

## Exploring the Role of a WhatsApp Online Community in Supporting the Needs of Women Living with Endometriosis in Malaysia: An Interview Study

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### Abstract

The internet and social media offer women new opportunities to reach out and connect with others in a safe, anonymous and mutually supportive environment. For women affected by endometriosis, considerable challenges often have to be addressed with limited or no help from traditional support networks. Using “MyEndosis” WhatsApp group as a case study, this research explored the experiences of women who access this novel form of support. Fifteen women (aged 34 to 51 years) participated in a qualitative interview. Using inductive thematic analysis, three interrelated themes were generated: 1) *Unmet support needs* - the impact of endometriosis on the lives of the women and their unmet support needs. 2) *Connecting with similar others* - This theme captures the importance of finding other women who share similar experiences and connecting with them online, and 3) *Sharing and caring online* - This final theme explains how women living with endometriosis engage with and benefit from the “MyEndosis” WhatsApp community. Our findings illustrate how the novel WhatsApp community provided a safe and supportive community through which women affected by endometriosis could address their various unmet support needs (e.g., informational, emotional), share experiences and learn from others. Furthermore, our findings confirm how the many and considerable challenges of living with endometriosis in Malaysia appear to have persisted over time but provide encouraging evidence that through everyday digital technology and social media, previously hidden and isolated women may become empowered to help not just themselves but also others around them.

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### Key words

Endometriosis, online support, technology, WhatsApp, women.

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## Introduction

Endometriosis is a chronic condition that affects women of reproductive age. It is defined as the presence of endometrial tissue outside the uterine cavity, which induces a local inflammatory response (Kennedy et al., 2005). It is characterized by pain and subfertility with associated reduced quality of life (Moradi, Parker, Sneddon, Lopez, & Ellwood, 2014). Estimates suggest that it affects between 2% and 17% of the female population (Culley et al., 2013), though the prevalence can be as high as 47% in women with fertility issues (Meuleman et al., 2009). In other words, 1 in 10 women are at risk of endometriosis (Ghai, Jan, Shakir, Haines, & Kent, 2020; Soliman, Coyne, Zaiser, Castelli-Haley, & Fuldeore, 2017). Furthermore, endometriosis is thought to have contributed to a decrease in the national fertility rate in Malaysia's national fertility rate, which is expected to decline to the lowest level recorded since the founding of the state in 1963, with 15.8 births per 1,000 people compared to 16.1 in 2017 ("Reaching out to endometriosis patients", 2018).

Women typically to experience delays before diagnosis (Ballard, Lowton, & Wright, 2006; Hadfield, Mardon, Barlow, & Kennedy, 1996; Husby, Haugen, & Moen, 2003) with the focus of long-term care being directed toward symptom management (Bergqvist & Theorell, 2001; De Graaff et al., 2013). As a result, they have been reported experiencing significant levels of depression, anxiety and emotional distress and poorer quality of life (Friedl et al., 2015; Jones, Jenkinson, & Kennedy, 2004; Lorrencatto, Petta, Navarro, Bahamondes, & Matos, 2006; Low, Edelmann, & Sutton, 1993; Lukas et al., 2018). Furthermore, endometriosis can have a detrimental influence on social life, work, daily activities, education, finances, life opportunities, personal relationship quality and physical intimacy (Denny & Mann, 2007; Gilmour, Hungtington, & Wilson, 2008; Nnoaham et al., 2011) and can lead to poorer mental health (Verket et al., 2018).

Social support is a critical source of health care, and a means of engaging with positive health outcomes (Sarason, Sarason, Shearin, & Perce, 1987). Extant studies assert that social support is conducive to maintainin good health as it reduces the stress linked with difficult health situations (Cohen & Wills, 1985; Kamarck, Manuck, & Jennings, 1990). For women living with endometriosis, there is an ongoing need for support as they endeavour to meet the multiple challenges associated with the condition (Whitney, 1998). However, such women often describe an absence of support (Cox, Henderson, Andersen, Cagliarini, & Ski, 2003; Markovic, Manderson, & Warren, 2008), experience feelings of isolation (Jones et

al., 2004), and report difficulties in disclosing their condition and symptoms to others due to feelings of stigma, shame and not being believed (Gilmour et al., 2008). These challenges are further compounded by a pervasive social taboo around women's reproductive health in Malaysia (Wilson, Mogan, & Kaur, 2020). Wilson and her colleagues revealed that women living with endometriosis in Malaysia may experience additional challenges, including fear, stigma, and shame, which may force them to hide their ongoing struggles from their spouses, wider family members, and health professionals (Wilson et al., 2020).

Existing research on women's disclosure of endometriosis has mostly focused on family, friends, and healthcare providers, revealing that women with endometriosis underestimate their symptoms and are hesitant to share their experience with the condition with others. First, since they are afraid of being judged negatively, women tend to downplay the intensity of their symptoms. Grogan, Turley, and Cole (2018) discovered that women suppressed or underestimated their symptoms for fear of being called a "hypochondriac." Young, Fisher, and Kirkman (2014) discovered that women's unwillingness to reveal and discuss their symptoms was caused by dismissive comments from friends, family, and healthcare practitioners. Second, women are reluctant to disclose such information because of "menstruation etiquette" (Laws, 1991) the habit of intentionally concealing menstruation from others. Seear (2009), for example, identified sharing of symptoms as a "discrediting attribute," one whose existence leads to an individual's stigmatization (Goffman, 1963). Despite the considerable negative impacts on women's quality of life, especially in the domain of coping with emotional distress, little is known about how women suffering from endometriosis cope with the physical and psychological distresses and what it means to them. A systematic review of the research into women's experiences of endometriosis shows a plethora of important and informative studies on the scientific and medical aspects of endometriosis but a comparative neglect of the psychological impact of the condition and social participation among women suffering from the condition (Young et al., 2014).

In this context, women face significant challenges in accessing information, advice and support through traditional routes and may therefore turn to the internet and/or social media to seek support (Neal & McKenzie, 2011; Whelan, 2007). With the proliferation of the internet and the exponential rise in the popularity of social media, women living with endometriosis in Malaysia have new opportunities to access appropriate information, advice and support (Wilson et al., 2020) through engaging with online peer support communities.

Online peer support communities are an important avenue for women living with endometriosis to engage with other women experiencing similar challenges (Shoebotham & Coulson, 2016). Such communities are typically created using asynchronous discussion forum platforms, thereby creating opportunities for members to access support twenty-four hours a day, seven days a week (Revere & Kovach, 2011). Such online peer support communities can also be underpinned by various other platforms, including social media (e.g., Facebook, WhatsApp). Access to these peer support communities can be via desktop PCs, laptops, or handheld devices (e.g., mobile phones). One of the unique characteristics of the majority of online peer support communities is that they rely predominantly on individual members to both generate and consume content (Malinen, 2015).

Social media has enhanced individual contact and promoted direct engagement by users. This is expected to have direct implications for health communication systems, sparking efforts to identify new social media potential to improve population health (Thackeray, Neiger, Hanson, & McKenzie, 2008). Understanding these advances and their impact on health communication is crucial given the rapid transformations in the communication environment caused by participatory internet usage and social media. Social networking is a collection of web-based applications that facilitate the creation and sharing of user-generated content. It has swept the globe, changing the way we connect as a society (Lim, 2012; Luarn, Yang, & Chiu, 2015; Yavuz & Toker, 2014), especially in the medical and health care community, where the sheer amount of medical and healthcare-related information is noticeable (Eysenbach, 2008; Fischer, David, Crotty, Dierks, & Safran, 2014; Wentzer & Bygholm, 2013).

Weblogs, online forums, online podcasts, and social networking sites and pages (e.g., WhatsApp and Twitter) are all about improving and accelerating communication. As a result, we will be able to shift away from the traditional paradigm of one-to-one interaction (for example, conversing on the phone with another person) and toward one-to-many communication (e.g., blog posts, tweets). According to Jin, Zhou, and Yu (2019), the internet was utilized by 80% of the patients in their to search for and obtain medical and healthcare-related information. Because of the internet's enormous availability and accessibility in modern times, social media platforms are increasingly being used to engage in information retrieval and contribute to serious conversations on medical and health topics (Zhou, Zhang, Yang, & Wang, 2018).

According to the literature, WhatsApp has been employed in healthcare and showed positive effects (Boulos, Giustini, & Wheeler, 2016; Iftikhar & Abaalkhail,

2017; Yale, Kumar, & Sharma, 2018). For example, Yale and her colleagues discovered that WhatsApp can function as a new teledentistry tool that can be used for a variety of purposes in oral health care, increasing convenience for dental practitioners, patients, dental students, and educators in various settings, and thereby improving access to high-quality oral health care. The possibility of employing WhatsApp as an instant messaging tool is especially relevant given that it is now one of the most widely used programs on mobile phones and desktops (Yeboah & Ewur, 2014). According to Bhaskaran, Kumar, and Janodia (2017), people use WhatsApp more than any other way of networking to check about diseases and drugs. Meanwhile, health professionals from a Malaysian public hospital's medical and casualty departments, including nurses, medical assistants, medical residents, medical officers, and physicians, discovered the benefits of using WhatsApp in practice. The research set the groundwork for quality improvement advances in the provision of inpatient care via m-Health technology (Ganasegeran, Renganathan, Rashid, & Al-Dubai, 2017).

However, despite the popularity of social media, very little is yet known about how participation in an online community for women affected by endometriosis in Malaysia can address their support needs and impact illness experiences, psychosocial well-being and quality of life. Therefore, the primary aim of this study was to explore women's experiences of accessing this novel form of mutual support.

## Methods

### Design

Individual semi-structured interviews were employed to explore women's experiences of engaging with "MyEndosis", a WhatsApp *online support group* and the subsequent influence on women's health outcomes. According to Engleberg and Wynn (2010), a *group* comprises interdependent people seeking to achieve shared goals. One form of group is a self-help group, often known as a support group, which aims to offer support and encouragement to members who want or need help with personal problems. Hence, "MyEndosis" is a WhatsApp online support group or a platform for women with endometriosis. The aims are to exchange knowledge and information about endometriosis and relevant activities, provide updates for the social good, and promote community social networking.

Two of the authors (SM and SW) are members of the WhatsApp group; there-

fore, they would be deemed emic researchers. According to Morey and Luthans (1984), the word “emic” refers to an insider’s or “informant’s” perspective on reality. This approach stresses that the researcher is the best arbiter of the study and the adequacy of the analyses. Purposive sampling was undertaken until data saturation was achieved in relation to the study’s aims (Etikan, Musa, & Alkassim, 2016). To recruit potential participants, information about our study was shared with the “MyEndosis” WhatsApp community. This included study aims, procedures, how to get involved, and confirmation that the study had received ethical approval from the host academic institution. Sampling was based on the following criteria: i) age; ii) time since diagnosis; iii) membership of the MyEndosis support group.

A multistep sampling procedure was used to recruit interview participants. Specifically, we developed a semi-structured interview schedule (see Table 1) based on our understanding of the relevant literature in the field of online support communities and the psychosocial impact of endometriosis, as well as our considerable experience of dealing with and supporting endometriosis patients in Malaysia. A series of pilot interviews were undertaken with three women living with endometriosis. As a result of this, several minor edits were made to the semi-structured interview schedule to facilitate participant comprehension and engagement with the interview process, as the women who were being interviewed did not want to be recorded in any way. We then undertook a series of one-to-one in-depth semi-structured interviews (with members of the “MyEndosis” WhatsApp support community) to explore their experiences of engaging with the community and the subsequent impact of those experiences. Participants were invited to take part through either an asynchronous email interview or a synchronous WhatsApp video call. These options were suggested as data collection occurred during the early months of the COVID-19 pandemic when face-to-face social interaction was restricted. Interviews were conducted by members of the research team (SM and SW), with the video call interviews lasting between 30 and 45 minutes.

Each interview began with an overview of the research study aims, which included an opportunity for the women to ask any questions and they were invited to respond to a series of background questions about their experiences with endometriosis to date. The women were then explicitly asked about their engagement with the “MyEndosis” WhatsApp community and, more broadly, about its role in both educating and supporting women living with endometriosis in Malaysia.

**Table 1**  
*Semi-structured interview schedule (illustrative)*

How are you?
How old are you?
Are you married?
Could you tell me about your educational experience to date?
When were you first diagnosed with endometriosis?
How were you diagnosed? Using what methods?
How long have you been living with endometriosis (or its symptoms prior to diagnosis)?
Could you tell me how endometriosis has had an impact upon your life?
How did you find out about the “MyEndosis” Whatsapo group?
How long have you been a member?
Why did you decide to become a member?
Do you post any messages to the group?
What kind of messages do you post?
Do you ever try to help other women, for example – emotionally?
Why do you offer support to other women in the group?
How do you decide what messages you are going to reply to?
Does the group help you? If so, how?
Have you had any negative experiences whilst being a member of the group?

## Data Analysis

Four interviews were conducted by email and therefore, no transcription was required. However, the contents of the remaining interviews ( $n=11$ ) were noted down by two researchers as the women declined to have their interviews recorded and wanted to remain anonymous.

Inductive thematic analysis (Braun & Clarke, 2006) was used to analyse the response to each interview question. Since the research team held no prior assumptions about our participants’ opinions, an inductive approach to the analysis was undertaken. The team read and re-read interview transcripts several times to familiarize themselves with the data, systematically coding all interesting and noteworthy features of the interview data into a coding framework. Each theme was generated to form links between separate codes and reviewed to determine coherence and consistency. The final themes were generated through further refinement. In the process of inductive analysis, it was concluded that the data generated by our interview participants were sufficient to provide saturation and for our three inter-related themes to be well developed, thereby allowing our research questions to be fully addressed.

## Ethical Considerations

Our study was undertaken in April 2021 with the full support and approval of MyEndosis, the Endometriosis Association of Malaysia. In addition ethical approval for the study was granted on 30/4/2019 by Universiti Tunku Abdul Rahman ethics committee (FM—IPSR—R&D—056). Finally, the volunteer moderators sought and received approval from the closed “MyEndosis” WhatsApp support community.

## Results

The participants were aged 34 to 51 years and seven reported they were married, with the remainder being either single ( $n=5$ ) or divorced ( $n=3$ ). The length of time since diagnosis of endometriosis ranged from 5 to 20 years (mean=11) and membership of the WhatsApp community ranged from 2 to 9 years (mean=5.3). Participants reported that they had found the “MyEndosis” WhatsApp community via friends ( $n=2$ ), news media ( $n=2$ ), Facebook ( $n=4$ ) or through personal invitation ( $n=7$ ).

Our results are reported by theme with verbatim data extracts used to illustrate the role of the WhatsApp “MyEndosis” community in the lives of our participants. Three interconnected themes were generated through our analysis: 1) *Unmet support needs*; 2) *Connecting with similar others*; and 3) *Sharing and caring online*.

### Unmet Support Needs

This theme describes the impact of endometriosis on the lives of the women and their unmet support needs. All our participants shared their experiences of struggling to live with the ongoing symptoms (e.g., pain) of endometriosis and how this negatively affected both work and social life. Particular challenges focused on fertility and the negative impacts on spousal relationships. Against this backdrop of significant medical and psychosocial difficulties, our participants elaborated on how their unmet support needs were essential drivers in their decision to engage with the “MyEndosis” WhatsApp community.

For some, the decision to join the WhatsApp community stemmed from a recognition that they had no “*support system*” [Participant 7, aged 34], whilst others simply explained that they were “*looking for support*” [Participant 6, aged 50]. A need ‘*to gain more understanding about endometriosis*’ [Participant 11, aged 36] was evident



across several responses, with some women providing a detailed insight into their specific informational support needs. For example, *“I needed to know what to do and where to go to get this help. Which doctors to see, which hospital to go to”* [Participant 3, aged 51]. In contrast, other women explained their reasons for membership through the need to obtain emotional support. As one participant explained, *“I just needed the emotional support from other women like me”* [Participant 1, aged 46].

### Connecting with Similar Others

As noted in the previous theme, our participants often had no support system in place to help them cope with the challenges of living with endometriosis. This theme, captures the importance of finding similar others and connecting with them online.

For some women, there was a need *“To get to know other endo patients”* [Participant 11, aged 36], and the online community represented a unique opportunity to achieve this. Indeed, this valuable opportunity was noted by some as they explained, *“It is the only group that I know of for endo patients, and it connects me with women who go through the same pain”* [Participant 10, aged 36]. Through membership of the “MyEndosis” WhatsApp online community, women appeared to benefit as they *“just needed that connection, that engagement”* [Participant 1, aged 46]. It was clear that the value of connecting with similar others was all the more important when women struggled with particular problems or challenges. In such instances, they described how they could interact with others who were going through similar thing: *“I tend to ask others in the same position what to do when I am faced with a problem relating to this horrible condition”* [Participant 3, aged 51]. The implication is that only similar others could truly understand the challenges or be in a position to provide advice and support: *“It helps me to know that others are having similar problems”* [Participant 10, aged 36].

### Sharing and Caring Online

This final theme builds on the previous one by capturing how women living with endometriosis engage with and benefit from the “MyEndosis” WhatsApp community. For several participants, the community provided a venue through which they could narrate their experiences with the condition and share *“personal stories”* or *“struggles”* [Participant 2, aged 44]. They valued the opportunity to share

their thoughts, feelings and experiences with others or simply to “*vent without being judged*” [Participant 9, aged 39].

Our participants recognized that through sharing their personal experiences, other women may also benefit. For example, as this participant explained, “*Sometimes my own experiences can provide some comfort and help to some women*” [Participant 6, aged 50]. Further, in deciding whether to respond to messages posted by other community members, our participants explained that they replied: “*if the question related to my own experiences*” [Participant 6, aged 50]. The messages posted to support other women varied in content, ranging from those who shared “*experiences on treatment and diet*” [Participant 6, aged 50] to those offering broader guidance on how to appraise or re-appraise life living with endometriosis. As one participant elaborated, “*They need to know that it is not the end of the world and all problems can be fixed*” [Participant 4, aged 50].

Thus, it would appear that the exchange of messages within the community may serve a dual purpose. On the one hand, sharing an experience was considered helpful to the individual posting the message, but it was also potentially beneficial to those reading it. Overall, it was evident that sharing and caring online appeared to be underpinned by a collective experience of *Unmet support needs* (Theme 1) and the value of *Connecting with similar others* (Theme 2).

## Discussion

This study was aimed to explore the experiences of women in Malaysia living with endometriosis who engaged with an online peer support community (i.e., “MyEndosis”) via the communication platform WhatsApp. As yet, both the experience of living with endometriosis in Malaysia as well as the issue of engagement with an online support community has received little empirical attention. Therefore, the present study addressed this by exploring the hidden and personal experiences of women through a qualitative interview design with women via email or WhatsApp videocall depending on their individual preference at the time of interview.

Our inductive thematic analysis generated three inter-related themes that captured women’s experiences and focused on: i) unmet support needs; ii) connecting with similar others and iii) sharing and caring online. However, the desire for anonymity was evident even from the point of initial data collection and for those women who did participate in our study, their insightful responses to our semi-structured interview questions underscored the pervasive belief that the topic

of endometriosis is a social taboo in Malaysia and cannot be openly discussed.

Looking across the themes generated, it becomes clear that even today women affected by endometriosis in Malaysia face many ongoing health, medical and psychosocial challenges, something which has long been acknowledged (Whitney, 1988) but which does not appear to have improved. However, our findings suggest that the WhatsApp platform may provide new and important opportunities for women living with this condition in Malaysia, whereby they can begin to address these unmet needs (i.e., learning about the condition, its symptoms, and its treatments) through connecting with similar others and sharing their experiences through posting messages. Indeed, the role of online support communities in helping women with endometriosis connect with each other has previously been acknowledged in the context of asynchronous discussion forums and Facebook (Shoebtham & Coulson, 2016).

The present findings suggest that the WhatsApp communication platform successfully brings women together for the purpose of mutual peer support. In addition, our findings illustrate how being able to connect and interact with similar others helps lessen feelings of loneliness and promotes a sense of control, especially for individuals who knew little about the disease. This is consistent with Southwick and Charney (2012), who argue that a low level of competence in an illness is addressed through inter-patient involvement, which eventually assists them progress to effectively managing their condition.

Despite the novelty and importance of our findings, this study does have a number of limitations that should be acknowledged and considered. First, the use of WhatsApp messages to promote support has certain limitations. Some of the women explained in our interviews that they were troubled by the pessimism shown by others when they described their difficulties. As a result, these individuals may choose to remain silent while observing others online. Future studies using mixed methods should try and document possible factors that affect their disclosure intention. Second, the limited number of respondents means that the women selected for interview cannot be seen as representing women with endometriosis in general. Thus, readers need to be cautious and not overgeneralize the results to all women in Malaysia with endometriosis. Furthermore, despite the fact that a small number of women who participated in our study expressed some reservations regarding the WhatsApp online community it might be the case that only women with particularly positive experiences responded to our invitation to participate. To overcome this limitation, future research should ideally use probability samples that consider and select from a broader range of important attrib-

utes, including those related to the condition itself, background socio-demographic characteristics as well as those related to engagement with the online community (e.g., “lurker” versus “imposters”).

It would be useful to explore the reasons why some women choose to disengage from an online peer support community. Some women might have their support needs met through engagement (e.g., informational needs) but then disengage soon after. Conversely, it may be the case that some women choose to disengage because their support needs are not being met by the online community because reading about other women’s experiences of endometriosis is too upsetting. In order to begin to address these complex issues, future research could analyze a sample of messages posted by women who are members of the WhatsApp “MyEndosis” online peer support community. This approach might help our understanding of how women integrate themselves into the online community, what types of support questions they typically ask at what point of their endometriosis journey and the responses offered by other members.

Setting these limitations to one side, we propose that our study contributes to a deeper understanding of how participation in an online community for women affected by endometriosis in Malaysia can address their unmet support needs and impact illness experiences, psychosocial well-being and quality of life. It is important to study women’s perceptions of the use of online support group as it can guide practitioners and social policy makers. The results highlight the fact that WhatsApp’s influence could aid in promoting togetherness and acceptance of their condition.

## Conclusion

This study makes a significant contribution to our understanding of how WhatsApp can assist women with this difficult disease. This platform encourages women to think that they are not alone in their distress in dealing with endometriosis. As they look through the posts shared in the WhatsApp group, they can compare themselves in terms of symptom severity. Our study demonstrated that the WhatsApp online support community appears to contribute to an enhanced ability to manage and cope with the disease and a reduction in feelings of loneliness among the women.

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