SOCIAL MEDIA SUPPORT FOR WOMEN WITH ENDOMETRIOSIS: A SYSTEMATIC REVIEW

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ABSTRACT

Background and Purpose: Social media is a key source of health information. Previous studies have indicated that women with endometriosis turn to the Internet for information about the condition and illness management. However, there is a dearth of studies on endometriosis online support groups. In contrast, studies examining the role of online support groups for other long-term conditions have been extensive. A systematic review of research on endometriosis support groups on social media and their efficacy was conducted to address this gap.

Methodology: Using a qualitative systematic review method and Meta-Analyses Protocols (PRISMA-P)., research databases, namely Research Gate, Springer, Wiley Online Library, Science Direct, Jstore, and PubMed, were manually searched using keywords such as "social support," "endometriosis support online," and "Facebook support & online communication". The review examined research related to endometriosis support on Facebook. Based on inclusion and exclusion criteria, 100 full-text papers were extracted from the initial 200 publications. 36 papers were selected following the appraisal stage and thematically analysed.

Findings: Social media platforms, namely Endometriosis Facebook support groups, are found to set expectations, provide education, and highlight ways to manage chronic illness. Three prominent themes were identified: (1) topics related to social media support groups, (2) the efficiency of Virtual Help Communities for Endometriosis Patients, and (3) forms of support that women with endometriosis require.

Contributions: The findings support two primary points. Endometriosis Facebook support groups educate women about the illness, connect them with others in similar situations, and promote illness discussion and networking, hence pointing to the potential benefit of Facebook support groups as a platform to provide both support and education.

Keywords: Health communication, women health research, social media, online support, endometriosis.

1.0 INTRODUCTION

Endometriosis is a chronic condition causing pelvic discomfort, stomach bloating, nausea, exhaustion, depression, anxiety, infertility, severe pain during periods, sexual activity, bowel motions and urination (Halimah, 2022). Even though it is one of the most common gynecological problems, it is also known as a fairly "unknown" illness that affects women physically, emotionally, and mentally as it is a long-term illness that often prevents women from having children (Pierret, 2003). About 25 to 50 per cent of infertile women have endometriosis (Bulletti et al., 2010). In Malaysia, 350,000 women living with endometriosis receive treatment for symptom control and quality of life. Nonetheless, it is surprising that in the 21st century, endometriosis is still stigmatized, with sufferers often feeling isolated and unbelieved (Krsmanovic & Dean, 2021). As a result, women living with endometriosis have trouble admitting their condition and symptoms to others (Whitney, 1998). Hence, these women need a lot of support (Gilmour, Huntington, & Wilson, 2008), and they are now turning to social media for online support. Moreover, informal online support allows patients with comparable diseases to recognize, communicate, and manage their sickness experiences (Frost & Massagli, 2008; Johnston et al., 2013). It also helps patients understand each other's feelings and evaluate the integration of their support system.

Internet and social media platforms have undoubtedly facilitated effective patient-to-patient communication and allowed patients to seek information on medical-related health issues without any restrictions in this age of modern technology (Coulson, 2005). Today's generation uses Facebook, Instagram, and Twitter daily (Andreassen, 2015). Past studies suggest that Facebook has become a platform in which people with illness seek support (Zhang, He, & Sang, 2013). Online support groups may aid persons with depression, as well as in other areas where patients require assistance, such as anxiety (Indian & Grieve, 2014), well-being (Huang, 2016), and physical health (Cavallo et al., 2014), isolation (Seo, Kim, & Yang 2016), fertility problems, and emotional support (Malik & Coulson, 2008) as well as peer support for dealing with fertility information (Grunberg et al., 2018). All these research areas demonstrate that the purpose of a support group is not only to provide knowledge, but also to provide assistance in other aspects of the patient's life. A recent study by Wilson et al. (2022) demonstrated how digital technology and social media, which formerly concealed and separated women, may now enable them to assist not only themselves but also those in their immediate vicinity. For example, WhatsApp communities provide a secure and friendly environment for women with endometriosis to fulfil their varied support needs by interacting with like-minded individuals and sharing disease related information.

The literature on women's social media health support group has so far focused on the three roles of social media support which: (1) facilitates communication between individuals with comparable conditions to recognize, share, and manage their illnesses; (2) allows patients to access medical-related health information without constraints in this age of modern technology; and (3) helps patients to better understand other's feelings and analyses how well this support system has integrated into their life (Frost & Massagli, 2008; Coulson, 2005). Nonetheless, an endometriosis-specific systematic review has not yet been conducted (Holowka, 2022). Therefore, a comprehensive evaluation of Facebook-based social support studies would provide future research with a useful analysis of the literature, methodology recommendations, and areas for future research for women with endometriosis seeking assistance.

Given the issues discussed thus far, this review examined the literature on social media with a focus on Facebook as a social support for endometriosis patients. Specifically, it attempts to answer: (i) What is the efficacy of Endometriosis Facebook support groups and (ii) What are the types of support given by Endometriosis Facebook support groups?

2.0 LITERATURE REVIEW

2.1 Online Health Support Groups and Illness Management

The best way to conceptualize social support is in terms of four broad ideas: emotional support (providing comfort and showing affection), instrumental support (providing aid in the form of goods and services), informational support (providing aid in the form of practical, problem-solving advice or feedback), and appraisal support (providing information and feedback that is useful in self-evaluation (Zhang, 2017). Support groups and social media give patients a sense of direction about their condition without judging, misinterpreting, or shaming them. Support groups on Facebook, Instagram, Twitter, and WhatsApp may improve patients' experiences (Wilson et al., 2022).

Social media support for cancer patients offers positive social support, provides illness-related materials and provides patients with a pleasant information search experience (Ahlberg & Nordner, 2006). Similarly, according to Sormunen et al. (2020), chronically ill people may receive different types of social support depending on the form and content of their networks. The study revealed that users' interactions were based on knowledge, emotion, and community building, which are key elements of health care (Wright, 2000). Therefore, more research is needed to determine what types of information and support lead to pleasant online experiences and how health professionals may help patients avoid negative experiences.

Endometriosis patients need constant attention and support. Managing the condition might cause stress and other health issues. In fact, many women do not seem to have any kind of support or sympathy, and feel alone and isolated (Jones, Jenkinson, & Kennedy, 2004). According to Cox et al. (2003), Matkovic, Manderson, and Warren, (2008), some of these women are reluctant to talk about their illness for fear of being stigmatized, ashamed, or disbelieved (Gilmour et al., 2008). In particular, menstruation is a taboo subject in many Asian cultures and because of this, many women feel isolated and try to conceal their condition, pain, and suffering from family, friends, employers, and medical practitioners. However, various research (e.g., Cohen & Wills, 1985; Kamarck, Manuck, & Jennings, 1990) have shown that social support reduces health-related stress and improves thinking.

2.2 Social Network Sites and Women's Illness

The popularity of social media platforms in general has grown, with Facebook approaching 2.936 billion monthly users. Facebook and other social media platforms allow community members to join groups with similar interests or experiences and learn about their needs (Nadkarni & Hofmann, 2012; Oh et al., 2013). Several studies (e.g., Jones et al., 2004) have

shown that these platforms are used to shape and understand expectations, provide knowledge about various illnesses, and depict how people with chronic illness manage their health needs. In addition, a considerable body of research has examined Facebook as a mechanism for increasing social support. With over 1.74 billion people accessing Facebook via mobile devices, Facebook has become a mainstay in developed countries. It is interesting that Facebook has been used as a platform to support women with chronic pain and illness via online social support groups. These groups do not only provide social support for their members, but also access to patients' lived experience with treatments and therapy.

Several studies have shown that online support groups are becoming more popular as patients turn to the Internet for health information and support (e.g., Sormunen et al., 2020; Li et al., 2018; Malik & Coulson, 2008). Patients use online social media support groups to seek advice on current medical practices and explore the internet for new findings and disease information, which is available 24/7 and helps them understand their ailment (Sormunen et al., 2020). A recent study by Avery et al. (2020) found that online polycystic ovary syndrome (PCOS) support groups gave women new opportunities to connect and learn. This study found that PCOS women seeking socio-emotional support online were more likely to receive it than those seeking informational assistance since the internet is convenient, confidential, and accessible.

Needless to say, support groups allow women to safely engage in a discussion about delicate topics. Hence enhancing personalized awareness of experiences that impact women, such as self-esteem, body image, treatment trauma, and physical/sexual abuse, which increases the speed and efficiency of therapy. By joining a same gender support group, an individual gets acceptance, respect, and empowerment.

3.0 RESEARCH DESIGN

This paper examines recent studies on social media health support groups for women with Endometriosis using an approach known as "qualitative systematic literature review". A systematic review is a scientific strategy for learning and understanding a specific topic. It has aided researchers in identifying and filling research gaps, as well as identifying patterns in the current study. The purpose is to manage relevant data that fits particular criteria in order to answer a research question. The systematic review in this paper focuses on publications indexed in several reputable databases to provide a comprehensive picture of the social media support group in the last twenty years. It adheres to Moher et al. (2015) reporting items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P).

3.1 Systematic Literature Review

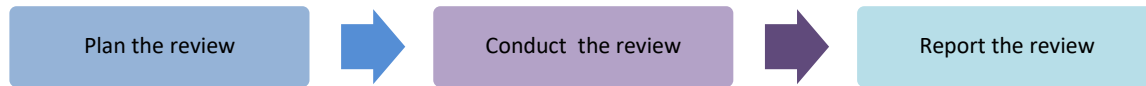We divided the review into three parts based on the PRISMA-P statement as shown in Figure 1:

Plan the review ➤ Conduct the review ➤ Report the review

Figure 1: Three stages of PRISMA-P Statement

3.1.1 Planning the systematic review

A comprehensive search of reputable databases such as Research Gate, Springer, Wiley Online Library, Science Direct, Jstore, and PubMed was carried out to locate research articles for the review. Google scholar, in addition to other databases was also used to find related studies, these databases were chosen because they are regarded as one of the most comprehensive bibliographic and full-text electronic libraries of science, technology, and medicine. The topic area of this review has a surprisingly limited number of papers; hence, using only one database may limit the research findings in this field. Incorporating the six databases will ensure that as many relevant studies published in the related area will be found. This methodological approach is required to ensure not only that related research publications within the subject of this study are examined, but also to minimize researcher's bias.

3.1.2 Conducting the systematic review

Conducting a systematic review helps researcher in gaining recognition of their credibility for achieving the mission of fact-finding and fact-checking in the search. The number of credible sources quoted the greater the validity and reliability in the eyes of the readers. In this phase, there are three primary stages: Stage 1: Searching and Scrutinizing, Stage 2: Applying the Inclusion and Exclusion Criteria/Checking Eligibility of Papers, and Stage 3: Excluding Duplicates & Examining the Papers/Removing Duplicates, as seen in Figure 2.

Databases
Wiley Online Library
Research Gate
Springer
Jstore
Science Direct
PubMed

Search Terms
Health Communication; Women Health Research; Social Media Online Support; Endometriosis

Stage 1: Searching & Scrutinizing Results: 200 Papers

Limits

a. Time frame from 1998 to 2022
b. Endometriosis-related scholarly articles concerning support groups on social networking sites.
c. Accessible in abstract
d. Title and abstract criteria for inclusion in the area of analysis

Stage 2: Applying the Inclusion and Exclusion/Inclusion Criteria/Checking Eligibility of Papers
Results: 100 Papers

Inclusion Criteria:

a. Abstract or full text
b. Complete study or a literature review paper
c. Support system via social media for women with endometriosis
d. Available articles

Exclusion Criteria:

a. The effects of endometriosis on family and partners
b. Doctor Patient relationship in communicating online
c. Articles Editorial

Stage 3: Excluding Duplicates & Examining the Papers/ Removing Duplicates
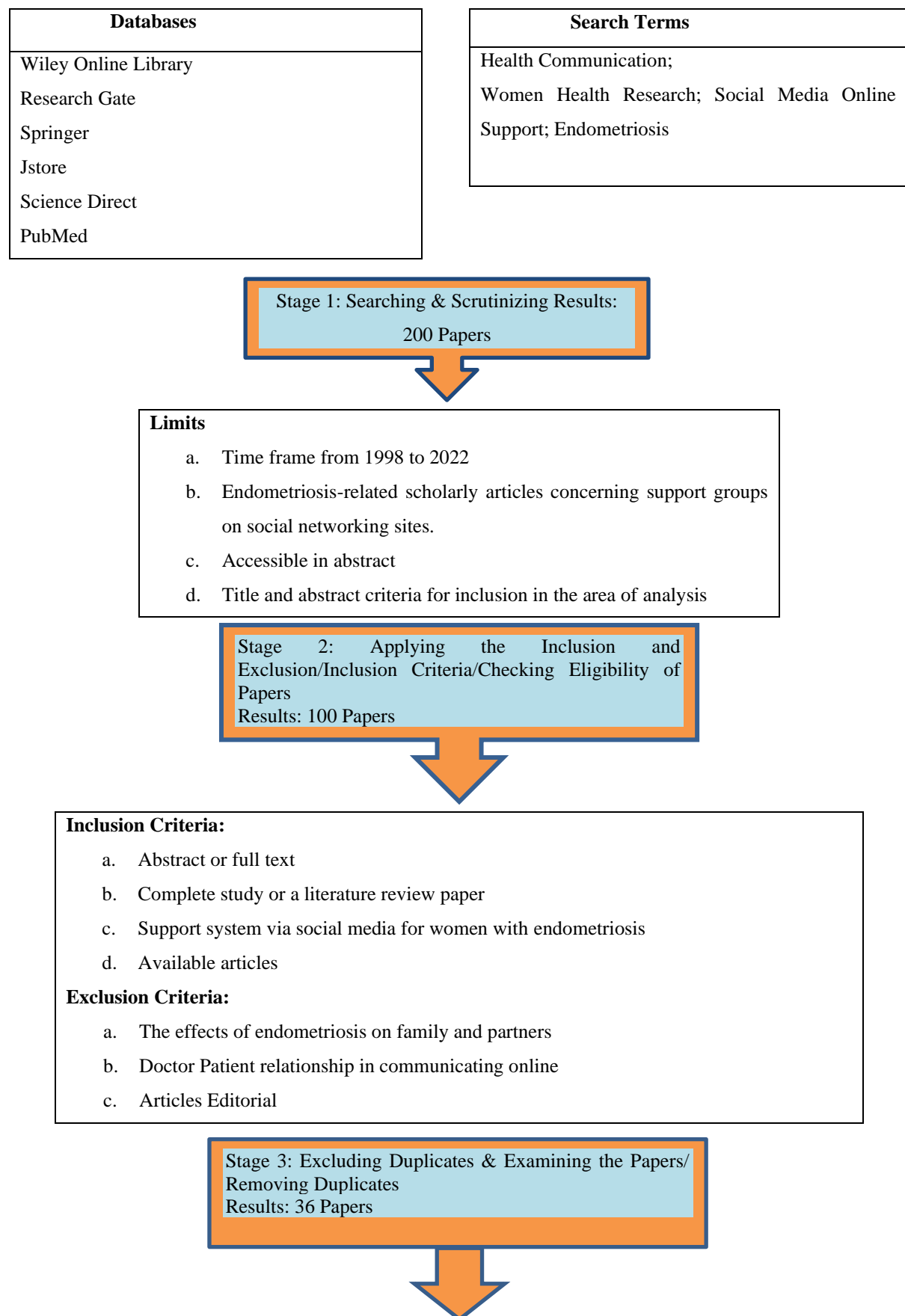**Results: 36 Papers**

Figure 2: Systematic literature review procedure

Inclusion and exclusion criteria are necessary to ensure relevant papers are selected, while establishing the parameters for the systematic review, ensuring uniform and protocol-based searches. The inclusion criteria ensure the objectivity of the article selection, and the exclusion criteria define the eligibility of the items. Only endometriosis-related scientific works about social networking support groups and their relevant contexts were reviewed. This corresponds to the articles' research objective and methodology.

3.1.3 Conducting the systematic review

After carefully reviewing the relevant papers, classifying them, and removing duplicates, the search results were reduced from 200 to 100, and then further scrutinized to only 36 articles. Before selecting the articles, keywords in the title and abstract were manually examined. The results were carefully recorded in this paper's review. Table 2 shows the selected studies chronologically from the earliest to the most recent year of publication.

Table 2: Summary of the selected studies in chronological order

No.	Author	Year	Area & Objective of Research	Data Collection Method	Results
1	Whitney	1998	To evaluate social support as a coping technique for endometriosis.	Survey was developed to inquire into participants' interactions within social support on internet	Participants wanted their support network to understand endometriosis, symptoms, and them. .
2	Preece	2001	To determine what makes online communities social and usable.	User satisfaction surveys, heuristic evaluation, walkthroughs, and ethnography used to test usability.	Determinants and measures are chosen by usefulness and sociability. Data users determine metrics.
3	Cleak & Howe	2004	To study later life health and social networks.	Survey was developed to comprehend the relationship between their health status and their social networks.	Elders benefited from supported housing and information but social support couldn't help elderly with serious health concerns.
4	Coulson	2005	To examine socially beneficial communication in an IBS support network via computer.	Using deductive thematic analysis,	Support received in symptom interpretation, illness treatment, and health care professional involvement.
5	Gao et al.	2006	A systematic literature review on endometriosis' effects on adult and adolescent HRQL.	Comprehensive review of 1999-2006 research	Endometriosis impacts HRQL in pain, psychological, and social areas.
6	Ahlberg and Nordner	2006	To determine the impact of support	Data were gathered through semi-	Shared experience ruled. Trust,

			group participation on women newly diagnosed with ovarian cancer. .	structured interviews and analysed using grounded theory.	openness, and flexibility were noted.
7	Arora et al.	2007	To investigate the helpfulness of information, emotional and decision making received by women with breast cancer	Patients survey- Post diagnosis and post baseline	Diagnosis reduces assistance. Support helps cancer sufferers cope.
8	Pickles et al.	2007	To evaluate prostate cancer active surveillance men's psychological needs and barriers.	analysed and evaluated studies on this topic that have been published in since 1994	Psychosocial issues include fear, uncertainty, and a lack of patient support, especially during treatment planning.
9	Malik and Coulson	2008	Examine a men's online infertility support group bulletin board to learn about their experiences and needs.	Inductive thematic analysis of 728 messages	Online social support, partner relationships, reduced isolation, information, empowerment, and unfavourable communities were observed.
10	Gilmour, Huntington, & Wilson	2008	The effect of symptomatic endometriosis on women's social and working life.	Feminism approach. The data from 18 women was analysed thematically.	Nurses can help women with endometriosis by thoroughly assessing them and sending them for diagnostic tests.
11	Frost & Massagli,	2008	To examine how online platform- "PatientsLikeMe" users reference personal health information in	A qualitative analysis of 123 comments	123 community answers (2%). Data was used to discover similar people to answer health questions,

			patient-to-patient conversations.		give disease-management recommendations, and create relationships.
12	Bulletti et al.	2010	To understand Endometriosis and infertility	Randomized controlled trials to show how well different treatments work.	Surgery and IVF-ET are the best treatments for infertile endometriosis patients.
13	Tunin, Uziely, and WoloskiWruble	2010	To evaluate how well women with first-degree relatives with breast cancer are informed and supported.	156 women participated. Information was gathered via questionnaires	Disease prevention information trumped support. Information was better than help. Doctors advised most.
14	Nadkarni & Hofmann	2012	To review the literature on Facebook use.	Searched PubMed, PsychInfo, and Cochrane Library for Facebook-related articles.	Facebook use is driven by two basic social needs: belonging and self-presentation.
15	Johnston, Worrell, Gangi, & Wasko	2013	To examine how online health communities, give knowledge, social support, and indirect patient empowerment.	Interviews with moderators of 18 online health groups and a field survey of 153 members were used.	Online health community participation offers information, support, and patient empowerment.
16	Cavaggioni et al.	2014	To examine if endometriosis causes psychiatric disorders, psychopathological symptoms, and alexithymia in Italians.	37 Italian patients with surgically proven endometriosis and 43 controls without clinical and ultrasound symptoms were studied.	Endometriosis causes mood, anxiety, alexithymia, OCD, and sorrow.

17	Indian & Grieve	2014	To determine if Facebook social support predicted subjective well-being better than offline support in socially anxious and non-anxious people.	Two hundred and ninety-nine Facebook users were samples of the investigation	Social support predicted well-being in low- and high-social anxiety groups.
18	Cavallo et al.	2014	To investigatee social support & post-exercise social support (esteem, informational, companionship) from Planned Behaviour Theory.	data from a randomized controlled trial and134 female undergraduates participated in the study.	Physical activity was balanced by social support. Companionship and self-esteem may boost physical activity in this demographic.
19	Andreassen	2015	To explore online social network site (SNS) addiction	Comprehensive Review& Questionnaire	The empirical database on SNS addiction, particularly in youth, is limited.
20	Frison & Eggermont	2016	To understand the links between Facebook use, online social support among male and females handling depression	Developed a complete Structural Equation Model that (1) separates Facebook use, (2) examines perceived online social support as a mediator, and (3) analyses adolescent users' gender.	Facebook affects adolescent sadness differently. Gender matters in indicated interactions, as perceived online social support impacted girls' bad mood and active Facebook use.
21	Huang	2016	To study endometriosis and mental disorders' temporal relationship (depression and anxiety disorders)	From 1998 to 2011, Taiwan National Health Insurance Research Database tracked 10,439 endometriosis patients and age-	Later-life depression and anxiety increased with endometriosis.

				/sex-matched controls.	
22	Seo, Kim, &Yang	2016	To identify temporal link between Endometriosis and mental problems (depression and anxiety disorders)	Matching crawled data with self-reported data from mobile Facebook users	Friends on Facebook benefit. The study demonstrated that social connection and friends' feedback matter.
23	Mirabolghasemi & Iahad	2017	To examine cognitive, social, and technological variables affecting cancer patients' Facebook performance (SCT) using Social cognitive theory framework	Questionnaires to 178 breast cancer patients in Peninsular Malaysia support groups.	SNS performance improved with support, anticipation, and self-efficacy. It supports cancer patients' social networks. Meeting patients' needs saves money.
24	Barak, Boniel-Nissim, & Suler	2008	To review to understand participating in an online support group could foster personal empowerment	Review of quantitative and qualitative studies	Online support groups improve self-esteem, relationships, and feelings. Online support groups may encourage problem-solving. Participation can cause online addiction, loneliness, and unhealthy habits.
25	Grunberg et al.	2018	To determine infertile patients' interest in online peer support, associated factors and preferred features.	4 Ontario and Quebec clinics treated 236 men and 283 women. An anonymous online questionnaire assessed	Online support groups promote self-esteem and well-being. Infertile couples benefit from online peer support models.

				demographics, perceived stress, fertility, and online infertile peer support interest.	
26	Li et al.	2018	To focus on factors that influence social media users' health information seeking and sharing.	A net valence model was based on social support theory and e-service adoption. Italy and China tested it.	Digital fluency affects social media engagements, enjoyment, and information demands but promotes social network expansion.
27	Palant & Himmel	2019	To understand and describe possible negative effects of social support.	narrative interviews	Conflict arose. The overwhelmed resented social support. Some interviewees stopped talking about their illness.
28	Gundi & Subramanyam	2019	To investigate menstrual health communication among Indians	Semi-structured 21-boy/21-girl interviews, 12 key-respondent interviews, and 1421 Nashik, India youth cross-sectional survey. Qualitative data.	Teen menstruation taboos varied socially. Girls' menstruation was discouraged. Menstruation communication neglected boys more than girls.
29	Sormunen et al.	2020	To explore the role of social media for infertile people.	Quantitatively and qualitatively. Infertility and social media survey responses totaled 132.	Infertility forums provide support and information on fertility treatments.
30	Roystonn et al.	2020	To assess the prevalence of online support group's use and factors related with it.	Online mental health support groups interviewed 18-year-old Singaporeans using	Online mood and anxiety support groups may improve treatment. Online mental

				the WHO Composite International Diagnostic Interview 3.0.	health support helps youth.
31	Avery et al.	2020	To look at how group leaders provide women with emotional, social, and informational support.	The study analysed 15 full-text papers about PCOS women and support organisations.	Support groups improve evidence-based information for healthcare professionals and professional associations.
32	Krsmanovic and Dean	2021	To investigate how women, reveal endometriosis at work	open-ended survey	Frequency, location, openness, content, and dialogue partner determine workplace endometriosis disclosure. Openness in the workplace was surveyed.
33	Marki, Vasarhelyi, & Rigo	2022	To understand patient self-management, social support, and the needs of patients in handling enodometriosis	Focus group interview	Social support, doctor-patient care, and active coping solved difficulties. Ecological health promoted women's needs.
34	Van den Haspel et al.	2022	To investigate the usage of social media (SM) by endometriosis patients as a self-management tool.	100 endometriosis sufferers participated. Survey Monkey used frequency counts, cross-tabulation, descriptive statistics, and semantic thematic	76% used health social media. Younger SM users reported six-month pelvic discomfort, greater endometriosis symptoms, and psychological

				analysis to analyse free-text responses.	impairment. SM rose 76%.
35	Wilson et al.	2022	To analyse women's experiences with Using "MyEndosis" WhatsApp group as a case study	Using inductive thematic analysis & qualitative interview.	WhatsApp may benefit endometriosis patients. Studies reveal that social media can help lonely and isolated women help themselves and others.
36	Holowka	2022	To identify endometriosis patients, utilise social media to understand, experiment with, and navigate their symptoms.	Surveys and interviews	Social media helps endometriosis patients and clinicians learn.

After identifying, extracting, and summarizing the publications, two relevant key areas were discovered: (1) the efficacy of virtual Support Communities for Endometriosis Patients and (2) types of support women received from social media support groups. To identify the gap and draw conclusions, 36 studies were chosen from the following years: 1998, 2001, 2004, 2005, 2006, 2007, 2008, 2010, 2012, 2013, 2014, 2015, 2016, 2017, 2018, 2019, 2020, 2021 and 2022.

4.0 RESULTS

The 36 articles selected for the systematic review were published between 1998 to 2022. The 24-year period search is adequate to observe recent research trends on social media support for women with endometriosis, specifically in the context of health and fertility. Seven key themes of online support for women with endometriosis were found as illustrated in Figure 3.

4.1 Themes Derived from Research on Support Groups on Social Media Platforms

Various themes emerged from the careful reading of the selected 36 research papers on social media health support groups for endometriosis patients. The seven themes are presented in Figure 3.
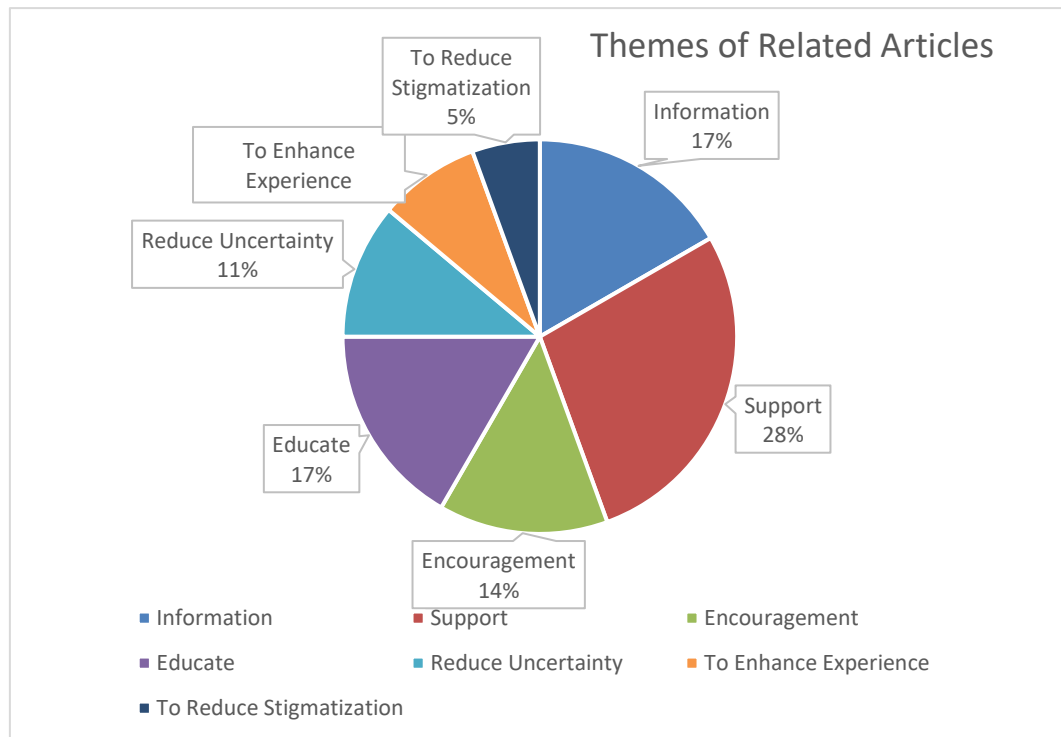

Figure 3: Themes of related articles

28% of research publications indicate that receiving support is the main reason to join a social support group. Followed by Information and Education Seeking with 17% respectively. Encouragement 14%, Reducing Uncertainty 11%, Enhancing experience 8%, and reducing Stigmatization 6% respectively. Overall, the number of publications on endometriosis support groups revealed the important reasons why women seek illness-related support groups. The finding is similar to many social network researchers Wilson, Mogan, and Kaur (2020); Coulson (2005); Moradi et al. (2014); Sormunen et al. (2020) suggest chronically ill people may receive different types of social support depending on the form and content of their networks. This pattern encourages researchers to include more social support studies in women's health settings in the future.

4.2 Main Findings

4.2.1 Examining the efficacy of virtual support communities for endometriosis patients

Over time, research on social support groups on platforms like Facebook has used numerous methods to construct, analyse, and evaluate their efficacy in patients' lives. Figure 4 shows a summary of how these platforms were efficient in providing support for Endometriosis patients. The 36 selected articles had overlap in the above-mentioned efficiency of Endometriosis support group.
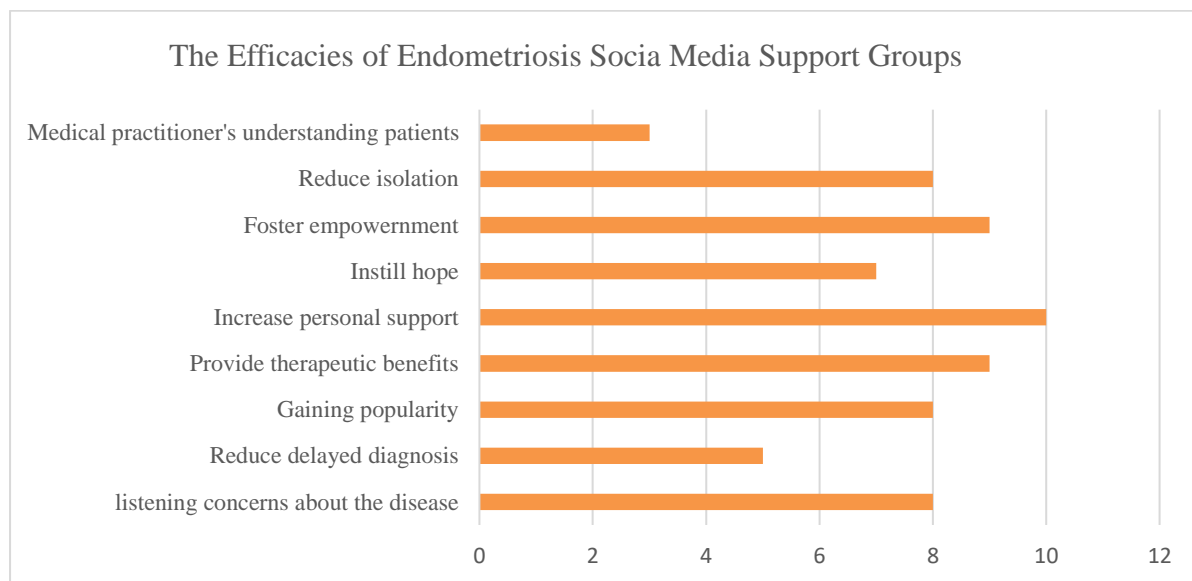

Figure 4: The efficacies of endometriosis social media support groups

4.2.2 Enhancing understanding among medical practitioners

Figure 4 outline ways in which social media support groups for endometriosis patients enhances understanding. Medical practitioners improved understanding of patients' needs will help them to better connect with patients and provide them with suitable treatment and support (Marki, Vasarhelyi, & Rigo, 2022). Many physicians and nurses are unaware that user interactions were oriented around knowledge, emotion, and community building (Wilson et al., 2020). Endometriosis support group in Malaysia, for example, was designed as a social network in which peers offer support, establish friendships, and exert cultural interactions (Wilson et al., 2020). Thus, several support group members reported using them not only for emotional but other kinds of support. Three reviewed articles showed that researchers, doctors and nurses must be more aware of patients' diagnosis but also their needs.

4.2.3 Reducing isolation

Online support groups can also reduce loneliness, empower, inspire optimism, and increase personal support (Malik & Coulson, 2008). This is evident in the review in which eight (8) articles made reference to support groups and their role in reducing isolation. The articles mentioned that support groups play a huge role in helping patients feel less lonely, increase social skills and have a better awareness about their diagnosis.

4.2.4 Fostering empowerment

According to Barak (2008), online support group membership and outcomes may increase personal empowerment. These personal experiences can emerge through writing, which provides an emotional outlet, conceptual understanding of the disease, emotional relief, knowledge sharing, and interpersonal relationships. Out of 36 articles reviewed, nine (9) mentioned how social support groups play a role in empowering patients.

4.2.5 Instilling hope

Social support is viewed as a coping mechanism that instils patients with optimism over their illness management (Whitney, 1998). Similar to a community that provides both comfort and hope, these social support groups enable patients to share their stories and experiences, while other patients sympathise and offer hope, particularly to women with infertility. Seven (7) articles reviewed indicated the value of social support as a coping strategy (Whitney, 1998).

4.2.6 Increasing personal support

The benefits of social support groups in enhancing personal support for patients was discussed in ten articles. Participating in a support group surrounds patients with others who share similar sickness or illness experiences. Mutual understanding among support group members is crucial and helps to diminish loneliness, worry, despair, and exhaustion from managing illness alone. It is clear from these studies, meeting people with similar difficulties helps to boost personal support (Coulson, 2005).

4.2.7 Providing therapeutic benefits

According to the data shown in Figure 4, nine (9) publications assert the therapeutic advantages received by patients online. The four therapeutic benefits of online support groups, according to Shoebotham and Coulson (2016), are (1) the ability to connect, which allows people to share advice, confide in someone, and lift their loneliness; (2) the capacity to learn, which comes

with the ability to connect; (3) the ability to communicate their stories and read about others' stories; and (4) the ability to self-present.

4.2.8 Gaining popularity

According to the review, about eight studies revealed that support groups are gaining popularity. Many of these groups were founded on the idea that people going through similar struggles could help each other (Coulson, 2005). Patients' symptoms and concerns may accompany other gynaecological or non-gynaecological disorders including pelvic inflammatory disease, irritable bowel syndrome, and adenomyosis. Endometriosis, on the other hand, is a chronic disease with unrelated stages and symptoms. It is also underdiagnosed, underreported, and understudied (Gao et al., 2006). Therefore, there is a pressing need for further research to be conducted on endometriosis support groups in order to gain a better understanding of the condition from the patient's point of view.

4.2.9 Reducing delayed diagnosis

Delays can be caused by failing to order a diagnostic test, establish a differential diagnosis, or obtain and assess pertinent clinical information. Nine (9) or 25 percent of articles reviewed, discussed how these support groups are overcoming delayed diagnosis which can bring negative impact on patients' health. Surveys and interviews from the research conducted shows that people with endometriosis utilise internet to understand, experiment with, and navigate their symptoms (Marki et al., 2022). Researchers and practitioners should recognise these efforts since patients are gaining knowledge and understanding of their ailment through Internet and social media, which lowers delayed diagnosis.

4.2.10 Listening to others' concerns

Listening to patients' complaints is also important in improving the efficacy of these platforms. Eight (8) articles reviewed revealed that people want to discuss their health concerns. Cleak and Howe (2004) discussed the interaction between patient health, health status, and social networks, which affects informational and emotional decision making to manage sickness and the management of a recently diagnosed illness (Ahlberg & Nordner, 2006; Aurora et al., 2007).

4.2.11 Types of support women receive on social media support groups

The data below shows types of support that women receive from social media support groups specifically for endometriosis patients:

Types of Support
Moral Support
Educational Support
Assistance support
Emotional Support
Informational Support
Community Building Support
Esteem Support
Network Support
Tangible Support

Figure 5: Types of support

Different online support groups help women in different ways (Sormunen et al., 2020; Wilson et al., 2020). People often talk about their medical treatments and medications on their Facebook walls, with some even mentioning names of specific medications (Wilson et al., 2020). In addition, members of social support groups may provide information on medications and procedures (Coulson, 2005). For instance, people who participate in infertility forums gain access to knowledge regarding fertility therapies and emotional support as they work through the challenges of dealing with infertility (Sormunen et al., 2020). According to Coulson's (2005) paradigm, five types of assistance help patients deal with the debilitating effects of their illness: (1) emotional support, (2) esteem support, (3) information support, (4) network support, and (5) tangible support. Indeed, Malik and Coulson (2008) discovered four primary motivations for requesting online assistance: (1) the support is available 24 hours a day, seven days a week, (2) the anonymity of online contact allows for free discussions of feelings and support, (3) candid and very personal conversations of sensitive, difficult, and negative situations and emotions, and (4) a focus on women's experiences.

Fertility may affect patients experiences and support needs. For example, endometriosis patients may begin treatment with little knowledge of the processes involved, such as multiple surgeries, medication, dietary concerns, the search for a skilled gynaecologist, efforts to conceive, the latest medical interventions, and many other related concerns, and they may want

to talk to other patients who have similar experiences. Our findings also echo the research by Grunberg et al. (2018) in which patients seeking infertility treatment expressed interest in mobile peer support that allows for monitored peer-to-peer communication and access to fertility-related information.

Several studies have shown that Facebook (FB) is an effective platform with many benefits, such as the ability to reach a hidden segment of the population for improved health care interventions. Increasing trends in online health-seeking behaviour among the public have been discovered in published literature and local surveys in Malaysia (Zhao & Zhang, 2017). These findings show that Facebook is a unique online platform that helps people form support groups that provide moral support, knowledge, and help in dealing with disease and communication issues. To the researcher's knowledge, no study to date has examined Malaysia's Endometriosis Online Support Groups. This review allows women to discuss their condition online without fear or prejudice. Empowering Malaysian women facing infertility and creating online support groups could improve patient-provider communication.

5.0 CONCLUSION

This paper provides a comprehensive evaluation of research on social media support groups for women with endometriosis in a variety of health settings from 1998 to 2022. There were 36 publications examined, covering a wide range of topics related to online female communities. Researchers have studied the effectiveness of social media support groups for women with endometriosis and the different forms of support these women have received in recent years (2018-2022). The study reveals seven prevalent themes derived from the 36 articles, with the top three being, (1) support, (2) information (3) education pillars for endometriosis patients being in an online support group.

It also investigated the efficacy of these online support groups and found that these groups are efficient in (1) increasing personal support (2) providing therapeutic benefits and (3) fostering empowerment. The types of support give researchers an idea of the kind of support is available for this patient. We believe that this study will help inform other researchers about the gaps in the current research and help them better position their future investigations. The paper suggests more research on social media support groups for women's illnesses, especially infertility, using mix method research to analyse more women's groups and examine their role in allowing women to discuss their illnesses online without fear of repercussions. Empowering Malaysian infertile women and creating online support groups could improve patient-provider communication.

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