

Therapeutic affordances of online support group use in women with endometriosis

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Background: The Internet has provided women living with endometriosis new opportunities to seek support online. Online support groups may provide a range of therapeutic affordances which may benefit these women.

Objective: To examine the presence of therapeutic affordances as perceived by women who use endometriosis online support groups.

Methods: Sixty-nine women (aged 19 to 50 years; Mean = 34.2; 65.2% UK; 21.7% USA) participated in an online interview exploring online support group use. Participants had been using online support groups on average 2 years and 4 months (Range = 1 month to 14 years, 9 months). Responses were analysed using inductive thematic analysis.

Results: The analysis revealed 4 therapeutic affordances related to online support group use; i) “connection” i.e. the ability to connect in order to support each other, exchange advice, and to try to overcome feelings of loneliness; ii) “exploration” i.e. the ability to look for information, learn and bolster their knowledge; iii) “narration” i.e. the ability to share their experiences, as well as read about the experiences of others; and iv) “self-presentation” i.e. the ability to manage how they present themselves online. The associated outcomes of use were predominantly positive, such as reassurance and improved coping. However, a number of negative aspects were revealed including: concerns about the accuracy of information, arguments between members, over-reliance on the group, becoming upset by negative experiences or good news items and confidentiality of personal information.

Conclusions: Our findings support the SCENA model (Self-presentation, Connection, Exploration, Narration and Adaptation) proposed by Merolli et al., (2014) and reveal a range of positive aspects that may benefit members, particularly in relation to reassurance and coping. However, negative aspects need to be addressed in order to maximise the potential benefit of support groups. Some of these can be addressed relatively easily through making privacy policies clearer, including health

professionals to moderate content and structuring forums to encourage the sharing of positive stories.

Introduction

Endometriosis is a chronic condition that affects women of reproductive age. It is defined as the presence of endometrial like tissue outside of the uterine cavity, which induces a local inflammatory response [1]. Common symptoms include chronic pelvic pain, dysmenorrhoea, fatigue, heavy menstrual bleeding and dyspareunia. Estimates of the prevalence of the condition range between 2 and 17% of the female population [2], however the prevalence can rise to up to 47% in women with fertility issues [3]. Women typically experience a delay before diagnosis [4-6] with long term care focussed on symptom management [7-8]. Psychosocial impacts are also common, including high levels of depression and anxiety [9-11], emotional distress [12,13] and poorer quality of life [9,14]. Endometriosis can negatively impact on social life, work and daily activities [15-17] as well as education, finances, life opportunities [18], personal relationship quality [8] as well as physical intimacy [19].

Women living with endometriosis typically need considerable support to meet the various challenges associated with the condition [20] and access to it may yield benefits through a reduction in illness-related stress [21] and improvements in well-being [22]. However, women with endometriosis often describe a lack of support [23,24], encounter feelings of social isolation [13] and find it difficult to disclose their condition and symptoms to others due to embarrassment or a fear of not being believed [16]. It can be difficult for these women to find an understanding and knowledgeable source of support, especially as the support may be needed for many years [20]. Finding other women with endometriosis, who understand the constant struggles, is therefore potentially a valuable source of support for them [16,20]. However, women often lack contacts with other women with the condition [23], or they may be unable to attend local support groups, should any exist, due to pain restrictions. The Internet therefore becomes a key resource when seeking the support of other women living with endometriosis [16,20].

Over recent years, the popularity of using the Internet for information and support has been growing; in 2013, 43% of adults in the UK [25], and 72% in the US [26] accessed health information online. Furthermore, 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 [26]. The

popularity of using the Internet for such purposes maybe explained by its flexibility; it does not have the same restrictions as face-to-face support groups with regards to set times or locations [27]. The lack of face-to-face contact can also help users to feel less inhibited and talk openly about embarrassing topics [28] or stigmatised health conditions [29].

Previous research has suggested that women with endometriosis do find the Internet to be a valuable source of information regarding both the condition and its medical management [30,31]. To date however, there is a lack of research into the use of online support groups for endometriosis. In contrast, research exploring the role of online support groups across other long-term conditions has been extensive, and has found their use to have benefits including the provision of emotional support [32], instilling hope [33], fostering empowerment [32,34] and reducing feelings of isolation [35].

However, although such benefits are common, there can also be negative aspects of online support group use. Research has indicated that their use can lead to distress, particularly when reading about other's negative experiences [35]. Users can also become obsessed with the groups [35], or display disinhibition due to the anonymous interface of the groups [28]. Furthermore, there is a risk that the medical information that is shared online is potentially inaccurate [36].

In order to understand how the use of online support groups might influence the outcomes of those living with endometriosis, the present study will consider the therapeutic affordances of online support group use. The origins of affordance theory stem from perceptual and cognitive psychology, and are based on how individuals perceive the objects in their environment; pertaining to both what the object is, and what potential uses it affords [37]. The properties of an object will therefore contribute to its perceived affordance. Furthermore, the differing experiences, beliefs, and goals of an individual will lead to different perceived affordances, and so affordances are unique to each individual [38]. The emphasis in the theory is on the interaction between the user and the object and its resulting outcomes.

Therapeutic affordances can therefore be seen as the 'actionable possibilities' of the object as determined by the user [39] and the object in this instance is online support groups. Studying therapeutic affordances allows us to look at both the uses and effects of online support groups. This research will therefore provide further insight into the use of online support groups than previous research, as it will examine the underlying mechanisms that drive the observed effects and outcomes of support group use [39].

Previous research on therapeutic affordances within a health context is lacking. However, Merolli et al. [39] examined the therapeutic affordances of social media use in people with chronic pain. They identified five therapeutic affordances of social media; self-presentation, connection, exploration, narration and adaptation. The results highlight both the 'actionable possibilities' of social media use, i.e. connection, and the therapeutic value of such, i.e. not feeling alone. This work will provide a good point of comparison for the current study, however there are important differences such as the health condition being studied and the different 'object'. Online support groups have different properties than social media, and therefore may enable different affordances. Specifically, online support groups tend to use an asynchronous discussion forum format, through which individual group members can post messages to start new conversations, or reply to messages within existing conversations, thereby creating a tree like structure of discussion threads.

The aim of the current study therefore is to explore the therapeutic affordances of online support group use in women with endometriosis and the resulting outcomes. The results of this research will yield a richer understanding of both the therapeutic benefits of online support groups, as well as the needs of women living with endometriosis.

Method

Procedure

This research involved the recruitment of women (aged 16 or over) who use online support groups for endometriosis. They were recruited through messages posted onto the boards of such support groups, during a 4-week recruitment period from 16th June to 13th July 2015. In order to identify potential recruitment channels, searches were conducted on Google, using terms such as "online support group endometriosis" and "endometriosis support group", as well as similar searches on Facebook. The groups that appeared to be the most recently active (some had been dormant for a number of months) were selected as potential recruitment channels.

Initial contact was made with the board moderators to seek permission to recruit their group members via a message posted onto the boards of the groups. It was made clear to the moderators that the research focused on women's experiences of using such groups, and they were given the opportunity to review the message prior to posting. Once permission was granted, the recruitment message was posted, which explained the aims of the study and invited those interested to click on a link to the survey, hosted by Bristol Online Surveys. There was a degree of variation in the final

boards used for recruitment, having one general endometriosis online support group, one hosted by an online fertility support group, and one group hosted by Facebook.

When directed to the survey page, participants were provided with additional information about the study, and they were then required to complete a consent form before beginning the survey. Participants first completed a series of short answer questions relating to their background (date of birth, country of residence, diagnostic status etc.) and use of online support groups (frequency, period of use). Next, they were invited to respond to a set of open-ended questions that explored their motives and experiences of using online support groups, and whether their use has any impact on how they cope with or manage the condition.

Data analysis

In order to provide a rich account of the data, the responses to the open-ended questions were qualitatively analysed using deductive-inductive semantic thematic analysis [40]. This analysis approach allows for the identification of common themes across the dataset, and therefore closely reflects the data and the language used by participants. This is particularly important given the aims of the present study.

The analysis was carried out by the first author (AS) according to the guidelines proposed by Braun and Clarke [40], and QSR's NVivo 10 software was used in order to maintain an audit trail. Firstly, to become familiarised with the data, the transcripts were read and re-read several times and initial ideas about the data were noted down. Next, interesting features of the data were coded, keeping codes close to the language used by participants where possible. Codes were then organised into meaningful groups to form potential themes. Codes that appeared consistently throughout the data were automatically considered as a potential inductive theme. Data relevant to each potential theme was gathered, and then themes were reviewed, refined and given a clear definition and name. Reviewing the common language used in these themes allowed them to be organised into the final therapeutic affordances. To reduce bias and check whether the themes reflected the data, an independent researcher read through some of the transcripts and agreement was reached on the final themes.

Ethical Considerations

Prior to data collection, the research was reviewed and approved by the University of Nottingham (UK) institutional ethics review committee. In order to maintain ethical requirements, participants

were provided with full study information that informed them of their rights as a research participant, procedures of withdrawal and full contact details of the researchers. Before beginning the survey participants were required to complete an online consent form indicating that they understood such rights. They were each asked to provide a unique password to allow for their data to be withdrawn if they so wished after survey completion, and given a timeframe within which they could withdraw. They were informed that in order to maintain privacy and confidentiality, no personally identifiable information would be reported in the results. Furthermore, they were able to indicate during consent if they were happy for their responses to be quoted in research reports (3 participants chose not to have their responses quoted). In order to meet ethical requirements, quotes provided in the report only identify participants by their responder number (i.e. resp. 17).

Results

In total, 69 participants completed the online survey. The respondents were aged between 19 and 50 years old, with a mean age of 34.2 years, and the majority were residents of the United Kingdom (65.2%) or the USA (21.7%). 66 of the respondents (95.7%) had received a confirmed diagnosis of endometriosis, which was made between 1 month and 20 years prior to survey completion (mean time since diagnosis = 4 years 1 month). Participants had been using online support groups for endometriosis for between 1 month and 14 years 9 months (mean use period = 2 years 4 months), and the majority of participants (59.4%) accessed the groups more than 5 days a week.

Following deductive-inductive thematic analysis, the therapeutic affordances that were present in the data were “connection”, “exploration”, “narration” and “self-presentation”. Quotes were largely positive however participants did pertain to some negative aspects afforded by online support groups. Table 1 describes the inductive themes that emerged from the data analysis within each affordance, and the key language used by participants.

Table 1. Final therapeutic affordances, inductive themes and descriptive language

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Connection

The most frequently cited affordance of online support groups was the ability to connect with others, and participants used this connection to support each other, exchange advice, and to try to

overcome feelings of loneliness. They benefited from the freedom to connect to a large number of individuals, and at all hours of the day or night.

Participants frequently commented on their ability to connect with other women who have endometriosis through the online support groups. They demonstrated a sense of relief at finding those who 'understand' what they are going through: '...to be able to connect with others suffering the same just gives you some piece of mind.' (resp. 28) and '...having a place to speak freely with people who completely understand & offer love, encouragement & advice is a great help at times of need.' (resp. 11). Finding an understanding support network had also significantly helped women to cope with the condition: 'After years of struggling with GP's finding other people who understood played a huge part in making me feel normal again.' (resp. 25) and 'I think one of the reasons I haven't had a nervous break down or gotten depressed is because of the groups. I have people who understand what I'm going through and can give me advice.' (resp. 10).

Participants spoke positively of the support they were able to offer each other through online support groups: 'The support is great.' (resp. 29) and '[I] have found the support online invaluable.' (resp. 4). In some instances, this support had a marked impact on women's lives, enabling improved coping and confidence in seeking better treatments: '...talking through some of the darker times with women who know what I'm going through has been hugely helpful and I feel I am coping better than I was before.' (resp. 16), 'I also received support from lots of ladies when I didn't know how to make myself heard...' (resp. 32) and 'I am also going to ask to be referred to a specialist because of support from others on this forum.' (resp. 5).

Receiving support was described by many as a key motivation for online support group use. However, some women also talked favourably about providing support to others, finding the process to be rewarding, and even of psychological benefit: 'I feel I can provide some help & support to the ladies because I have a lot of experience...' (resp. 11) and '...the rewarding feeling following directly supporting others has improved my mental wellbeing...' (resp. 16).

A large number of participants spoke about how online support groups had allowed them to share advice, either on general matters, or those related to treatments or self-management behaviours. Participants often used words such as 'appreciate' or 'valuable' when talking about advice received from others: 'The advice and support received is invaluable...' (resp. 25), 'I also really appreciate the advice and support these groups offer.' (resp. 27) and 'I have had valuable advice on symptom relief,

side effects of treatments, post op care etc etc.’ (resp. 51). Women also found it helpful to provide advice to others, experiencing a positive feeling from doing so: ‘...I feel like it is helpful to me to be able to help other women, with comments and advice.’ (resp. 13).

Advice in general was gratefully received, although some participants expressed caution at the medical advice shared through these platforms: ‘...I’m not going to take medical advice through Facebook.’ (resp. 42). Some indicated that although they do read the advice, they would usually ultimately check it with their medical professionals and follow their advice: ‘I feel that the online group helps answer any questions... but I have always gone ahead with what I thought or the medical staff say.’ (resp. 33) and ‘I do listen to the advice but in the end I usually go with what my consultant suggests even if it’s not what I want.’ (resp. 67).

The most frequently occurring theme within “connection” was that of mitigating isolation; the online support groups had allowed participants not to feel alone. The word ‘alone’ was mentioned by several respondents, and many talked about the isolating nature of endometriosis: ‘I feel less alone in the groups- I know I’m not the only one experiencing this.’ (resp. 22), ‘Also knowing you are not alone in your struggle, as endometriosis can be very isolating...’ (resp. 9) and ‘I was feeling so alone and very down before I discovered there was others just like me who understood what a struggle constant pain could be.’ (resp. 25).

Having found others in a similar position to themselves, women were able to feel acceptance of their condition: ‘Now I know that there are other women suffering I can accept that this is actually happening to me!’ (resp.22) and ‘...knowing that what I’m feeling is real...that I’m not alone.’ (resp. 23). They were also able to feel reassured about any unusual symptoms experienced: ‘There are symptoms I’ve experienced that I thought was unique to me only to find that many others have the same issues. It was through the online support groups that I found I wasn’t alone.’ (resp. 60).

Connections made through online support groups could be very strong, with some talking of the relationships they had formed with other people. They often used words such as ‘friends’ and ‘community’ when talking about their connections with others: ‘I’ve made quite a few friends who I speak with regularly.’ (resp. 22), ‘I’ve made good friends.’ (resp. 20) and ‘...I have increasingly used the forum to seek community...’ (resp. 8). One woman particularly emphasised the role of these online support groups in enabling connections she could not have found elsewhere: ‘I find a sense of community there that I can’t find in the physical world.’ (resp. 8).

However, connecting to others through the support groups did not always foster positive outcomes. Participants alluded to problems in communication that they had witnessed between other members, such as arguments: 'There are sometimes arguments about what is the best treatment.' (resp. 22) and 'I have seen many posts get out of order & things can escalate quickly...' (resp. 11). This was also re-iterated by a member of the administration team for one support group: 'As an admin on [name of OSG], I do sometimes have to deal with arguments and the usual sort of online drama...' (resp. 50). Although such incidents caused frustration, they were only mentioned by a minority of participants. One participant even found the positive side to it, citing it as a source of entertainment: 'I visit the group now far more due to fear of missing a scandal! It's a hive of bitchiness - better than a soap opera' (resp.18).

The final theme relating to "connection" was how online support groups allowed participants the freedom to access people. This could be access to a large number of people: 'In the groups I could ask 100s /1000s of people questions...' (resp. 22). Or access at any time of the day or night: 'The main benefits of being in an online support group is that you have access 24/7.' (resp. 1). Access to such high volumes of people meant that online support groups enabled women to get help and support quite quickly if they needed it: 'Any time I have a question I can post and get reassurance and answers rather quickly.' (resp. 22). This could be particularly comforting at times when participants were suffering physically or psychologically; '... I have had three laparoscopies in the past and to know others are there whenever in need is lovely' (resp. 29) and 'Knowing that there is always someone there to listen when things get bad or I am feeling down.' (resp. 67).

A small number of women described potential pitfalls arising from this freedom of access. Having constant access to such platforms could cause preoccupation: 'Possibly a bit pre occupied with the group.' (resp. 41) and 'My life revolves round Facebook etc because I can do so little.' (resp. 18). Furthermore, one woman felt that access to so many people actually negated her the support she was seeking: 'No one responds to my posts. There are too many posts/people and not enough support to go around.' (resp. 24).

Exploration

The second largest affordance of online support groups for those with endometriosis was "exploration". Women were able to look for information, learn and bolster their knowledge, and doing so appeared to feel more empowered.

Participants frequently described how their use of online support groups had enabled them to seek out information; from either general information about the condition, to more specific information on treatments, research and specialists. Many commented on how they were able to find information that had not been provided by medical professionals: 'Additional information that may not have been given by my own consultant' (resp. 44) and 'I do not think I would have obtained the high quality of this information from the medical community directly.' (resp. 37). Again, positive words were used when describing the information gathered through online support groups: '...obtaining invaluable information on the condition...' (resp. 14) and '...and overall wealth of information has been immensely helpful.' (resp. 38).

Although the majority of participants valued the information found through this platform, some expressed concerns about the quality of information being given on such sites: 'However it was / is also a minefield of myths and misinformation...' (resp. 61) and 'I feel like someone a bit younger might fall pray to some of the misinformation some women provide.' (resp. 2). In a similar vein, some questioned the credibility of the sources of information, and were concerned about people self-appointing themselves as experts: 'There are some who think they are experts but really are not.' (resp. 51). Participants generally felt the information was credible if it came from a medical expert: 'I tend to only really listen to the advice from the specialists who post and answer questions, regarding current research.' (resp. 55). Alternatively, a number of women stated that they will do further research on any information obtained: 'I conduct my own web based research in order to validate information I have obtained from online support groups.' (resp. 37).

A common theme talked about by participants was how online support groups had facilitated their learning and knowledge. This learning encompassed a wide range of factors as it could be about the disease itself, the symptoms, treatment options or self-management techniques: 'In the forums I've learned so much about what the disease is, the proper surgery (excision vs ablation), the best doctors, and how to deal with the day to day misery of this disease.' (resp. 62) and '...I've learned about books to read, and diet, and supplements, and various other ways to deal with the symptoms.' (resp. 20). Again, participants alluded to how the learning facilitated by these groups went above and beyond what they could have received from their doctors: 'The information received from the medical community doesn't even come close to the details of what I have learned in online Support groups.' (resp. 37).

This new knowledge received through the online support groups facilitated improvements in the self-management of the condition: 'It has improved my health literacy around managing my own condition, which I am really grateful for.' (resp. 8) and 'I know about staying ahead of the pain now. In times where I have previously gone to hospital with extreme pain I have piggy-backed painkillers as suggested in forums and been able to manage things at home.' (resp. 19). It also helped to foster a sense of reassurance for the women, that what they have been experiencing is normal: 'I also understand a lot more so I can rationalise what is happening to me.' (resp. 22) and 'It has helped me understand why I have continued pain, despite multiple surgeries, and what I need to do to hopefully help revolve [sic] or at least reduce it.' (resp. 50).

A particularly pertinent outcome of the learning and knowledge facilitated by online support groups was a sense of empowerment. This was mentioned by many participants: 'Knowing more about the condition from the group has made me more empowered.' (resp. 19) and 'I feel a lot more empowered now that I have a reasonable understanding of the disease, this allows me to feel more in control and be better informed in the decisions I make about treatment.' (resp. 61). In fact, many participants talked about how they now felt in control or more knowledgeable about their treatment options. As a consequence, they were able to attend medical appointments feeling more prepared and confident: '...the information obtained from online support groups helps me to be more prepared when speaking with medical practitioners...' (resp. 37) and 'I feel more confident about seeing medical professionals and getting a good standard of care as the support groups have provided me with sources of information that I have used to educate myself.' (resp. 19).

Narration

Although slightly modest in size compared to the previous two affordances, participants did frequently comment on their use of online support groups to share their experiences, as well as hear the experiences of others. Through such narration, and that of others, participants were provided with a sense of reassurance, although at times it could also cause feelings of distress and disheartenment.

The majority of the "narration" quotes related to accessing the experiences of others, but a few did talk about how they had shared their own experiences with the condition. In doing so, participants described positive feelings and reassurance: 'My mental health has improved by being able to share my experience...' (resp. 16) and 'I had a few really painful examinations I shared this with the group and found support and was also told this was not uncommon with woman with endo...' (resp. 68).

Some also mentioned the benefits of sharing experiences as a two-way process: 'I also benefit from the fact that we are able to discuss and share our experiences and outcomes with specialists...' (resp. 50) and 'It is nice to share stories and hear from others about their journey with endometriosis.' (resp. 3).

The responses which related to accessing the experiences of others were relatively evenly spread with regards to whether they fostered positive or negative outcomes. On a positive note, participants talked about how hearing those experiences have helped them: 'Seeing other people's stories, be it success or negative stories as you can learn from both and gain some insight...' (resp. 62) and 'The personal experiences the other women have had and their outcomes of different treatments. Helps me to decide what to do next.' (resp. 43).

The experiences of others provided participants with feelings of reassurance about what they themselves had been experiencing. For example, one woman stated: 'I feel reassured that many women with endo have similar frightening symptoms.' (resp. 7). Another found that it helped to validate her own experience: 'Hearing the testimonies of women living all over the world and knowing that what I'm feeling is real...' (resp. 23). Others simply found reassurance when reading other's experiences by realising that things could be worse, for example: 'it's made me realise how lucky I am that I manage very well day to day compared to a lot' (resp. 4).

However, many women also found that accessing others' experiences could be disheartening. Some commented on the tendency for others to only share sad or negative stories: 'There are so rarely any positive posts. People only seem to feel the need to post when they have something bad to report.' (resp. 18) and 'The problem is that everyone talks about problems, very bad stories that make you feel more depressed, you never read happy things or happy stories!' (resp. 42). Hearing such negativity from others could be quite distressing: 'Have felt disheartened and even a little depressed when reading some women's experiences...' (resp. 49) and '...people repeating on multiple posts that it destroyed their lives to not have kids. As someone who has been diagnosed since 14 and is only 22 now it can be very overwhelming...' (resp. 65).

At times participants described the propensity for some women's narratives to be almost competitive in nature, which was seen as counter-productive, as it prevented them from wanting to share anything themselves: 'I rarely comment in these groups now because it's like a competition. My endometriosis is worse than your endometriosis. I need to take more pills than you. My

gynaecologist says mine is the worst case he's seen etc.' (resp. 18). One woman also talked about the opposite, how other women could be patronising about the severity of others' symptoms if they had not had them as badly themselves. The negative outcomes she felt were quite extreme: 'There are also other ladies who tend to be a bit patronising and don't accept that endo can be different for everyone...This can make me feel quite insecure and pathetic when I am off work for the 6th time this year...' (resp. 32).

Finally, although it was mentioned by many that there was a tendency for women to post negative stories, many participants reported that when positive stories were shared, such as a new pregnancy, it could cause a lot of distress in a group of people who frequently suffer from fertility issues. Although none of the women themselves said they felt this way, they often reported seeing other people getting upset about it, and sometimes even having arguments: 'I have seen other members argue with each other about posting sensitive information, such as posting pregnancy announcements without "trigger warnings"...' (resp. 37) and: 'There are those that, like myself, are infertile because of Endo. They cannot stand to see women make announcements that after having surgery or some form of treatment they are now pregnant...they will get upset and type angry rants and basically shoot down another EndoSister that is having a good experience right now.' (resp. 60).

Therefore, it would appear that rather than the potential positive outcomes of sharing such success stories such as feelings of hope, they may in fact exacerbate the distress felt by some women about their condition.

Self-presentation

This affordance relates to how the user's present themselves to others via online support groups. Although only a small number of participants alluded to this affordance, those that did placed great emphasis on its importance. To some, the confidential nature, or 'privacy' of the support groups was beneficial: 'Knowing i can discuss something, in private, amongst fellow sufferers.' (resp. 58) and 'I knew it was confidential because it was a closed group. Only people within the group could see- not all my facebook friends and family!' (resp. 22). Having this private, anonymous platform enabled some to disclose matters they might not usually, or allowed them to 'preserve' their offline relationships: 'It helps me deal with it "privately" because I don't have to "bother" the people I am close with and spend every day with about my health concerns. I just ask my endo sisters.' (resp. 13) and 'Having an outlet for sharing personal and embarrassing symptoms...' (resp. 16).

Conversely, some worried about how confidential the platform really was, stating fears over whether other online friends were able to see what they were posting: 'One concern that I have is the fact that I am posting very sensitive medical and personal information about my symptoms onto Facebook, and I do not feel that my personal information is secure on this platform despite the fact that these online support groups are on "secret" pages.' (resp. 37). 'The only problem I have is that not all the support groups are "secret" or private. Though sometimes I like to share the details of this disease with others who experience the same, I don't particularly want everyone of my Facebook friends to know about all my period pains or symptoms such as infertility.' (resp. 39).

This issue appeared to be mainly apparent in those who were recruited from the online support group hosted by Facebook, on which users are not anonymous, and usually go by their own name rather than a pseudonym. However, their language used indicates it as an important factor in their use of online support groups.

Discussion

The aim of this research was to explore the therapeutic affordances of using online support groups for endometriosis. The results revealed four therapeutic affordances in this population; "connection", "exploration", "narration" and "self-presentation". In comparison to the results of previous research of online support groups, this study has uncovered similar therapeutic effects, including emotional support, reduced isolation, improved coping, reassurance, knowledge and empowerment [32,34,35]. However, this research has also enabled a more in depth exploration of the underlying mechanisms which generate the observed therapeutic outcomes, which suggests that the study of therapeutic affordances is a valuable way to research online support groups. Furthermore, the positive outcomes observed from online support group use have provided an indication of the potential influence that social support can have on those who are managing endometriosis.

The resulting therapeutic affordances are comparable to those found by Merolli et al. [39] in their research on social media use in people with chronic pain. They too found the same four therapeutic affordances, however their research also uncovered a fifth affordance, "adaptation". This refers to the way that social media allows users to adapt their self-management needs in relation to their health status/illness flare-ups. In the current research, only two participants provided quotes which could have been viewed as suggestive of this theme, but they were coded into "connection" and the 'freedom of access' theme – as they talked of how they were able to access online support even at

times of illness flare up. Therefore, the SCENA model (Self-presentation, Connection, Exploration, Narration and Adaptation) proposed by Merolli et al. [39] to explain their results, may be considered a valid model despite their being some differences, which can arguably be related to the different sample being examined and the fact that our work focussed solely on online support groups rather than a range of social media.

The lack of evidence for the “adaptation” affordance in the present research could simply be because it was not commented on by participants, or because the affordance does not exist here. It is important to consider the differences in the ‘object’ studied, as this research focused on online support groups rather than social media as studied by Merolli et al. [39]. ‘Social media’ encompasses a wider variety of platforms such as blogs, social networking sites, video-sharing sites and chat rooms. This wider variety could afford different uses and outcomes than online support groups alone. This might too account for the different emergent themes found within each affordance compared to Merolli et al.[39]. Another possible explanation for the differing findings is that different health conditions were examined. Users perceptions may therefore differ based on their goals, experiences and beliefs, which is an important factor in affordance theory [38].

Outside of the health domain, researchers have attempted to further develop the concept of therapeutic affordances by categorising them into types based on their underlying function [41-43]. The results of the present study can be interpreted using the framework proposed by Zhao et al. [43], in which the perceived affordances are categorised into physical, cognitive, affective and control functions. “Connection” may be seen as an affective affordance, allowing users to find a community, seek support and feel less alone. “Exploration” may best be categorised as a cognitive affordance as it helps to facilitate the user’s thinking and learning. “Self-presentation” may fall under control, as it allows users to control their environment, by maintaining their privacy for example. However, as Zhao et al. [43] explain, affordances do not need to fall into these categories exclusively, for example “narration” may be both affective, in providing reassurance/distress, and cognitive as it allows users to learn from others’ experiences.

These theoretical frameworks allow us to understand the user’s perceptions of and reactions to online support group use. By interpreting the results in relation to previous research in endometriosis, we can further improve our understanding of the affordances we have found. “Connection” was the most prominent therapeutic affordance in this study, with women frequently expressing their gratitude at finding others with endometriosis, who could understand their struggle

and offer them support. Past research has reported that contact with other women with endometriosis is highly valued in this population [16,20], however it can be difficult to obtain [23]. This might explain the large number of responses relating to “connection”, as using online support groups can enable them to achieve such contact. Many women in our sample talked of how alone and isolated their condition made them feel, which has been a common theme in previous qualitative research [12,13,31]. The lack of an understanding support network further intensifies this isolation [13], and so finding those with experience and knowledge can be a great sense of support [20].

The “exploration” affordance also received significant attention in the present study, and in particular women talked of the ability to use online support groups to search for information related to their treatment. Previous literature has highlighted the struggles that women face with regards to their treatment, including lack of effective treatments [13], pain continuing post treatment [23], and concerns over side effects [44]. Furthermore, women have often felt let down by medical professionals, or complained of a lack of information from them [4,12,13,18], feelings which were also reiterated in the current study. They have therefore taken it upon themselves to search for the information they need, and the internet and online support groups provide a platform to do this [31]. Finally, research has indicated the tendency for women to want to self-manage their condition, and the empowering experiences of such [16,45], which again was a common theme in this research.

Comparisons to previous research suggest that the affordances enabled by online support groups, which were revealed in this research, may be effective aids when coping with and managing endometriosis. These results imply that the use of online support groups might form a meaningful part in the self-management of endometriosis. However, until clinicians can make decisions about whether to recommend their use for such, further research is needed which accurately measures the impact of support groups on health outcomes. Recently, Merolli et al. [46] studied patient-reported outcomes (PROs) of social media use in those with chronic pain, and found that it had a positive impact on psychological, social and cognitive aspects of health. Similar research is needed to corroborate these findings in those with endometriosis before online support group use can be recommended as a tool for self-management.

It is also necessary to consider the negative outcomes that were reported in the research, such as feeling disheartened by others’ experiences. By accurately measuring PROs in future research it

might be possible to determine exactly how much of an impact these negative experiences are having on group users. It may also be useful in future research to try to measure the potential contribution of individual differences on perceived affordances. It may be the case that the therapeutic affordances offered by online support groups are only effective for certain types of individuals. Furthermore, the current research cannot be generalised to other conditions, and so to further our understanding of the therapeutic affordances of online support group use, more research is needed to consider them in other chronic health conditions.

Our findings highlight a number of concerns that online support groups users may have that may impact on the quality of their online experience. Our analyses revealed concerns over the accuracy and credibility of online information. One possible strategy to address these concerns might be to deploy an online moderator, such as a health professional, who can directly intervene to correct any misinformation or to validate information provided by a group member. Other 'lay' moderators may similarly have a role to monitor online activity and ensure that members engage in a mutually respectful way. In terms of privacy concerns, a clearer statement of the privacy policy within online support groups may help to address this issue, though it should be noted that such concerns were restricted to Facebook groups. Finally, whilst there is clear value in people sharing their experiences, views and opinions online, we did note that both negative and positive stories can have a detrimental impact on users. This is a difficult issue to address, but may be dealt with partly through the development of specific sub-forums that focus on specific issues or experiences. In addition, there may be sub-forums devoted solely to 'good news' and members would hopefully have more freedom to choose the content they wish to be exposed to.

The present study has a number of potential limitations. Firstly, it is not possible to determine how representative this sample is of the whole population. Recruitment messages indicated that participants would be asked about their experiences of using such groups, and so there may have been a tendency for only those with more positive experiences to participate. Secondly, although the recruitment message was posted on three online support groups, over half of respondents (62.3%) were recruited from one group, the one hosted by Facebook. The support groups used varied considerably, both by platform and by group purpose, for example one focused more on fertility issues associated with endometriosis, while another provided users with access to specialists. While the motives for accessing the groups were fairly standard across respondents, these differences may have enabled users with different opportunities and therefore different affordances. Some evidence for this was highlighted by the "self-presentation" theme, in which

participants from the Facebook group expressed more concerns over the privacy of the group than those recruited from the other two groups. Unfortunately, as specific between-group comparisons were not made, it is not possible to understand the potential influence of group type on the resulting affordances. However, the inclusion of a variety of group types will hopefully have provided a more diverse range of participant characteristics and experiences.

Conclusion

This study has offered a unique exploration into the therapeutic affordances of online support group use in women with endometriosis. Through our analysis of the responses by participants to a series of open-ended questions, it has been possible to identify a number of therapeutic affordances arising from engagement with online support groups. Our findings reveal many positive aspects that may potentially benefit group members. However, several negative aspects are also revealed, particularly in relation to communication, personal information and the presence of negative stories online. A number of strategies are recommended to mitigate against these problems, including the presence of an explicit privacy policy, sections of the group where positive stories can be shared and the presence of a health professional to address misleading or inaccurate information.

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Conflicts of Interest

None declared

References

1. Kennedy S, Bergqvist A, Chapron C, D'Hooghe T, Dunselman G, Greb R, Hummelshoj L, Prentice A, Saridogan E. ESHRE guideline for the diagnosis and treatment of endometriosis. *Hum Reprod.* 2005 Oct 1;20(10):2698-704.
2. Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, Raine-Fenning N. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update.* 2013 Nov 1;19(6):625-39.
3. Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. *Fertil Steril.* 2009 Jul 31;92(1):68-74.
4. Ballard K, Lowton K, Wright J. What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertil Steril.* 2006 Nov 30;86(5):1296-301.
5. Hadfield R, Mardon H, Barlow D, Kennedy S. Delay in the diagnosis of endometriosis: a survey of women from the USA and the UK. *Hum Reprod.* 1996 Apr 1;11(4):878-80.
6. Husby GK, Haugen RS, Moen MH. Diagnostic delay in women with pain and endometriosis. *Acta Obstet Gyn Scan.* 2003 Jul 1;82(7):649-53.
7. Bergqvist A, Theorell T. Changes in quality of life after hormonal treatment of endometriosis. *Acta Obstet Gyn Scan.* 2001 Jul 1;80(7):628-37.
8. De Graaff AA, D'Hooghe TM, Dunselman GA, Dirksen CD, Hummelshoj L, Simoens S, Bokor A, Brandes I, Brodzky V, Canis M, Colombo GL. The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Hum Reprod.* 2013 Jul 11:det284.
9. Sepulcri RD, do Amaral VF. Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. *Eur J Obstet Gyn R B.* 2009 Jan 31;142(1):53-6.
10. Low WY, Edelmann RJ, Sutton C. A psychological profile of endometriosis patients in comparison to patients with pelvic pain of other origins. *J Psychosom Res.* 1993 Feb 28;37(2):111-6.
11. Lorencatto C, Vieira MJ, Pinto CL, et al. (2002) Evaluation of the frequency of depression in patients with endometriosis and pelvic pain. *Rev Assoc Med Bras* 48: 217-221.
12. Cox H, Ski CF, Wood R, Sheahan M. Endometriosis, an unknown entity: the consumer's perspective. *Int J of Consum Stud.* 2003 Jun 1;27(3):200-9.
13. Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obst Gyn.* 2004;25(2):123-33.

14. Friedl F, Riedl D, Fessler S, Wildt L, Walter M, Richter R, Schüßler G, Böttcher B. Impact of endometriosis on quality of life, anxiety, and depression: an Austrian perspective. *Arch Gynecol Obstet*. 2015 Dec 1;292(6):1393-9.
15. Fourquet J, Báez L, Figueroa M, Iriarte RI, Flores I. Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril*. 2011 Jul 31;96(1):107-12.
16. Gilmour JA, Huntington A, Wilson HV. The impact of endometriosis on work and social participation. *Int J Nurs Pract*. 2008 Dec 1;14(6):443-8.
17. Nnoaham KE, Hummelshoj L, Webster P, d'Hooghe T, de Cicco Nardone F, de Cicco Nardone C, Jenkinson C, Kennedy SH, Zondervan KT, Study WE. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril*. 2011 Aug 31;96(2):366-73.
18. Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D. Impact of endometriosis on women's lives: a qualitative study. *BMC Womens Health*. 2014 Oct 4;14(1):123.
19. Denny E, Mann CH. Endometriosis-associated dyspareunia: the impact on women's lives. *J Fam Plan Reprod H*. 2007 Jul 1;33(3):189-93.
20. Whitney ML. Importance of lay organizations for coping with endometriosis. *J Reprod Med*. 1998 Mar;43(3 Suppl):331-4.
21. Martins MV, Peterson BD, Almeida VM, Costa ME. Direct and indirect effects of perceived social support on women's infertility-related stress. *Hum Reprod*. 2011 May 18;26(5):157-63.
22. Dukes Holland K, Holahan CK. The relation of social support and coping to positive adaptation to breast cancer. *Psychol Health*. 2003 Jan 1;18(1):15-29.
23. Markovic M, Manderson L, Warren N. Endurance and contest: women's narratives of endometriosis. *Health*. 2008 Jul 1;12(3):349-67.
24. Cox H, Henderson L, Andersen N, Cagliarini G, Ski C. Focus group study of endometriosis: Struggle, loss and the medical merry-go-round. *Int J Nurs Pract*. 2003 Feb 1;9(1):2-9.
25. Matthews D. (2013) Internet Access - Households and Individuals, 2013.
26. Fox S, Duggan M. Health online 2013.
27. Potts HW. Online support groups: an overlooked resource for patients. *Health Info Internet*. 2005 Apr 1;44(1):6-8.
28. Eysenbach G. The impact of the Internet on cancer outcomes. *CA-A Cancer J Clin*. 2003 Nov 1;53(6):356-71.

29. Wright KB, Bell SB. Health-related support groups on the Internet: Linking empirical findings to social support and computer-mediated communication theory. *J Health Psychol.* 2003 Jan 1;8(1):39-54.
30. Neal DM, McKenzie PJ. Putting the pieces together: endometriosis blogs, cognitive authority, and collaborative information behavior. *J Med Libr Assoc.* 2011 Apr;99(2):127.
31. Whelan E. 'No one agrees except for those of us who have it': endometriosis patients as an epistemological community. *Sociol Health Ill.* 2007 Nov 1;29(7):957-82.
32. van Uden-Kraan CF, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qual Health Res.* 2008 Mar 1;18(3):405-17.
33. Vilhauer RP. Perceived benefits of online support groups for women with metastatic breast cancer. *Women Health* 2009 Oct 19;49(5):381-404.
34. Buchanan H, Coulson NS. Accessing dental anxiety online support groups: An exploratory qualitative study of motives and experiences. *Patient Educ Couns.* 2007 Jun 30;66(3):263-9.
35. Malik SH, Coulson NS. Computer-mediated infertility support groups: an exploratory study of online experiences. *Patient Educ Couns.* 2008 Oct 31;73(1):105-13.
36. Esquivel A, Meric-Bernstam F, Bernstam EV. Accuracy and self correction of information received from an internet breast cancer list: content analysis. *BMJ.* 2006 Apr 20;332(7547):939-42.
37. Gibson JJ. *The Ecological Approach to Visual Perception: Classic Edition.* Psychology Press; 2014 Nov 20.
38. Norman DA. *The psychology of everyday things.* Basic books; 1988.
39. Merolli M, Gray K, Martin-Sanchez F. Therapeutic affordances of social media: emergent themes from a global online survey of people with chronic pain. *J Med Internet Res.* 2014 Dec;16(12).
40. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psych.* 2006 Jan 1;3(2):77-101.
41. Day D, Lloyd MM. Affordances of online technologies: More than the properties of the technology. *Austral Educ Comp.* 2007;22(2):17-21.
42. Zhang P. Technical opinion Motivational affordances: reasons for ICT design and use. *Commun ACM.* 2008 Nov 1;51(11):145-7.
43. Zhao Y, Liu J, Tang J, Zhu Q. Conceptualizing perceived affordances in social media interaction design. In *Aslib Proc* 2013 Mar 1 (Vol. 65, No. 3, pp. 289-303). Emerald Group Publishing Limited.
44. Denny E. Women's experience of endometriosis. *J Adv Nurs.* 2004 Jun 1;46(6):641-8.
45. Cox H, Henderson L, Wood R, Cagliarini G. Learning to take charge: women's experiences of living with endometriosis. *Complement Ther Nurs Mid.* 2003 May 31;9(2):62-8.

46. Merolli M, Gray K, Martin-Sanchez F, Lopez-Campos G. Patient-reported outcomes and therapeutic affordances of social media: findings from a global online survey of people with chronic pain. *J Med Internet Res*. 2015 Jan;17(1).

Table 1. Final therapeutic affordances, inductive themes and descriptive language

Therapeutic affordance	Themes	Language
CONNECTION	Contact with others with endometriosis Support Exchanging advice Forming relationships Mitigating isolation Freedom of access	Talk Advice Alone Support Friends Community Understanding
EXPLORATION	Information seeking Credibility Learning/Knowledge Empowerment	Find Learn Discover Look Know
NARRATION	Sharing experience Reassurance Disheartening	Stories Share Hear Experiences Competition Negativity
SELF-PRESENTATION	Privacy Disclosure	Confidential Private Embarrassing