

## Research Article

# Understanding the Needs of Women with Adenomyosis Through Social Media

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### Abstract:

**Aims and objectives:** The aim of this study was to explore patient experiences and perceptions of adenomyosis.

**Background:** Adenomyosis is a benign gynaecological disease characterised by abnormal presence endometrial tissue (the inner lining of the uterus) within the myometrium (the thick muscular wall of the uterus). To date there is little data that reflects the experiences and perceptions of women with adenomyosis. Nevertheless, there is an abundance of Internet-based discussion forums and support groups related to women's health which provide a low-cost resource for support and assessing patient experiences.

**Methods:** A qualitative explorative approach was used to look at the experiences and perceptions of women with adenomyosis. Online comments posted between September 2013 and August 2014 were scanned and then women were invited to volunteer and participate in a closed discussion group where data was analyzed for thematic content.

**Results:** Three broad categories emerged from the discussion group: reassurance of finding others with the same health issues and supportive communication; length of time associated condition and diagnosis; challenges faced on a daily basis living with adenomyosis. Data revealed particular concerns for women with adenomyosis: length taken for diagnosis and treatment, wide variations in treatment experienced, healthcare practitioners' views and treatment options varied widely and the loneliness felt by women.

**Conclusions:** Online communities may provide information and support about topics that concern women and offers an alternative arena to discuss issues, such as pain experienced, medication, treatment options and side effects. Data highlighted potential issues that may not be a priority to healthcare practitioners but are nevertheless important to patients.

**Relevance to clinical practice:** Despite the growing use of online health-related communities, there is little researching to how online communities can contribute to patient support in identifying patient issues regarding diagnosis, early treatment and on-going care, provision and service development.

**Keywords:** Adenomyosis, women's health, qualitative research, social media

### Introduction

The health benefits of social media have been subjected to public debate. The positive impact of social media however clearly outweighs the negative with research showing that social media offers many clear health benefits of being online and connected [1]. New technologies have changed the way we communicate and

social media (including email, blogs, online forums and social networking sites such as Twitter, Facebook, Tumblr, Flickr, Youtube and LinkedIn) allows the sharing of information and staying connected with people without physical barriers and geography being an issue. They facilitate social interaction, build communities and can help with help-seeking behavior [1]. Many people use social media as a motivation tool to help them to achieve health goals. This paper focuses on one aspect of women's health called adenomyosis and the use of social media as a support mechanism.

## Background

Adenomyosis, also referred to as “uterine endometriosis,” is a benign disease confined to the uterine muscle [2]. Adenomyosis occurs when endometrial tissue thickens which abnormally lines the uterus [3]. Endometrial cells that line the endometrial cavity migrate from that lining into the posterior side or back wall of the uterus [2]. The prevalence of adenomyosis ranges from 5 to 70% with Granziano et al (2015) suggesting this variability depends on several factors for example diagnostic criteria, characteristics of sample and investigator skills.

Adenomyosis is most frequently seen in women in early to middle 40s and is often associated with hormone imbalance with an excessive estrogen supply [4]. Various published studies have shown that 12% of patients with adenomyosis also have been diagnosed with endometriosis in other sites outside the uterus, within the pelvis [3,5]. As high as 62% of women who had hysterectomy were found to have this disease on pathology reports [3,6]. The symptoms include long-term or heavy menstrual bleeding, painful menstruation, which becomes increasing intense and pelvic pain during intercourse. The ‘benign invasion of endometrium into myometrium’ that occurs in adenomyosis can lead to enlargement of the uterus and reactive hyperplasia and hypertrophy of the neighbouring myometrium [6]. While adenomyosis appears to be a common condition, in Wright’s (2010) personal account of diagnosis not one health care professional mentioned the condition.

The more the disease spreads, the greater the symptoms [2]. Many patients with adenomyosis can be without symptoms (asymptomatic) just like fibroids and endometriosis [4,7], but most commonly women report the following symptoms associated with their enlarged uterus: dysmenorrhea (painful periods), hypermenorrhea (heavy periods), prolonged bleeding cycles, cramps, pressure on the bladder, dragging sensation down the thighs and legs, heavy and prolonged bleeding with large blood clots, abdominal bloating, back pain, severe and increasing abdominal pain throughout the month, painful intercourse, nausea and vomiting [3,6,8]. Consequently, this can have a dramatic impact on women of reproductive age [9].

Unfortunately, adenomyosis is difficult to distinguish and consequently an area of concern. It is difficult to distinguish adenomyosis clinically from uterine leiomyoma, since many symptoms of these two conditions are similar [6]. Further, adenomyosis and leiomyoma are not easily distinguishable. Magnetic resonance imaging (MRI) is an accurate and non-invasive technique which is currently regarded as the best imaging tool for the differential diagnosis [5,6] however Graziano et al (2015) suggests while MRI is traditionally considered more accurate than transvaginal sonography (TVS), a recent review of studies have proved that the two

techniques are comparable especially when 3D-TVS is used.

Research studies on the etiology or cause of adenomyosis is unknown [3,6,9] and diagnosis remains difficult. Women diagnosed with adenomyosis commonly have excess levels of the hormone estrogen, which encourages the disease to spread monthly [10]. A known genetic link is also present, as with endometriosis, and it does tend to run in family history [2]. There has been an increase in the disease because of tubal ligations, women who have had both cesarean sections and pregnancy terminations (suction or curetting D&C), however the reason for the disease continues to be inconclusive [5,10].

Chen et al (2014) found adenomyosis to be a common, non-neoplastic, chronic gynecologic disorder detected in 5% to 70% of hysterectomy specimens. It is characterized by the presence of ectopic endometrial glands and stroma within the myometrium, and it occurs mostly in late reproductive age women. Adenomyosis has a propensity to present in the uterine fundus and is rarely seen in the cervix. At present, the most reliable way to diagnose adenomyosis is by pathologic examination of the hysterectomy specimens [11].

In a systematic review on prevalence, diagnosis, treatment and fertility outcomes Maheshwari et al (2012) found little data on the epidemiology of adenomyosis associated with sub-fertility. They suggest there might be a higher prevalence of adenomyosis in a sub-fertile clinical population, especially in the presence of endometriosis and alongside symptoms such as dysmenorrhoea and/or menorrhagia. In the review, definite conclusions were not possible in the current literature. Both MRI and ultrasounds are non-invasive tests with equivalent accuracy in diagnosing adenomyosis. However, Maheshwari et al (2012) found there are no agreed criteria for diagnosing adenomyosis based on these tests. In fact, they found no international consensus on the histological criteria used to define adenomyosis in hysterectomy specimens, which is considered the gold standard. The method of performing biopsy for diagnosing adenomyosis also needs standardization [12].

With the widespread use of the Internet and low cost social media, especially social networking, it is no surprise that it is being adopted by healthcare professionals and patients. There has been a growth in its use, especially social networking in healthcare. Shachak and Jadad (2010) argue that the use of social networks will eventually lead to a more patient-centered healthcare system that will improve communication and information flow between patients, service providers and administrators [13]. Other studies have suggested Facebook users seek health information and social networking websites are beginning to cater for social networks devoted to providing health information [14,15]. However as social media grows and develops in healthcare, the impact of social me-

dia on patients and patient care will need more consideration.

Patients can use social media for a variety of reasons that include education, obtaining information, networking, research support, goal setting, and tracking personal progress [1,16]. Patients have more autonomy with the ability to express themselves, share their stories, learn from others and spread health knowledge [17]. Social media creates a forum for patient participation that extends beyond the scope of the hospital, clinic, community care setting or local GP practice. These forums can empower and uplift patients when the experiences of others are shared. Social media is seen to be beneficial for patients with chronic diseases, cancer, rare diseases, depression and patients with questions or goals relate to women's health, pregnancy and baby/infant care, wellness and preventions and weight management [17].

People dealing with chronic disease are increasingly communicating their health concerns online [18] with increasing stigmatization, poorer health, isolation and being disconnected cited as the main reasons for patient online interactions [19]. Social media has created new opportunities for the management of health, illness and disease [20]. While social media is well established, its use with the involvement of people is a recent development [21].

The popularity of health-related social media sites could indicate a shift towards patient empowerment particularly within women's healthcare provision [22]. The traditional models of health seeking behaviour need to accommodate the wider use of social media and accommodate electronic devices. The reliance or access to healthcare professionals may reduce due the wider availability and convenience of these online interactions with other women who share symptoms, problem solving and advice. This combined with the fact that smartphones are widely used by women has the potential to modify women's experiences of healthcare provision. Therefore, it is important that healthcare professionals and policy-makers are more aware of these new developments, which are likely to influence healthcare and alter health-seeking behaviour. In addition, healthcare professionals need to consider whether to discuss the use of social media as a resource with the women in their care.

Antheunis, Tates and Nieboer (2013) conducted a descriptive online survey among 139 patients and 153 healthcare professionals in obstetrics and gynaecology to investigate motives and use of social network sites. They found that patients primarily used Twitter (60%) to increase knowledge and exchange advice and Facebook (52%) for social support and exchanging advice. Professionals tended to use LinkedIn (70%) and Twitter (51%) for communication and networking with colleagues. Patients identified privacy and unreliable information as the main barriers to social media whereas the professionals found inefficiency and lack

of skills as main barriers.

Despite the growing use of online health-related communities, very little research makes use of this low-cost resource for identifying patient issues regarding patient-oriented treatment, service development and provision [19,23].

## Research Design

The aims of this study were to explore patient experiences and perceptions of adenomyosis through social media. A qualitative exploratory approach was taken where online data from a women's adenomyosis support

Group was explored and examined retrospectively over time frame covering a 12-month period (September 2013-August2014). It is felt that the concerns expressed by women warranted exposure to everyday practice. However, there are ethical issues concerning the use of online public material. Online data while out in the public domain belongs to the individual and using this data may identify them. So, while ethical approval was sought from the local university for the project as well as permission from the online administrator of the support group it was felt because of further investigation in to social media research that the publication of complete narratives would be unethical without the participant's approval. The researchers decided to approach the support group and requested volunteers to come forward. Ten women volunteered and consented to share the contents of their experiences from an online group discussion. The initial online posts were scanned and evaluated, developing a thematic coding scheme and framework which formed a guide to structure the data collected from the 10 volunteers.

## Data Collection

From the initial scanning of the online support group, 221 users were identified in a series of 336 comments from wall posts and discussion topics. This online data was scanned and organized to inform and assist in the data collection. This inductive approach was used to develop a set of questions and approach women in the group. Table 1 below provides the guide that was used with each participant and questions were used in the same order.

Guide for online questions
• Tell me about your experience of adenomyosis. Do you have a history?
• Length of time to diagnosis
• Pain?
• Any medication or treatment?
• Impact on home/family life/work
• Are you waiting or contemplating surgery?

• If you have had a hysterectomy, what did you do for pain relief?
• Age
• Country of Residence

**Table 1:** Guide for online questions.

Online data was collected and collated from the 10 women and organized during MAXQDA to assist in the immersion of data. Ritchie and Spencer (1994) refer to this as “familiarization” meaning time was spent reading and re-reading the data. A framework analytical approach [24] was used which allows the researcher to systematically appraise and reappraise transcriptions, to develop ideas and meanings behind the phenomena of interest, in this case women’s health issues and social media. Ten women volunteered, data were anonymously missed throughout coding and analysis resulting in a range of narratives.

### Data Analysis

All the transcripts were reviewed independently line by line to identify data relating to each theme and adding new ones as they arose. MAXQDA was used to code and facilitate the analysis of data. This involved a five-step process: familiarization; identifying a thematic framework; indexing; charting; mapping and interpretation.

Firstly, the overall common and emerging themes from the 10 women were identified, and a coding scheme was developed. Data for each theme was reviewed with illustrative narratives.

The study aim was to describe and interpret what was happening from the perspectives of the participants rather than generating more overarching theories, the ‘thematic framework’ approach was found to be suitable [24]. The range of data collected demonstrates the range of themes women raise and the complex overlapping relationships that co-exist in women health issues pertaining to adenomyosis.

### Sample

From the initial online sample, which consisted of 221 postings from different women discussing adenomyosis: 32% reported a confirmed diagnosis of adenomyosis, 22% reported having had a hysterectomy (which confirmed diagnosis), and 5% confirming no more pain or symptoms after hysterectomy. The participants ranged in age from 20-56 posting comments between September 2013 and September 2014 across the globe (UK and Europe, USA, Asia, Australia). The online group were approached looking for volunteers to share their experiences and 10 women volunteered. The criteria for selection were: already participating in the online group and a diagnosis of adenomyosis. Table 2 provides details of the age and country of residence of the 10 women who volunteered further information.

Age and Country of residence	
AGE	Country
18-25 1	UK - 6
26-35 2	USA - 3
36-45 4	Australia - 1
46-55 3	
<56	

**Table 2:** Age and Country of residence.

### Results

The results from the online group identified three broad themes and these were entered into table 3 and grouped into categories and sub-categories identifying the different theme dimensions: (i) Reassurance of finding others with the same health issues; (ii) Time associated with condition and diagnosis; and (iii) Challenges faced daily in terms of living with adenomyosis.

The transcripts were verified and confirmed by participants and the coding scheme developed. Most of the themes defined evolved during the data collation. The analysis identified some significant emerging themes when asking about the length taken for diagnosis and treatment which included wide variations in treatment experienced, healthcare practitioners’ views, treatment options varied widely and the loneliness felt by some women.

The most frequent symptoms were associated pain, cramps, backache and the use and wide variations in pain relief and associated treatment. Surgery was the final treatment and for some the only main way to answer or diagnose the ongoing problems. Some were undergoing regular follow-up examinations from one to five years. Certain participants had been diagnosed recently and this was often cited as one of the main reasons for joining the online group. The decision-making period for hysterectomy ranged from three to six months some much longer (range of years). The main reason for women who decided not to go down this route was because of their age and desire to have children. Those who finally opted for the hysterectomy route used the abdominal procedures (LAP) with some depending on gynaecologist preference had vaginal hysterectomies.

Through the data it was easy to immerse yourself and have a real insight into how this debilitating condition affects some women. Through the data, the reality of women’s experiences was expressed and their thoughts about “another medication to try or another procedure to endure”. It became understandable why the women yearned for a “normal life”.

The women joined the group because they were either looking for advice about their new diagnosis or had been diagnosed and were looking for support and advice because of a long history

of pain (see table 3). Most came upon the site by searching for what was adenomyosis was or just by chance. Other women were referred by others who were experiencing the same problem(s) and thereby expanding the support network.

Data Analysis		
Main Theme	Sub-theme	Theme dimensions
Reassurance	Finding others with the same issue	Women searching for support
		Relief to have found others
		Lots of questions
		Sharing of experience
	Wide variations in treatment	GPs vary in responses and treatment
		Global treatment variations
		HCPs know little
	Mutual support	Lots of chatting
		Lots of single posts
		Thanks for access to group
		Lots of shared experiences
	Advice	Posts giving advice
		Experiences shared
		Where to seek help by location
Time	Age related issues	Women who have not had children
		Women who are reared a family
		Menopausal women
		Disease
	Length of time associated with condition	Details on length of time
		Impact on self
		Impact on family
	Length of time for diagnosis	Time taken till diagnosis
		Frustration
		Lack of knowledge
	Length of time until treatment	Time taken until decision made
		Personal decisions
		Time till treatment
	Specialist	Advice on locations
		Levels of treatment
		Seeking gynaecologist
Challenges	Living with Adenomyosis	Daily impact
		Family
		Work

Loneliness	Feel alone
	Reliance social media
	Responses are immediate
Level of pain	Daily pain
	Monthly hormonal pain
	Bloating, weight gain
Pain relief	Range of analgesia
	Medical treatment options
	Complimentary therapies
Views of health care professionals	Variable support from GPs
	Few specialist gynaecologists
	Not widely articulated

Table 3: Data Analysis.

Reassurance was a main theme about finding others with the same health issues. Many women were immediately comforted when joining the group as similar symptoms were described and shared (Table 3). Some women described it as a “knowledge bank” and found a “sense of unity” by being in the online group. They felt “reassured that they were not alone”. Comfort came through this mutually supportive online communication.

“I was so relieved when I came across this group, I got lots of advice and told them what happened” (P1).

“Once accepted on the group I just kept asking questions, and got answers. Different women share so many different experiences” (P5).

“I could just type something in usually it was late and I’d get a response soon after” (P2).

“If I was having a really bad day or confined to bed I’d post something or add a picture and then someone would respond I wasn’t alone anymore. And they’d check too how you’re feeling, hot water bottle, painkillers and rest” (P9).

Advice appeared not to be forthcoming from healthcare professionals and many women commented that knowledgeable practitioners were hard to find. On to other healthcare Many women found good and understanding General Practitioners (GPs) hard to find, often being referred professionals with further pain relief and left to struggle for a long time.

“We often discussed how our GPs were like unapproachable and many times I felt stupid going. The group encouraged me to keep going until I got something” (P2).

“They don’t believe you, the pain. I don’t know how long it’s been going on. Too long I guess” (P7).

Many women go through years of pain and describe long histories of different pain relief and short-lived treatments such as Transcutaneous Electrical Nerve Stimulation (TENS), mirena coil, and surgical interventions like ablation.

“You get this TENS on trial, and they follow up by phone it was hard but I tried my best it actually made me worse and it was irritating as it was difficult to wear all the gear. That was difficult” (P9).

“I have tried just about everything my doctors have suggested, meds that were all nerve based like Neurontin which did nothing for me, tramadol which helped a little bit mostly seemed like a joke” (P3).

“I also get nerve blocks every 3-4 weeks in my groin to help deal with pain from trapped nerves” (P6).

Length of time associated with the condition, diagnosis and living with adenomyosis is a challenge that many women face daily (table 3). Many women say, “I don't have time for this” with many reporting having children, a husband and a job to juggle.

“Before the hysterectomy the decision was one that caused stress we were only 23 at the time I wanted more children and my husband wanted me to feel better we argued a lot about it often but in the end, I agreed” (P3).

“I always had painful periods, they said it would get better after having children it never did. I had my children and I wanted it to stop I couldn't cope any more with the kids, work, home and every month and a lot more it got worse I just collapsed in bed some days” (P9).

Many of the women describe the length of time they have been in pain, the length of time they bled, they length of time “it has gone on for”, the length of time from consultation to some form of treatment, to then try another and then another form of treatment.

“It's gone on a long time too long I agreed in the end my children and husband deserved a happy pain free mom and wife” (P8).

“I have had the coil twice now and that's over 5 years now coping after the kids, he'd make me try this and I tried and in the end, I change consultant” (P7).

They reported on the length of time they have had to wait for an initial scan, then follow up, often another type of scan, waiting to see the consultant, and then to be put on the waiting list to wait for a hysterectomy and the agonizing wait for laboratory confirmation of the final diagnosis.

“Every time you had one thing you had to wait appointments, scans the follow-up and that was with each one, sometimes I despaired we talked a lot about this on the group” (P6).

“After the surgery I just wanted to know what he'd seen, he said it was bad but had to wait on the results” (P5).

Similarly, it was difficult to find a medical practitioner who was supportive of the condition and this took a long time. If found they were very specialized and found in fertility clinics or had other specialist gynaecological interests.

“Eventually I find someone that listened, he understood it all, and he understands the whole lot. Someone in the group had something similar and suggested the change” (P9).

The challenges faced daily in terms of living with adenomyosis. The level of pain that many of the women describe is revealing (table 3).

“It's so frustrating but I try to keep from getting me down I have two happy little boys that keep my spirits up” (P4).

“Just doing the housework was hard, I'd be in agony after and well work was another thing” (P10).

Some describe constant pain, which become chronic over months and years. Some describe how they “put up with the pain”, cope with the pain and manage the pain.

“It was there all the time, that pulling pain, the lower back ache I have loads of hot water bottles.” (P9)

“You just have to put up with it, it wears you out though. I have taken so many tablets and some days nothing works, I just go to bed I cant do anything when I am that way and it takes over” (P5).

“It's been a long time gone on and on and no one listens but you cope with it but it got difficult to manage and to painful” (P10).

“Even after the hysterectomy they don't tell you about the adhesions. The stats on adhesions is 93% of all abdominal surgery will grow adhesions and 53% of that 93% will have adverse effects from adhesion i.e. abdominal pain etc.” (P3).

There are many descriptions of heat therapy, long soaks in the bath, over the counter medication and then seeking advice and referral from the General Practitioners. In other countries, depending on insurance and what it covers, their medical insurance does not cover unspecified pain of long-term chronic conditions.

“Everyone has a hot water bottle. We often talk about baths and what too soak in. I've tried several good salts for the bath” (P1).

“They (insurance) did not want to cover the surgery I was too young they said and I'd want another (baby). In the end I had it (hysterectomy) eventually but took along time to sort.” (P2).

“To sum up I'm still in pain even after the hysterectomy now have inter cystial systitis and the urologist said is was all the surgeries around my bladder with all the adhesions so more pain” (P3).

Weight gain was a common reported symptom as well as bloatedness. On the support group women described how the weight increased, how it affected them, leading to a lack of exercise because of the inability to walk due to pain.

"I get bloated and have to watch what I eat and with all this it can get quite uncomfortable" (P1).

"I was really active before all this started and then suddenly it started. Its been hard trying to keep the weight off and trying to keep active after the surgery" (P5).

"Two years on and I don't do much really walk, swim, a bit of yoga to strengthen my core. Have to watch what I eat" (P9).

A lot of women described chronic fatigue and how the constant pain made them tired, or the fact they were in so much pain they could not sleep. Many women also found this a lonely and isolating experience and once on this support group were overwhelmed by the support and felt enthused and "not alone" and "reassured".

"I was always tired, the pain just drains you" (P1).

"I did feel alone but I'd type something out, someone always replied from the group" (P4)

"At times it just gets too much always popping something I must rattle. Sometimes you done sleep and it gets exhausting" (P7).

"Its painful and lonely, I was always so tired" (P8).

Many women put up with the burden of pain, chronic suffering, and constant pelvic pain yet are expected to led normal working lives, keep a family and/or work. Many say they have suffered alone and others have said their families have suffered too.

"My doctor was convinced a hysterectomy would relieve my pain and that was what I needed more" (P3).

"Its been difficult and I really luck to have him, to have a good hubby but its not fair. He wanted it to stop. And the kids checking on me it wasn't fair" (P9).

Failed methods of birth control, analgesics and procedures that heighten the risk of more adhesions which add to adenomyosis symptoms. Most of the data shows the gratitude the women find by using social media; a way of releasing their fears and being able to ask questions that they may feel too embarrassed to ask the doctor or healthcare professional.

"I'd asked the group first and then go so I'd have my questions clear in my head" (P1).

"They (group) told me to go that I should ask and keep going till I got want I needed. It was hard at first" (P10).

"Id check into the group first and see what they'd say, often so helpful giving options" (P4).

"I still go to group and now it's my turn to give advice, so many women like me" (P7).

Others have described how unhelpful the workplace is, especially those who have to work and who receive little benefits from their employment. Many describe difficult lives.

"It was difficult at work, no sympathy and I'd just go sick or leave early because I was no good to anyone" (P2).

"In the end it got so tiring, and the date for surgery came and went, I had a long time off Id not done that before. Only now do I feel normal but that's 2 years now since the surgery. Its been a long time" (P8).

Each story you read shows the years of pain and de-sensitized doctors that just see another "women's problem" in their office. Going through the motions of pain relief, birth control, invasive procedures and finally in some cases a doctor that actually understands the suffering and has some answers. There seems to be a pattern of how this condition is treated, the routes each doctor takes appear to be similar as if a "tick box" approach is used each time.

"I had to go through the process first, had I done this, had I tried this, he did not want surgery despite my pain. I was not too young and he was quite adamant" (P7).

"I was lucky to find him (the surgeon). He listened and really knew about it. I was on his list but he's gone now" (P9).

## Discussion

Reassurance was one of the main themes from the data because participating in the support group, many felt supported, more informed and gained increased awareness of the issues surrounding adenomyosis and associated issues. Some participants reported that because of the support group, they felt more informed and therefore more likely to visit the GP armed with the confidence to ask direct questions about their on-going conditions. This supports Shachak and Jadad (2010) who argue that the use of social networks will eventually lead to a more patient-centered healthcare system. Househ (2011) suggested it would improve communication and information flow between patients, service providers and administrators. Other studies have suggested Facebook users seek health information and the participants' narratives were concentrated on their personal experiences and sharing stories of healthcare interactions. Social networking websites appear to be catering for social networks devoted to providing health information [14,15] adenomyosis, improving access to healthcare and improving patient outcomes.

The women in the group also described living with adenomyosis, the failed treatments, chronic fatigue, chronic pain and loneliness. Merolli et al (2008) described many people with

chronic disease are increasingly communicating their health concerns online. Walker (2013) suggests the increased stigmatization, poorer health and isolation are cited as the main reasons for patient online interactions. Furthermore, Haigh et al (2012) argues that social media has created new opportunities for self-management of health, illness and disease.

Many women described years of pain and long histories of different treatments. Length of time associated with the condition, pain, diagnosis and living with adenomyosis is a daily challenge. Suggested treatment for adenomyosis include: pain medication and/or hormone manipulation, minor outpatient procedures and ultimately hysterectomy [6,10]. Many women describe alternative treatments such as heat therapy mainly in the form of a hot water bottle or warm baths. However, the emotional and psychological effects of adenomyosis produces challenges, that can significantly affect a woman's lifestyle [6]. As symptoms progress, many patients begin to feel "trapped" finding it difficult to escape this disease. The women described daily challenges which include living with painful intercourse, lengthy periods, heavy bleeding and clots as well as the excruciating pain that often accompanies this diagnosis [25]. Many women experienced days of complete bed rest, nausea and vomiting and a life shattering inability to function occurring monthly and Graziano et al (2015:1146) confirms this description of adenomyosis as having a dramatic impact on women in reproductive age.

Adenomyosis is an important clinical challenge in gynaecology and healthcare economics particularly when weighing up the cost of diagnostic treatment [26]. In its fully developed form, hysterectomy is often used to treat it in premenopausal and perimenopausal women. Symptoms of adenomyosis typically include menorrhagia, pelvic pain and dysmenorrhea but adenomyosis and leiomyomas commonly coexist in the same uterus making diagnosis problematic [9]. The women in the group describe the length of time in relation to pain, diagnosis, living with adenomyosis. They also describe the length of time of waiting for a scan(s).

Gynaecology and gynaecological examinations are essential to care but is often a taboo subject and can be very difficult to discuss, even amongst women in themselves [27]. Gynaecological examinations are often found to be difficult for some women and can provoke negative feelings such a fear, embarrassment and pain [27]. The prospect of an internal examination by gynaecologist who is likely to be a male surgeon often fills women with dread and can lead to higher rates of non-attendance [28]. Women describe long histories and multiple examinations with no hope of recovery which can lead to high levels of anxiety, depression or complete loneliness.

Minimally invasive surgical techniques (endometrial ablation/resection, myometrial excision and/or reduction, myometrial electrocoagulation, uterine artery ligation) have had limited suc-

cess in the treatment of adenomyosis, and the reported data for these procedures have been obtained from case reports or small case series with only short follow-up times. However, newer techniques including uterine artery embolization (UAE) and magnetic resonance imaging guided focused ultrasound (MRgFUS) show promise in treating adenomyosis [9]. Most of the data shows the gratitude the women find by using social media so they can discuss the options, the limited success of the treatments, what they have experienced from failed methods of birth control, analgesics and on-going procedures.

Currently literature suggests hysterectomy is the best treatment and the most reliable way to diagnose adenomyosis through pathologic examination of hysterectomy specimens [11,12]. However, this is not always the best outcome for women particularly those who have not had children, and those who have not given much thought to long-term relationships or having children. Surprisingly there are many younger women suffering in silence and are alone with painful symptoms. The options are to wait or choose some form of treatment and learn to cope with the symptoms. A gynaecologist will only offer a hysterectomy as a last resort to give each woman the chance to conceive. However, the findings from this research highlight how difficult and painful it can be for some women to bear. The data from the women highlighted the age group of the women who were aged 20-56. Yet NICE (2013) guidelines suggest adenomyosis is most frequently seen in women in early to middle 40s so there appears to be some discrepancy here and the need for further investigation.

Another key theme that emerged from this study was the need for more information and advice about adenomyosis from healthcare professionals, possible treatments and whether hysterectomy is the right choice. While the GP is well placed to provide general advice about women's health and treatment options they are not always supportive or up to date. Each woman is an individual; they have their case and their problems, yet when the women experiences are examined it appears health care professionals are insensitive or lack knowledge. Gynaecologists, GPs, practice nurses and other healthcare professionals need to be aware of the possible problems and listen to the woman who have a long history of symptoms. Listening to the woman can provide a detailed picture often indicating the passage of time and pain.

The women described managing in the workplace and finding it difficult to cope. Sympathetic employers are needed as unfortunately diagnosis is a lengthy process however with a comprehensive history and assessment taken properly, and with advancing diagnostic tests the whole process could be shorter and reducing the length of time before diagnosis and treatment for some women. Coincidentally, Coexist a community interest company in Bristol has become one of the first companies to introduce a "period policy" to try and be flexible with the "monthly trauma for women" [29].

Awareness and improvement in protocols and diagnostic pathways are required as well as comprehensive support package for women. This study suggests that women who go on to have a hysterectomy continue to have pain suggesting a long on-going recovery process unique to each woman. Often prescribed anti-depressants and counseling are offered without giving the much needed time and understanding. The correct analgesia and a comprehensive assessment of the woman's gynaecological history is needed with a better explanation of the use of anti-depressant drugs for neurological pain caused from surgery. Women need time and reassurance in the long post-operative recovery phase which can last years.

## Study Limitations

This is a relatively small exploratory study and the authors recognise the study limitations. This is the first qualitative study of this kind that explores women's perspectives and experiences of adenomyosis. What is

not explored in this paper are the potential differences in cultural backgrounds, health care systems and language. Further limitations include the use of social media itself and understanding its value a methodology yet limited because of the reliance on self-reported behaviours and information. Furthermore, while this is a relatively small study (n=10), the initial participants screened from the online support group (n=221) were from all over the world thereby only revealing a snapshot of the reality of adenomyosis.

## Conclusion

This research study highlights that adenomyosis is a "silent condition" experienced by many women. Women describe "immeasurable pain" and there are many "suffering alone". This is a dilemma faced by many women who are unable to talk or bring themselves to face a GP/physician with often many barriers to overcome. The journey to recovery is often described as "long and lonely". There is a need for healthcare practitioners to be more in-tune with women's health and offer more support. With hysterectomy being deemed as final resort; other forms of treatment need to be explored and more research is needed to raise awareness and bring it out in to the public domain.

## Implications for practice

Gynaecology itself is often a taboo subject and can be very difficult to discuss even amongst women themselves. Social media through online discussion is of value to women where they can discuss difficult and embarrassing problems with like-minded women and sharing experiences is easier when not constrained to time, place or meeting new people.

Further implications for practice include shortening the

woman's length of time and experience of diagnosis to earlier treatment, increased awareness amongst healthcare practitioners, advances in clinical research, and the role of support in this area needs to be investigated further. Specific roles for example for clinical nurse specialists in gynaecology and the role of online support groups should be explored further.

## Recommendations

Online health related communities such as discussion forums and support groups may be a low-cost resource for identifying patient priorities to guide patient outcomes or indeed provide much needed support from healthcare practitioners [23].

Technology is making a significant contribution to the evolution of the social network and consequently becoming a big part of healthcare provision. Clinicians and researchers need to be encouraged to participate in the cyber-world as a way of enhancing theoretical and scientific progress [20].

From a patient perspective, the study identifies flaws in parts of women's health services. This study could lead to prospective research possibilities and furthermore highlights the importance of patient involvement in research and social media. Further clinical trials are required in this field of gynaecology to explore efficient ways of dealing with the pain experienced by women with adenomyosis particularly younger women. There are many online social networking sites that exist on disease-specific information and they have become an important source of information, support and engagement for the public and patients living with chronic conditions.

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