ended survey, and up to 10 participants to the interview, each being an appropriate number for conducting a detailed Thematic Analysis (TA) on online survey and interview-elicited data (Braun, Clarke, Boulton, Davey, & McEvoy, 2020).

Data Collection

Whilst interviews have been utilized widely throughout previous research, the lack of anonymity often restricts disclosure from participants due to a perceived pressure to appear socially acceptable (Grogan, Turley, & Cole, 2018), a particularly important consideration given the focus on experiences of healthcare. Therefore, online qualitative surveys, hosted on Qualtrics, were adopted in an attempt to increase participants' anonymity, disclosure and gave participants the opportunity to answer the questions in their own time to avoid fatigue (an important consideration when exploring experiences of chronic pain; Braun, Clarke, Boulton, Davey, & McEvoy, 2020; Grogan, Turley, & Cole, 2018). Alongside this, participants were invited to participate in a semi-structured interview to discuss their experiences in further depth.

Questions were developed to identify and explain the potential determinants of help-seeking behavior for endometriosis, and identify areas for behavior change, guided by the Theoretical Domains Framework (Atkins et al., 2017). For both the online survey and the interviews, this resulted in 12 open-ended questions (see Table 1). Within interviews, the researcher adopted a more flexible approach in order to respond to participant priorities (McGowan et al., 2020), ensuring that participants had the space to talk about issues considered important to their personal experiences.

Analysis

Data analysis followed a framework approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Inductive Thematic

Table 1. Interview/Survey questions

1. Please tell us about your experience of seeking help for endometriosis.
    a. What has helped you to feel able to seek help?
    b. What has stopped you from being able to seek help?
2. To what extent do you believe you have been offered/had access to a sufficient range of effective management/treatment options, both medical and non-medical? Please explain your response.
3. Please tell us about any emotional impact your experience of seeking help for endometriosis has had on you and how you have managed this, if at all.
4. Please tell us about any social impact (e.g. on your family or working life) your experience of seeking help for endometriosis has had on you and how you have managed this, if at all.
5. Please tell us about your experience of communicating with healthcare professionals about your experiences in relation to endometriosis.
    a. Please tell us about examples of both helpful and unhelpful interactions you might have had with healthcare professionals and the frequency that these kinds of interactions occur.
6. What does effective help-seeking and communication mean to you?
7. How confident do you feel in your ability to communicate with healthcare professionals and/or seek help for endometriosis, particularly considering more sensitive issues related to endometriosis such as painful periods?
8. How has your experience of seeking help and communicating with healthcare professionals impacted your social/family life/working life, and how has your social/family/working life impacted your ability to seek help and communicate about endometriosis?
9. How would you define the area that you live in (e.g. urban, deprived, rural, affluent)? To what extent do you feel this has affected your ability to get help for endometriosis?
10. What suggestions do you have for improving people's confidence in seeking help for endometriosis?
11. What suggestions do you have for improving communication between people with endometriosis and healthcare professionals?
12. Is there anything you would like to add that hasn't been covered within the questionnaire/interview?

Analysis (Braun & Clarke, 2022) was used in the initial open coding of the data to investigate a priori objectives using the TDF and COM-B model to describe data and identify barriers and facilitators. Each survey response was read and re-read numerous times by JH and KB, each interview was read and re-read by JH and LB. Transcripts were coded line by line and analyzed to identify similarities and differences. Following open-coding, broader categories were mapped onto the domains of the TDF and then, directly onto the six components of the COM-B model identifying themes relating to enablers and barriers to help-seeking and pain management. All data were coded by JH, KB, and LB.

Methods to Ensure Rigour

To address the issue of trustworthiness of the study findings, credibility and transferability were considered (Shenton, 2004). Credibility was enhanced by building rapport with the participants in interviews which helped them develop a sense of self-determination (autonomy, competence, relatedness; Martin, 2017) to ensure honesty in data collection (Shenton, 2004) and using participants' extracts to report the study findings. To ensure transferability, detailed contextual information is presented in addition to an information rich sample of participants.

Ethical Considerations

Ethical approval was granted by the Manchester Metropolitan University Research Ethics Committee. All participants were provided with detailed study information and provided informed consent to participate. Data submitted via the online questionnaire were anonymous and upon completion of interview transcription all recordings were destroyed and personal data (such as names, places discussed in interviews) replaced with pseudonyms.

Results

Sample

Four women with a medical diagnosis for endometriosis took part in the interviews. Their ages ranged from 25 to 44 years old ($M = 35.5$ years), and they had been diagnosed with endometriosis for between one year and 22 years. The final online survey sample comprised of 33 participants aged between 20 and 48 ($M = 28.4$ years); 21 had a diagnosis of endometriosis and 12 were in the process of obtaining one (e.g. were discussing the possibility of endometriosis with a HCP, or had been referred for further investigations).

Identification of Enablers and Barriers to Help-Seeking and Effective Communication

Five of the six categories of the COM-B framework were apparent in the data: reflective motivation, social and physical opportunity, and physical and psychological capability (automatic motivation was not reflected in the data). The components are presented in the analysis in order of importance/prominence in the data and mapped in Table 2.

Social Opportunity

The main barrier to help-seeking behavior was the lack of social opportunity to engage in help-seeking, driven in whole by the TDF domain of "social influences". Multiple challenges were highlighted: social norms, group identity, perceived medical gaslighting, power, and mistrust. Social norms around discussing menstruation, endometriosis, and women's gynecological health drove participants to conceal concerns:

> Menstruation is still such a taboo topic, and still feels embarrassing to talk about. Especially when I have to call in sick to work (and even more so when I have to speak to a male manager), I feel embarrassed. Even though it is absolutely completely

Table 2. Summary of themes mapped to TDF and COM-B domains

COM-B Domain	TDF Domains	Core themes	Data samples
Social Opportunity	Social influences	Social norms, systemic sexism and oppression in the form of disbelief and dismissal, shame, embarrassment, disempowerment.	*No there is not enough support for any part of the process. Women's health is seen as a joke and there is such a lack of research therefore women are not believed and there is pretty much no support in diagnosis and management. (Emily, 22, seeking diagnosis)* *It's hard to explain absence from work or a need to take breaks when these things are due to heavy bleeding and extreme pain. My managers have all been male and all told me I was exaggerating. (Paula, 46, confirmed diagnosis)* *I have always been very open about menstruation and as I grew conscious of the stigma and patriarchal norms surrounding them I became more and more vocal about the issues that AFAB [assigned female at birth] people can experience. (Lucy, 26, confirmed diagnosis)* *More options are 1000% needed, these current options are definitely something to just keep us quiet for as long as possible. (Olivia, 21, seeking diagnosis)* *I'm telling you this is not cleared up this is something that's ongoing and I could not for love nor money get anyone to pay attention to me. My GP was like "yeah do some Pilates, do some HRT, just relax!" So I'm sure you can sense I've got a lot of injustice and frustration there as well. (Ruby, 44, confirmed diagnosis)* *Before I was formally diagnosed, I explained to my (male) OBGYN that I was experiencing pain 3 out of 4 weeks of the month. He actually scoffed at me, and told me it was impossible that I was in pain that often and said birth control would help. It wasn't until I was urinating blood with blood clots with no infection detected 4 times in one year, and was experiencing bloody bowel movements that he decided to send me for further testing for endometriosis. (Jane, 32, confirmed diagnosis)* *I have been treated like the pain is not as severe as I make it out to be and that I am simply complaining and weak. This has affected my ability to speak about it. I have particularly experienced this from my family who gives me useless advice like asking me to exercise more or telling me I will outgrow it. (Natalie, 23, seeking diagnosis)*

Reflective Motivation	Social influences Reinforcement Knowledge Emotions Beliefs about consequences Intentions Social/professional role and identity	Beliefs about impacts of different treatment options, negative past experiences informing future expectations/motivations through mistrust and embarrassment.	*I've lost confidence in doctors due to the embarrassment of being misunderstood [. . .] (Alice, 27, confirmed diagnosis)* *It has majorly impacted my trust in the health care system causing me to suffer in silence rather than seek help. (Helen, 31, confirmed diagnosis)* *I feel like at times I'm a red hot mess and I don't think anybody knows what to do with that, especially when they are not psychologically trained. (Ruby, 44, confirmed diagnosis)* *There's just not a lot of communication. And I haven't got my medical records to read, but a part of me is very scared about what I'll find in there. I do want to get them and read them, but there is a part of me that's scared and anxious to read them. And I think it's not a good time to do that; I'm probably not ready. And I know certainly a lot of people who have got their files and the amount of stuff that they weren't told you know, and you start to think, "why can't you just be honest and upfront? You want me to tell you everything that's been going on with me. You want me to be as honest as possible about what I've been experiencing, what I'm going through, and I'm communicating as openly and honestly as I can with you. But you're not giving me the same regards." (Elizabeth, 38, confirmed diagnosis)*

(*Continued*)

Table2. (Continued)

COM-B Domain	TDF Domains	Core themes	Data samples
Psychological Capability	Beliefs about consequences Beliefs about capabilities Emotions Knowledge Social influences Skills Self-efficacy Environmental context and resources	(Dis)belief in one's own symptoms and ability to seek and receive support, overwhelming fear, sense of helplessness.	*I feel helpless when I try to manage my pain. I feel overwhelmed and I can sit there for a while and just not know what to do. I feel like I have given up trying to manage my pain. I've noticed it has become part of my life and I am used to it, to the point where I don't notice the mild discomfort anymore. I don't think I even realise that a healthy person doesn't have this constant pain. (Emma, 21, seeking diagnosis)* *It took numerous years and visits to my GP to get this addressed. It makes you feel as though you are making symptoms up, before you are finally referred to gynaecology. (Leah, 41, confirmed diagnosis)* *I have been to the doctors many, many times, and each time I've felt disregarded. After multiple tests for Colitis, Crohn's, PCOS, coeliac disease, etc, and all tested negative. I suggested many times "could it be endometriosis?" as I knew it was under researched and harder to diagnose. But my questions were always disregarded or not looked into. It took so long before someone listened to me and agreed that it could be, I think it was around 1.5 years. This really knocked my confidence in my doctors and it was really disheartening to be ignored, I felt like "why is no one listening to me?" It was tiring and an awful experience really. (Emma, 21, seeking diagnosis)* *With people that I know do not understand, I don't waste my mental effort trying to explain it to them. (Jaden, 24, seeking diagnosis)* *I have a medical PhD and know how to speak doctors so it made them take me seriously. I still feel like I got poor care so I can't even imagine what someone without this advantage would have faced. (Isobel, 28, confirmed diagnosis)* *I back away from asking all questions so I always go in with a big list and then sometimes I get almost embarrassed that I'm taking up too much of their time and start ignoring some of the questions. Whereas I feel like he [partner] would be like "no you've missed that one out." He would be a lot more like forceful. I guess it's a bit of moral support; he would push the things I wouldn't ask when I'm shying away… I've taken up enough of their time they are busy and important people. (Elaine, 25, confirmed diagnosis)* *I constantly feel nauseous and I'm often worrying about my pain and sickness having an effect on my work as a self-employed person. I then get very overwhelmed and exhausted, so tend to end up sleeping a lot instead of using alternative pain management methods. (Louise, 24, seeking diagnosis)*

Physical Opportunity	Environmental context and resources	Lack of supportive employment, lengthy waiting times, inconsistent provision and quality of care, the affordability of private healthcare.	*I almost lost my job because I was having so much time off with bad period pain. (Charlotte, 21, seeking diagnosis)* *My job wasn't supportive whilst I was getting diagnosed and I couldn't get the time off. (Amy, 31, seeking diagnosis)* *I am privileged because I could pay for private healthcare. (Lucy, 26, confirmed diagnosis)* *The best endometriosis specialists are private, but I am unable to see a consultant privately as I can't afford to(Jen, 23, confirmed diagnosis)* *My previous job was quite male heavy. I feel like they would've got quite embarrassed if I started talking about it. As well as that I spoke to HR and she said "don't tell anyone about it as it might affect your chances of a promotion.”(Elaine, 25, confirmed diagnosis)* *I wanted to do a pain management programme but it was during work hours and I can't get the time off work. It was really frustrating because I had three months off during COVID where I was asking if I could do it and they were running things and I just didn't get onto the waiting list quick enough.* (Elaine, 25, confirmed diagnosis) *It's great you have all these specialists, but I think there needs to be someone there to look after your emotional and mental wellbeing that you can talk to. Not just one person, but there needs to be a team that you can talk to, that you can communicate with, sort of therapy in a sense? Because it impacts those parts of you so much as well and it's not just the hormone treatments or the surgeries, it's the things that people say to you; it's being told it's a bad period, being brushed off, and feel like you're getting ignored. (Elizabeth, 38, confirmed diagnosis)*
Physical Capability	Skills Emotions	Lack of energy, stamina, and effective coping strategies.	*Sometimes I can't be bothered to do yoga, it's easier to just take a bunch of advil strap on a heating pad and suffer through it. The emotional exhaustion of trying new things gets to me a lot. (Isobel, 28, confirmed diagnosis)*

> normal, periods are still a taboo topic. Even when talking to a doctor, I feel like it's something too private to talk about openly. I must stress, I have no problem talking about - but it is people's and society's reactions to the topic that makes me feel as though I cannot say anything. Almost as if, it is a women's issue that you must deal with quietly and alone.
>
> *(Emma, 21, seeking diagnosis)*

Twelve participants further discussed this in the context of adversarial relationships with HCPs and perceptions of HCP attitudes as dismissive and alienating. Viewed as a systemic issue, the lack of appropriate support and resources were persistent concerns, which deterred help-seeking. Many viewed their experiences as medical gaslighting, defined as the downplaying or dismissal of patients' self-reported symptoms or experiences of an illness (Bailey, 2020), with experiences reflecting feelings of mistrust and dismissal:

> I feel a lot of mistrust towards the health care system in general, simply because I have been told that my pain was in my head, that I must have a low pain threshold or that I was in pain because I was fat.
>
> *(Alice, 27, seeking diagnosis)*

The experience of medical gaslighting may be an unintentional consequence of HCPs understandings of, and attitudes toward, endometriosis or women's pain more generally. Participants reflected that these medical encounters, in which HCPs become a gatekeeper to further healthcare, are "normalised" experiences, consequently leading women to doubt their own perceptions of pain. These experiences reinforce that social norms surrounding the gendered experience of pain and the acceptability of discussing gynecological health remain barriers to help-seeking and support. Some participants reflected on these issues as demonstrative of systemic sexism, oppression and a patriarchal society:

> Because of the stigma it is [sic] to have periods and how normalised period pain is when it is not actually normal and the pain can't be that bad… it's another way women are oppressed.
>
> *(Emily, 22, seeking diagnosis)*

Reflective Motivation

Connected to social influences, participants reflected on the impact of their experiences on their reflective motivation to engage or disengage from help-seeking and healthcare more generally. This was manifested in the TDF domains of "social influences", "reinforcement", "knowledge", "emotions" (fear, anger, frustration, depression, anxiety, pessimism), "beliefs about consequences", "intentions", and "social/professional role and identity". HCP lack of knowledge and understanding appeared to drive this disengagement from healthcare:

> This gap in communication, lack of consistency throughout my consultations and general "trial and error" approach to my treatment made me feel mistrusting of the diagnosis process and subsequent treatment.
>
> *(Sophie, 30, confirmed diagnosis)*

Sophie's experience reflected the "social influences" and "reinforcement" TDF domains, with lack of understanding of endometriosis impacting relationships with HCPs and confidence in seeking help in future. Reflective motivation to engage in healthcare was likely compounded by the regularity in which participant's experienced concerns regarding (dis)continuing treatment:

> I was put on several different types of birth control to no benefit in pain reduction, GnRH [gonadotropin releasing hormone] analogues, anti-inflammatories … prescription only opiates … These are not long-term solutions … We end up with other symptoms from taking these medications; addiction, stomach acid issues, stomach ulcers, constipation, unable to drive, unable to socialise, unable to work, depression, weight gain, suicidal ideation, anxiety, unable to try for a baby. The list is endless to be honest.
>
> *(Lisa, 38, confirmed diagnosis)*

A sense of helplessness characterizes participants' reflections on medication taken, given the long list of possible side effects ("beliefs about consequences" TDF domain), alongside a resignation that this is the only option because of the lack of specialized knowledge of endometriosis in the health system ("knowledge" domain). Experiencing side effects may reinforce ("reinforcement" domain) further help-seeking (to find another solution) or as a reinforcement for avoiding help-seeking (if evaluated as the only option). This was also reflected in discussions about surgical interventions:

> I have been offered surgery but was told that regardless of whether I have the surgery or not the end result is the same (pain management such as the pill), so they made me feel like surgery was pointless.
>
> *(Charlotte, 21, seeking diagnosis)*

Despite being given some element of choice in a treatment plan, this choice was essentially taken away from Charlotte through the provision of information that undermines the efficacy and goals of an intervention. This again contributes to the feelings of resignation and a decision to not pursue surgery as an option.

Psychological Capability

Psychological capability and TDF components underpinning this, including the "beliefs about consequences", "beliefs about capabilities", "emotions", "knowledge", and "environmental context and resources", was also found to influence the likelihood of an individual engaging in help-seeking for their endometriosis:

> It definitely reduces confidence in your own feelings and makes getting help significantly difficult. It makes you doubt doctors [sic] and feel as though you are just a burden. I have totally lost faith in my own thoughts and feelings and feel genuinely terrified to try and speak to more doctors.
>
> *(Samantha, 22, confirmed diagnosis)*

The domains of "beliefs about consequences" and "emotions" are demonstrated by the loss of confidence resulting from past experiences. Participant's experiences were characterized by beliefs that their symptoms were illegitimate, unimportant, and burdensome, and repeated reinforcement of this led to potent feelings of fear. Whilst managing the various symptoms of endometriosis was commonly prioritized, this was compounded by the lengthy process of obtaining a formal diagnosis taking a psychological toll, leaving little energy for help-seeking and advocacy:

> It took me 8 years to get a diagnosis. I feel as though I don't have it in me to fight and advocate for myself anymore as it's just so exhausting. Particularly as even though I have a diagnosis, doctors still don't fully understand it.
>
> *(Jen, 23, confirmed diagnosis)*

This links to the "emotion" domain of psychological capability, with participants reflecting on their resignation and/or conscious decision to preserve their mental energy rather than using it to advocate for their health and to help others to understand. This is especially prominent in the current context given the concerns raised by participants concerning stigma. In contrast, psychological capability was bolstered when participants felt they had knowledge, skills, and confidence to advocate for themselves:

> Discovering endo was frightening but empowering. I felt like everything made sense, and I am slowly learning how to talk about endometriosis with people and sharing my story - since then, I have discovered that some friends also have chronic illnesses but feel like they need to be silent about them.
>
> *(Lucy, 26, confirmed diagnosis)*

This demonstrates the ways in which the "knowledge", "skills", "self-efficacy", "social influences" and "environmental context and resources" domains add nuance to the degree of psychological capability one might have in advocating and seeking help. When the initial fear of diagnosis is overcome, transforming this into a sense of empowerment may be beneficial in enhancing feelings of social support, especially when this connects people to others with shared experiences.

Physical Opportunity

Participants reflected on their working/financial circumstances and geographical locations, which either afforded or denied participants the time/resources to obtain appropriate care, underpinned by the TDF domain of "environmental context and resources":

> The job I was at when I had my operation were annoyed [that] I had time off for my operation, so I went back a week early.
>
> *(Hannah, 28, confirmed diagnosis)*

Such responses pose a barrier to the physical opportunity one has to seek appropriate and effective management of their endometriosis, and in Hannah's case, sufficient time to recover from surgery. This suggests a need for enhanced workplace-specific education and reasonable adjustments. Private healthcare was discussed as a route to better care but seen as a privilege for those who could afford it:

> Having a larger income would have enabled me to seek private care many years ago. I am still unable to afford private surgery so will likely need to wait another 2 years minimum to get to that stage. The NHS is not competent in the management and diagnosis of women with endometriosis in the UK.
>
> *(Louise, 24, seeking diagnosis)*

Without financial means to pay for private healthcare, participants were "*in the hands of the NHS, and now COVID delays" (Lisa, 38, confirmed diagnosis)*, feeling as though they were facing a lower standard of care. The expense of private healthcare therefore acted as a barrier to receiving the care that they desired. This was also seen in relation to geographical locations:

> There is definitely a clear difference between the care I have received in this small city, compared to when I was living in a more urban and larger city. This small city has many waiting lists, low availability and lower quality of care - I understand that COVID has impacted this further, but there has always been a lower quality of care at a much slower pace than the larger city.
>
> *(Jaden, 24, seeking diagnosis)*

Distinctions in the quality of care provided across different localities may represent and reinforce inequalities in healthcare access. Some participants discussed the distance to travel to their nearest specialist as a potential barrier to help-seeking: *I have to travel 52 miles to my gynaecologist. (Leah, 41, confirmed diagnosis)*, demonstrating the lack of availability and accessibility of care for people with endometriosis.

Physical Capability

Physical capability manifested in reflections on physical *in*capability to access support and engage in valued social activities, due to symptoms:

> I can't manage a social life or relationships due to pain and exhaustion. I've lost friends due to the way my symptoms limit my life. There are times I've missed GP appointments because I can't get out of bed with exhaustion. I've been this way for more than half my life.
>
> *(Paula, 46, confirmed diagnosis)*

> It gets difficult to maintain healthy eating and exercise that can help. It also gets to a point where you don't want to get out of bed or do anything which just adds to symptoms like fatigue and achiness.
>
> *(Samantha, 22, confirmed diagnosis)*

Underpinned by the TDF domains of "skills" (coping strategies) and "emotions" (i.e. cognitive overload/tiredness/burnout), participants' lack of physical energy, or stamina, prevented them from living the social lives they wanted, attending appointments, and even to advocate for themselves. This demonstrates the way in which responsibility for broader societal understanding of endometriosis as well as help-seeking is placed on those living with endometriosis.

Discussion

This study collated qualitative evidence to understand barriers and enablers to help-seeking for endometriosis. The TDF and COM-B model provided a theoretical framework (Michie, van Stralen, & West, 2011) through which to understand behavioral determinants of help-seeking and effective communication. This provides the foundation for future development of high-quality, practical training and tools that address the challenges identified, and to develop patients' and HCPs' confidence in having effective and empathic conversations around the impact and management of endometriosis. Specifically, influences identified are:

1. Social Opportunity - systemic sexism and oppression in the form of disbelief and dismissal, shame, embarrassment, disempowerment, and the social norms surrounding discussions of gynecological concerns.
2. Reflective Motivation - beliefs about impacts of different treatment options, negative past experiences informing future expectations/motivations through mistrust and embarrassment.
3. Psychological Capability – (dis)beliefs in one's own symptoms and ability to seek and receive support, overwhelming fear, sense of helplessness.
4. Physical Opportunity - the lack of supportive employment, lengthy waiting times, inconsistent provision and quality of care, the affordability of private healthcare.
5. Physical Capability - lack of energy, stamina, and effective coping strategies.

This study suggests that interventions to improve help-seeking and pain management should focus on social opportunity, in particular targeting social norms, stigma, attitudes, and expectations surrounding women's health and pain. However, negative experiences outweighed positive ones; such experiences were characterized by HCPs' lack of knowledge, normalizing or doubting symptoms, being dismissive, or criticizing women for not exerting enough effort to manage their endometriosis. As a result of this, people seeking help for endometriosis perceive this to come with risks (dismissal, shame etc.) which act as a significant deterrent to the actual behavior, informing reflective motivation to disengage, and contributing to lengthy diagnosis delays, worsening symptoms, and distress. This was also reflected in O'Hara et al.'s (2019) systematic review, which indicated that strong relations with health professionals, including effective communication, were central to positive experiences of navigating healthcare.

Cultural change and improved patient-professional communication in the health system is essential to legitimize the experiences of those with/seeking diagnosis for endometriosis. This is critical to addressing mistrust (Mikesell & Bontempo, 2022) and reducing diagnostic delays (Markovic, Manderson, & Warren, 2008), particularly given evidence that lack of awareness can result in HCPs giving low priority to establishing the diagnosis of endometriosis (Van der Zanden et al., 2020). Interventions to change social norms within health professional groups have been successful across a wide range of clinical behaviors, including prescribing, management and communication around health conditions, in both primary and secondary care (Cotterill et al., 2020). Such interventions are therefore recommended to be extended to endometriosis to improve outcomes in this population (and therefore improve social opportunity).

Participants reported (dis)belief in their own symptoms and ability to seek and receive support, overwhelming fear, and a sense of helplessness (psychological capability). Likewise, a lack of confidence to challenge medical experts meant that participants were likely to accept the medical discourse and avoid seeking help in future. Participants with more bargaining power (e.g. higher education), were more likely to challenge dismissal of their symptoms and felt more confident navigating the health system, though this was uncommon. Developing confidence in one's bodily experience and ability to articulate this is essential to support people with endometriosis to position themselves as "lay experts", their authority deriving from their personal experience. This positioning should be done with care; becoming a "lay expert" can both reduce and compound existing stresses for people with endometriosis (Seear, 2009). Helping patients and healthcare professionals to improve their communication skills in a healthcare context and attempting to de-stigmatize sensitive and potentially embarrassing symptoms may be key to increasing patient reporting of these.

Physical opportunity emphasizes the role of supportive employment, along with waiting times, consistency of service provision and quality of care. Whilst evidence is limited, one study based in Puerto Rico examined healthcare disparities experienced by women with endometriosis with public vs private health insurance (Fourquet et al., 2019); those without private health insurance were 3.5 times less likely to have a laparoscopy, and 2.7 times more likely to be prescribed opioids. This supports the recommendation for the development of clear diagnosis and referral pathways for people with endometriosis irrespective of socioeconomic status, and further health disparity research in the UK. Additionally, sensitive and responsive employment, along with severity of endometriosis symptoms have been demonstrated to affect women's on-the-job productivity (Fourquet, Báez, Figueroa, Iriarte, & Flores, 2011; Krsmanovic & Dean, 2022; Soliman, Surrey, Bonafede, Nelson, & Castelli-Haley, 2018). Given the Equality Act (2010) defines discrimination against people who have a disability (of which it is argued that endometriosis could be defined as) as unlawful, refusal to assist someone with endometriosis in the development and application of reasonable adjustments (such as time off to attend appointments, flexible working hours) may be seen as discriminative, and it is essential that employers are aware of this to ensure that women's rights remain protected.

Finally, energy and stamina required to advocate for oneself alongside managing symptoms were prominent challenges in the present study, which may result in physical and psychological deconditioning in relation to health-related fitness, sleep quality, and health-related quality of life (Álvarez-Salvago et al. 2020). Broader societal change/awareness that reduces the emphasis on individuals having to advocate for themselves and repeatedly educate others on their experience is essential to support the wellbeing of this group and improve their experiences of managing their health in the long-term.

Implications and Future Research

People seek help (or avoid doing so) for many reasons, many of which remain under-researched, leaving healthcare and societal awareness at suboptimal levels. Behavioral change interventions are necessary to encourage both people with/seeking a diagnosis of endometriosis and health professionals to support help-seeking in an appropriate, timely fashion to minimize delays and distress associated with endometriosis. Some investigations of psychological/behavioral interventions exist, focussing on yoga and/or cognitive behavior therapy for improving quality of life (Boersen et al. 2021; Mikocka-Walus et al., 2021) or pain (Donatti, Malvezzi, Azevedo, Baracat, & Podgaec, 2022), and psychological interventions for improving pain, distress, sleep, and fatigue (Evans, Fernandez, Olive, Payne, & Mikocka-Walus, 2019; Van Niekerk, Weaver-Pirie, & Matthewson, 2019). mHealth and eHealth interventions also exist, using SMS-based messaging to provide reassurance and support in managing endometriosis (Sherman et al., 2022) and apps for pain management (Trépanier et al., 2023), without attention to the development of cognitive or behavioral skills. O'Hara et al. (2019) reported that no comprehensive investigations (and no randomized controlled trials) of endometriosis self-management interventions that were informed by a comprehensive definition and theoretical framework were available. Unfortunately, this remains the case; we could find no behavior change interventions targeting people with/seeking a diagnosis of endometriosis, nor targeting health professionals, despite the potential utility of these. For example, educational, skills-based interventions for health professionals that provide education on endometriosis (and gynecological health more broadly), guidance on appropriate responses to gynecological health disclosures, along with prioritization of gynecological health issues by targeting of long waiting lists, will help to minimize issues of mistrust and dismissal experienced by those with endometriosis.

These findings underpin a range of potential interventions that could influence capability (communication and coping skills development), opportunity (education to address societal norms surrounding women's health, targeting dismissal, stigma, and disempowerment) and motivation (e.g., improving confidence and trust in the health system). Each domain can be mapped on to the Behavior Change Wheel (a method of intervention design; Michie, van Stralen, & West, 2011), so that optimum BCTs can be selected to maximize potential behavior change. For example, psychological capability, influenced by the domain of "beliefs about consequences", prevented people from seeking help and may be targeted with BCTs such as "covert learning" or "comparison of outcomes", whilst social opportunity, impeded by "social influences", may be enhanced with "social support" and "antecedents" (including restricting the physical and social environment). The use of the Behavior Change Wheel in this way can help to inform future interventions through a range of policy categories such as communication and marketing (reflective motivation, social opportunity), environmental and social planning (physical opportunity), fiscal measures (physical opportunity), legislation (physical opportunity) and service provision (automatic motivation; Michie, van Stralen, & West, 2011).

Strengths and Limitations

The use of the TDF and COM-B model allows the barriers to, and facilitators of, help-seeking identified in the present study to be mapped onto a number of theoretical domains of health behavior (Cane, O'Connor, & Michie, 2012). This has the advantage of enabling the development of a theoretically driven individually tailored intervention to support and empower people with endometriosis to seek help for their symptoms as recommended in MRC guidance (Craig et al., 2008) and provides the foundation for developing theory and evidence-based interventions to improve outcomes for people with endometriosis.

The relatively large sample size (for a qualitative study), along with the use of both interview and qualitative survey data, allowed for a broad and in-depth understanding of experiences. While we have drawn inferences from the data regarding the importance of the barriers identified based on prevalence within the data, a fuller understanding of the ways in which people with endometriosis would prioritize these barriers is needed, through a large-scale quantitative exploration. Likewise, additional work is required with HCPs to establish the barriers and facilitators to effective and comprehensive care provision from their perspectives.

Conclusion

This is the first study to identify barriers and facilitators of help-seeking in light of established behavioral change theory and frameworks for intervention design. This work provides a comprehensive explanation of why people do/do not seek help for endometriosis and represents the necessary first step in the development of complex interventions to improve help-seeking, communication, diagnosis rates, and pain management for people with endometriosis. In future research, we will use the behavior change wheel to systematically develop an intervention to improve help-seeking in endometriosis. Developing such an intervention that targets these salient barriers to help-seeking will have greater potential to change behavior.

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