van den Haspel Kelly (Orcid ID: 0000-0002-7799-626X)
Reddington Charlotte Caroline (Orcid ID: 0000-0003-1030-6807)

ANZJOG Title Page

Title: The role of social media in management of individuals with endometriosis: a cross sectional study.

Running title: Social Media and Endometriosis

Investigators:

Dr Kelly VAN DEN HASPEL (corresponding author)

Royal Women's Hospital, Parkville, Melbourne

Obstetrics and Gynaecology

6 Didsbury Street, East Brisbane 4169

+61 400370801

kvandenhaspel@gmail.com

ORCID ID https://orcid.org/0000-0002-7799-626X

Dr Charlotte REDDINGTON

Royal Women's Hospital, Parkville, Melbourne

University of Melbourne, Department of Obstetrics and Gynaecology, Australia

A/Prof Martin HEALEY

Royal Women's Hospital, Parkville, Melbourne

University of Melbourne, Department of Obstetrics and Gynaecology, Australia

Dr Rebecca LI

Royal Women's Hospital, Parkville, Melbourne

Obstetrics and Gynaecology

Dr Uri DIOR

Hadassah-Hebrew University Medical Centre, Jerusalem, Israel

Dr Claudia CHENG

Royal Women's Hospital, Parkville, Australia

University of Melbourne, Department of Obstetrics and Gynaecology, Australia

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Abstract

Background: To better understand the potential role of social media (SM) as a self-management tool for individuals with endometriosis and to assess its current use by endometriosis patients.

Aims: The primary outcome was use of SM for health in patients with endometriosis. Secondary outcomes included preferred SM platforms for health information sharing and factors that influenced use, positive and negative experiences and reported impacts on health.

Materials and Methods: A single centre, cross sectional study performed within benign gynaecology units at a tertiary hospital in Melbourne, Australia. One hundred patients with a confirmed diagnosis of endometriosis participated. Individuals did not have to be users of social media. Data was collected through an electronic third-party survey tool (SurveyMonkey®). Analysis methods included descriptive statistical analysis, frequency counts, as well as cross-tabulation to examine statistical association between variables. Free text responses were qualitatively analysed using deductive-inductive semantic thematic analysis.

Results: SM was used for health in 76% of patients with endometriosis in this study. SM users were younger, had pelvic pain for more than six months and report higher rates of psychosocial impact and symptoms from endometriosis. Respondents reported overall positive impacts on psychological, social and cognitive health outcomes (76%) from SM use.

Conclusion: In our cohort, a high number of people with endometriosis are using SM for health. These individuals are more likely to suffer both physical and psychosocial impacts from endometriosis. Hospitals and health organisations may consider support of the endometriosis community through SM.

Tweetable abstract: *Social media has a role as a beneficial self-management tool, and is already being used by individuals with endometriosis.*

Introduction

More than 830,000 individuals are affected by endometriosis in Australia - a chronic, potentially debilitating condition impacting the quality of life of one in every nine Australian women aged 18–44 years [1]. Sufferers often describe a lack of support and encounter feelings of social isolation, embarrassment or fear of symptoms not being believed [2, 3]. Finding understanding and knowledgeable contact networks can be challenging [4]; the Internet therefore becomes a key resource for seeking support and information [5]. Online support groups and social media have been proposed as a potentially beneficial self-management strategy for chronic pain conditions, helping with provision of emotional support, instilling hope, fostering empowerment and reducing feelings of isolation [6, 7].

Social media (SM) is an umbrella term referring to websites and applications that enable users to create and share content or participate in social networking [8]. The reach of these platforms is undeniable, with Facebook reporting 2.7 billion monthly active users in 2020 [9]. There are numerous endometriosis support groups on Facebook, and Instagram hashtags such as #endowarrior and #endometriosisawareness have propelled endometriosis into the public eye and conversation. SM is providing individuals living with endometriosis new opportunities to seek support, information and connectivity online. The aim of this study was to assess the use of health SM in individuals with endometriosis, and to clarify preferred SM platforms for health information sharing. Additionally, factors that influence use, online behaviours, positive and negative experiences and reported impacts on health were investigated.

Materials and methods

This was a single centre, cross sectional study performed at a tertiary hospital in Melbourne. It was approved by the Royal Women's Hospital Human Research Ethics Committee (Project number 19/23). Participants were recruited from outpatient and post-operative clinics of a gynaecology unit that has a focus on endometriosis and pelvic pain. This unit sees on average 940 new patients and performs 400 laparoscopies for endometriosis or pelvic pain annually. Included were participants aged 18 or above with a confirmed diagnosis of endometriosis via surgical visualisation or histological diagnosis and a minimum 6-week timeframe since surgery.

We excluded non-English speakers and individuals with undiagnosed pelvic pain or with other gynaecological and non-gynaecological causes of pelvic pain who did not have endometriosis. Individuals with a confirmed diagnosis of endometriosis completed an electronic questionnaire, via a third-party online survey tool (SurveyMonkey®) on their own devices. Participants did not have to be users of social media to participate and could complete a paper-based survey if requested. The questionnaire was modelled on a global online survey of regarding SM use in people with chronic pain by Merolli et al [7]. This was a robust survey building on previous studies in the domain and validated survey models. Questions covered demographic and health information, use of a Likert scale to address statements regarding SM use and free text responses addressing research questions and allowing a mixed-method analysis. Patient information and consent forms were completed before commencement of the survey, see supplementary material.

The primary outcome of this study was to assess the use of SM use for seeking health information and support in individuals with endometriosis. Secondary outcomes included identification of SM platforms used for health information sharing, frequency of access, online behaviours, positive and negative experiences on SM, patient or disease factors that influence use, reported impacts on health from SM use and any gaps in information and services.

Statistical Analysis

Data analysis methods included descriptive statistical analysis, frequency counts and univariate Firth logistic regression to assess all variables when comparing SM users versus non-users. A P value of <0.05 was considered significant. SPSS 27.0 (SPSS Inc., Chicago, IL, USA) and STATA 16 (Stata Corporation, College Station, TX, USA) were used for data analyses. Responses to free text questions were qualitatively analysed by the first author using deductive-inductive semantic thematic analysis, allowing for identification of common themes across the dataset, therefore closely reflecting language used by participants Transcripts were read a number of times and initial ideas about data transcribed. Next key words were identified and grouped together by common themes. These themes were then reviewed and refined to capture key messages, sentiment and ideas expressed by participants, including use of direct quotes. A sample size of 100 respondents were chosen as very limited data surrounding prevalence of SM use in this particular cohort has been documented.

Results

Demographics, Health Characteristics and Social Media Use

Data was obtained from 118 participants from December 2019 - July 2020. Five were excluded due to being non-English speaking and 13 excluded due to significant missing data, leaving 100 subjects. The majority identified as female, with one identifying as non-binary/female. Age range varied from 19 to 50 years of age (median 30.0). Seventy-three percent (73/100) were married or partnered and 76% (76/100) reported having a post-high school qualification. Work status was predominantly employed, with about half, 51% (51/100), working full time. Of the 21 participants not working for pay, 90% (19/21) indicated that endometriosis was a contributing factor.

The majority of participants reported accessing general SM sites more than once per day (75% 75/100), with another 15% (15/100) reporting once daily use. Of the 100 participants, 76 stated they have used SM to seek health information and support regarding their endometriosis. Table 1 compares demographic information between users of health SM (76/100) and non-users (24/100).

Of 76/100 participants using SM for health, 10% (7/76) reported daily use, 31% (23/76) weekly, 27% (20/76) monthly and 32% (24/76) less than once a month. Table 2a outlines the distribution of SM platforms used for endometriosis. A flare up in endometriosis symptoms was a driving factor for increased frequency of use reported by 62% (47/76) of respondents. Activity across SM platforms related to endometriosis was varied, with both passive (e.g. reading or liking others posts) and active behaviours (e.g. connecting with others or posting information) displayed in Table 2b.

Qualitative data and Feedback on SM use

Data collected from Likert 5-point scale statements and free text responses were used to answer research questions about how health SM users describe their use, online behaviours, positive and negative experiences, reported impacts on health and gaps in information. Table 3 outlines themes from the qualitative data and key descriptive language used by respondents. The final themes identified were connection, education and narration.

Content on SM about endometriosis had been viewed by 92% (70/76) of respondents who used SM for health. More than half 55% (42/76) reporting they had given or shared personal advice or stories; 49% (37/40) had received advice. The majority 76% (58/76) reported positive experiences on SM with regards to endometriosis. Connection was the most commonly cited theme, predominately feeling less alone, the importance of community and connecting to other sufferers. The word "alone" was the most frequently used word in free-test responses. Half (38/76) reported they liked to connect/form relationships with other women suffering endometriosis on SM, and 80% (61/76) felt empowered seeing women share their stories, falling under the theme of narration. "I like feeling connected to other women who also suffer from endometriosis. It gives me a sense of belonging to connect with other women in the same position I am, and helps to hear other people's stories" [respondent 1].

Feelings of support, encouragement, reassurance and understanding were reported by 87% (66/76). Within the theme of education, a positive impact on cognitive health was expressed by numerous respondents, encompassing an ability to take in new information, learn, understand, aid real-life decision making and improve disease specific knowledge. Users felt seeing posts and communicating online about endometriosis raises awareness about the disease for the general public 89% (68/76). Accessibility was another positive, being able to connect with people on a global platform at flexible times. "I have access to a community sharing their experiences available on a platform I can access when it suits me. It allows me to consume a vast variety of health-related content at my leisure" [respondent 47].

A number of negative aspects of health SM were reported, with a key concern surrounding misinformation highlighted by 32% (24/76) of participants. Many responded that they had seen incorrect or biased information posted and worried users may be left ill-informed 49% (37/76). Some indicated that frequent use can also lead to distress, particularly when reading about others' negative experiences. Feeling sad or upset by seeing other individuals' stories on SM was reported by 49% (37/76) of participants. One woman stated that access to so many people actually negated the support she was seeking: "I made a post in a time of desperate need, as I felt I had nowhere to turn to and no one that would understand. Unfortunately, this post went unanswered/unseen/missed in the masses of posts on the page, and I was left feeling lost" [respondent 85]. False advertising on SM platforms, including advertising for "endometriosis cures" including specific diet and exercise plans, devices and medications, most with no evidence-based foundations was reported in free-text responses. Negative interactions including feeling bullied or attacked was reported by 1.3% (1/76), and 24% (18/76) raised concerns regarding privacy.

Participants reported an overall lack of available endometriosis information on SM, 90.8% (69/76) agreeing or strongly agreeing that they would follow a hospital/medically run SM platform regarding endometriosis. Key areas of lacking information highlighted included diet, exercise and lifestyle advice, pain management strategies including non-medical alternatives and mental health support. SM impacted real-life decision making/treatment for 40% (30/76) of respondents. Participants also expressed the desire for links to real life resources and often expressed wanting access to evidence-based resources and to read about new advances and clinical research.

Discussion

The main outcome of this study was that SM use for health in individuals with endometriosis was extremely common with 76% reporting use within our cohort. More than 80% of

Internet users browse online for medical support and information; with SM rapidly emerging as platforms on which to find medical knowledge. The ability to share personal vignettes and engage with other users contribute to their appeal and utility [10].

Demographic data from our cohort reflected young women, predominantly in relationships, who were well-educated and employed. Of the proportion not working for pay, the majority attributed this to endometriosis. Multiple studies report negative impacts on social life, work, daily activities as well as education, finances, life opportunities, personal relationship quality and physical intimacy as a result of endometriosis [2, 3]. Most participants were users of general SM and displayed a high level of internet literacy. This demographic profile was not unexpected, given that endometriosis mainly affects reproductive aged individuals and symptoms often begin in adolescence.

Our study showed that individuals who were more symptomatic of endometriosis physically and psychologically were more likely to be users of health SM. It is recognised that psychological wellbeing is an important pillar in chronic pain management, with many interventions focused on this aspect of care [10], this is equally true in long term management of people with endometriosis. Young individuals who are suffering high levels of psycho-social burdens from endometriosis are potentially vulnerable to misinformation, highlighting the importance of being able to access accurate, evidence-based health information.

The identified themes from qualitative data analysis of connection, education and narration highlight the psychosocial health domains that can potentially be impacted by SM use. Positive impacts on “emotional stressors” was the most commonly referenced health outcome. This included mitigating loneliness, building community, the emotionally therapeutic effect of sharing stories and experiences online and connecting to a shared narrative. Improving disease specific knowledge has been recognised as a strategy to aid self-management of chronic conditions, including endometriosis [12]. Several other studies report improved social well-being and empowerment from SM interventions and engagement, especially during times of increased social isolation such as during the current Covid 19 pandemic [7, 11]. Use of SM did not always foster positive health outcomes. Consuming a large volume of negative narratives left some participants feeling overwhelmed, depressed and anxious regarding their own diagnosis and situation.

Participants in this study indicated a preference for social networking sites (SNS). Facebook being the predominant SNS, hosts several disease-specific support groups. Its ease of access and familiarity in day-to-day use has direct clinical relevance and make it an easy starting point for both patients and health services to potentially access and deliver information and support for endometriosis. A recently study published in JMIG 2021 concluded that Facebook pages offer emotional support and education to people with endometriosis, and most information found on these pages is evidence based [10].

Strengths

The main strength of this study was the survey design. It was based on previously conducted validated survey models in this field specifically targeted at patients with chronic pain [7]. This helps make the findings comparable and add to the body of information in this area and improve the understanding of the role of SM specific to the endometriosis population. The survey was short and able to be completed in less than 15mins, resulting in a high completion rate. This also mitigated survey fatigue which can be an issue in longer questionnaires and result in missing data due to skipped questions.

Limitations

Participants involved in this study may represent a self-selecting population with a higher-than-average SM use and level of internet literacy. During recruitment, it was specifically stated that individuals did not have to be users of SM to participate. However, those willing to participate in a study about SM may already be more enthusiastic about the topic. The sample size of only 100, and lacking data regarding the total number of patients offered participation in the study means an accurate calculation of true prevalence is not possible. However, to our knowledge, this is the first study to look at SM use in this targeted group of endometriosis patients and can be built upon in subsequent studies.

In our cohort, a high proportion of individuals with endometriosis are using SM for health information with mainly positive experiences. Users of health SM reported higher physical and psychosocial impacts from endometriosis. Most stated they would follow and engage with hospital run social media content related to endometriosis. SM is already influencing real-life decision making and management for a number of individuals in this cohort. These findings support the potential role of SM as a widely accessible self-management tool for hospitals/heath organisations to disseminate accurate health information and support the endometriosis community.

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Appendices

Table 1: Comparing demographics/health information of users of SM vs non-users (n=100)

Variable	**SM health users (n=76)**	**Non-users (n=24)**	**Odds ratio[1] of SM users**	**95% CI**	**P value**
Age in years, mean (SD)	30 (7)	33 (7)	0.93	0.88-0.99	0.047*
Single (vs partnered), n(%)	21 (28%)	6 (25%)	1.10	0.40-3.07	0.85
Education level					
Year 10	5 (7%)	0 (0%)	3.73	0.20-70.58	0.38
Year 12	14 (18%)	5 (21%)	0.89	0.30-2.71	0.84
Post-high school	57 (75%)	19 (79%)	Referent		
Employment					
Full time	41 (54%)	10 (42%)	Referent		
Part-time/casual	17 (22%)	11 (46%)	0.39	0.14-1.05	0.06
Not working for pay	18 (24%)	3 (13%)	1.34	0.35-5.05	0.67
General SM use †					
Multiple times/day	60 (79%)	15 (63%)	Referent		
Once/day	10 (13%)	5 (21%)	0.49	0.15-1.58	0.23
Once/week	3 (4%)	1 (4%)	0.60	0.08-4.38	0.61
Once/month	1 (1%)	0 (0%)	0.77	0.03-19.80	0.87
Rarely	1 (1%)	2 (8%)	0.15	0.02-1.26	0.08
Never	1 (1%)	1 (4%)	0.26	0.03-2.64	0.25
Time from endometriosis diagnosis	18 (24%)	7 (29%)	Referent		
<6mths	15 (20%)	7 (29%)	0.84	0.25-2.83	0.78
6-12mths	24 (32%)	6 (25%)	1.53	0.46-5.13	0.49
1-5yrs	9 (12%)	3 (13%)	1.10	0.25-4.89	0.90
5-10yrs	10 (13%)	1 (4%)	2.84	0.42-19.16	0.28
>10yrs					
rASRM stage ‡					
Min/mod (stage 1-2)	17 (22%)	5 (21%)	Referent		
Mod/severe (stage 3-	30 (39%)	9 (38%)	1.01	0.30-3.36	0.99
4)	29 (38%)	10 (42%)	0.88	0.27-2.90	0.84
Unknown					
Symptoms					
Dysmenorrhoea	71 (93%)	16 (67%)	6.70	2.02-22.21	0.002*
HMB	52 (68%)	11 (46%)	2.52	1.00-6.32	0.05
Infertility	17 (22%)	5 (21%)	1.04	0.35-3.09	0.94
Dyspareunia	53 (70%)	11 (46%)	2.67	1.06-6.73	0.04*
Bladder/bowel	51 (67%)	10 (42%)	2.79	1.11-7.04	0.03*
Pelvic pain >6mths	58 (76%)	13 (54%)	2.69	1.05-6.93	0.04*
Psychosocial impacts	46 (61%)	6 (25%)	4.34	1.59-11.84	0.004*
Depression	50 (66%)	11 (46%)	2.24	0.90-5.59	0.09
Anxiety	52 (68%)	8 (33%)	4.16	1.60-10.83	0.003*

Low self-esteem/body image	34 (45%)	4 (17%)	3.70	1.21-11.28	0.02*
Social isolation	29 (38%)	5 (21%)	2.20	0.77-6.30	0.14
Embarrassment	57 (75%)	10 (42%)	4.07	1.58-10.49	0.004*
Emotional distress	44 (58%)	7 (29%)	3.19	1.21-8.41	0.02*
Relationship stress	50 (66%)	7 (29%)	4.45	1.68-11.80	0.003*
Negative work impact					

*statistically significant $p = <0.05$

[1] odds ratio derived from univariate logistic regression

† for reasons other than health

‡ revised American Society for Reproductive Medicine score (rARSM)

Table 2a. Social media platforms used by women specific to endometriosis

Platforms	**“Yes” to use, n (%)**
Social networking sites e.g. Facebook	63 (83)
Blogs	36 (47)
Wikis e.g. Wikipedia	17 (22)
Microblogs e.g. Twitter; Tumblr	7 (9)
Tagging/aggregation sites e.g. Digg; Reddit	7 (9)
Video sharing sites e.g. Youtube; TikTok	28 (37)
Photo sharing sites e.g. Instagram; Flickr	30 (40)
Discussion forums/message boards	36 (47)
Chat rooms	5 (7)
Virtual environments e.g. Second life	2 (3)
Other	4 (5)

Table 2b. Online activities on social media in relation to endometriosis

Activity	**N (%)**
Status update	20 (26)
Post to someone’s profile/page	10 (13)
Like a comment/post	51 (67)
Comment on someone’s post/content	36 (53)
Tag content	19 (25)
Private message	31 (41)
Add friend/connection	18 (24)
Chat	24 (32)
Other	17 (23)

Table 3. Key themes and descriptive language used in free text responses

Theme†	Language
Connection	Talk Advice Alone Support Friends Community Understanding Engagement Support Exchanging advice Forming relationships Isolation Accessibility Freedom of access
Education	Find Learn Discover Understanding Awareness
Narration	Stories Sharing experiences Reassurance/validation Competition Comparison Negativity Sad

†Repeated, commonly used words used in free text answers were collected by the first author after numerous reviews of responses. These were then grouped together and common themes identified.