**Study Title:**

**The prevalence and Impact of Social Media to seek Support and**

**Health Information in Women with Endometriosis.**

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**Background and Rationale:**

The internet and social media platforms are providing women living with endometriosis new opportunities to seek support, information and connectivity online. Previous studies have identified the possible therapeutic role of social media in patients with chronic pain and the role of online support groups in women with endometriosis. However; there is no published information regarding the actual prevalence of social media use for the purpose of seeking support and health information in women with endometriosis. Clarification around the use and impact of this potentially wide reaching self-management tool could give both women and health care providers a better understanding of ways to maximise the potential benefit of social media in healthcare.

Endometriosis is a chronic condition affecting approximately 10% of reproductive aged women; an estimated 200 million women and teens worldwide [1]. It is defined as the presence of endometrial tissue outside the uterine cavity which induces an inflammatory response [2]. Common symptoms include chronic pelvic pain, dysmenorrhoea, fatigue, heavy menstrual bleeding and dyspareunia. In addition to physical symptoms, endometriosis can have significant psychosocial impacts. These include depression and anxiety, emotional distress and reported poorer quality of life. Multiple literature reviews report negative impacts on social life, work, daily activities as well as education, finances, life opportunities, personal relationship quality and physical intimacy [3].

Stigma around menstrual issues and societal normalisation of women’s pain remain key factors in delayed diagnosis and reluctance of women to seek care, support or discuss symptoms of endometriosis [4]. Women with endometriosis often describe a lack of support and encounter feelings of social isolation, embarrassment or fear of symptoms not being believed [5, 6]. Finding understanding and knowledgeable contact networks for these women can be challenging; the internet therefore becomes a key resource for seeking support and information [7].

The popularity of the internet and social media for health information and story sharing is ever present in modern society. A study in 2013 suggested that up to a quarter of internet users have gone online to read about other people’s experience of a health-related problem and 16% to find others with the same problem [8]. Previous research has supported the hypothesis that online support groups and social media use can be beneficial as a self-management strategy for chronic pain conditions and help with provision of emotional support, instilling hope, fostering empowerment and reducing feelings of isolation [9, 10]. Since then numerous social media platforms have exploded in popularity with access and information at the tips of our fingers 24 hours a day, available on our phones, computers and televisions.

Social Media is an umbrella term that refers to websites and applications the enable users to create and share content or to participate in social networking [11]. These platforms are varied, and encompass groups from social networking sites e.g. Facebook, to blogs and microblogs e.g. Twitter, video sharing sites e.g. YouTube, discussion forums, chat rooms and photo sharing sites e.g. Instagram. The reach of these platforms is undeniable, with Facebook reporting 2.38 billion monthly active users worldwide as of the first quarter of 2019 [12]. Over recent years even celebrities have taken to social media to share their own personal health stories. Women such as Selena Gomez, who shared her battle with Lupus (Gomez is one of the most followed people on Instagram with over 150 million followers) and actress Lena Dunham’s struggle with endometriosis and resultant hysterectomy at age 31. Support groups such as Endometriosis Australia on Facebook and Instagram hashtags such as #thisisendometriosis and #endometriosisawarenessmonth have propelled endometriosis into the public eye and conversation.

Hospitals and health care providers are slowly getting on board with participation in social media, with large centres such as our own Royal Women’s Hospital having Instagram and Facebook pages. With unique access to a large patient population of women with endometriosis, study into the prevalence of social media use to seek health information and support can be investigated. Resultant information gathered will contribute to the current evidence surrounding the possible therapeutic role of social media as a self-management strategy for endometriosis including both positive and negative aspects. The results of this study will help heath care providers better understand the online health information and support seeking behaviours of their patients. Additionally, the study aims to inform the need for development of a Royal Women’s Hospital social media presence specific to endometriosis.

**Objective:**

This study aims to identify if women with a diagnosis of endometriosis are using social media to gain health information, share stories and both provide and receive online support regarding endometriosis.

**Primary objective:**

To assess the prevalence of social media use for seeking health information and support in women with a diagnosis of endometriosis.

**Secondary outcomes:**

* Identification of the most frequently used social media platforms for health information sharing
* Frequency of access of these platforms
* Proportion of experiences that are positive or negative
* Define what makes a positive vs negative health interaction/experience on social media
* Patient or disease factors that influence social media use
* Motives, barriers and expectations of health information sharing/support
* Gaps in information and services

**Methods:**

A cross sectional study.

We will recruit women with a confirmed diagnosis of endometriosis who are patients of the Royal Women’s Hospital. Recruited participants will be provided with an electronic questionnaire (appendix 1) to complete. The survey will use skip technology and be able to be completed in less than 20 minutes to encourage participation. Basic demographic information will be captured followed by more in-depth questions regarding social media use pertaining to the primary and secondary outcomes. This questionnaire and the subgrouping of social media platforms is modelled after an online global survey of social media use in patients with chronic pain [10]. It has then been modified to patients with endometriosis and to meet our desired study outcomes.

Questionaries will be distributed via a third-party online survey tool (SurveyMonkey) to be completed on the patent’s personal electronic devices. Participants can ask to complete a paper-based survey if they wish. These will be provided to women to be filled out at the time of engagement with the study. Patient Information and Consent Forms (PICF) will be provided at the start of the questionnaire. In both the electronic and paper formats; the PICF will need to be read and accepted prior to commencing the questionnaire. This allows all recruited participants to consent. Information on how to access the online survey tool will be provided to potentially interested parties at the initial interaction. This will be via email link. **Participants will undergo treatment and care as usual, with management not affected by their enrolment in this trial.** This will be made clear by the clinician at time of offering participation in study. The study will be offered at the end of the consultation to minimise any disruption to the patient-doctor therapeutic relationship. As the questionnaire is to be completed in the patient’s own time, independent of the gynaecology consultation, we do not anticipate any feelings of pressure to participate.

For ease of data collection, social media platforms will be grouped together on the survey with a brief description and example to help patient’s identity each platform. The following groups will be used:

|  |  |  |
| --- | --- | --- |
| Social media platform | Description  | Example  |
| Social Networking sites  | Online community platforms that allow users to connect and share interests and/or activities.  | Facebook |
| Blogs | Platforms that allow users to post information, narratives or generate discussion |  |
| Wikis  | Shared sites/platforms of collections of linked webpages that enable users to collaborate and coordinate information | Wikipedia  |
| Microblogs | Short form of blogging that allows users to send brief information, short status updates or media to be viewed publicly or privately  | TwitterTumblr  |
| Tagging/aggregation sites | Allow users to save, collect, tag, manage and share links to web content (often in a centralised location). They sometimes also allow users to vote/rate content resulting in the most popular content being more visible on the site. | DiggReddit  |
| Video sharing sites  | Platforms that enable the publishing and sharing of video content | YouTube |
| Photo sharing sites  | Enable the publishing and sharing of photo content | InstagramFlickr  |
| Discussion forums/message boards | Earlier social web technologies that enable users to post message and interact via message threads or topics (normally specific to an area of interest).  |  |
| Chat rooms | Platforms that allow for synchronous communication between people, all online at the same time (they are normally specific to an area of interest).  |  |
| Virtual environments  | Simulated environments that allow users to interact with eachother and the surrounding environment | Second life  |

**Measures**

*Participant demographics* - the first domain of the questionnaire asks participants about general demographic information. These questions are modelled on the World Health Organisation’s World Health survey for construct validity [13].

*Health-specific information* – Questions 7 through 11 ask participants questions related to their physical and psychosocial health and endometriosis. Definitions used are in line with RANZCOG definitions of chronic pelvic pain and infertility.

*Social media and heath information* – Questions 12 through to 20 ask participants specifically about their use of social media with regards to endometriosis. This is the most comprehensive section of the survey and explores the relationships between social media use and patient reported outcomes. Participants will be defined as users of social media for the purpose of prevalence calculation if they answer yes to question 13 ‘Have you ever used social media to see health information/support for endometriosis?’ Initial questions in this section identify frequency of use, platforms participants engage with and general behaviours online. Question 19 employs a 5-point Likert scale to further investigate secondary study outcomes.

*Gaps in information services* – the final question provides participants an opportunity to identify patient perceived gaps in current information provision.

Data analysis methods include descriptive statistical analysis, frequency counts, as well as cross-tabulation to examine any statistical association between variables. Analysis will involve comparing categorical outcomes using Chi squared tests and comparing continuous variables using t-tests. If the data does not have a normal distribution a non-parametric tests such as the Mann Whitney U test will be used. P value of <0.05 will be considered significant. Responses to free text answers will be qualitatively analysed using deductive-inductive semantic thematic analysis. This approach allows for the identification of common themes across the dataset and therefore closely reflects the data and language used by participants.

Information from this study will contribute to the current evidence surrounding the possible therapeutic role of social media as a self-management strategy for endometriosis. The results will help heath care providers better understand the online health information and support seeking behaviours patients. Additionally, the study aims to inform the need for development of a Royal Women’s Hospital social media presence specific to endometriosis or development of written patient information about the topic including online resources.

**Setting:**

* This is a single center study performed by the benign Gynaecology Units and specialist clinics at the at The Royal Women's Hospital, Melbourne, Victoria. Australia
* The Royal Women’s Hospital is a tertiary level Obstetrics and Gynaecology hospital located in one of Australia’s capital cities. The benign gynaecology units at the hospital include Gynaecology 1 Unit, which has a focus on heavy menstrual bleeding and fibroids; and the Gynaecology 2 Unit, with a focus on minimally invasive surgery and specifically endometriosis. The Chronic Pelvic Pain clinic is a multi-disciplinary service for women with complex pain issues.

**Participants:**

Study participants will be women with a confirmed diagnosis of endometriosis engaged with the Gynaecology 1 or 2 teams at the RWH. Women will be recruited via the outpatient clinical setting in clinics, primarily the Gynaecology 1 and 2 post-operative clinics, general clinics and the specialised chronic pain clinic. Women do not have to be users of social media to participate. As investigators are wishing to collect data on prevalence, both use and non-use of social media will be important information to be captured. Women may be approached and asked to participate by clinicians including consultants, registrars or residents, research assistants or clinical nurses. A flier will be made highlighting potentially appropriate participants and attached to the front of their chart by the lead investigator prior to commencing clinic to aid recruitment (appendix 2).

An additional method of patient recruitment will occur via phone contact. Gynecology 2 theatre lists and team audit data for the last 6 months will be reviewed by the lead investigator. Possible study participants will be identified if they meet the following criteria:

1. They are a patient of the Gynaecology 2 unit, RWH
2. They had surgery within the last 6mths
3. They had a surgical diagnosis of endometriosis

These women will then be contacted by phone by the lead investigator and offered to participate in the study. This will be done during allocated research/teaching time in business hours. A standardised script will be used (appendix 3). If women agree to participate, an email link to the study can be sent via the Women’s health research email-SMS service.

**Inclusion criteria:**

Women ≥ 18yrs of age

Confirmed diagnosis of endometriosis via surgical visualisation or histological diagnosis.

* This can be a pre-existing diagnosis prior to engagement with the RWH.

A minimum 6 week timeframe since the confirmed diagnosis was given to the woman

**Exclusion criteria:**

Non-consent

Non-English speaking

Women with undiagnosed pelvic pain

Other gynaecological/non-gynaecological causes of pelvic pain without a diagnosis of endometriosis

**Sample size calculations:**

This is an observational study to collect data primarily on prevalence of social media use for health information sharing and support. There is currently no prevalence data reported in literature surrounding the use of social media in either for chronic pain self-management or specifically in women with endometriosis. Previous studies used participant numbers from 69 through to 231; however only recruited people who identified as users of social media/online support groups. As no previous data on this topic has been collected a sample size of 100 participants would be sufficient to provide insight into this area. This is based on sample size calculations using prevalence of 0.5 and precision 0.1 values.

**Study timeframe:**

The majority of patients will be recruited through the Gynaecology 2 Unit which operates on 5-10 cases of endometriosis per week. The targeted clinics include General Gynaecology 1 and 2 clinics and post-operative clinics, each of which is held once a week. The number of women seen in these clinics range between 30-40; with at least 10 per clinic likely to meet inclusion criteria. Additional patients will be approached in chronic pain clinic and via phone. The survey only needs to be done as a once off participation event and therefore high rates of survey completion are predicted. With a conservative estimate of 25% of approached women completing the survey, recruitment of 100 participants is expected to be achieved over a six-month period. Data entry will occur concurrently with recruitment, with a further 3 months allocated to analysis of results. Therefore, a generous timeframe for completion of the study would be 12 months.

**Study flow chart**

Patient meets inclusion criteria

No Yes

Patient not included Patient offered to participate in study

 No Informed consent obtained

 Yes

 Patient reads and accepts PICF

Patient completes questionnaire

Data analysis

**Potential bias:**

Selection bias

* The use of technology such as SurveyMonkey on an electronic device may potentially select those participants who are more computer literate. Providing the option of completing the survey via paper copy aims to reduce this effect
* Recruitment of participants from the Royal Women’s Hospital only may limit the overall generalisability of results to the wider community. We aim to decrease this bias by recruiting women through both the gynaecology 1 and 2 teams and the specialist chronic pelvic pain clinic. This provides access to women from a wide referral net in the broader community.

**Confidentiality and data protection:**

Consenting participants will be allocated a unique patient identifier and all data will be recorded in this de-identified manner. All information will be kept secure: all paperwork from the project will be kept in a locked room and all computerized information will be kept in a database that is password protected. All information will be kept for a period of 7 years after the project is completed, at which time hard copy records will be shredded and computer files deleted by the current Gynaecology 2 Senior Registrar. In any publication, information will be provided in such a way that participants cannot be identified. This will be ensured by providing summarized data or else by referring to individual results by their study number.

Access to SurveyMonkey’s technology resources is only permitted through secure connectivity (e.g., VPN, SSH) and requires multi-factor authentication. SurveyMonkey’s information systems and technical infrastructure are hosted within world-class, SOC 2 accredited data centers. Physical security controls at the data centers include 24x7 monitoring, cameras, visitor logs, entry requirements, and dedicated cages for SurveyMonkey hardware.

**Funding:**

Nil funding has currently been sourced for the completion of this trial. A research grant application has been made to AGES for this study, the outcome of which is pending. Registrars participating in the trial are allocated paid research time as part of their employment agreement.

**Conflict of interest:** None declared

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