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Breaking the Silence: Unveiling the Cultural Barriers to Endometriosis Disclosure in Malaysia

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ABSTRACT

Endometriosis is a debilitating disease that affects many women globally during their reproductive years of life. However, cultural barriers often prevent women from disclosing their condition, leading to delayed diagnosis and treatment. This study explores how cultural barriers in Malaysia impact the avoidance goals of disclosure among women living with endometriosis. Online in-depth interviews were conducted via the Zoom platform using a semi-structured interview guide. Fifteen Malaysian women living with endometriosis were recruited from Endometriosis Malaysia online support group based on purposive sampling. Thirteen of them are married, seven of them have children, and the remaining two informants are single. Analysis was done using thematic analysis. Findings revealed five main themes on cultural barriers why Malaysian women living with endometriosis chose to stay silent over disclosures: (1) stigma and being judgemental, (2) conservative upbringing, (3) language barriers, (4) gender preferences, and (5) spoon feeding culture. In conclusion, it is imperative to comprehend the impact of cultural values on the disclosure of experiences by women living with endometriosis. Cultural barriers need to be dismantled, and women with endometriosis should be empowered to overcome them. By shedding light on this issue, we aspire to increase awareness and foster open communication about endometriosis. It is high time to break the silence and empower these women to voice their concerns and educate the general public about this debilitating condition.

Keywords: *Cultural barriers, endometriosis, disclosures, Malaysia, women.*

INTRODUCTION

Endometriosis is a chronic gynaecological, endocrine, and inflammatory disease that affects approximately 10% (190 million), a significant proportion of women globally during their reproductive years (Capezzuoli et al., 2022; World Health Organization, 2023; Saguyod et al., 2018). However, this estimate may not provide a complete representation of women suffering from endometriosis, particularly in Asian countries where many women may choose not to disclose their symptoms due to cultural barriers. Most of the women living with endometriosis suffer from chronic pelvic pain and infertility (Harris & Tsaltas, 2017; Markham et al., 2019).

Self-disclosure, or making personal information known to others, is integral to social interaction. Disclosure can allow one to express thoughts and feelings, develop a sense of self, and build intimacy within personal relationships. Reluctance to share and disclose may eventually lead to a knowledge gap in Endometriosis. The act of denial and difficulty in

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accepting the fate of this disease would cause a delay in diagnosis (Simpson et al., 2021). It typically takes 7-10 years from the onset of symptoms for most women to receive a proper endometriosis diagnosis.

Culture is often seen as the key inhibitor of effective knowledge sharing (McDermott & O'Dell, 2001). Study indicates that when individuals disclose their identity, they experience advantages, including enhanced social support and better outcomes in both physical and mental health (Camacho et al., 2020). However, this is not always necessary to the advantage of the person disclosing his/her status, and there could be some normalcy in not disclosing (Greeff, 2013).

Cultural barriers refer to the challenges that arise from different cultures, customs, values, and social norms between individuals or groups. Cultural barriers can impede disclosure openness (Cogan et al., 2024; Greeff, 2013; McDermott & O'Dell, 2001; Smith, 2020). While endometriosis can cause various challenges to the patients, such as period pain, chronic pelvic pain, infertility issues, and painful sex, disclosures can be even more difficult, especially among the marginalized and minorities who are suffering from this disease (Tan & Ling, 2022; Wilson et al., 2022).

Malaysia boasts a rich and varied society with many ethnicities, including Malays, Chinese, Indians, and indigenous communities. Each group has its unique cultural norms and practices, making for a diverse range of perspectives. As such, disclosures made by women living with endometriosis in Malaysia may be influenced by various cultural barriers and viewed through different cultural lenses.

The objective of this study is to explore how cultural barriers in Malaysia impact the avoidance goals of disclosure among women living with endometriosis. Currently, empirical studies are scarce on the disclosures from the cultural perspectives of women living with endometriosis in Malaysia.

Malaysia, with a population of 33.4 million, is located in Southeast Asia (Xinhua, 2023). Malaysian society values collectivism and is well-known for multiculturalism, where various ethnic groups coexist with unique cultural practices. By understanding the cultural barriers that women with endometriosis may face, researchers can gain insight into why some women choose to suffer in silence. This understanding can provide valuable information that may assist researchers and healthcare providers address issues related to breaking the silence of endometriosis more effectively by promoting a more informed and empathetic approach. Failure to consider cultural barriers can hinder a complete understanding of the impact of the disease on their lives.

Every culture and community has its unique characteristics. For women with endometriosis who may not have visible symptoms, it is important to consider cultural nuances when deciding whether to disclose their condition. Although Bougie et al. (2019) found a correlation between race, ethnicity, and endometriosis, cultural barriers can significantly impact how disclosures are received. Many cultural groups still have a stigma surrounding illnesses (Robinson, 2012).

Understanding disclosure decisions is crucial, especially for women dealing with lifelong, incurable, debilitating diseases like endometriosis and many of whom also face infertility issues. The decision to share information and disclose hinges on weighing the potential benefits and risks within the context of the disclosure decision-making model (Yan et al., 2016).

LITERATURE REVIEW

Miyazawa (1976) has highlighted that Japanese women are more susceptible to endometriosis compared to Caucasians and black women. Progressively, Arumugam and Templeton (1992) also supported the notion that Asian women have a higher risk of developing endometriosis as compared to Caucasians. At present, Velarde et al. (2023) have posited that endometriosis was found to be more prevalent in advanced stages among Asian women. These findings align with the clinical impressions from previous years. However, the prevalence studies on Endometriosis and its disclosure among Asian patients are still scarce.

Malaysians are generally known for their polite behaviour. However, the advent of social media might have influenced changes in their communication style (Zulkifli et al., 2019). In the online space, it has become increasingly common for users to exhibit impolite and uncivilized behaviour, particularly in the comments section. This can create a significant barrier for individuals with endometriosis to share their experiences.

The prevalence of harsh and offensive language among younger generations is an issue of growing concern. It is important to note that this trend is not limited to a specific demographic but is a universal phenomenon that has become increasingly prevalent. The use of such language is inappropriate and can have adverse effects on social dynamics. Therefore, addressing this issue is imperative and ensuring that the younger generation understands the gravity of using offensive language (Anwar et al., 2021; Saidil Morsalin & Adnan, 2022).

From the study Rao et al. (2023), it has been discovered that a considerable number of women in Malaysia who are currently suffering from endometriosis are experiencing a significant decline in their marital satisfaction. To address this issue effectively, it is crucial to comprehend the underlying reasons for silent suffering. The key factor in enhancing marital satisfaction is establishing open communication between partners. This necessitates a willingness to engage in dialogue, active listening, and exchanging ideas. Such an approach fosters trust, mutual respect, and a deep understanding between partners. Consequently, couples need to prioritize effective communication. By doing so, they can cultivate an environment conducive to healthy and fulfilling long-term partnerships.

At the same time, Zhang et al. (2017) also mentioned that disclosing one's mental health struggles involves several dimensions, including quantity, quality, sincerity, purpose, and tone of the information shared. Research suggests that considering the pros and cons of disclosure and seeking peer support can impact one's experience. It is important to study the impact of avoidance goals on disclosures to encourage women with endometriosis to speak up and raise awareness.

Meanwhile, Ní Chorcora and Swords (2021) posited that certain Asian cultures place great importance on emotional self-control. As a result, individuals may find it challenging to discuss their mental health difficulties and seek support from others. This approach may result in a more self-sufficient attitude toward managing mental health problems and a reluctance to reveal personal information. It has been noted that some individuals may struggle to open up about their issues due to various reasons, such as a lack of confidence in their English proficiency, fear of burdening others, and a tendency to express psychological issues through physical symptoms (Cogan et al., 2024). However, keeping one's emotions bottled up can have negative consequences, especially for marginalized and minority groups (Smith, 2020).

In this conservative society of Malaysia, it is a great challenge for most LGBTQs to come out as who they are. The existence of gays has been denied in Malaysia (McKirdy, 2019). The marginalized and minority populations often rely on online communities to find acceptance and support for who they are. Tuah and Mazlan (2020) revealed that LGBTQ youths tend to conform to societal norms in real life but may reveal their true identity on social media as it provides a space away from stereotyping and judgment.

The term "cultural safety" has been introduced in Malaysia, but there remains a lack of information regarding the LGBTQIA+ community. Marginalized and minority populations in Malaysia often do not disclose much due to stigma and stereotypes in healthcare. While religious beliefs, spiritual healing, and social support are protective or healing factors for mental health issues, particularly among the heterosexual population, LGBT communities in Malaysia have limited coping mechanisms, family support, and peer support due to religious restrictions. As a result, they often live in fear and guilt, leading to a reduced quality of life. Additionally, they frequently face judgment and discrimination from the local society (Tan & Ling, 2022). In line with social stigma and discrimination, disease awareness and public education are pivotal measures to break down the cultural barriers to encourage patients to come forth to receive support (Ahmed et al., 2017).

Berry et al. (2019) have also highlighted that stigma can hinder individuals from seeking help due to their concerns about negative repercussions that may arise from disclosing their struggles. Furthermore, societal stigma is perceived as a reputational risk and may delay disclosures or prevent individuals from seeking assistance. Among Malaysian-Chinese high school students, seeking help is often not considered a priority due to a lack of seriousness towards the issue, fear of speaking up, being too preoccupied to ask for help, doubts about the competence of counsellors, and a preference for traditional faith healers.

There is a study on HIV patients and their non-disclosures. Syed et al. (2015) highlighted that family emotions were the most significant reason patients wished to withhold the illness in order not to hurt their loved ones. Lack of community awareness creates stigma issues and social discrimination towards the patients themselves. Some patients are fearful of losing their jobs, especially those who are low in socioeconomic status. In this study, disclosures were hindered mainly due to the fear of stigma and discrimination and getting marginalized by the public and the authorities.

Patients may encounter discrimination from others due to the stigma surrounding their medical conditions. Such actions can have a profound effect on their emotional and mental well-being, potentially exacerbating the negative effects of their health issues (Dahalan & Abd Kadir, 2022).

It is crucial to comprehend the impact of cultural values on the experiences of women with endometriosis. The cultural values may support or impede these women when they disclose their condition. To ensure that women with endometriosis can overcome cultural barriers, it is essential to dismantle them and empower these women. Therefore, an in-depth understanding of how cultural values build up or tear down women with endometriosis in their disclosures is crucial. It is imperative to break down cultural barriers and empower women with endometriosis to overcome them.

THEORETICAL FRAMEWORK

This study applies the Disclosure Decision Model (DDM) to understand how informants decide on their disclosure decisions, particularly regarding health information and experiences. It suggests that individuals strategically manage their disclosures to regulate their social circles

and achieve social and personal goals (Omarzu, 2000). According to Chaudoir and Fisher (2010), disclosure is critical to people's experience with concealable, stigmatized identities. The antecedent goals representing approach and avoidance motivational systems moderate the effect of disclosure on numerous individual, dyadic, and social contextual outcomes.

Generally, patients hesitate to disclose much if the potential risks exceed the perceived benefits. From past empirical studies, it has been shown that the disclosure decision has been studied in different areas of health disclosure, such as pregnancy loss and infertility (Andalibi & Forte, 2018; Steuber & High, 2015), HIV disclosures (Monroe et al., 2018; Qiao et al., 2013; Saeed et al., 2018), dementia (Bhatt et al., 2023), the proliferation usage of social media (Ostendorf & Brand, 2022; Ostendorf et al., 2020), etc. To fill in the research gap, researchers are keen to explore how cultural barriers in Malaysia impact the avoidance goals of disclosure among women living with endometriosis (Figure 1). According to the social exchange theory, individuals make deliberate disclosure decisions by meticulously assessing perceived risks and benefits (Figure 2).

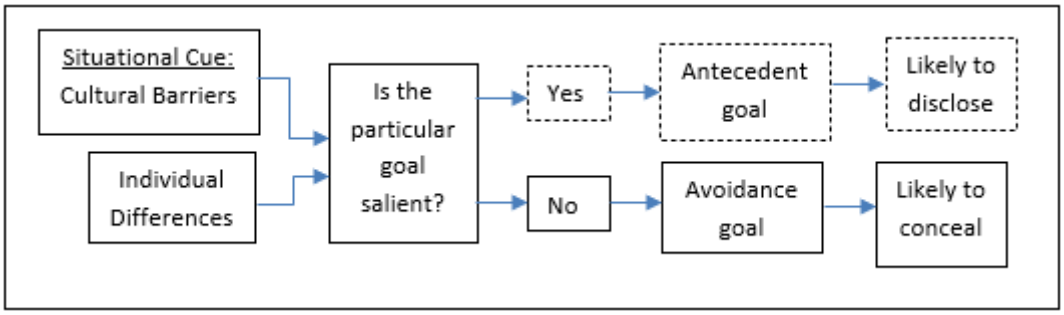

Figure 1: A partial study of the Disclosure Decision Model (Omazu, 2000)

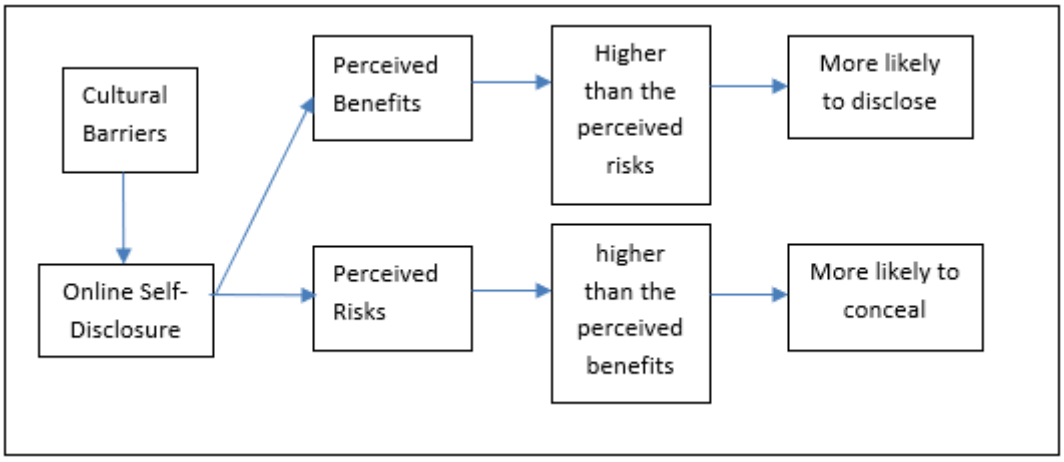

Figure 2: Disclosure decision is weighed against the perceived benefits and perceived risks

METHODOLOGY

This section explains the research methodology used to explore and understand the cultural barriers that prevent women living with endometriosis from disclosing their health condition and experience sharing. Since this is a preliminary study, the researchers aimed to explore using a single case study based on the earliest formed, largest, and women-based endometriosis online support group in Malaysia to achieve its research objective in this study.

Participants

For this study, a total of 15 informants were interviewed. These informants were women diagnosed with endometriosis, and their ages ranged from 24 to 46. Of the 15 informants, 13 were married, and 2 were single. The ethnic composition of the group was 11 Malays, 3 Chinese, and 1 Indian. Interestingly, only 7 of the married women had children. All of the informants were proficient in English and could communicate in English throughout the interviews effectively. Additionally, 13 informants resided in Peninsula Malaysia, while the remaining 2 were from East Malaysia.

Data Collection and Data Analysis

In this research study, we utilized a qualitative and exploratory approach, employing a semi-structured and in-depth interview guide to gather valuable insights. Due to the restrictions brought about by the pandemic lockdown, we conducted the interviews using the Zoom platform to ensure the safety and convenience of both the participants and the researchers. Before the interview phase, we conducted a pilot test to refine and ensure the clarity of the interview protocol. Each interview session with the participants lasted between 45 minutes to one hour, allowing for in-depth discussions.

To ensure ethical conduct, we obtained approval from the administrators of a well-known online Facebook support group for women living with endometriosis. This enabled us to recruit participants for our study. A recruitment poster was posted to invite the online support group members to join in the interview. We made it a priority to reassure participants that their responses would be kept confidential and used strictly for academic and research purposes.

Following the interviews, our research team applied a thematic analysis technique to systematically identify and highlight the primary themes emerging from the collected data (Braun & Clarke, 2012). This method allowed us to comprehensively understand the participants' experiences and perspectives, enriching the findings of our study.

Ethics clearance

This study has been approved by the Universiti Putra Malaysia's Ethics Committee for Research Involving Human Subjects under the JKEUPM 2021-414 reference number.

RESULTS

Based on the analysis, the researchers interviewed a total of fifteen informants.

Table 1: Summary of participants interviewed

Race	Marital Status	Married with children	Employment status
11 Malays	2 Single	7 married women - Yes	8 Full-time job
3 Chinese	13 Married	6 married women - No	3 Part-time job
1 Indian			2 Unemployed
			2 Full-time students

Table 2: Profiles of informants being interviewed

No	Informant's Pseudonym	Race	Location	Age	Employment Status	Marital Status	Any kids?	Trying to conceive
1	Raathi	Indian	Selangor	28	Full-time student	Single	No	No
2	Roziah	Malay	Alor Setar	46	Full-time employee	Married	Yes	No

3	Norlia	Malay	Selangor	37	Freelancer	Married	Yes	No
4	Puteri Kay	Malay	Pulau Pinang	24	Full-time student	Single	No	No
5	Belle Tan	Chinese	Selangor	45	Full-time employee	Married	Yes	No
6	Murni	Malay	Selangor	37	Full-time employee	Married	Yes	No
7	Nul Ain	Malay	Selangor	41	Freelancer	Married	No	No
8	Salwah	Malay	Kota Bharu	36	Full-time employee	Married	No	Yes
9	Rozita	Malay	Malacca	32	Unemployed	Married	No	Yes
10	Siew Ling	Chinese	Selangor	41	Full-time employee	Married	Yes	Yes
11	Amalina	Malay	Sabah	42	Full-time employee	Married	No	Yes
12	Mizatul	Malay	Selangor	41	Unemployed	Married	Yes	Yes
13	Normi	Malay	Selangor	40	Full-time employee	Married	Yes	Yes
14	Siek KC	Chinese	Sabah	42	Full-time employee	Married	No	Yes
15	Nur Fiqah	Malay	Selangor	37	Part-timer	Married	No	Yes

Suppressing one's feelings about the symptoms or experiences relating to the disease can hinder the overall recovery process. However, due to cultural barriers, some individuals have opted to restrict their disclosures related to endometriosis. This study has identified five themes of cultural barriers that contributed to this decision: (1) stigma and judgemental, (2) conservative upbringing, (3) language barrier, (4) gender preferences (5) spoon-feeding culture.

Stigma and Being Judgemental

One factor that hinders patients from sharing is the fear of being stigmatized, judged, and stereotyped (Syamsuddin et al., 2023; Andalibi, 2020; Idris et al., 2022). Women living with endometriosis will try their best to cover up and stay away from being judged. In Malaysia, many care for their loved ones, such as their spouse, partner, and daughter, more than themselves.

Fearful of Being Labelled Negatively

Some of them are fearful of being labelled as “less of a woman” since infertility is a huge challenge for those who are suffering from endometriosis. Setting up boundaries will enable them to live stress-free lives without disclosure.

> Malaysians judge. I fear people commenting that I share too much – too open. I was not ready to disclose. Keep marriage issues to myself. Women don’t talk about period pain. Purchase pads by wrapping them up so people do not know they are buying pads… I am not ready to share 100% as I am still afraid of people’s judgment, which might affect my emotions. I want to live a stress-free life. (Amalina, aged 42, married without children)

Besides that, there is another informant who is married with a young daughter mentioned that she was afraid to disclose much on endometriosis, fearing that people might

label and judge her daughter later on. She knows endometriosis is hereditary (Koninckx et al., 2021; Koninckx et al., 2019). She has expressed that endometriosis is not a punishment due to our acts but is something that God has measured to test our faith. Hence, there should not be a blame game here, but we should receive it openly with grace.

> Having a daughter myself, it is true that our society and relatives are like this. I started to feel worried about opening up about this, but there is not much we can do. People can talk about anything at any time. If it is not about this disease, maybe something else. It is not about the individual but what God has given us. We have to stop blaming this. We don't cause this. Make peace with faith. Otherwise, we will question and compare with others and never be at ease. The emotional torture is even bigger than what we are going through. (Normi, 40, married with 1 child)

Understandably, some young women who are still single may feel hesitant to share their experiences with endometriosis. Being judged unfairly by their future partner or in-laws can be overwhelming and frightening. It's completely normal to feel vulnerable and apprehensive in such situations. It's important to remember that endometriosis is a medical condition that requires compassion and empathy, not discrimination or judgment. Women who suffer from endometriosis deserve our support and understanding, and creating a safe space for them to share their experiences is crucial. Let's work together to promote inclusivity and acceptance and to help women feel empowered to talk openly and honestly about their health.

> I think even in my family, nobody knows except for my parents. It's a big taboo. So, yeah, basically, I never spoke about it. (Raathi, 28, single)

An informant raised another interesting point. Women who lead an LGBT lifestyle often face judgment and stigmatization, particularly in Malaysia. However, despite their different lifestyle choices, they still have the same biological body and can suffer from endometriosis. Therefore, it is important to have an open mind and provide them with emotional support without any judgment.

> Even the LGBT, I used to be closed-minded. However, the overseas groups I joined even have a subgroup of LGBT. It changes my perception… We need to help the patients of LGBT although their lifestyles changed. I will still share the awareness and information in the group. Some view LGBT patients as useless people. Aiya, pity lah. Your life is not the same. They are not in the same boat. They want to help the patients, but their intentions are like… hmmm… If they are willing, I prefer to meet face-to-face. I don't feel awkward because we are in the same boat. (Siek KC, 42, married without children)

It is worth noting that endometriosis is a condition that affects women of all ages during their reproductive years, causing distress even for those who are single, married without children, married with children, or even leading a life of LGBTQ+. Hence, women should protect themselves from potential harm caused by others.

Harsh and Nasty Comments

It is essential to recognize that individuals who lack knowledge of endometriosis or have not personally experienced it may unintentionally judge and cause emotional distress for women who suffer from this condition, potentially discouraging them from disclosing their experiences. Furthermore, negative and disparaging comments can dissuade them from seeking assistance or sharing their stories on social media platforms.

In light of this, it is crucial to promote a supportive and empathetic environment for individuals diagnosed with endometriosis. Doing so can foster community and encourage individuals to share their experiences, seek assistance, and gain the required support.

> Some people who are not in this online support group, who do not have endometriosis, commented me `mengada-ada' (pretending). Why do you feel like this? Why are you so weak? Other women will usually soldier on… Also, this one time, I knew my period was coming…. I asked if pineapple is good for us to consume during our period because it is `tajam' (too acidic), but this lady gave me a piece of her mind. I asked politely, but why is she being so harsh on me? I feel bad for asking. (Nur Afiqah, 37, married and trying to conceive)

Women living with endometriosis do not expect or anticipate others to lend them emotional support due to a lack of awareness and understanding of this disease.

> The hardest thing is people don't understand us. I can't perform like any other normal woman. They are aware that I have endometriosis, but they cannot relate to why this is happening. Side effects are hard to explain. E.g., bulging stomach. People will look down on me, and I won't explain it to everyone. They won't understand… It is like 50-50 to get their emotional support. You cannot blame them because they do not know or understand. Speaking to the same group of people (endometriosis patients) will certainly understand what we are going through. We are here for each other. (Normi, 40, mother of one child)

Language Barriers

It is worth noting that some women may remain silent in certain instances due to language barriers that limit their ability to communicate effectively. Specifically, some experience discomfort in writing at length and publishing their work to the public within an open group setting. Therefore, it is important to acknowledge the potential impact of language barriers on the ability of women to participate in such activities actively and to ensure that sufficient support is provided to help them overcome such obstacles.

> I prefer one-to-one direct messaging or personal messaging (DM or PM) as I am more open to detail when asked. If it is on an open platform, I tend to write very simple sentences. (Murni, 37, married with one child)

It has been noticed that certain women tend to be self-conscious by nature. During the interviews, many of these women admitted that they initially preferred to remain silent and read through the conversations upon joining an online support group. Some consider themselves newcomers, while others should muster the courage to speak and share their thoughts. Language capability is one of the cultural barriers that they must overcome.

Conservative Upbringing

Conservative values often play a role in shaping societal norms and expectations. In Malaysia, individuals prioritize group harmony, family, and community over their needs and desires since most Malaysians value collectivism. Some informants were found to be reserved in disclosing, especially those from a more traditional family with a conservative upbringing.

Cultural Traditions

Generally, an implicit social expectation exists that women should bear children to continue the family line, thereby ensuring a lasting legacy. Regrettably, infertility issues can lead to negative societal perceptions, causing significant distress to married couples. Moreover, male sterility can sometimes be the cause of infertility, leading to additional challenges for couples. In such cases, wives are often expected to protect their husbands and families from the shame associated with infertility.

In light of preserving the well-being of their loved ones, it has been observed that women tend to limit their disclosures. This practice has been described as a sacrifice, wherein individuals keep certain information undisclosed to protect their loved ones. This act of selflessness indicates the lengths women are willing to go to preserve the well-being of their loved ones. Some remote areas still adhere to traditional beliefs, respecting social norms to avoid judgment and shame on their families.

> Culture is introduced by the elders. I have been afraid of people's judgment. Feeling insecure always. Infertility is caused by endometriosis. I have a very understanding and supportive husband, but it is very hard to explain to the elders. I am from a very conservative family background. Very, very hard... (Amalina, 42, married without children)

Muslim males are allowed to marry more than one wife (polygamy) in Malaysia. Women, especially from the Muslim community, have expressed insecurity somehow, especially when they are facing infertility issues. Some women felt pressure and guilt for not being able to provide descendants (children) for their husbands. Some women have decided not to disclose their incapacity to others.

> In the online support group, when they talk about husbands' and wives' relationships, the Muslims can have 4 quotas. It's not the same for me. Some people said, while I try to conceive, my husband can go for other women to overcome the `zuriat' (descendant) problem. (Siek KC, 42, married without children)

In societies where family traditions and marriage customs hold great importance, the effects of endometriosis on the ability to have children and plan a family can be a sensitive and delicate issue. People may feel hesitant to discuss their fertility struggles or reproductive health problems openly due to societal expectations and norms.

Cultural Taboos and Superstitions

One of the most prominent myths shared by the elderly is that there will be no more pain after childbirth. This myth has caused many young women to have hope in waiting and has delayed the diagnosis further, which is uncalled for in endometriosis patients.

Apart from that, women with endometriosis also have reservations about disclosing when people are sceptical about their practices, such as drinking more rose petals and applying castor oil to relieve pain.

> If it doesn't work, I won't share. However, I will also not share even though I feel the benefits when people are sceptical about it. (Nul Ain, 41, married without children)

Cultural barriers may affect the treatment of endometriosis among Muslim women, particularly when it comes to their customs and practices. For instance, some women may experience prolonged bleeding for up to two months, making it difficult for them to determine their purity period for prayer and fasting. During this time, they are not allowed to participate in prayers or fasting, which can discourage them from seeking help or disclosing their condition.

> For the Malays, if it bleeds for too long, we need to discuss `suci' (pure) or `not suci' (unpure). However, I prefer it to be discussed among the golongan "hawa" (female) group alone. (Roziah, 46, married with three children)

According to Chinese cultural beliefs, it is considered taboo to discuss topics related to menstruation and sanitary pads, particularly in business settings. By doing so, it is believed to bring bad luck to businessmen. Therefore, individuals often refrain from openly discussing conditions such as endometriosis, especially in business associates' presence. This cultural norm reinforces the importance of maintaining appropriate decorum and avoiding inappropriate or impolite topics in certain contexts.

> Chinese businessmen are very pantang (superstitious). They cannot see pads and periods. If something bad happened, how? Better abstain and believe it. The Hokkien people have a lot of superstitions. I come from a very traditional upbringing. (Siew Ling, 42, married with one child)

In some Malaysian cultures, traditional beliefs and taboos regarding menstruation may persist. As a result, there is often a lack of open discourse surrounding menstrual health issues, which can present challenges for women with endometriosis who wish to share and disclose their experiences. Such cultural norms can act as a barrier to effective communication and may hinder the creation of a supportive environment for women with endometriosis, thereby exacerbating their difficulties. It is important to recognize and address

such cultural factors to ensure that women with endometriosis receive the care and support they need.

Interestingly, another informant has also raised her reservation from a different perspective. She has encountered a black magic spell over her. She has been demoralized with no improvement in her overall well-being as compared to others despite going after many treatments. She noticed that she has withdrawal syndrome, to stay as low profile as possible.

> For Malays, some might consider Endometriosis as a spiritual struggle. When we are weak, `orang lain ada buat lah' (someone is sabotaging behind me). My condition has worsened after surgery upon surgery. I thought it happened because I am `lemah' (weak), but it was not because of my weaknesses. It is because there are people at work. Memang ada orang buat lah (Real people at work are trying to cast the spell of black magic upon me). I found out after my recent surgery. So, I went to a healer, knowing this was a spiritual challenge. After the spiritual healing treatment, my condition has slowly improved. (Nul Ain, 41, married without children)

Gender Preferences

Most interviewed individuals have underscored the importance of educating the male population about endometriosis. Nonetheless, they have also expressed a greater propensity to share and disclose personal information if the online support group remains exclusive to women, or `*golongan hawa*.' The establishment of a unisex online support group could potentially lead to resistance among numerous women suffering from endometriosis and impede their willingness to divulge personal information.

> Good to have the online support group restricted to only females. (Siew Ling, 41, married with one child)

> No men in the group, please, as information sharing will be restricted. Malays should only be open to their husband and not before other men. Not comfortable. (Roziah, 46, married with three children)

Nevertheless, permitting individuals of opposite genders to engage in collaborative learning and exploring this disease can offer various benefits.

> It is easier to communicate and talk openly to only females in the endometriosis online support group initially, but after joining the IVF groups, which allows the husband to join, it allows the husband to learn more. It is easier for men to digest the content according to their time since they are more egoistic. It is good for husband and wife to learn together since trying to conceive is a couple's journey. It allows the couple to discuss and learn better. It enhances understanding of this disease. (Rozita, 32, married without children)

In certain Eastern cultures, collective well-being and family harmony are often prioritized over individual concerns. As a result, individuals grappling with endometriosis might be apprehensive about divulging their condition, as they may fear that it could disturb familial dynamics or trigger concerns about marriage prospects, particularly if their fertility has been impacted.

Spoon Feeding Culture

Several informants have expressed exhaustion and frustration while attempting to share and disclose their thoughts with others. This is due to the excessive dependence and passivity of a significant number of women in online support groups when it comes to seeking out knowledge and supplements on their own. Furthermore, while Malaysia is recognized as a polite society, declining requests can pose a challenge. Examples of scenarios that happened in the comments after posting:

> Where do we get this supplement, and how do you consume these supplements?" These questions make me tired. Please look up on your own. I want to keep up with my sanity. (Nul Ain, 41, married without children)

> I was bashed up by others in the comments. Eh, why didn't you know about this? You have to read lah. Why did you keep asking? All these depend on your body's receptivity. You have got to try it out yourself. I hated it. (Nur Afiqah, 37, married without children)

It is important to realize that some individuals may not take the initiative to seek information and supplements, which can be frustrating and concerning for those trying to provide support. Cultural expectations can also impact how needs and boundaries are communicated. Therefore, it is crucial to recognize these challenges and create a supportive environment that promotes independent information-seeking and open communication. Whether one is ignoring others or being ignored, patients will ultimately need a break and practice self-care to maintain their well-being.

DISCUSSIONS

The findings of this study revealed the challenges that women with endometriosis face, including stigma, judgment, and stereotyping that deter them from sharing their experiences. Since Malaysia practices collectivist and high-context cultures, there is a highlight on particular pressures where women prioritize their loved ones and fear being seen as "less of a woman" due to infertility. Creating a safe, non-judgmental space for these women to share their stories is emphasized.

Besides that, it is also noted that the hereditary nature of endometriosis and the additional burden of potential judgment towards unmarried women or those in the LGBTQ+ community were also raised. There is a need to advocate for compassion, empathy, and inclusivity in addressing and supporting women with endometriosis, emphasizing that it affects women of all ages and lifestyles (Nursanti et al., 2023).

Moreover, it's also crucial to understand that a lack of awareness about endometriosis can lead to judgment and emotional distress for those suffering from the condition, discouraging them from sharing their experiences or seeking help. Creating a supportive

environment is essential to foster community and encourage open communication. Language and cultural barriers can also hinder women from participating in discussions or seeking support. Recognizing and addressing these barriers is key to providing effective support for women with endometriosis.

In Malaysia, conservative values prioritize group harmony and family interests above individual desires, leading to a reserved attitude towards personal disclosure. Infertility issues can cause significant distress and societal shame, particularly affecting women who are expected to safeguard their family's honor. Women's sacrifices in limiting personal disclosures to protect their loved ones' well-being highlight their selflessness. The practice of polygamy among Malay men exacerbates insecurities among women, especially when dealing with infertility. Discussing fertility issues and reproductive health remains a sensitive matter due to societal judgment and expectations.

Cultural barriers, such as the reluctance to discuss menstrual health openly in Muslim, Chinese, and Malaysian cultures, can hinder or delay women from seeking help or treatment. These barriers include taboos around discussing menstruation and the impact of prolonged bleeding on religious practices. Additionally, there is also a highlight from the informant who feels demoralized and believes in being affected by black magic, contributing to her reluctance to speak up openly. Recognizing and addressing these cultural factors to support women with endometriosis is emphasized.

From the findings, it is noted that informants in the study emphasized educating men about endometriosis. However, the women-only support groups were preferred for personal sharing. A unisex group could discourage openness. Cross-gender learning could benefit, but cultural norms and personal preferences must be considered. Endometriosis sufferers may fear disturbing family dynamics or marriage prospects. Support groups must balance inclusivity and sensitivity to cultural norms.

Besides, individuals in an online support group have also expressed exhaustion and frustration due to excessive dependence and passivity among some women when seeking knowledge and supplements. Declining requests can be challenging in Malaysia's polite society. It's crucial to cultivate an environment promoting independent information-seeking and open communication. Patients must take a break for self-care to maintain their well-being.

Endometriosis patients in Malaysia tend to conceal their condition due to various cultural and religious beliefs. Many women value modesty and humility and may be hesitant to discuss personal health matters, especially those related to intimate areas of the body. Moreover, Malaysian society places a higher importance on the group or society as a whole rather than individual concerns, which can prevent women from sharing their experiences. Women may also feel submissive toward authoritative figures like their fathers or husbands, leading them to withhold their disclosures.

It has been observed that individuals who suffer from Endometriosis find comfort and support by being part of the online community, even if they prefer to read rather than share their own experiences. While some women prefer to share their experiences in a closed group on Facebook openly, others prefer to keep their personal issues private and only share them through personal messaging and direct messaging, which is less embarrassing and more discreet for them. However, some members may find it challenging to express themselves due to language barriers or limitations in writing skills.

Cultural and religious beliefs may also impact how endometriosis patients communicate about their condition. In Malaysia, where Islam is the dominant religion, women may feel hesitant to talk about their experiences due to cultural norms. Recognizing the role of cultural factors in women's social and emotional well-being is crucial to creating a more supportive and inclusive environment for all women.

Unfortunately, some netizens can be harsh and rude, especially in their comments, which hinders endometriosis patients from disclosing. What is alarming is that the younger generation has become accustomed to using offensive and harsh words, making it challenging for women to share their experiences. Therefore, it is crucial to approach comments related to endometriosis with empathy and understanding.

Besides, healthcare professionals can significantly contribute to online communities to enhance the quality of healthcare services. By doing so, they can establish their credibility, ensure confidentiality, and mitigate the spread of misinformation (Lin & Shorey, 2023). This approach's manifold benefits are evident in improving healthcare outcomes, patient satisfaction, and overall healthcare delivery. Therefore, healthcare professionals should consider joining online communities to contribute to advancing healthcare services.

To provide comprehensive and culturally sensitive care to women in need, healthcare professionals must consider traditional cultural barriers and concerns. By acknowledging and respecting cultural beliefs related to endometriosis, healthcare professionals can provide better treatment and support to women.

CONCLUSION

Overcoming cultural barriers to endometriosis in Malaysia requires a thoughtful and culturally sensitive approach. This may involve education and awareness campaigns and efforts to reduce stigma in ways that consider the country's diverse cultural landscape. Working alongside community leaders, religious figures, and influencers can help bridge the gap between different cultural perspectives and healthcare understanding, creating a supportive environment for those affected by endometriosis.

It is crucial to be aware of cultural differences in Malaysia when dealing with issues related to health disclosure. Effective communication strategies, education about privacy rights, and promoting non-judgmental healthcare environments can help overcome cultural barriers and encourage individuals to share relevant health information for their well-being.

Based on Figure 3, cultural barriers are crucial in understanding why women's silence about endometriosis affects their ability to seek help. Concealing the condition can protect women from prejudice and discrimination but also limit their access to necessary social support.

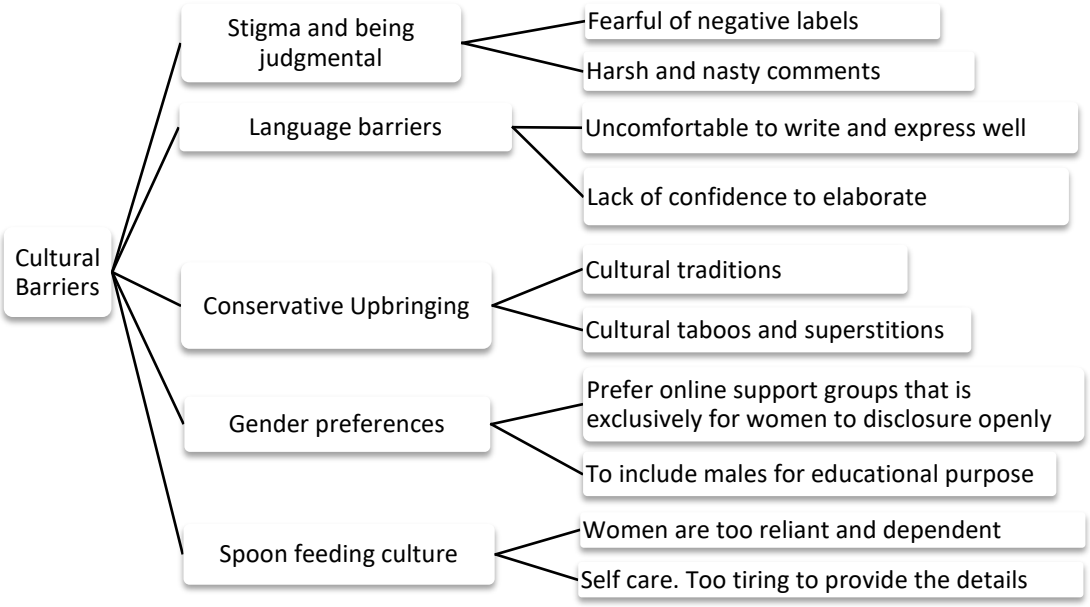

Figure 3: Summary of main and sub-themes for cultural barriers in disclosures in Malaysia

Theoretical and Practical implications

This study aims to expand the Disclosure Decision Model (DDM) by incorporating cultural values and settings, particularly from the perspective of Malaysians. It underscores the influence of cultural barriers on disclosure decisions and illustrates how these barriers can impact both avoidance goals and disclosure outcomes.

Besides, this study's findings highlight a need to equip healthcare professionals and online support group administrators to be more culturally sensitive when handling endometriosis patients, whether online or offline. Moderators of the online support group should also be more empathetic and culturally sensitive so that they are trained to handle sensitive discussions and negative comments in the posts effectively. This would help the women living with endometriosis to be more open in their disclosures to receive help rather than staying concealed due to stigmatization towards endometriosis. Women should be empowered to advocate for their health and well-being. Obtaining the right information and resources with experience sharing will help them make better decisions about their well-being.

Limitations and Recommendations

In the present study, it is duly acknowledged that the extent of digital inclusion is circumscribed due to the limited accessibility and comfort levels of all women suffering from endometriosis about digital platforms and online support groups. This constraint may, in turn, restrict the representation of findings associated with online communities and digital disclosures.

It is advisable to incorporate a cross-sectional design and employ additional qualitative research methodologies, such as longitudinal or ethnographic studies, for prospective research endeavours. Longitudinal studies help to understand the long-term impacts of cultural stigma and support interventions for women living with endometriosis. These approaches can effectively capture the implications of disclosure decisions and the evolving cultural attitudes toward endometriosis. Also, future researchers should consider a more diverse sample to capture a wider range of experiences among these women in

Malaysia. This includes different ethnicities, socioeconomic statuses, or geographical locations, especially between the Peninsula Malaysia and East Malaysia.

In conclusion, tackling cultural barriers among endometriosis patients in Malaysia requires a comprehensive approach that considers cultural sensitivity in healthcare practices, awareness campaigns tailored to specific cultural contexts, and community education initiatives. Healthcare providers should establish a secure and non-judgmental atmosphere that fosters open communication, ensuring that women living with endometriosis feel comfortable sharing their experiences and seeking appropriate medical care.

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