

RESEARCH ARTICLE

Barriers to self-management of patients with adenomyosis: A qualitative study

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Abstract

Aim: This study aims to explore the barriers to self-management of patients with adenomyosis.

Design: Phenomenological qualitative methodology.

Methods: Totally, 18 patients with diagnosis of adenomyosis participated in this study. We used purposive sampling for recruitment until data saturation. A qualitative research was conducted using in-depth interviews, which were tape recorded and transcribed verbatim. Colaizzi's method was used to analyse the contents of interviews.

Results: This study presented important information about the barriers to self-management of patients with adenomyosis in China. Four themes were identified: "lack of disease knowledge," "challenges and dilemmas of daily life," "multidimensional negative emotions" and "personalized supporting requirements."

Conclusion: The study provided new insights into the barriers to self-management of patients with adenomyosis, including physical, psychological, daily life and self-image problems, and the patients need emotional and social support, which recommended that professionals should provide authoritative health education and multiple support.

KEYWORDS

adenomyosis, Chinese women, nursing, qualitative research, self-management

1 | INTRODUCTION

Adenomyosis is a benign gynaecological disease characterized by the presence of ectopic glandular and stromal tissues in the myometrium (Yeh et al., 2018). Its pathogenesis remains unclear (Li et al., 2018; Orazov et al., 2017). The prevalence of adenomyosis varies among different ethnic groups, ranging from 5% to 70% (Taran et al., 2013). Reports show that approximately 20% of adenomyosis patients are less than 40 years old, whereas 80% are between 40 and 50 years of age (Harada et al., 2016). The major clinical manifestations of adenomyosis include menorrhagia, dysmenorrhea, infertility, chronic pelvic pain and enlarged uterine volume (Bergeron et al., 2006; Farquhar & Brosens, 2006). Multiple treatments have

been recommended, including hormone therapy, traditional Chinese medicine treatment (CMT), surgery, interventional radiology, minimally invasive therapy and high-intensity focused ultrasound (HIFU) (Streuli et al., 2014; Vannuccini et al., 2018; Zeng & Li, 2017; Zhou et al., 2011). Hysterectomy is the only definitive treatment to cure adenomyosis (Abbas et al., 2020); however, it is unacceptable for those young patients who want to keep their fertility.

2 | BACKGROUND

Chinese folk culture has historically regarded adenomyosis as "undead cancer," because patients generally suffer from physical and

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mental dilemmas with it. Adenomyosis is a chronic active disease, no matter what treatment is given, patients are always at risk of recurrence, especially for young, conservative patients. Management of chronic diseases needs active participation of patients, and self-management represents the cornerstone during the treatment of adenomyosis. Self-management is stated as "engaging in activities that protect and promote health, monitoring and managing symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes in partnership with health professionals and community resources." (Gruman & Korff, 1996). Studies have revealed that good evidence has significantly improved health outcomes by adopting self-management strategies, including reducing hospitalizations and service demand, improving consumer and clinician satisfaction, et al (Ryan & Sawin, 2009).

However, numerous adenomyosis patients experience multiple barriers to effective self-management, an understanding of the experience of patients with adenomyosis could thus help in the identification of targeted nursing strategies, provide better quality self-management education and support for this particular ethnic population. The purpose of this study was to conduct qualitative interviews and explore the barriers to self-management of adenomyosis in Chinese patients.

2.1 | Research question

The aim of this study was to analyse the barriers to self-management the patients with adenomyosis have when they are diagnosed, in order to provide targeted nursing intervention to improve the quality of life of patients. The research question was: "what barriers to self-management do patients with adenomyosis have and what requirements do they want?"

3 | METHODS

3.1 | Design

The study was undertaken from August 2018 to March 2019, which was qualitative descriptive research using Colaizzi's phenomenological approach (Huang et al., 2019). In this study, a semi-structured in-depth interview was conducted to investigate the barriers to self-management of patients with adenomyosis.

3.2 | Setting and sample

This study was implemented at the gynaecology ward of Shanghai First Maternity and Infant Hospital, School of Medicine, Tongji University, Shanghai, China. There are 6 gynaecology wards in this specialized tertiary teaching hospital. Purposive sampling was used to ensure the recruitment of patients of diverse ages, education,

time of illness and history of birth. Patients were eligible to participate in this study when they met the inclusion criteria: Adenomyosis was diagnosed based on ultrasound or magnetic resonance imaging (MRI); Mandarin speaking; provided their informed consent and were willing to participate in this study; and age ≥ 18 . The exclusion criteria were as follows: withdrawal halfway through the study; have a history of mental illness; and communication disorders. The sample size was determined using the data saturation principle, that is when the information mentioned by the interviewees was similar to or repeated by another previous participant (Ding et al., 2015). When the 18th participant finished her interview, no new information emerged, and thus, the final sample size was 18.

3.3 | Data collection

The interview site was at the head nurse's office, which was arranged as a private and quiet room. The researcher explained the purpose, method and significance of the research to the participants and obtained informed consent prior to the interview. Each participant was regarded as a case in the study, who accepted a one-on-one, face-to-face, in-depth interview, and the duration of each interview was from 30 to 60 min.

The interview was conducted according to the semi-structured interview guide as follows: (a) When were you diagnosed with adenomyosis? (b) Can you describe your experience of the disease after diagnosis? (c) Does adenomyosis affect your daily life? If yes, how? (d) What barriers do you have to manage adenomyosis? (e) What kind of support would you want to receive after being diagnosed with adenomyosis? (f) Is there any other information you want to share with me? The participants were aware and agreed to have the entire interview recorded by audio. The interviewer began with an open question in Mandarin, encouraging every participant to express their barriers, experience, feelings and demands, and noting the participants' speaking tones, facial expressions, body language and emotion (Polit & Beck, 2008).

3.4 | Data analysis

The tape recording of each interview was transcribed verbatim into Chinese 24 hr after the interview. The descriptive phenomenology method was used for data analysis based on Colaizzi's seven steps including First, the researcher read and reread all statements to identify and understand the phenomenon. Second, meaningful statements were derived from marking phrases and sentences. Third, a restatement with a general form was conducted from a meaningful statement. Forth, an attempt was made to identify similar statements at the stage of deriving the meaning formed from the meaningful statement and the restatement. Fifth, after integrating analysed contents, a final description was made through a collection of topics and categories that symbolized the essential structure of the research phenomenon. Sixth, an attempt was made to

describe the phenomenon as accurately as possible with a complete description representing the essential structure. The most appropriate statement describing the topic as a quotation was then selected. Seventh, seeking verification of the fundamental structure (Amiresmaili et al., 2019; Lee, 2021). An expert in qualitative research reviewed the process. Participants' quotes were translated into English by a bilingual investigator (Chinese and English). We used consolidated criteria for reporting qualitative studies (COREQ) checklists for methodological quality assessment.

3.5 | Ethical considerations

The study was approved by the ethics committee of Shanghai First Maternity and Infant Hospital, School of Medicine, Tongji University, Shanghai, China (Approval number 2018–[29]), which was based on

the principle that the investigation is voluntary, confidential and harmless. The participants signed the informed consent prior to participation in the study. Participants could withdraw at any time without any explanation, and their participation in the study would not influence their treatment and nursing care. All the information on the participants was treated confidentially.

4 | RESULTS

The age of the study participants ranged from 27 to 50 years, and the mean age was 38.89 ± 5.76 years. Their duration of illness was from 2 to 13 years, and the mean duration was 6.00 ± 2.57 years. Other demographic characteristics of the participants in this study are shown in Table 1. Data analysis identified four themes. One common feature of the themes was that almost all the participants did not

TABLE 1 Demographic characteristics of the participants

Patient	Age (years)	Educational background	Employment status	Duration of illness (years)	Marital status	History of childbirth ^a
N01	42	University	Staff member	4	Married	1-0-0-1
N02	37	University	Teacher	5	Married	1-0-0-1
N03	50	University	Manager	5	Married	1-0-2-1
N04	42	University	Teacher	6	Married	1-0-2-1
N05	37	College	Freelance	10	Married	2-0-2-2
N06	34	University	Staff member	8	Married	1-0-0-1
N07	43	High school	Staff member	6	Married	1-0-2-1
N08	27	Middle school	Waitress	2	Married	1-0-1-1
N09	44	University	Nurse	13	Married	1-0-1-1
N10	34	University	Staff member	5	Married	1-0-0-1
N11	34	University	Staff member	5	Single	0-0-0-0
N12	34	College	Staff member	7	Married	1-0-0-1
N13	42	College	Freelance	6	Married	1-0-1-1
N14	40	College	Salesperson	6	Married	0-0-3-0
N15	48	College	Staff member	4	Married	1-0-0-1
N16	33	Primary school	Freelance	3	Single	0-0-2-0
N17	41	University	Teacher	8	Married	1-0-2-1
N18	38	University	Staff member	5	Married	0-0-6-0

^aChildbearing History indicates term delivery–premature–abortion–survival.

Themes	Subthemes
Lack of disease knowledge	Insufficient understanding of adenomyosis Confusion of treatments
Challenges and dilemmas of daily life	Impact on quality of life Changes of appearance and original roles
Multidimensional negative emotions	Mood swings from adverse symptoms Concerns relating to future pregnancies
Personalized supporting requirements	Psychological support Social support

TABLE 2 Themes and subthemes of the study

fully understand the disease; thus, they blindly tried various treatments, with no statistically significant improvement. Aggravated symptoms affected their lifestyle and mental state, thereby increasing their need for additional patient support, for example psychological support AND social concerns. The details on the themes and subthemes are presented in Table 2.

4.1 | Theme 1. Lack of disease knowledge

This theme includes two subthemes: "insufficient understanding of adenomyosis" and "confusion of treatments."

4.1.1 | Insufficient understanding of adenomyosis

Most gynaecology patients and their family do not understand the term "adenomyosis." Since they lack knowledge of the disease, they do not know how to deal with adenomyosis:

Adenomyosis is not as popular as other common diseases such as fever. It is unintelligible. Actually, I have not heard of it.

(Participant No.12)

Because of the ignorance of disease, some patients are unable to recognize pathological clinical manifestations and complications:

At that time, I did not have the special feeling about the quantity of vaginal bleeding, because it was always too much when I was young, later I found that people around me did not look like this...

(Participant No.01)

Some patients who accept some treatments cannot recognize related abnormal conditions:

In order to relieve the pain, I used the Mirena (one kind of intrauterine devices, IUD), but within 2 years, it was becoming increasingly painful again, and the ring had dropped unexpectedly by B-ultrasound examination.

(Participant No.04)

All the participants want to obtain correct information to learn more about the disease, but most of them experience some trouble. They obtain disease information through the Internet, but it is difficult for them to distinguish whether the information is correct or not. Those participants who use misinformation suffer physical and psychological harm:

I have learned a lot from the Internet about my symptoms and joined various WeChat (is a Chinese

multi-purpose messaging, social media, and mobile payment app) (<https://en.wikipedia.org/wiki/WeChat>) chatting groups. Several treatments that were recommended on the Internet seemed effective. However, I was concerned with my economic loss and health damage caused by ineffective treatments due to a lack of professional judgment.

(Participant No.02)

Upon diagnosis, some participants do not know what treatment is appropriate for them and have no idea about the appropriate person to consult about the disease:

I was looking for the appropriate treatment in Shanghai, Guangzhou, and Zhengzhou to cure this disease. Finally, the doctors gave me one word, "remove," I really did not want to have my uterus removed (crying). I am still young...I have no children. Is there any other better way to treat this condition? I need the help of a doctor...

(Participant No.14)

4.1.2 | Confusion of treatments

Many participants have experienced ineffective treatments and have accepted the idea that various treatments are only temporary solutions and there is no radical cure for adenomyosis:

I have undergone basic treatments, including taking medications, using Mirena to reduce uterine volume, CTM, and folk prescriptions, but these were ineffective. Later, I chose HIFU. But I heard its recurrence probability could be relatively high.

(Participant No.05)

Participants are generally confused about how to relieve symptoms by self-management:

As the symptoms get worse, I have no idea how to manage it by myself in daily life.

(Participant No.11)

If all the treatments are deemed ineffective, then the removal of the uterus will be an alternative. However, in eastern conservative cultures such as that in China, the uterus is regarded as an important female feature and thus without it, a woman is incomplete:

Ninety percent of the doctors whom I've consulted have recommended hysterectomy, and my friends have told me that the uterus completes its role after delivery. However, I am a perfectionist, from the

bottom of my heart, I think, as a complete woman, no matter young or old, I should maintain the integrity of the body. For me, I think it's the best choice to keep my uterus, and I refuse to undergo a hysterectomy.

(Participant No.03)

4.2 | Theme 2. Challenges and dilemmas of daily life

This theme includes two subthemes: "impact on quality of life" and "changes of appearance and original roles."

4.2.1 | Impact on quality of life

Some participants cannot sleep well. The continuous pain or heavy bleeding compels them to get up, thus preventing them from getting good quality sleep:

...I would pace the living room and could not fall asleep at all when the pain was particularly severe... Out of exhaustion I would take a nap, then again be awakened by pain.

(Participant No.08)

During my cycle I experienced heavy bleeding like a waterfall...I used the longest sanitary napkin and put the towels on the bed to prevent blood from leaking. I would not dare sleep too early or too deep. I wake up once or twice during the night to change the sanitary napkin as routine; otherwise, I have to wash the sheets the next morning. Do you have a better way to change this status?

(Participant No.17)

Some young participants complain that complications of adenomyosis cause sexual dissatisfaction:

Using Mirena has resulted in longer vaginal bleeding that causes me to have a poor sexual life...I sometimes feel pain when we have sex...

(Participant No.10)

All the participants describe that they have suffered from progressive aggravated dysmenorrhea and menorrhagia, which have severely affected their normal social activities such as daily work, travel and social gathering:

I changed jobs last December, and my adenomyosis attack was particularly severe during the internship. The severe abdominal pain prevented me from going to work, and I had to ask for leave. I was diagnosed with adenomyosis, with complication of pelvic

inflammation. During every menstruation, I would have a fever and experience fatigue and pelvic pain. I could not work properly, so I asked for a two-week break during my probationary period.

(Participant No.01)

We had to cancel our planned trip to avoid the complications associated with my menstrual period. Now I don't even want to go out for leisure because after the end of menstruation, I still experience abdominal pain...it usually lasts for one to two weeks.

(Participant No.12)

4.2.2 | Changes of appearance and original role

During treatment, some participants have experienced adverse effects, which generally affect their external appearance:

After using Mirena, I got fat, I gained over 5 kilograms, just like a steamed stuffed bun. I was really at a loss how to get back in shape.

(Participant No.02)

My face developed red blotches while taking Drospirenone (a short-acting contraceptive), especially when basking in the sun.

(Participant No.06)

The participants have expressed that the symptoms of adenomyosis have resulted in emotional instability and poor working energy, making the patient's role change, being unable to undertake the original family and workplace responsibilities, thus impacting their relationship with family members, as well as their quality of work:

My husband is always very busy, and now he has to temporarily put his work aside to accompany me to the hospital. Um...my daughter, I cannot care for her either...it is impossible to give filial piety to my parents. In a word, I cannot play the role of a wife, a mother and a daughter, it has affected the quality of family life.

(Participant No.03)

When my abdominal pain is severe, I (as a teacher) can only go to class and ask students to do their homework, because I have no energy to speak.

(Participant No.02)

4.3 | Theme 3. Multidimensional negative emotions

This theme includes two subthemes: "mood swings from adverse symptoms" and "concerns relating to future pregnancies."

4.3.1 | Mood swings from adverse symptoms

The participants also indicate that having their monthly menstruation is stressful. They become nervous and anxious when their period comes. Sometimes, they cannot control their emotions, often affecting their family members and friends:

When I'm about to have my next period, I feel stressed out and anxious. I could not imagine how to go through those painful days...During my menstruation, my little son feels confused. Why is mum not speaking to me? Usually, during my period, I have mood swings, I could not control my emotions, even when dealing with my child, I often lash out at him.

(Participant No.05)

The participants often experienced awkward situations because they consider adenomyosis as a disgrace and thus most often chose not to disclose their disease to others:

Once I played Mahjong (a popular Chinese game) with my friends, when I stood up after sitting for hours, it (blood) went through my pants and onto the chair, how embarrassing I did not know how to explain what happened, because I always felt that it was a strange disease.

(Participant No.04)

The participants express despair and hopelessness because of endless and useless treatments, which merely cure the symptoms and not the disease:

Every month (during menstruation) I feel that I have lost my mind. I do not want anything, I do not want money, any high position...The pain is so intense that I would wish that I did not have to live like this, and I would just hit my head against the wall.

(Participant No.03)

4.3.2 | Concerns relating to future pregnancies

Participants who have no previous history of childbirth wish to become pregnant and at the same time are anxious that they could not provide a safe environment for the baby:

I have been trying to get pregnant for the past few years. I am so worried that the womb would not be a safe haven, if it harmed the baby.

(Participant No.18)

In addition, those who have had a child are worried whether they could have another child as recently allowed by China's Two-Child policy:

I want to have a second baby especially after the implementation of China's Two-Child policy. However, the doctor told me that the probability of abortion during my next pregnancy would be higher than that of normal women, so I am really worried and hesitant to get pregnant again.

(Participant No.09)

4.4 | Theme 4. Personalized supporting requirements

This theme includes two subthemes: "psychological support" and "social support."

4.4.1 | Psychological support

Participants who struggle with the disease are generally exhausted and are psychologically affected, thus requiring emotional support, particularly from their husbands:

A lot of men feel that most women have dysmenorrhea and it is normal. So, he (my husband) thinks that I just suffered from pain for five days. But I was so miserable and suffered for five days. I need my husband's emotional support, he is my spiritual comfort, and no one else can replace him.

(Participant No.02)

E.L. Trudeau has said "To Cure Sometimes, To Relieve Often, To Comfort Always." The professional medical staff always plays an important role in providing psychological support:

Sometimes when the patient is confused and helpless, her brain is abnormal. At this time, she needs the guidance of doctors and nurses as well as help in teaching self-management of symptoms and analysing the advantages and disadvantages of the treatment. When I stay in the hospital and see endless white walls, I cannot sleep at night. While the clock is ticking, I feel very lonely and feel as if I'm in prison. If the doctors or nurses could provide psychological care, maybe I would feel better. Therefore, psychological care and professional medical guidance would be very helpful to the patients.

(Participant No.03)

Some participants consider other patients as effective peer support, and they prefer to stay in the same ward and share their experiences on the disease and treatments:

I hope to stay in the same room with patients who have the same disease so we can talk about the disease. I would ask about their treatment and barriers, if they had Mirena, prophylactic, or HIFU. I will also share with them what I know so they do not have to receive ineffective treatments.

(Participant No.09)

4.4.2 | Social support

Adenomyosis is a disease that is not known to the public, so the participants appeal to strengthen the popular science propaganda of it in the community and workplace, so that more women can learn it and recognize it in time once there is abnormality:

The doctors and nurses can organize an event to provide medical information on adenomyosis to the community, working unit, and university and let the public understand.

(Participant No.12)

What causes adenomyosis? How do you prevent it? It would be helpful if this information was shared with young women so they could understand the severity of the disorder.

(Participant No.17)

Some participants advise that the hospital could provide a comfortable and quiet space for them to rest, which may also keep them preoccupied and decrease the chances of thinking about the disorder:

The hospital can create a relaxed environment. There are all these patients in the ward that make me feel that I am sick, just like them. It is better to provide a small room for patients to listen to music and watch TV, and possibly ease the anxiety that we feel when we are in hospital.

(Participant No.03)

The patients with adenomyosis who have undergone major suffering wish that society should take additional measures in caring for women:

I appeal to my employer to provide more healthcare benefits to female employees, including healthy women, by giving them a one-day holiday each month when they have their period. Having a day off each month would be helpful.

(Participant No.12)

5 | DISCUSSION

Chronic diseases are diseases that last for a long duration and progress slowly. Adenomyosis is obviously a kind of chronic disease. Self-management approaches are designed to assist patients and their families to better manage their own chronic diseases, and these programmes typically focus on symptoms recognition, self-monitoring and medication adherence, etc. The programmes benefit patients in terms of knowledge acquisition, performance of self-management behaviours, self-efficacy and overall health status as well (Barlow et al., 2002; Ha Dinh et al., 2016; Jonhson et al., 2008; World Health Organization, 2003). Qualitative studies on adenomyosis are limited (Nelsen et al., 2018). It is important to explore and understand the barriers to self-management of patients with adenomyosis to promote self-management and provide more effective nursing strategies. The present study findings show that patients with adenomyosis face diverse self-management challenges and dilemmas such as lack of knowledge, affecting daily life, negative emotions and personalized supporting requirements, which inspire professionals to provide scientific education, emotional support and social concerns.

In this study, most patients have not learned adenomyosis before diagnosis, and they were unable to recognize the relationship between dysmenorrhea and adenomyosis, merely 16.7% patients went to see the doctor. The patients generally lacked the capability to recognize the abnormal condition, and they have no idea on identify correct information about it. The patients were also confused about what treatment to choose. If healthcare professionals can help patients develop the connection between themselves and their body and empathize with the patient-centred disease empowerment process, then it will be worthwhile progress (Wu et al., 2011). Thus, the self-management health education of adenomyosis should diversify in forms, individualize in ways, and particularize in contents. As for the aspects of the forms and ways of health education, in addition to traditional manuals and oral education, it is becoming increasingly popular to promote health education by popular science articles on the network and peer support from WeChat groups in the aspects of the forms and ways of health education.

Patient's challenges and dilemmas of daily life are closely related to severe symptoms and complications. The patients experienced various barriers, such as sleep disturbance, sexual dissatisfaction, disruption in social activities and changes of appearance and original roles. The research findings are in line with those of Nelsen et al (Nelsen et al., 2018). Thus, it is an effective way to help patients to choose effective treatments and relieve symptoms in order to get rid of dilemmas in daily life. It is recommended to take some medicine, such as GnRH- α and Danazol, to relieve symptoms. Healthcare professionals are expected to guide patients to self-observe the effects of drugs and identify the adverse effects in time. The purpose of health education also includes the correct method and exact time of taking the medicine, as well as the right time to follow-up with the doctor. If the patient has Mirena, she should take a B-ultrasound

examination regularly to prevent expulsion of the ring. Another interesting observation in the study is that CTM plays an important role in the treatment of patients with adenomyosis. Obviously, cultural influence should be taken into consideration, and CTM reflects Chinese cultural philosophies. In the mind of the Chinese population, CTM can help them regain body balance, and it is beneficial to health for long-term conditioning (Chen, 2001). In this study, women always mixed CTM with Western biomedicine to treat adenomyosis. Therefore, healthcare providers explain treatments and alternatives to patients and help them choose the treatment option that best aligns with their preferences and their unique culture (Wu et al., 2019). Once the patients do not accept hysterectomy, professionals can analyse and compare the advantages and disadvantages of HIFU, CTM, and medicine treatment to cater to patients' wills.

The patients generally reflect that they have different degrees of negative emotions, and mood swings in the stage of illness. Symptoms and complications caused by the disease have caused inconvenience, discomfort and embarrassment to patients' daily situations. It is suggested that professionals should guide patients on how to relax, for example when they have dysmenorrhea, for example deep breathing, aerobics, listening to music, the exercise to relax muscles, to relieve discomfort and tension (Dessouky et al., 2019). A very troubling treatment option is hysterectomy. In this study, the option is unacceptable to all women regardless of age. The participants have expressed their concern relating to future pregnancies, especially under the new Two-Child policy in China. To a certain extent, this new policy encourages senior women to plan their second child. These women thus are worried about future pregnancy and refuse to undergo hysterectomy, preferring to seek other treatments. Another cultural perception in China is that the uterus is a female feature, and hysterectomy is believed to lead to endocrine disorders, rapid ageing, early menopause and incomplete women (Ding et al., 2015).

The study shows that patients need psychological support from 3 categories: the husband/male partner, doctors and nurses, and fellow patients. Family support is mainly provided by the husband/male partner, which may help patients in coping with adenomyosis (Culley et al., 2013; Simoens et al., 2012). Patients depend on their husband/male partner for spiritual support and desire understanding and care from him. However, when the symptoms of the disorder are severe, the patient usually feels angry at her husband/male partner for no apparent reason, making him feel stressed and frustrated. Culley et al., (2017) reported these findings in male partners of endometriosis patients. Men express an aggrieved feeling when they see their partner become emotionally unstable due to the disease. However, men also often consider pain as a normal phenomenon during menstruation. This incorrect notion leads to a gap in understanding the disease between couples. This is an area where further research focusing on couple-centred issues is needed. Professional support is mainly provided by doctors and nurses. It is suggested that nurses can invite patients' partners to participate in the nursing process, so that the partner can understand the sufferings of patients and overcome diseases together with patients. Meanwhile, adenomyosis patients regarded doctors and nurses' encouraging language as an important source of emotional support. A previously published

study (Moradi et al., 2014) showed that health professionals have no time to listen to their patients' concerns or answer their questions and even considered them making up stories to get their attention. This attitude gives patients negative emotions and unsatisfactory experience with the healthcare providers. Patients depend on their healthcare providers to give them more attention, even a smile or brief communication, which they consider the best form of emotional support. Professionals can take some actions to train patients' ability of self-training and emotion control, so that they can adapt to the changing environment with effective stress mechanisms and achieve physical and mental balance. Moreover, fellow patients are considered to have effective emotional support, as they could exchange experiences and barriers. Our study participants expressed that knowing that a fellow patient experiences the same symptoms gives them some kind of relief (Ding et al., 2015).

It is essential to mobilize the social support system. Hospitals may provide a private space for qualified patients to relieve their negative emotions. Professional staff could get into community, campus, workplace to popularize the health knowledge of adenomyosis and appeal for caring for women, understanding and respecting women through network, and not looking at these adenomyosis patients with strange looks is our future direction. Patients would like to receive some help from society in spreading information on the disease, including symptoms, treatment and prevention. The findings of the present study are in line with those of Moradi et al. (Moradi et al., 2014), which suggested that beneficial actions should be taken for women, such as increasing information for patients and awareness and educating the society and schools of this disorder. However, reports describing adenomyosis in China are limited. In other countries, De Montfort University and the leading UK charity Endometriosis UK ([www. Endometriosis-uk.org](http://www.Endometriosis-uk.org)) have established useful resources for women such as online information, a film describing real-life patients, educational intervention and advice from a clinical psychologist (Culley et al., 2017). Similar efforts may also be helpful to patients with adenomyosis. It will help patients get out of social difficulties and be competent for various roles through continuous nursing.

5.1 | Limitations

The study was limited to a small sample size of only 18 participants. However, data saturation was achieved, which suggests that the sample size was adequate. The main strength of the present study lies in analysing the barriers to self-management of patients with adenomyosis in multiple dimensions. However, the strength is undermined by the generalizability issue inherent to qualitative studies.

6 | CONCLUSION

This study has described the barriers to self-management of patients with adenomyosis. They often ignore the condition and blindly choose various treatments that are often ineffective and

even aggravate symptoms, thereby resulting in poor quality of life, changes of appearance and original roles and negative mental state. Furthermore, patients with adenomyosis need different kinds of support, particularly from their husbands, healthcare professionals, and fellow patients and social support. It is worth mentioning that some findings were based on the cultural environment of Chinese patients, including their refusal to undergo hysterectomy, fears relating to future pregnancies under the new Two-Child policy, which prompts them to rely on CTM. Taken together, the findings of the present study indicate that healthcare professionals should provide more information on adenomyosis such as in the form of online films or educational intervention applications. These professionals could also educate patients about self-management and pay more attention to their complaints. We also encourage the husbands of patients with adenomyosis to provide strong support as well as their peers to share their experiences. Moreover, we should fully respect patients' cultural background and provide them with a therapeutic nursing programme that considers the Chinese norms.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

H. Jiang and R. Huang conceived the study and developed the study design. R. Huang drafted and revised the manuscript. X. Li and Q. Li collected and analysed the data. Specially, H. Jiang supervised the overall study process. All authors have read and approved the final manuscript.

DATA AVAILABILITY STATEMENT

Not applicable.

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